

Mayo University Hospital My Stroke Journey

A book for stroke survivors,
families and carers



Keep this with you from hospital to home

About Mayo University Hospital's "My Stroke Journey"

Most people don't know a lot about stroke until they or someone they know has one. My Stroke Journey will give you the information you need. Keep this book with you – it belongs to you.

How to use this book

This book contains information about stroke and how stroke can impact on you and your family and friends. It provides details on hospital processes and rehabilitation, as well as information to help prepare you for leaving hospital. Also included are contact details for support and services available in the community.

You don't need to read "My Stroke Journey" from cover to cover. Use the Contents page to find the information you need, when you need it.

Stories from stroke survivors and families give you an idea of the road ahead. We are very thankful to them and their families for sharing their experiences.

We also wish to thank the Nursing & Midwifery Planning & Development Unit, HSE West Mid West for funding this booklet and the Stroke Foundation Australia for kindly giving us permission to adapt their booklet for our local needs.

Thanks also Rob de Boer, the Stroke Team in Beaumont Hospital Dublin and BridgesSelfManagement.org.uk for use of their images in the booklet.

Finally, we wish to acknowledge the hard work and dedication of Colette Murray (CNM2) and Professor Tom O'Malley (Consultant Physician) in their efforts in establishing The Acute Stroke Unit in 2008. Their commitment in the delivery of a quality stroke service in Mayo University Hospital remains steadfast. This book is another step in the pursuit of their vision for a quality patient centred stroke service for Mayo.

Niamh Murtagh (Candidate Advanced Nurse Practitioner in Stroke) and Niamh Kelly (Senior Occupational Therapist), on behalf of the Stroke Team, Mayo University Hospital.

Table of contents

What is a stroke?	4	What happens after my hospital stay?	41
Types of stroke	5	Discharge planning	41
Tests	6	For family and carers	44
Treatment	7	Carers Supports and Services	45
About your admission to hospital	8	Driving	48
		Work	49
		My leaving hospital checklist	51
How will my stroke affect me?	17	Local and National Services and Supports	52
Brain Pathways	18	Croí	53
Effects of stroke	19	Irish Heart Foundation	55
Who can I ask about this?	23	Living Well	56
Neuroplasticity	24	Acquired Brain Injury Ireland	58
Rehabilitation	25	Age and Opportunity	58
Tips for making the most of rehabilitation	26	Age Action	59
Break down your goals into smaller steps	27	ALONE	60
		Aware	60
		Citizens Information Board	61
		Exercise: Easy chair based exercises for older adults (HSE)	61
		The Family Centre Castlebar	62
		Flourish	62
		Headway	63
		Irish Men's Sheds Association	63
		Irish Wheelchair Association	64
		Local Link Mayo	64
		Memory Technology Resource Room	65
		National Council of the Blind	65
		Quest Brain Injury Services	66
		The Samaritans	66
How do I take care of my health?	29		
Causes of stroke	29		
Medical risk factors	30		
Lifestyle Risk Factors	36		

1. What is a stroke?

Stroke happens when the blood supply to the brain is interrupted or is blocked completely.

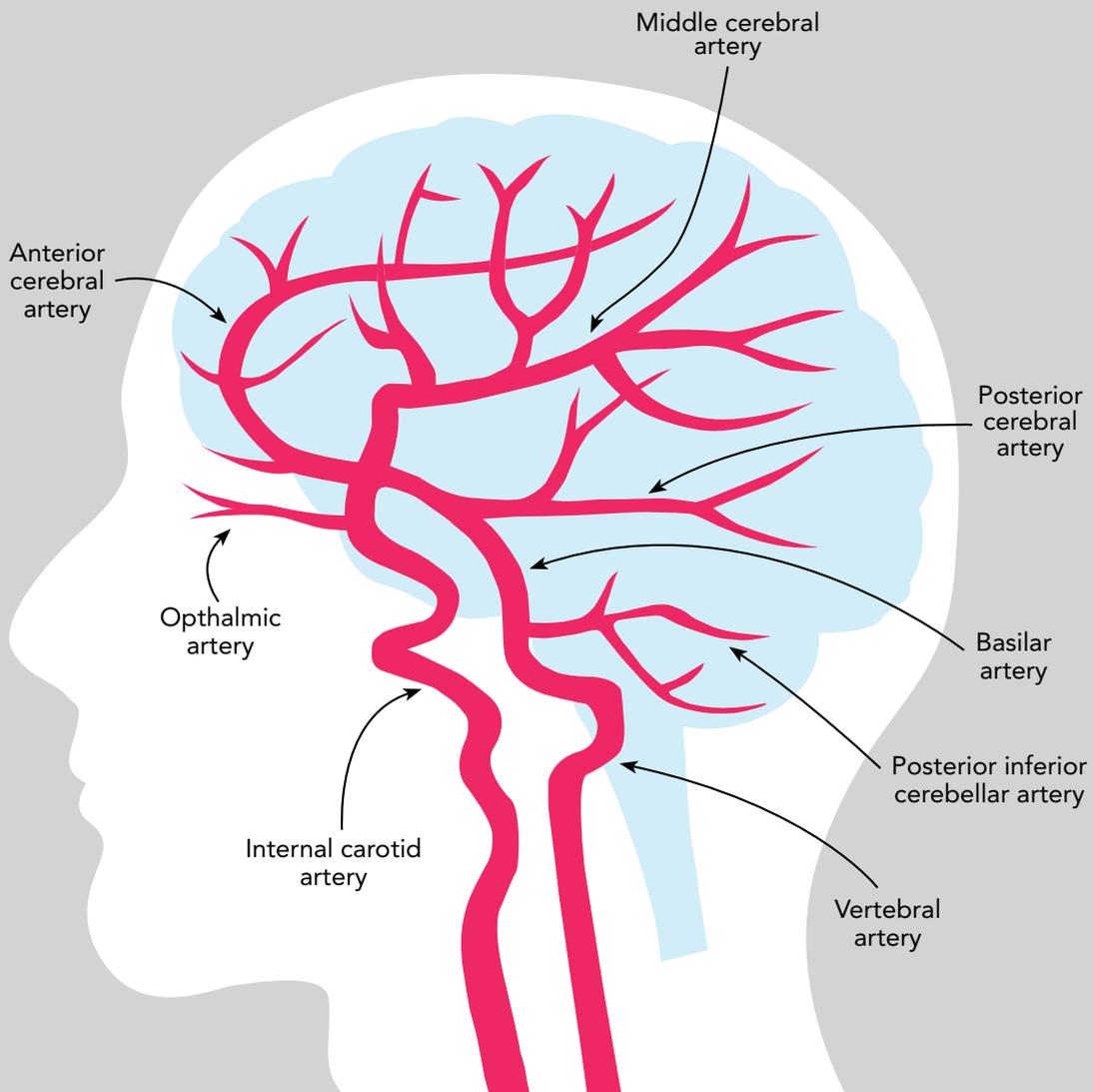
Blood is carried to the brain by blood vessels called arteries. The picture below shows the different arteries in the brain.

Blood contains oxygen and important nutrients for your brain cells to live. Blood may be interrupted or stop moving through an artery because the artery is blocked or has burst. Without blood, your brain cells do not get enough oxygen or nutrients, and so brain cells start dying.

Nearly two million neurons or brain cells die every minute when a stroke starts. Some brain cells can last a few hours if the blood supply is not cut completely.

Stroke is a medical emergency and needs urgent medical care. If the blood supply can be returned in the minutes and hours after the stroke, some of these cells may recover. If the blood supply does not return, the affected part of your brain will be injured.

Arteries carry blood through your brain.



Types of stroke

1. A blocked artery

A stroke can be caused by an artery being blocked by a blood clot. This type of stroke is called an ischaemic stroke, pronounced is-key-mick and accounts for about 80-85% of strokes.

If a blood clot forms somewhere in the body (usually the heart) it can travel through the bloodstream to the brain. Once in the brain, the clot travels to a blood vessel that's too small for it to pass through. It gets stuck there and stops blood from getting through. These kinds of strokes are called **embolic strokes**.

Cholesterol-laden 'plaques' can form in the inner wall of the artery. Over time, these plaques can increase in size and narrow or block the artery and stop blood getting through the artery. In addition, a blood clot can form on the plaque and block the artery. In the case of stroke, this mechanism most often affects the major arteries in the neck taking

blood to the brain. Strokes caused in this way are called **thrombotic strokes**.

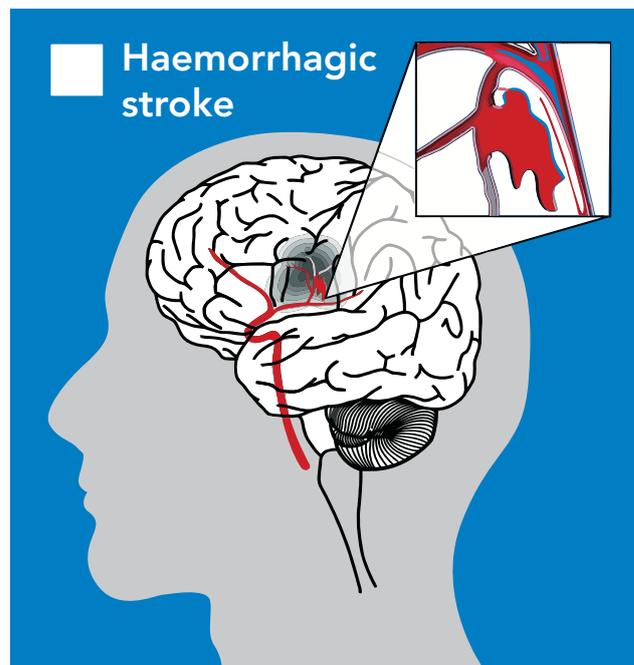
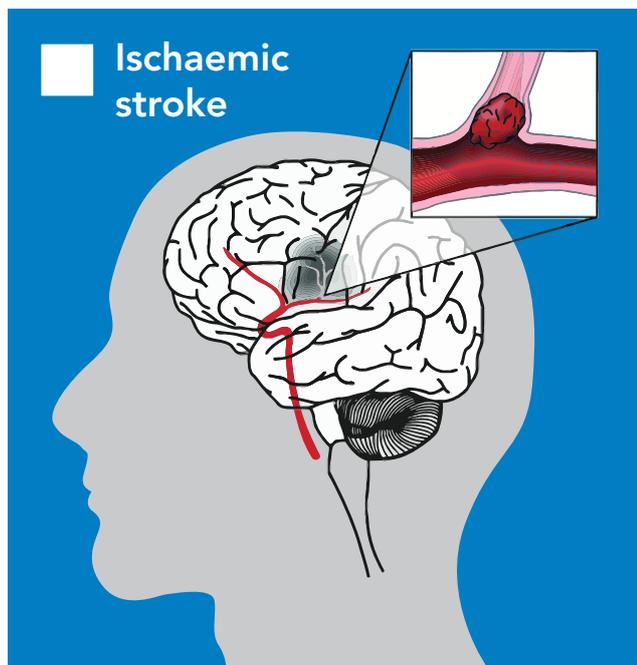
2. A ruptured or burst artery

A stroke can be caused if an artery breaks or bursts in the brain. Blood leaks into the brain, again stopping the delivery of oxygen and nutrients, injuring that area of the brain. This is called a haemorrhagic stroke (pronounced hemm-orr-ragic).

Haemorrhagic strokes can be caused by a number of disorders which affect the blood vessels, including uncontrolled high blood pressure, ruptured cerebral aneurysms or rupture of abnormal collection of blood vessels (arteriovenous malformation).

In an intracerebral haemorrhage stroke, bleeding occurs within the brain itself.

My stroke:



Other details:

Tests

Early assessment of stroke

You will usually be admitted to hospital through the emergency department. The doctors will do some tests to:

- › Find out what type of stroke you had
- › Find out what area of the brain was affected
- › Work out how severe the impact of the stroke was on the brain
- › If possible, find out and start treating the cause of the stroke

Everyone will need a different set of tests. Common tests include:

Brain scans and tests

Computerised Tomography (CT Brain scan) and Magnetic Resonance Imaging (MRI Brain). These tests take pictures of your brain that show areas of damage and swelling and to work out the type of stroke (ischaemic or haemorrhagic).

They may be repeated later to see how much of the brain has been affected by the stroke, or if your condition changes.

Cerebral angiogram. A small tube called a cannula is inserted through a blood vessel in the arm. A dye is injected through the tube and X-ray images of the brain are taken. The images show how dye moves through the arteries and veins of the brain. Doctors can see if there is a blockage or clot within the blood supply with the blood supply to the brain and where the problem is.

Carotid Doppler Ultrasound. The carotid arteries in the neck carry blood to the brain. An ultrasound of the neck arteries show if these are narrow or partly blocked. The carotid ultrasound is a painless test performed by a radiographer who places a probe on your neck to see your arteries.

Heart tests

Your heart pumps blood to your brain, so problems with your heart can cause a stroke. Heart tests include:

Electrocardiogram (ECG). Electrodes placed on the skin of the chest record the electrical activity of the heart. This test for abnormal heart rhythm or heart disease is recommended for everyone after a stroke.

Holter monitor (ECG). A wearable device which measures your heart rate and rhythm continuously, usually for 24–48 hours to monitor for an irregular heart rhythm called atrial fibrillation. Longer monitoring of 3 or 7 days may be needed.

Echocardiogram (Echo). Ultrasound to look at the structure and function of the heart. An Echo can show if there is a large blood clot in the heart, if the chambers of the heart are enlarged or the valves are not working properly. An Echo will also look at heart's ability and effectiveness to pump blood around your body.

Transoesophageal echocardiogram (TOE). A tube-like device is passed down the throat into the oesophagus. This test gets a clearer view of the heart muscles, valves and area around the heart. A TOE is also performed to check if there is a clot in the top left chamber of the heart or check if there is a hole in your heart. A TOE is performed in one of the Galway hospitals.

Blood tests

Blood tests can help diagnose health problems that may have caused your stroke. The most common tests measure:

- › The time it takes your blood to clot (your International Normalised Ratio or INR)
- › Kidney function
- › Blood sugar levels
- › Salt levels
- › White blood cell count
- › Cholesterol levels

Treatment

Treatment cannot repair injury to the brain. Instead, treatment is given to minimise the injury to the brain.

Treatment for ischaemic stroke

To minimise the damage caused by an ischaemic stroke, some people may be suitable for thrombolysis and endovascular clot retrieval.

Early treatments for ischaemic stroke are called reperfusion therapies. The aim is to dissolve or remove the clot, returning the blood supply to the brain.

Before any treatment, a brain scan is done to confirm it is an ischaemic stroke. Haemorrhagic strokes are not treated with thrombolysis medications because these clot busting drugs can make bleeding worse.

Treatment is not appropriate for everyone. Your doctor will decide whether treatment is appropriate for you and will discuss their recommendation with you or with the person making the decision for you.

Thrombolysis is when a drug is given to dissolve the clot. It is given as an intravenous injection in your arm. Thrombolysis should be given as early as possible, generally within 4.5 hours of the stroke starting.

Thrombectomy or Endovascular clot retrieval is another treatment used to return blood flow to the brain, often in conjunction with thrombolysis.

Thrombectomy is the physical removal of a clot from a large artery. A small tube called a catheter is inserted into an artery in the groin or arm and moved up into the brain arteries. A suction device or metal net called a stent is used to capture and remove the blood clot that is blocking the artery and causing a stroke.

In Ireland, thrombectomy procedures are carried out in Beaumont Hospital, Dublin and Cork University Hospital. Patients are transferred from Mayo University Hospital to Beaumont if the thrombectomy procedure is required.

Other treatment

Aspirin or other blood thinning medication is given in hospital to people who have had an ischaemic stroke to reduce the risk of another stroke. If you haven't had thrombolysis it's given within the first 24 hours. If you have had thrombolysis, it's given after the first 24 hours provided there is no bleeding on a routine repeated CT Brain scan.

Carotid endarterectomy is a surgical treatment for severe but not total blockage of the carotid arteries. The carotid arteries carry blood to the brain.

Surgery. Very occasionally surgery is needed to reduce and relieve swelling on the brain following an ischaemic stroke. This is performed in Beaumont Hospital, Dublin.

Treatment for haemorrhagic stroke

Treatment focuses on controlling the bleeding in your brain and reducing the pressure caused by the bleeding. Haemorrhagic strokes are not treated with thrombolysis medications because these clot busting drugs can make bleeding worse.

Other drugs can be used to reduce blood pressure to decrease the risk of ongoing bleeding.

Surgery may be needed to treat a haemorrhagic stroke. This includes repair of the damaged artery to stop the bleeding and/or relieving the pressure caused by the build up of blood.

Surgery may be needed to seal or remove:

- › A weak or thin spot on an artery wall (an aneurysm)
- › A tangled mass of arteries and veins (an arteriovenous malformation or AVM)

About your admission to hospital

Stroke Team

The stroke team is a group of health professionals who will work with you to treat the different problems that can occur after a stroke. The team will work with you and your family while you are in hospital.

It can be helpful to write down the names and contact details of your stroke team members in the following section. You may have questions or problems you would like to discuss.

Remember you and your family are also important members of the team. You need to work together with the health professionals to manage the impact of your stroke.

Stroke Team Meetings

The stroke team members meet weekly on the ward to share information and review your tests to plan and make decisions about your treatment, and discuss discharge planning.

Sometimes meetings between your family and the team members are arranged to keep you and your family up to date, and provide an opportunity to ask questions of any member of the stroke team. If needed, onward care and discharge planning will also be discussed.

Early progress

Your health professionals will work with you to ensure you make the best improvement possible. Everyone progresses differently in the first few days after a stroke. Some people will make a good improvement quite quickly after their stroke, whilst other people may make slower progress. Some people will suffer complications after their stroke however most people will survive and go on to make improvements in their function.

As with any serious medical event, it's very normal to feel strong emotions after a stroke, even if you make a good recovery. Talk to your team, family and friends about how you are feeling.

Decision Making

With your permission, the hospital staff can share information with your chosen first point of contact (next of kin, trusted friend). However, they cannot make any decisions for you in relation to your care. You are the person in the driving seat.

If you wish to plan around your healthcare preferences for the future, consider filling out the Think Ahead form (<https://hospicefoundation.ie/programmes/public-awareness/think-ahead/what-is-think-ahead/>) or speak with your local Citizen's Information Board, see page 61 for contact details.

Useful items and clothes for your family to bring in to hospital

Useful Items	Clothing and Footwear
Mobile phone	Pyjamas
Phone charger	Nightdress
Hearing Aids	Tracksuit
Glasses	Loose fitting clothes
Toiletries	Runners
Shaving kit	Closed footwear
Tablets/iPads/laptop	Day clothes

Delia's story

I was just back from Spain where I was on holidays with my family. On holidays I felt a sore throat coming on and I was due back to work the following day. So, I made an appointment with my GP for after work. My GP took my blood pressure and it was perfect so he advised me I could go home. By now a pain had started in my right eye, it was shooting up into my head like when you would eat ice. It was now getting later in the evening and the pain was lasting longer and I was getting weaker. My husband brought me to the local hospital. They were only treating me for migraine as I was showing no signs or symptoms of stroke i.e. FAST positive.

I was moved from there to Galway GUH, where I was diagnosed with a rare syndrome. At this stage staff informed my family that I had already had three strokes. The following night I had another stroke which ended up taking my walk.

Then I was moved to Beaumont hospital where I had two more strokes. In Beaumont they eventually got me sorted. I lost my voice, swallow and was paralyzed on my left-hand side. I can't remember part of my journey until I was brought back to Galway to do my rehab. I am blessed with my family and forever grateful to the staff and the hospitals for the care given to me. I am also very grateful for my home care support, family home help, nurse, OT and GP.

It's hard at the beginning when you come home. For me a lot of adjustments to the house had to be made. You want life to be like it was but it's not. But you are a survivor and I am eternally



grateful to be one. There is a lot more support available now than there was 4 years ago. I am doing good taking each day as it comes, little improvements all the time. I can now use my left side more than I used to and I can walk with a cane.

Take small steps and small goals until you get into a routine, as routine is very important as is rest during the day. Stroke affects everyone differently. I found the Mayo Stroke Support Group very helpful to connect with other stroke survivors. We meet once a month and there are also other supports out there. Staying positive is very important.

Delia, Stroke Survivor.

Stroke team member	Questions you might ask your stroke team member	Name of your health professional and contact details
<p>Dietitian</p> <p>A Dietitian will help you if you are having problems eating enough food because of swallowing difficulties or poor appetite. They will check your nutritional needs and order special meals if required.</p> <p>They can also give you advice about healthy foods and reading food labels. This can help reduce your risk of another stroke.</p> <p>A Dietitian will work very closely with the speech and language therapist to ensure adequate intake in line with their recommendations.</p>	<p>I can't swallow normal food at the moment – what else can I eat?</p> <p>Can my family bring food in for me from home?</p> <p>What can I change in my diet to reduce the risk of stroke?</p> <p>I don't feel that I am eating enough at the minute – is there anything else I can do?</p>	<hr/>
<p>Occupational Therapist (OT)</p> <p>An OT can help you get back to doing the day-to-day tasks that you want or need to do- such as getting dressed, making meals or your leisure activities.</p> <p>They do this by exploring difficulties that may arise with the following skills as a result of your stroke:</p> <ul style="list-style-type: none"> › Cognition/thinking (e.g. your ability to concentrate/ memory problems) › Physical (e.g. how your arm feels and moves) › Vision or perception (e.g. bumping into things, difficulty reading) <p>They can also provide information on driving and returning to work.</p>	<p>How can my family help?</p> <p>How can I use my daily activities to work on my difficulties?</p> <p>What can I do to help manage my memory problems?</p> <p>What do I need to do to get back to driving?</p> <p>Will I be able to get back to work? How?</p> <p>How can I get back to my hobbies?</p>	<hr/>

Alec's story



My stroke happened in December 2012 and I could only be moved by a hoist. I lay on my back in a hospital bed, totally confused as to what had happened and I felt so helpless. I then began to think of what I could do to help myself and looked to the ceiling.

Sometime later, the Ward Manager noticed me staring at the ceiling with the polystyrene squares and asked me if I had counted them. I told her yes, $4 \times 6 = 24$, and that behind each one I had created a special image that I could bring into my head to help me. If I went 2 down and 3 in, I could bring my big brother John into my head to help me sleep as I was used to sleeping tablets, but was not able to take them after my stroke. And John could sleep anywhere. I could visualise him on the couch after a meal in our home when we were children, with his mouth open wide sleeping like a baby, which helped me to drift off to sleep.

Another square had the waterfall by my cottage for helping me wee. When I was really depressed I had special happy squares I could think about. When I was very young on Christmas Eve my Auntie and Uncle would call to our house and Mummy would have her porter cake wrapped in a brown paper tied with string in the cake tin not to be opened till they arrived. Daddy would have 2 cigars. One for my Uncle, and one for himself and he also had some homemade brew that they would share. He would be proudly standing in front of the fire awaiting their arrival. My Uncle always banged loudly on the front door and my heart would race with excitement as they brought such love and joy. I could bring that feeling back and it helped me so much. I had some other nice childhood times behind some other squares. This all helped me with deal with my stroke when I was in the stroke unit, during the early stages of my stroke journey. I was in the Stroke Unit until New Years Day 2013. Then was transferred to the Sacred Heart Hospital to the rehabilitation unit for a further 4 months before I was discharged home.

Alec, Stroke Survivor.



2. How will my stroke affect me?

Our brain controls everything we think, feel, say and do.

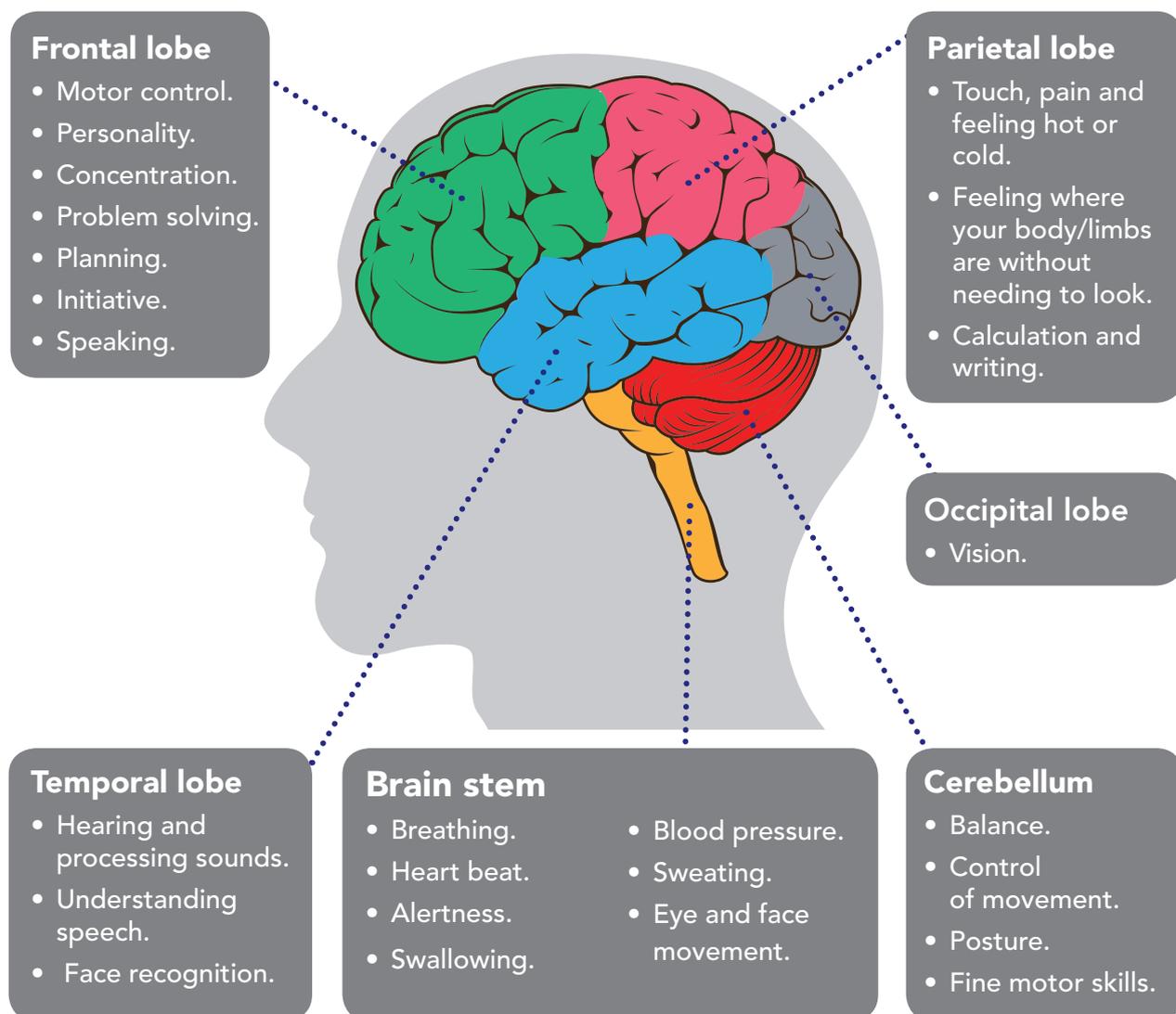
The brain has two sides: the right and left hemispheres. The right hemisphere controls most functions on the left side of the body. The left hemisphere controls most functions on the right side of the body.

Each side of the brain is divided into areas called lobes. Each lobe controls different things.

Everyone's stroke is different. How your stroke affects you depends on the area of your brain that is injured and how badly.

Keep in mind most people improve with time and rehabilitation.

Areas of the brain



Brain Pathways

What is more important to understand than the function of the areas of the brain, is that they are all connected or “talk” with each other all of the time.

There are many pathways throughout the brain, along which information travels. Thus damage to one part, may not only affect that particular function, but may also affect a wide range of other skills. These pathways are called neural networks. All parts of the brain are constantly communicating with each other through these networks.

Damage to one part of the system may impact on other non damaged parts so messages cannot be sent around the brain in the same way, which can result in you having difficulty functioning as normal. This may mean that stroke effects may be present which are not predicted by the area of damage.

It is worth remembering that your brain has the ability to change through neuroplasticity. This will be explained further on page 24.



Effects of stroke

Moving and walking

Stroke can affect your ability to sit, stand, balance, walk and move.

Moving and walking may be difficult because:

- › One side of your body is weak or doesn't move at all
- › You can't plan or coordinate movement
- › Your muscles are stiff and tight, or floppy and loose
- › You feel off balance, unsteady or dizzy

Changes to your hand, arm and shoulder (your upper limb) are common after stroke. Weakness, stiffness, looseness or trouble coordinating movement can all affect your upper limb.

Communication

Stroke can affect your ability to speak, understand, read or write.

When these difficulties are caused by injury to the language area of the brain, it's called aphasia. You may find:

- › It's hard to think of the right word
- › You use the wrong word or sound
- › You don't understand what someone is saying
- › Words on a page don't make sense

Other issues can affect communication too. Sometimes after a stroke the muscles you use to speak are weak or don't work at all. It can also be difficult to plan and coordinate movement of these muscles.

This can make your speech slurred or changes your voice, making it difficult to understand you.

Thinking, memory and judgement

Stroke can affect your thinking, memory and judgement. This is called cognition.

Changes to your cognition make it hard to:

- › Pay attention and not get distracted
- › Plan how to do something
- › Do things in the right order

Problems with your short-term memory mean you don't remember things that happened a short time ago.

Problems with judgement mean you have difficulty making decisions. Problems with judgement can affect your ability to judge distances which could lead to falls. It also may mean that you experience impulsive or inquisitive behaviour.

Carole's Story

My haemorrhagic stroke came out of the blue at 1:20am, as I was reading. At first I thought I was just very tired and I should go to bed. Fortunately my husband Tom saw what had happened and immediately called the ambulance. I have long term hypertension and recent Atrial Fibrillation, but both were well medicated. A & E was virtually empty so luckily I was treated immediately. Tom's prompt action and that of the emergency team at Mayo University Hospital did much to prevent any further damage.

My initial overwhelming feeling of panic, and the growing anxiety that this could be my life from now on, began to ease a little when the dedicated stroke team took over. Their encouragement and positive attitude was just right and with only six days in hospital I felt I was recovering well. I had worked in physiotherapy in the UK, so I knew how to motivate myself to continue the early progress and then build on it.

At 71, I was fairly active, walking, swimming, gardening etc, but the changes to my life surprise me. Firstly the fear it would happen again, my confidence when being alone was gone. My speech would get jumbled, really annoying me and I tired quickly. Outwardly, I guess I looked the same, so everyone said they would not have thought I'd had a stroke, but I knew the changes were there.

Now, just a year on, I'm back driving and doing all my other daily activities living life to the full; just as before. I'm determined not to let the stroke define me; I'd like to think it hasn't. Unfortunately, my stamina is not as strong as previously. I get tired easily and muddle my words during conversations, and still find it frustrating, also I can get annoyed suddenly, but it's usually over quickly. I can still finish Tom's crosswords, still crochet, cook daily, grow vegetables and still paint my watercolours. Believe me I know how incredible my recovery has been.

Yes life has changed to some degree, some aspects are different, but it's with the abilities not the person. Every morning I wake up delighted to be gifted another day, I'm a work in progress, and I'm still me.

Carole, 72, stroke survivor.



Personality and behaviour

Stroke can affect your personality. Some personality traits can become much stronger. People can also behave in ways that are out of character for them. Personality changes after a stroke can include:

- › Not feeling like doing anything
- › Being irritable, aggressive or lashing out
- › Acting without thinking
- › Saying or doing things that are not expected or usual

Vision and senses

Stroke can affect how well you can see. It can also affect how you sense and perceive things.

Vision. You may have visual field loss. This is like a blind spot only bigger – it's as if people and things in the missing part of your vision aren't there.

You may have blurred or double vision. You can also have problems controlling eye movement. Your eyes may be more sensitive to light.

Senses. Your ability to feel touch, pain or temperature can change. Your sense of taste and smell may change. You may have numbness or pins and needles.

After a stroke, you may be overwhelmed by busy, noisy environments. Our brains identify and filter out unnecessary sensory information. When your brain has difficulty doing this it can make you feel overwhelmed and confused. This is called sensory overload.

Perception. You may not recognise objects or even parts of your body. You may ignore people and things on the side of your body affected by your stroke. You may not be aware of where parts of your body are or how they're moving.

Other effects

Swallowing. Stroke can affect the muscles you use to move food around in your mouth and how well you can swallow. This creates difficulties swallowing food, drink or even your own saliva. Food or drink can go down the wrong way and get into your lungs, causing an infection.

Appetite. Physical, cognitive, emotional and sensory changes can mean you don't have much of an appetite after your stroke.

Incontinence. Incontinence is being unable to control your bladder or bowel – having 'accidents'. You might not know when you need to go to the toilet, be unable to get there in time or ask for help.

Pain. After a stroke you may feel pain from changes to your body. Stiff or tight muscles are a common reason for pain.

Pain can also be caused by damage to the brain's pain-processing pathways. This is called central post-stroke pain (CPSP) or nerve pain. You experience pain even though there is no observable injury or problem in your body. You may also have headaches.

Emotions and mood

Emotional reactions. It's very normal to experience strong emotions after a stroke. You may feel anxious about why you had a stroke and whether you will recover. You may be angry it happened to you. You might feel grief or sadness at the change from how you were before. You may feel gratitude at survival, hope about your recovery and love for family and friends.

Emotional lability. This is when your emotional responses don't make sense or are out of proportion. You may cry or laugh uncontrollably. Your emotional responses may not make sense for the situation you are in.

Depression and anxiety

Depression and anxiety are common after a stroke. You may have depression if you feel sad or down for more than two weeks. You may lose interest in things you normally enjoy, lack energy, have difficulty sleeping, or sleep more than usual. You may find it difficult to concentrate, to solve problems and to keep appointments.

You may have anxiety if anxious feelings do not go away once a stressful situation is over, or if you are anxious for no particular reason.

Depression is most common in the first year after a stroke; however it can happen at any time. The more severe your stroke, the more you are at risk. Having difficulty communicating after your stroke puts you at higher risk.

Never ignore the signs of depression or anxiety. Depression and anxiety are highly treatable and recovery is common.

Speak to your doctor or other stroke team member.

Fatigue

Fatigue is very common after stroke. It is a feeling of weariness, tiredness or a lack of energy. Fatigue after stroke is not improved by rest, so it is not like typical tiredness.

It can be physical, cognitive or both. Cognitive fatigue is often described as 'brain fog'.

Fatigue may make the effects of your stroke worse. For example, it may be harder to think of the right word.

Fatigue can affect anyone, no matter how mild or severe their stroke. It is most likely to start in the first weeks after a stroke but for some people it can start months later.

For many people it does improve with time; however it is unpredictable and can last longer than you expect.

Sex and relationships

Stroke can affect how your body feels and works and how you feel about yourself.

It can also affect your relationship with your partner.

Get help

Find out who you can talk to on the next page if you are experiencing any of the issues in this section.

Effects of stroke: Who can I ask about this?

You could be experiencing some of effects of stroke listed in the table below. If so, you can ask the relevant person listed in the corresponding boxes, about these effects.

Tick box	Effect	Who can I ask about this?
	Appetite	Dietitian Nurse
	Communicating	Speech and Language Therapist
	Moving and Walking Mobility and exercise	Physiotherapist Nurse
	Upper limb Arm/Hand problems	Physiotherapist Occupational Therapist Nurse
	Emotions Depression and anxiety Emotional and personality changes	Nurse Stroke Clinical Nurse Specialist Medical Social Worker Doctor
	Fatigue	Occupational therapist Physiotherapist Stroke Clinical Nurse Specialist
	Incontinence	Nurse Doctor Stroke Clinical Nurse Specialist Health Care Assistant
	Pain	Doctor Nurse Physiotherapy Occupational therapists
	Sex and Relationships	Nurse Stroke Clinical Nurse Specialist Occupational Therapist Medical Social Worker Doctor
	Swallowing	Speech and Language Therapist Nurse
	Thinking, memory and judgement Perception	Occupational Therapist Stroke Clinical Nurse Specialist
	Vision and senses	Occupational Therapist Stroke Clinical Nurse Specialist Ophthalmologist

Neuroplasticity

Neuroplasticity

Neuroplasticity is your brain's ability to change. This can happen in two ways:

1. The damaged area of the brain may repair itself and start working again. This can sometimes happen naturally in the early stages of stroke recovery.
2. Other parts of the brain can take over the tasks the injured area used to do. This can happen when the injured area can't be repaired. This is known as "re-wiring" of the brain.

It may take many repetitions of a movement or task over several days or weeks before you see improvement.

Neuroplasticity is happening as you work on your rehabilitation and recovery.

Predicting improvement

A very common question at this time is 'How much will I improve?'

Your team can provide an indication of how much they think you will improve.

Factors your team will consider include:

- › The area of your brain that was injured and how badly
- › The effect of any medical treatment you received

It's still difficult to be definite about what will happen. Your stroke team may instead talk about what is likely to happen.

There are lots of different factors that influence recovery and there are some unknowns too. Just like everyone's stroke is different, everyone's recovery is too. Even if recovery doesn't seem probable, it may be possible.

Not knowing how much you will improve is hard and it can be difficult to make plans. Setting goals and taking steps to achieve them will help. Talk to a member of your stroke team and to your family and friends about how you are feeling.

Rehabilitation

The purpose of rehabilitation is to drive recovery after a stroke. Rehabilitation helps you relearn or find new ways of doing things that have been affected by your stroke.

The brain has the ability to change and adapt after a stroke. This ability is called neuroplasticity as previously mentioned in this section. Through changes in brain pathways, you may learn to use other parts of your brain to help you recover. Rehabilitation aims to stimulate neuroplasticity.

After your stroke, health professionals such as physiotherapists, occupational therapists, speech and language therapists and dietitians will begin working with you as soon as possible. Rehabilitation can start very soon after your stroke, while you are still on an acute ward or stroke unit.

Once you no longer need acute hospital care, you may be transferred to an inpatient rehabilitation unit (eg. The Sacred Heart Hospital).

Some people go directly home. Each person recovers differently after a stroke. It is often difficult to predict how much improvement you will make. Some people return to 100 per cent or very close, whilst other people may continue to have difficulties. The most rapid improvement usually happens in the first six months however improvements can continue for years after a stroke.

How much rehabilitation will I get?

The amount and type of therapy you get depends on your individual needs and how much you can manage. Undertaking therapy tasks with family and friends throughout the day can help your recovery. Talk to your therapists about tasks you and your family can do when you are not with your therapists.

Fatigue

Feeling tired is common after a stroke. Making sure you are getting appropriate rest can help improve general fatigue. However, sometimes you may experience fatigue related to the stroke which may not improve with rest. Talk to your therapists about having your therapy at times when you are feeling most alert as therapy is a very important part of recovery.

Goal setting

Goal setting is a vital part of your rehabilitation and recovery. After a stroke, it is often difficult to see a path from where you are now to where you want to be.

Setting goals can break things down into manageable steps to get you there. The process starts as early as possible after your stroke and continues when you leave hospital. Goal setting is about defining what you want to achieve and making a plan to get there. It doesn't matter if it doesn't seem realistic right now, it gives you and your family a target – something to aim for. Your plan can outline the steps you will take and set milestones to keep track of your progress.

Tips for making the most of rehabilitation

Set Goals. There are many different ways to set goals. Talk to your stroke team about your goals and how to form goals. Your goals may change as your recovery progresses.

Here are some tips to help you set goals:

- › **Be specific** It is important that goals are specific (e.g. 'to be able to dress myself', rather than 'get better')
- › **Celebrate success** Celebrate your achievements along the way. Don't forget to stop and enjoy completing a step or reaching a goal
- › **Start small** Short-term goals can be stepping stones to achieve a bigger long-term goal. Your stroke team can help you to break your goals into smaller, achievable steps

Try writing down what's important to you here:

What's going well?

What would you like to do more of?

What are you having difficulties with?

Other tips

Share how you are feeling. You will have tough times. It's completely normal. It's impossible to be positive all the time. Be open about this – talk to your team and to a trusted family member or friend.

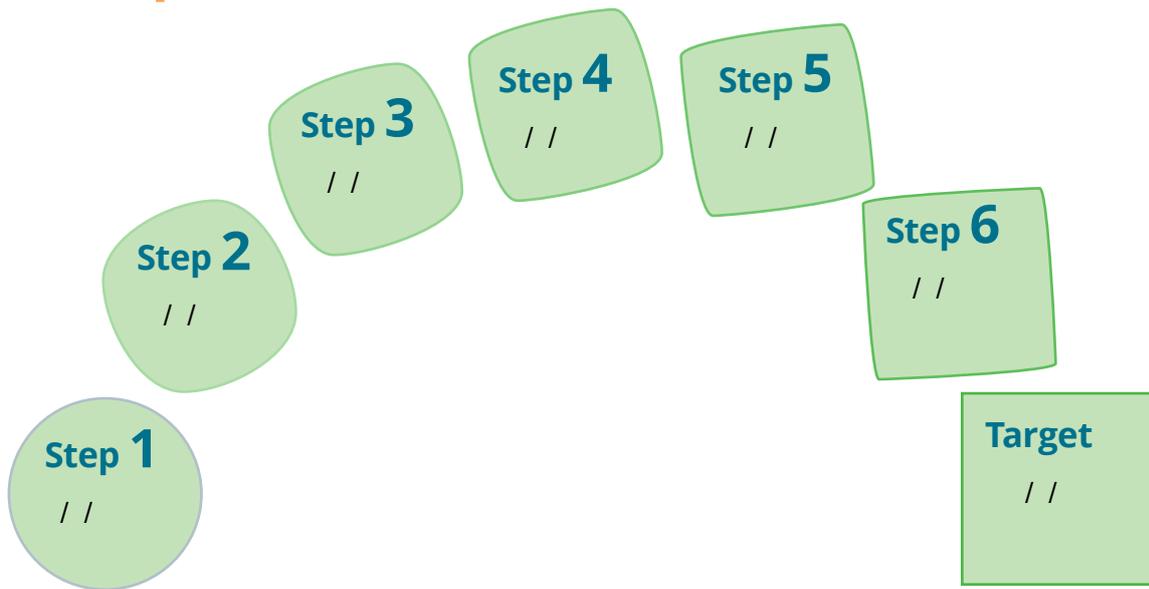
Balance activity and rest. Rehabilitation is hard work. Remember to take breaks. Practice and exercise outside of therapy time can be done in short bursts. Recovery and improvement is a marathon not a sprint.



Break down your goals into smaller steps

Used with kind permission from Bridges Self Management Organisation (UK) –
Website: bridgesselfmanagement.org.uk

Your steps...



Date started: / /

Date achieved: / /

Thing to do:

Step 1:
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Step 2:
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Step 3:
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Step 4:
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Step 5:
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Step 6:
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Dinny's story

I was a carpenter and for several years worked with an International Healthcare company in maintenance. I also had a suckler farm. This outlet was the only recreation I knew. In 2003 when I was 64 I suffered a stroke without any warning. Back in 2003, speed in diagnosis wasn't the main factor. I wasn't a smoker and just a social drinker.

This really changed my life and that of my whole family; many adjustments had to be made. I had 2 weeks in Mayo General Hospital and 13 weeks in the Sacred Heart home receiving Physiotherapy. I never recovered full power in my left side with none in my arm or hand.

The hardest thing to accept was lack of confidence, I was lucky to have a supportive family to encourage me. In my former life I couldn't go on holiday I was too busy! How would the cows survive? I had all the excuses imaginable not to go away. However, since 2003 I have had many holidays, including to Lourdes and I've had many trips from Knock Airport to the sun.

Getting back on the tractor was a turning point which restored my self worth. I am now almost 82 and my tractor is my life line, it gives me so much independence. Determination in whatever you wish to achieve is the key. Don't give up.

Dinny, aged 81, Stroke Survivor.



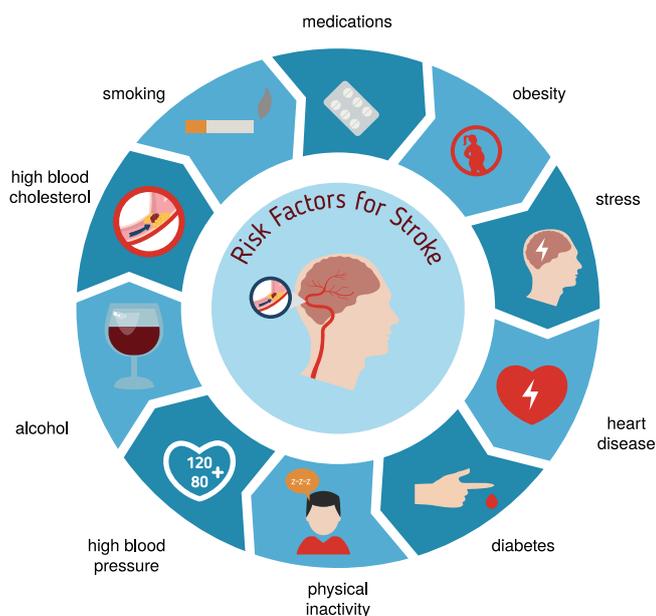
3. How do I take care of my health?

After a stroke, taking care of yourself is important.

Most survivors worry about their health and about having another stroke. The good news is there are things you can do to improve your health and reduce your risk of having another stroke.

After a stroke it's important to:

- › Talk with your stroke team – ask questions and share any concerns
- › After you leave hospital, attend any appointments arranged by hospital staff and see your General Practitioner (GP) regularly
- › Take the medication you are prescribed
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke
- › If you drink alcohol, drink only a safe amount. Read page 36 for advice



Causes of stroke

Your stroke team will tell you about your risk factors. If known, they'll tell you the cause of your stroke. Older age, being male, family history of stroke and having already had a stroke all increase your risk.

You can't change these things but there are other risk factors you can manage to reduce your risk of further stroke.

The most common medical risk factors are:

- › High blood pressure
- › High cholesterol
- › Atrial fibrillation (irregular heart rhythm)
- › Diabetes

Lifestyle factors also increase your risk. These include:

- › Smoking
- › Having an unhealthy diet
- › Unhealthy weight
- › Being inactive
- › Drinking too much alcohol
- › Stress

Medical risk factors

High Blood Pressure

High blood pressure is the biggest risk factor for stroke. High blood pressure is also called hypertension.

Your heart pumps blood through your body and brain. Blood pressure is a measure of the force with which blood presses on the walls of your arteries as it is pumped around your body.

If your blood pressure is too high, your arteries can thicken over time. They become weaker and less flexible. High blood pressure also increases the chance of blood clots forming.

High blood pressure can lead to a stroke in several ways:

- › It damages blood vessel walls by making them weaker
- › It can speed up common forms of heart disease
- › It can cause blood clots or plaques to break off artery walls and block a brain artery

Reduce this risk

- › Take anti-hypertensive medication to lower blood pressure
- › Ask your doctor or pharmacist to check your blood pressure regularly. You can also buy a monitor and check it yourself
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke
- › Keep salt to the recommended amount
- › If you drink alcohol, drink only a safe amount
Read page 36 for advice

120

80

Blood pressure is measured with two numbers:

Systolic pressure. The force your blood puts on the blood vessel walls as your heart pumps.

Diastolic pressure. The force your blood puts on blood vessel walls when your heart is resting between beats.

Normal blood pressure is around 120/80. If your blood pressure is regularly over 140/90, you have high blood pressure.

Atrial fibrillation

Atrial fibrillation (A. Fib) is an irregular heart rhythm.

With a normal heart beat the blood is pumped in and out regularly with the chambers of the heart completely emptying with each beat. In A. Fib the heart beats irregularly and sometimes rapidly and the blood does not move through the heart completely or smoothly. This increases the risk of clots forming in the heart and travelling to the brain causing an embolic ischaemic stroke.

If you experience symptoms such as palpitations (an awareness of your own heart beating, which may feel like fluttering, pounding, a thud or movement in your chest that might last for a few seconds or minutes), weakness, faintness or breathlessness whilst in hospital, it is important you report it to your nurse or doctor who can check your pulse. Your pulse should tick like a clock. If it feels irregular, they can arrange an electrocardiogram (ECG) test.

Talk to your GP or practice nurse if you are experiencing these symptoms when you go home.

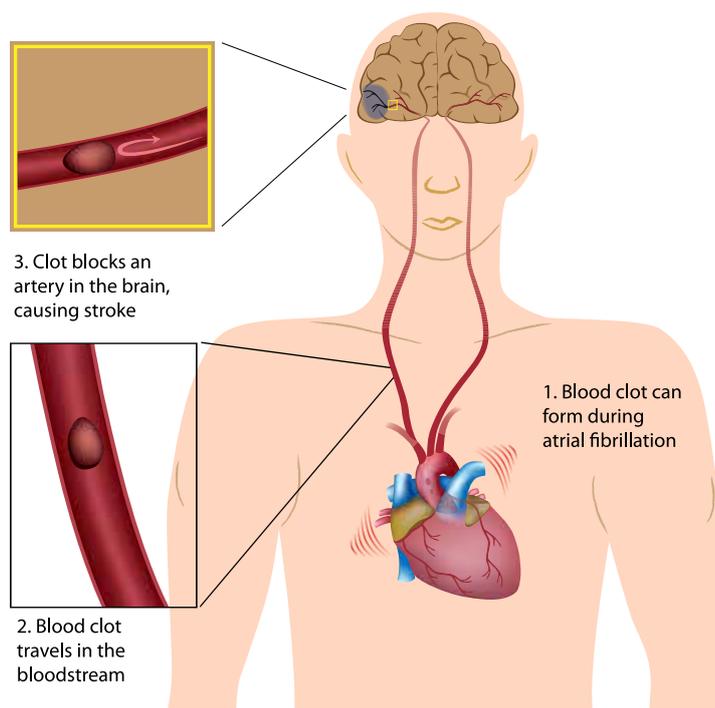
For most people, medication will be enough to control their A. Fib. Medication is used to control the heart's rhythm and to slow the heart rate. Anticoagulants ('blood thinners') are used to reduce the risk of blood clots forming and causing a stroke.

For some people, other treatment may be needed.

Reduce this risk

- › Understand the reasons for the medication you are prescribed
- › Receive education through anti-coagulation counselling by the clinical pharmacist or nurse if you have been newly prescribed anti-coagulants
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke

Atrial Fibrillation and Stroke



Cholesterol

Cholesterol is a fatty substance, which is vital for the normal functioning of your body. We need a certain amount of cholesterol as it helps form cell membranes and various hormones. Cholesterol is made in the liver but we can also get cholesterol from our diet.

If there is too much cholesterol in the blood, the body is unable to get rid of it and it gets deposited along the walls of the arteries which narrows or blocks the artery to the brain, and this can cause a stroke. High cholesterol is also known as hyperlipidaemia.

Cholesterol levels are affected by your family history, age, lifestyle, some medications and medical conditions. A high level of cholesterol increases your risk of having a heart attack or stroke.

There are two types of cholesterol:

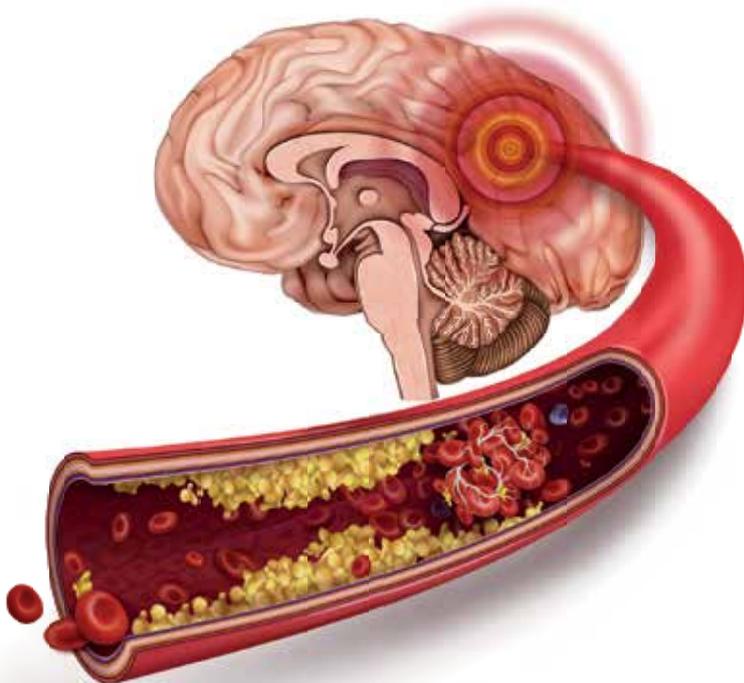
- › Low density lipoprotein (or LDL) is the 'bad' cholesterol that builds up on the artery walls

- › High density lipoprotein (or HDL) is the 'good' cholesterol. It is called the good cholesterol because it removes cholesterol from the blood stream to the liver where it is broken down and removed safely from our body

The ratio of good cholesterol to bad cholesterol is the key measurement of your stroke risk. The more HDL you have the lower your risk for stroke. The more LDL that you have, the greater your risk for stroke.

Reduce this risk

- › Take medication to lower cholesterol – most often statins
- › Ask your doctor to check your cholesterol regularly
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke
- › Ask for the '**Healthy Food for Life**' booklet for more in-depth dietary information
- › Reduce the amount of saturated fat in your diet



Cholesterol laden "plaque" on an artery wall due to high levels of bad cholesterol, causing narrowing of the artery and a subsequent thrombotic stroke in the brain.

Cholesterol levels

It is important that you know the recommended target levels for your cholesterol and get it checked on a regular basis following your stroke.

Cholesterol	Target	My own levels now	Date
Total cholesterol	No more than 5mmol/L		
LDL (bad) cholesterol	No more than 3mmol/L		
HDL (good) cholesterol	More than 1mmol/L (males) More than 1.2mmol/L (females)		
Triglycerides	No more than 1.7mmol/L		
If you have a history of heart disease or stroke or have diabetes your recommended targets are lower			
LDL (bad) cholesterol	No more than 1.8mmol/L		



Diabetes

If diabetes is left untreated or uncontrolled it increases the risk of vascular disease (disease of the blood vessels). This is when your artery walls become hard and narrow. This increases the risk of stroke, particularly ischaemic stroke.

People with diabetes are also more likely to have hypertension. This can also increase your risk of further strokes. If you have diabetes it is important to maintain healthy blood sugar levels to reduce your risk of having another stroke.

Reduce this risk

If you have diabetes it is important to keep your blood sugars within a recommended range.

- › Take the medication you are prescribed
- › Monitor your blood sugar levels regularly
- › Have a healthy lifestyle – be active, eat well, maintain a healthy weight and don't smoke
- › If you drink alcohol, talk to your doctor about what is a safe amount for you

Read page 36 for advice

- Talk to your doctor or Diabetes Clinical Nurse Specialist about the things you can do.



Other conditions

There are some other conditions that may increase your risk of stroke, including:

Aneurysm. A thin or weak spot on an artery wall. It can 'balloon out' and burst, causing a haemorrhagic stroke.

Patent foramen ovale (PFO). A hole in the heart that can allow blood clots to pass into the arteries, causing a stroke.

Contraceptive pill, hormone replacement therapy and pregnancy. Taking the contraceptive pill, using hormone replacement therapy (HRT) and pregnancy can increase the risk of stroke.

The contraceptive pill increases the risk of blood clots forming. HRT also increases the risk of blood clots forming, and it can increase your blood pressure. Pregnancy causes the levels of female hormones to rise, causing changes in the blood and the blood vessels. Blood pressure can also rise during pregnancy.

Rarer disorders that can cause stroke are often hereditary, meaning they are passed down through families.

Blood vessel disorders cause changes in the arteries, causing problems with the blood supply to the brain. These include:

- › Fibromuscular dysplasia (FMD)
- › Fabry disease
- › CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy)
- › Cerebral amyloid angiopathy (CAA)

Cryptogenic stroke

When a cause can't be determined it's called a cryptogenic stroke. Even if the cause of your stroke is unknown, it is important to understand all the risk factors and how to manage them.

Sean's story

I have had a few strokes. My first stroke happened in 2012. The strokes happened when I was asleep, after reading a book. I woke up in the bed not knowing what had happened. The last stroke was different.

I have some risk factors for stroke which I am now managing. Before my first stroke I would often have fries for breakfast, I didn't watch what I was eating and I got very little exercise. I am an ex smoker, having been off cigarettes for the past 11 years.

I was diagnosed with sleep apnoea in recent years, and use a BiPAP machine at night to regulate my breathing and reduce my risk of further stroke and heart events.

I have atrial fibrillation and that means my heart rate is very irregular. When you have atrial fibrillation this increases your chances of getting a stroke. To lessen the risk of getting a stroke I am taking anti-coagulation medication which my doctors prescribed. It is very important to take my anti-coagulation medication every day, as missing one dose can increase my risk of getting another stroke.

Since my strokes my life has changed and I too have had to make changes to my life. I now exercise regularly by going for cycles and walking with the dog. At breakfast time I enjoy porridge and enjoy overall healthier food in my diet. I can no longer drive a car or work because of my stroke, because I drove a truck for a living. It's hard not to be able to drive with the car outside the door. I do enjoy doing a bit of gardening and I have hens and ducks to look after. In the summer I save a bit of turf in the bog.



I feel better and healthier in myself after making changes with my lifestyle. If I had advice for anybody trying to change their lifestyle I would tell them to quit all the bad habits they have but take it in stages. Start with the one area first you want to make your changes, and move on to the next when you have achieved what you set out to do. Listen to the advice of the healthcare professionals and get help from them if you need any support to change your lifestyle habits.

Sean, aged 67, Stroke Survivor.

Lifestyle Risk Factors

Smoking

Smoking doubles your risk of stroke. The more you smoke the greater your risk of stroke. Smoking increases your stroke risk by increasing blood pressure and reducing oxygen in the blood. Smoking also increases the stickiness of the blood. This further increases the risk of blood clots forming.

Tobacco smoke contains over 4,000 toxic chemicals which are deposited on the lungs or absorbed into the bloodstream. Some of these chemicals damage blood vessel walls, leading to atherosclerosis (narrowing and hardening of the arteries). This increases the chance of blood clots forming in the arteries to the brain and heart.

Control this risk by:

Knowing it is never too late to stop smoking. Five to fifteen years after quitting, a person's risk for stroke becomes similar to someone who has never smoked. There is a lot of help available if you want to stop smoking. This includes telephone counselling, smoking cessation clinics, nicotine replacement therapy products and medication. Ask your doctor, nurse or pharmacist for advice.

HSE Quitline provides information and support:

QUIT freephone 1800 201 203
FREETEXT QUIT to 50100

Access  @Quit.ie

Alcohol intake

Drinking large amounts of alcohol increases your risk of stroke.

Regular, heavy drinking can raise blood pressure to consistently high levels. This increases the risk of both types of stroke (ischaemic and haemorrhagic).

Control this risk by:

You can reduce your risk of further strokes by limiting your alcohol consumption.

- › If you drink alcohol, speak to your doctor about when it is safe for you to start drinking alcohol again. Ask how much alcohol it is safe for you to drink

After the initial recovery period it is still important to limit alcohol intake.

What is a standard unit?



Weekly lower risk limits

MEN	WOMEN
17 standard drinks/units	11 standard drinks/units
170g alcohol over a week	110g alcohol over a week

National Website:

Ask about alcohol.ie - How alcohol affects your health and wellbeing



HSE Drugs and Alcohol Helpline:
Freephone 1800 459459 for confidential information and support.

Rethink your diet after a stroke

Having an unhealthy diet increases your risk of high blood pressure and cholesterol, increasing the risk of stroke. Being inactive, having a poor diet or both can increase your risk of high blood pressure, high blood cholesterol, diabetes, heart disease and further strokes.

Healthy eating is important for reducing your risk of further stroke. It will also help you get to and maintain a healthy weight. It impacts on a number of risk factors.

Control this risk by:

Ask your nurse or dietitian for the **'Healthy Food for Life'** booklet which has some top tips to help maintain a healthy balance diet.

Salt. Too much salt can raise your blood pressure. Aim to consume less than four grams of salt each day. This is about three quarters of a teaspoon. It's equivalent to 1600 milligrams sodium. Packaged and processed food already has salt in it. Include more fresh food in your diet. Don't add salt when cooking or at the table.

Sugar. Too much sugar can damage blood vessels. Ease up on sweets, cakes, biscuits and chocolate. Avoid sugary drinks such as soft drinks, energy drinks, and fruit drinks with added sugar.

Saturated Fats and Trans Fats.

These cause high cholesterol.

Saturated fats include butter, lard, palm oil, dripping, coconut oil and milk, hard cheese, cream and fatty meat.

Trans fats are found in biscuits, cakes, pastries, deep-fried foods.

Choose mostly polyunsaturated and monounsaturated oils and spreads which include rapeseed and olive oil, soya, sunflower and corn oils

Polyunsaturated fats can also be found in fish (especially oily fish), unsalted nuts (walnuts and brazil nuts), seeds (such as sesame), hummus and tahini.

Monounsaturated fats are also found in avocados and some unsalted nuts, such as almonds, brazils, and peanuts.

Unhealthy Weight

Being overweight can lead to high blood pressure, high cholesterol and diabetes, increasing your risk of stroke.

Body mass index, or BMI, is one way to assess whether your weight is in the healthy range. Your waist circumference is another way. A healthy waist measurement should be less than 80cm in women and less than 94cm in men.

How do you measure your waist?

To measure waist circumference correctly, you should use a flexible tape measure that is not elastic. The tape measure should not stretch when you are taking your belly measurement. You should also remove any bulky clothing that can add padding around the abdomen.

Sit up to get an accurate waist measurement. Then, wrap the tape measure around the widest part of your stomach, across your belly button. The tape measure should rest gently on your skin. Take the measurement two times to make sure you get a consistent result. Holding the tape too tight so that it digs into your flesh, or holding it too loosely so that it droops will cause you to get an incorrect result.

Control this risk by:

Find out what changes you need to make to your diet and how active you are. Set goals to get to and maintain a healthy weight.

If you are having difficulties keeping your weight within recommended levels ask a doctor, nurse or dietitian for help.

Getting to a healthy weight can take time. To get to and maintain a healthy weight, you'll need to understand what changes you need to make to your diet and how active you are.

Start by setting a small goal and think about the everyday things you can do that will help. Once you reach this goal, set another one.

Being Active and Exercise

Exercise.

Regular physical activity can reduce your risk of stroke.

Aim to be active for 30 minutes most days. It's okay to start small and build up gradually. Your 30 minutes can be made up of smaller bursts throughout the day. Exercise at a light to moderate intensity. You should be able to talk while exercising.

Start by setting a goal about how active you want to be and what you want to do. Think about the small things you can do every day to help you achieve your goal. Get into activities you enjoy and invite family and friends to join in.

People with high blood pressure should be careful with some types of exercises. If you have high blood pressure, talk to your doctor about an exercise program.

You can still exercise even if you have weakness or difficulties with mobility since your stroke. Physical activity leads to improvements in fitness, walking speed and endurance. Talk to your doctor and/or physiotherapist about the best types of exercise for you.

Prevent weight gain by being physically active and eating according to your energy needs. The **'Healthy Food for Life'** booklet has some top tips to help reach a healthy weight.

What else can I do to control my risk?

Medications

After a stroke, almost everyone will need to take medication for the rest of their life.

Medications to lower blood pressure and cholesterol are usually prescribed, even if your blood pressure and cholesterol are normal. These medications have been shown to reduce the risk of another stroke.

It's likely you'll be taking new or different medications after your stroke.

Make sure you understand:

- › What your medications do
- › How long you'll need to take them
- › What monitoring or follow up you need

Remember:

- › Ask your doctor or pharmacist if you are unsure or have questions
- › Your doctor or pharmacist can arrange a review of your medications at any time
- › Never stop taking your medication or change your dose without talking to your doctor

Make sure you have a list of medications when you leave hospital.

Using a blister pack or pill box may help you to remember to take your medications correctly.

"The Know, Check, Ask" campaign helps you to keep track of your medications and communicate about them with healthcare professionals and family members.

Visit www.safermeds.ie for further details.

How do I know if I am having another stroke?

It's important for you and your family and friends to know the signs of stroke so you can act quickly if necessary.

Remember stroke is a medical emergency. Never ignore the signs. Always call 999 or 112.

The **FAST** test is an easy way to remember and recognise the common signs of stroke.

FAST stands for Face, Arms, Speech, Time to act fast.

It is very important to seek medical assistance by calling **999**. The operator will help you work out what to do next.

Facial weakness, arm weakness and difficulty with speech are the most common symptoms or signs of stroke, but they are not the only signs.

Other signs of stroke may include one, or a combination of:

- › Weakness or numbness or paralysis of the face, arm or leg on either or both sides of the body
- › Difficulty speaking or understanding
- › Dizziness, loss of balance or an unexplained fall
- › Loss of vision, sudden blurring or decreased vision in one or both eyes
- › Headache, usually severe and abrupt onset or unexplained change in the pattern of headaches
- › Difficulty swallowing

If you or someone else experiences the signs of stroke, no matter how long they last, call **999** or **112** immediately. The faster you act, the more of the person you save.

Recognise Stroke signs
Time is brain!

F **ACE**
Has the face fallen to one side.
Can they smile?

A **RMS**
Can they raise both arms and keep them there?

S **PEECH**
Is their speech slurred or abnormal?

T **IME**
Act **FAST** this is an emergency!

The poster features four rows of illustrations: a woman's face with one side shaded, a hand holding a pen, a person's mouth with a speech bubble containing '???', and a hand holding a mobile phone next to a stopwatch.

CALL 999 or 112

Used with kind permission of the Department of Stroke Medicine in Beaumont Hospital, Dublin.

Gerard's story

Hello my name is Gerard, I am 58 years old. I am of average height, and would be quite active, regularly doing 10,000 steps a day. I worked as a Financial Advisor, but due to Covid-19 I was working for the HSE in Galway. I overcame T-cell Leukaemia as a 20 year old, and I suffered a stroke two weeks ago.

I am incredibly lucky, as I was at work when I suddenly took ill and developed weakness to my right side. The nurses where I worked recognised my symptoms and immediately called 999 and an ambulance arrived very quickly. Due to the swiftness of the nurses in my workplace, I'm alive today. I spent a week in University Hospital Galway and I am now in the Acute Stroke Unit in Castlebar receiving

excellent care there. If it were a half hour later, it might have been a completely different story, as I would be driving the 80km to my home in Castlebar.

I am now due to go to the Sacred Heart Home for the next phase of Occupational Therapy and Physiotherapy in order for me to improve and so I can lead a normal life. I can thank the nurses in my workplace, who saved my life by their quick intervention which meant I was in hospital very quickly.

Everybody's stroke is different; I will lead a different life from now and I look forward to the future. I had thought a stroke was associated with older people. I will listen to those who provide wonderful care and advice going forward.

I lost the power in my right hand side, and I am making a good recovery. Every day I'm a bit stronger.

I am alive to tell this story.

Gerard, aged 58, Stroke Survivor.



4. What happens after my hospital stay?

Discharge planning

This is when you and the stroke team start planning for things you may need as you leave hospital. Starting a discharge plan as early as possible is important. If needed, your stroke team will help organise services and make contact with key service providers before you leave hospital.

These services may include:

- › Community Nursing
- › Community services, e.g. home help, respite care
- › Specialist treatment appointments

Once you have been discharged, a letter should be sent to your doctor.

When you are in hospital many of the decisions made are about your health needs at that time. The advice and support of the stroke team has a lot to do with these decisions.

When you leave hospital you and your family will have more responsibility for making decisions. There is always help available.

You can:

- › Talk to your GP
- › Talk to your Public Health Nurse
- › See end of this section for other supports

Where do I go after my stroke?

There are four general pathways that may occur after someone has had a stroke at MUH.

You may:

1. Go directly home from the acute hospital
2. Be admitted to a specialised rehabilitation unit (e.g. Sacred Heart Hospital)
3. Go to a District Hospital to allow you time to recover
4. Receive palliative care

1. Going home from the acute stroke unit or medical ward

Everyone has different needs. You and your stroke team may decide the best option is to go straight home from the acute stroke unit or medical ward. If so, the stroke team will work with you and your family to help plan your discharge.

Rehabilitation is an important part of stroke recovery; you should discuss your ongoing rehabilitation needs with the stroke team.

2. Admission to a specialised rehabilitation unit

Sometimes people are admitted to a specialised rehabilitation unit. A rehabilitation team will work with you and your family to enable you to regain skills and learn new skills to help you continue your recovery and get on with life.

The Sacred Heart Hospital in Castlebar is a multidisciplinary, residential rehabilitation unit which provides rehabilitation to people after stroke and other illnesses. During your stay there, the staff will discuss with you and your family what care you may need in the future and whether these care needs can be met at home. Most people go directly home from rehabilitation units, but some may need to go to a nursing home because their care needs cannot be met elsewhere.

3. District Hospitals

A small number of people go to a District Hospital after stroke; these hospitals provide nursing, physiotherapy and some medical care. The level of physiotherapy provided in the District hospitals can be less than is provided in the Rehabilitation Units.

A stay in the district hospital can give the person time and care while they are recovering and allows time to assess and plan for future care. The stroke team will let you know if they think this is the best discharge option.

4. Palliative Care

A very small number of people who have a stroke may become gravely ill due to the stroke and they may benefit from Palliative care. Palliative care is specialised care provided to ease symptoms and support end of life care.

Palliative care includes assistance with physical, psychological, social, emotional and spiritual needs. The focus is on quality of life, providing relief from symptoms, pain and stress. Palliative care recognises how important this time is, and helps ensure family and friends can spend precious time together with their loved one.

Palliative care may be provided in the Hospital. It can also be provided at home with support from a palliative care team.



Margaret's story

I awoke on St. Stephen's morning in 2017 and felt fine. It was only as I went to get dressed that I began to lose my balance and my husband said that I was talking strange. When I reached for my clothes I couldn't grasp them. My husband helped me sit on the bed and what followed is mostly a blur but suffice it to say it was a very serious stroke.

What I do know is that my husband acted promptly as he feared I was having a stroke. I believe luck was on my side throughout the day.

The ambulance arrived within an hour and got me swiftly to Mayo University Hospital. There I was administered the thrombolytic injection to dissolve the clot and transferred immediately to Beaumont Hospital. My husband was informed post scans, that there would be no surgery as I wouldn't survive it. I was then moved to the ICU Unit where a wonderful doctor fought for me to have my surgery. Two days later I had major surgery. I have received my rehabilitation and the education to help me understand my



stroke via Mayo University Hospital (Stroke Unit), Beaumont Hospital, The Sacred Heart Home, The National Rehabilitation Hospital and Quest. I am eternally indebted to them. They have helped me physically, mentally, psychologically and emotionally.

I was just 54 at the time it happened and I just thought it was relatively young to get a stroke. The part of my brain mostly affected by my stroke is the frontal lobe area. This has impacted greatly on my cognitive skills – planning, organising, initiating, concentrating and memory recall. I did have some loss of function on my left side and my peripheral vision was impacted but now my vision is good again and I can drive. Overall I'm good physically.

My side effects post stroke are mainly fatigue, difficulty with processing and remembering information if concentrating on something else. I have also difficulty holding attention to a topic in conversations, planning family meals and completing domestic activities. A task that was once miniscule prior stroke has now become immense. An example of this is, is this article.

What should have taken me approximately an hour to write has taken a couple of weeks. Application, planning and scheduling took forever. That's one of my biggest frustrations post stroke. What used to be automatic has become conscious and it takes time and effort to retrain the brain back to the automatic stage. Psychologically, I am quite often confused, disorientated, depressed and anxious and have apathy on a large scale. I am not always aware of this condition and my family quite often bring it to my attention. I generally feel that I have had a complete personality change.

The assistance I'm receiving particularly at Quest; with strategies and daily maintenance plan is helping me on my journey. Nearly three years on I'm feeling stronger, attending Quest twice weekly and hence my days are complete, positive and rewarding. The group meetings with Croi have been very beneficial to me and my family. My fears, fatigue and other side effects are slowly diminishing. My goal is to source some voluntary work and hopefully return to paid employment in the near future.

The advice that I would give to any stroke survivor is to please use all the supports out there at your disposal. Have a daily maintenance plan incorporating exercise, relaxation and a rest period. They really make all the difference.

I would like to thank my husband Ian and family for being my Rock throughout all my illness. I feel Santa will be good this Christmas and spoil them a little.

Margaret, Stroke survivor.

For family and carers

Becoming a carer

As the time to leave hospital gets closer, you may find yourself taking on a carer role.

Some carers look after another person 24 hours a day. They help with all sorts of things, like feeding, bathing, dressing, helping go to the toilet, lifting and moving, and helping with medicines.

Other carers look after people who are fairly independent but might need someone to help with everyday tasks such as banking, transport, shopping and housework.

It is normal for carers to feel love for their family member and pride in themselves and their family. It's normal to feel grateful that your family member survived, and for the care they received. It's also normal to feel angry, resentful, scared, guilty and sad.

Becoming a carer might not be something you had ever imagined. While caring for another person is an expression of our love, respect and connection, it can take a toll. The impact on you can get lost amongst all the demands.

It helps to talk to a trusted family member or friend about how you are feeling. You can also talk to your trusted health professional e.g. a member of the Stroke Team or your GP. The following page has supports or services that may help too.

Getting ready to care at home

There may be things the survivor will need help with once they get home. It's important to talk to the stroke team about what life will be like at home.

You may need to be shown new ways to do things, whether the survivor is doing them independently or whether someone is helping. Equipment, and practice of using equipment may be needed.

Make sure the stroke team understand your other responsibilities. Make sure you are clear about anything you don't feel comfortable doing. Services may be available to help.

Before going home, make sure you feel confident about the plan to go home. Make sure you know who to ask if you need help. Make sure any questions you have are answered before you leave hospital.

Carer payments and services

Carer payments are available for people who provide care at home for someone with a severe disability, medical condition or who is frail and aged. Eligibility depends on your circumstances, and there is an income and assets test.

The Citizen's Information Board can provide more advice at

www.citizensinformationboard.ie

For full details of relevant contact numbers see page 61.

Get help

Speak to a trusted health professional e.g. a member of the Stroke Team or your GP as they may be able to provide support, as well as information about carer services and payments. Counselling is also available for carers – talk to your GP or see across for further information on local and national services.

Carers Supports and Services

Family Carers Ireland

Family Carers Ireland provide support, information and advice, support groups, training sessions and courses, respite opportunities, and home care services throughout county Mayo. You can contact us on **094 9041149** or Email mayosupport@familycarers.ie

Follow us on Facebook at www.facebook.com/FamilyCarersMayo for up to date information on events and activities.

The national young carers programme is available to all young carers aged 8-24.

They offer a range of supports and services including a free Young Carer Card, Assessments, One-to-one support, Online Young Carer Groups, Webinars and Online Workshops, Counselling, Care Planning, Respite Weekends, and run programmes in schools, colleges and universities.

You can also contact our Careline for advice and information on **1800 24 07 24**. Our website www.familycarers.ie contains information on all aspects of our service including links to information on rights and entitlements, educational opportunities, current and ongoing campaigns on behalf of family carers, as well as information and advice on specific caring situations.

Your Mental Health HSE Resource

This is a dedicated section on the HSE website. Includes advice, information and signposting to support services for mental health and wellbeing. Find this information at: www.yourmentalhealth.ie

West Be Well Website

www.westbewell.ie was developed by voluntary, community and statutory groups involved in wellbeing, mental health promotion, and suicide prevention initiatives in Galway, Mayo and Roscommon to provide health and well being resources. This common platform communicates key health messages and promotes education and training events.

The website provides contact details for a wide range of national and local services which are government funded and available in the community. Finally, it offers easy access to resource materials.

The Family Centre Castlebar offers a wide range of support services for families and individuals through Counselling, Flourish Social Prescribing Service, Mayo Suicide Bereavement Liaison Service, Support Groups, and Education & Training Programmes.

Sometimes after an experience of having a stroke and adjusting to a new way of living, it may be helpful to speak with a professional counsellor who can offer a confidential and non - judgemental space just for you to help you adjust and deal with this new change. All change impacts on us and our lives.

To enquire about the counselling service or any one of the other services and supports telephone **094 9025900**.

Email: info@thefamilycentre.com
Website: www.thefamilycentre.com

Croi Carers group provides an opportunity for family/friends of stroke survivors to meet others who are living with the effects of a stroke. Informal meetings take place where people can support each other by sharing experiences and information. Meets on Zoom every month. Tel: **091 544310** Or Email: healthteam@croi.ie

Irish Heart Foundation Carers Group on Facebook

The aim of this group is to create an online forum for carers of people affected by stroke in Ireland to discuss and share their experiences.

Becoming a carer for someone affected by stroke is an enormous undertaking physically, mentally, and emotionally. Within this group you will find useful information and resources as well as a safe space to share your thoughts and concerns with others in similar positions. Tel: **01 6685001** for further details.

Difficulties you may experience

Fear of having another stroke

For anyone who's had a stroke, one of the biggest fears is it happening again. Having a plan and taking action to reduce your risk of stroke can help.

While being afraid of having another stroke is very normal, it can become overwhelming. If some time has passed and you are struggling to cope with how you are feeling, you may need some help.

Get help

Speak to your stroke team members or GP about how you are feeling. Contact the Mayo Stroke Support Group for support and advice – details on page 53.

Fatigue and sleep

After you get home you may notice your fatigue is worse. You may notice the effects of your stroke more too, and feel like you are getting worse not better. This is very common as you get back into daily life and start doing more things for yourself.

You may also have changes with your sleep. Not getting a good night sleep can affect your thinking, mood, energy levels and appetite. Sleep-related breathing disorders can also develop after a stroke.

Getting enough good-quality sleep is an important part of recovery. Good 'sleep hygiene' will help you get a good night's sleep. It includes:

Work with your body clock. Get up at the same time every day; get enough early morning sunshine and go to bed when your body tells you it's ready.

Create a restful sleep environment. Make sure your bed and bedroom is comfortable, dark and quiet. Use earplugs if necessary. Use your bedroom only for sleeping and intimacy.

Avoid caffeine, cigarettes, drugs and alcohol. Sleeping pills should only be used as a temporary

last resort and under medical advice.

Relax before going to bed. Consciously do your worrying earlier in the day so you can 'knock off' at bedtime. Create a relaxing routine and try relaxation exercises.

Get help

Speak to your GP or other health professional if you have questions or concerns.

Stress

Stress is the body's response to a real or perceived threat. That response – a racing heart, tense muscles and sweating – is meant to get you ready for some kind of action and out of harm's way. You may experience stress in different ways. Often it is a mix of anxiety, depression, panicky feelings, poor sleep and poor wellbeing.

Stress can be helpful. But too much stress can harm your health and increase your risk of heart disease and stroke. There is "good" stress and "bad" stress. Good stress can be managed. It can stimulate you to get things done. You can handle good stress.

Bad stress, which can last for hours, days, weeks or more, is dangerous. It can harm your health and wellbeing. There are undeniable links between heart disease, stroke and stress. Stress can cause the heart to work harder, increase blood pressure, and increase sugar and fat levels in the blood. These things, in turn, can increase the risk of clots forming and travelling to the heart or brain, causing a heart attack or stroke. Having a serious health event like a stroke can also be stressful. And that stress can slow down the recovery process or even create health problems that weren't there before.

Get help

Talk to your GP or other healthcare professional if you are experiencing stress.

Find useful information on stress control at this website: www.stresscontrol.ie

Depression and anxiety

Depression and anxiety are common after stroke. Stroke survivors, carers and family members can all experience depression and anxiety.

It's normal to feel sadness and grief in the time shortly after the stroke. These feelings should start to fade as time passes. If some time has passed and you are still feeling down or anxious, or struggling to cope with how you are feeling, you may need some help.

You may have depression if you feel sad or down for more than two weeks. You may lose interest in things you normally enjoy, lack energy, have difficulty sleeping, or sleep more than usual. You may find it difficult to concentrate, to solve problems and to keep appointments.

You may have anxiety if anxious feelings do not go away once a stressful situation is over, or if you are anxious for no particular reason.

Never ignore the signs of depression or anxiety. Depression and anxiety are highly treatable and recovery is common.

Get help

Speak to your GP or other health professional if you are feeling depressed or anxious.

Further supports:

Counselling in Primary Care (CIPC)

Short-term counselling (up to 8 sessions) with a professionally qualified and accredited counsellor. Service is available free of charge, for people aged 18 years and over, with a full medical card.

Ask your Primary Care Provider e.g. GP, Practice Nurse, Public Health Nurse, for referral to this service.

The Family Centre Castlebar offers a wide range of support services for families and individuals through Counselling, Flourish Social Prescribing Service and Support Groups. Sometimes after an experience of having a stroke and adjusting to a new way of living it may be helpful to speak with a professional counsellor who can offer a confidential and non-judgemental space just for you to help you adjust and deal with this new change. All change impacts on us and our lives.

To enquire about the counselling service or any one of the other services and supports:

Tel: **094 9025900**

Email: info@thefamilycentre.com

Website: www.thefamilycentre.com

Your Mental Health HSE Resource

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www.westbewell.ie was developed by voluntary, community and statutory groups involved in wellbeing, mental health promotion, and suicide prevention initiatives in Galway, Mayo and Roscommon to provide health and well being resources.

This common platform communicates key health messages and promotes education and training events. The website provides contact details for a wide range of national and local services which are government funded and available in the community.

Finally, it offers easy access to resource materials.

Driving

You need medical clearance before you return to driving. Current medical guidelines (2020) say you should not return to driving after a stroke for at least:

- › Four weeks for Group 1 drivers (car, motorcycle or tractor)
- › Three months for Group 2 drivers (buses and trucks)

Most people can return to driving with the right advice and support from their medical team.

When considering if you are fit to drive your doctor and/or stroke team may assess the following:

- › Vision
- › Memory, attention, concentration, insight, perception
- › Sensation and power in limbs
- › Fatigue
- › Seizures

Speak to your doctor

Your doctor can clear you to drive if you have made a good recovery from the stroke and you don't have any remaining impairments affecting your ability to drive.

Some drivers may also need to do an on-road driving assessment with a specialist driving assessor.

You should inform your insurance company of your stroke or TIA. If you do not, they may not honour a claim that you might make in the future.

Even if you have physical disabilities after your stroke, you may still be able to drive safely if you drive a car. The National Standard Authority of Ireland (NSAI) website includes a list of companies approved for vehicle conversions.

Why is it important that I am fully fit to drive?

If you continue to drive against medical advice, the National Driver Licence Service (NDLS) and An Garda Síochána can take action to have your driving licence cancelled. This will also affect your motor insurance premium.

For further information:

NDLS: www.ndls.ie

Please find the Stroke, Transient Ischaemic attack and Driving Leaflet on the Stroke Information Display Board.

RSA: <https://www.rsa.ie/RSA/Licensed-Drivers/Safe-driving/Medical-Issues>

NSAI: <https://www.nsai.ie/certification/automotive/national-type-approva/vehicle-adaption-for-disabled-person/>

Stroke recovery can take a long time for some people, so be patient if you are advised to wait longer before you start driving again.

If you're unable to return to driving, community services may be able to help with transport for shopping and medical appointments. See details for Mayo Local Link on page 64.

Work

If you would like to consider returning to work, talk to your stroke team or your GP about the effects of your stroke, what to expect and strategies for a successful return to work.

You may need:

- › Changes to your duties and the hours you work
- › Equipment or modifications at work to make your job easier

You can then speak with your employer about the support you need to return to work successfully. When planning your return to work, keep in mind that fatigue can last longer than you expect.

Ongoing medical problems may prevent you from being safe or well enough to return to work. Medical clearance from your doctor is needed before you get back to work.

There are services to help you return to work, as well as services that can help if you cannot return.

For further information:

The **National Learning Network** offers a range of FREE rehabilitative and vocational training courses for people with extra support needs from 16 to 65 years of age. All courses at the National Learning Network provide the opportunity for individuals to gain the qualifications that they want in a way and at a pace that suits their needs.

These QQI accredited courses are delivered by instructors who tailor their teaching methods to the individual needs of students depending on the challenges that they face, be it illness, accident, injury or disability.

Due to COVID-19 they are now offering all programmes via a blended learning approach which combines classroom based & home based learning.

Programmes on offer include:

Computer studies and Office Skills: Enables students to gain the skills and qualification's needed to work in an office environment or progress on to further education and training, QQI level 4 or 5. **Based in Castlebar.**

Employer Based Training: Offers a mix of classroom-based learning and on-job-training. It gives structured training based with an employer of your choice, this QQI level 4 or 5 offers real opportunities and direct links to employers. **Available throughout County Mayo.**

Job Start: Is designed as a stepping-stone to getting a job for students who have little or no work experience or who are considering a change in career direction. Certification: QQI Level 3 or 4 in Employment skills. **Based in Castlebar.**

IT & Business Studies: Students are provided with a laptop and receive individual support from their instructor. Certification: QQI Level 5 in Information Processing or Office Administration. **Locations based in Castlebar and Belmullet.**

Sports Industry & Gym Instructor Studies: Offers a QQI level 4 or 5 in Sports, Recreation and Exercise as well as industry recognised qualifications such as ITEC Gym Instructor Diploma, & National Pool Lifeguard Award (RLSS). **Based in Castlebar.**

National Learning Network,
Castlebar,
Co. Mayo.
Tel: **0949022770**

Work continued

Employability

The aim of Employability Mayo is to work with people under 65 who by virtue of their condition, illness, impairment or disability who require support into open paid employment leading to independence and career progression.

EmployAbility Mayo

Greg Barry
Co-ordinator
Employability Mayo

Tel: **094 9043008**
Tel: **087 7988045**

Quest Brain Injury Services is funded by the HSE West, and the service is delivered to Galway, Mayo and Roscommon. We offer services to survivors of brain injury within the community setting from the main centre in Galway. Within Mayo and Roscommon, the service is delivered on an Outreach basis, with support from the main team.

The programme in Mayo addresses such areas as brain injury education, memory, general cognitive (thinking) skills, attention and concentration, daily living skills.

The Quest Team aims to assist individuals under 65 years of age to readjust post brain injury, often enabling a return to work, education, maximisation of independence, and an overall improvement in general function.

Further information and application forms can be obtained by contacting Quest:

Tel: **091 778850**
Email: quest@nln.ie

Financial

To obtain information about Social Welfare payments and entitlements (e.g. Disability benefit, Carer Support), Contact Citizens Information Board or your local Intreo Office (Department of Employment affairs and Social Protection).

www.citizensinformationboard.ie

For full details of relevant contact numbers of the Citizens Information Board see page 61



YOU'RE NOT ALONE

Alone can help you get the support you are entitled to if you have financial or legal issues, for over 60s.

All You Need To Do Is:

1. Contact us at: **ALONE National Support Line**
0818 222 024

or **Email** hello@alone.ie

2. ALONE staff will get in touch with you and meet you if needed

3. We will work with you to find a solution to your current challenge Finance and Legal

Website: www.alone.ie

ALONE HQ, Olympic House, Pleasant St.,
Dublin 8.

My leaving hospital checklist

Use this checklist to help you to get ready for leaving hospital

Medications

- I have a list of my medications
- I know why I take each of my medications

Services

- I know what services I need (e.g. home help)
- I know how these will be organised

Daily life

- I know how to do the things I want and need to do every day
- The people helping me know how to help and support me at home (if needed)
- I know what aids and items might help me be more independent at home

Home modifications

- I know where to get the information required to make adaptations to my home

Reducing my risk of another stroke

- I know how to manage my stroke risk factors
- I know the signs of stroke – F.A.S.T.
- I know to call 999 or 112 if I experience the signs

5. Local and National Services and Supports

This section outlines peer support groups, local and national services and supports that may be of use to you or your family or friends. Index of service and supports as follows:

Croí	Page 53
Irish Heart Foundation	Page 55
Living Well	Page 56
Acquired Brain Injury Ireland	Page 58
Age and Opportunity	Page 58
Age Action	Page 59
ALONE	Page 60
Aware	Page 60
Citizen Information Board	Page 61
HSE: Easy chair based exercises for older adults	Page 61
Family Centre Castlebar	Page 62
Flourish	Page 62
Headway (Brain Injury Services and Support)	Page 63
Irish Men's Sheds Association	Page 63
Irish Wheelchair Association	Page 64
Local Link Transport Mayo	Page 64
Memory Technology Resource Room	Page 65
National Council of the Blind	Page 65
Quest Brain Injury Services	Page 66
The Samaritans	Page 66

Peer and Healthcare Professional Support

Mayo Stroke Support Group



The aims of the stroke support group are:

- › To create a positive environment to meet others and share and learn from each other's experiences
- › To provide advice, education and support on stroke and good health
- › To encourage participation in activities beneficial to your wellbeing
- › Peer support and friendship

The group sessions are facilitated by the Croí Development Facilitator for the Stroke Support Groups. The group activities are planned and organised by a small steering group made up of members of the Stroke Support Group, HSE and Croí staff.

Who can attend a Stroke Support Group?

Everybody! We welcome people who have experienced stroke; partners; family and friends; carers; anyone who has been affected by stroke.

Mayo Croí Stroke Support Group is facilitated and meet on Zoom on the last Thursday of every month. New members always welcome.

Call: 091 544310

Or **Email healthteam@croi.ie** for more information.

Working Age Stroke Support Group

Working Age Stroke Support Group meet on Zoom every month.

Call: 091 544310

Or **Email [healthteam@croi](mailto:healthteam@croi.ie)** for more information.



Fighting Heart Disease & Stroke

Carers Group

The Croí Carers Group provides an opportunity for family/friends of stroke survivors to meet others who are living with the effects of a stroke. Informal meetings take place where people can support each other by sharing experiences and information. Meets on Zoom every month.

Call: 091 544310

Or **Email: healthteam@croi.ie**

MyStroke

Is a 6 week, group educational programme designed to help stroke survivors and their families understand stroke and explore their current lifestyle habits. Access to this programme is via referral via your Stroke physician/team.

Call: 091 544310

Or **Email: healthteam@croi.ie** for more information. This programme is facilitated virtually.

Heartlink West

HeartLink West offers a FREE support helpline with direct access to Croí's Cardiovascular Nurse Specialist and Croí's community specialist health team. If you are a patient or caring for someone who is living with heart disease or stroke or you have just been discharged from hospital following an event please call us on **091 544310** or email **healthteam@croi.ie** to speak to a member of the team.

Heartlink West also offers FREE virtual health chats covering discussions on topics such as heart health, diet, physical activity and stress management. To enquire about upcoming chats please call **091 544310** or email **healthteam@croi.ie**

Alec's story

Since my stroke I have had to learn improvisational skills as I have no power in my left side but the most important thing was to learn to have patience. Being involved with the Mayo Stroke Support Group has helped Ali, my wife, and I a lot and you get to share experiences with other people in the same position. Also, I am on Stroke Support Group steering committee and facilitate programmes for "The Living Well Programme". Helping other people helps me so much. Participating in the Stroke Support Group and Living Well Programme keeps my mind alert and gives me a sense of purpose.

I think the most important thing we learned is that the partner of the stroke patient is affected just as much if not more than the person who had the stroke as their world is also turned upside down. If one is lucky like me to have a partner, my wife Ali, who steps up to the plate and supports me 100%. I am very blessed indeed. Getting through the tough early days together has made us stronger. As a couple we both enjoy life together and are very happy. So in a strange way having a stroke turned out to bring Ali and me closer, and we understand and respect each other better. Hence the title of a book I am currently writing is called "A stroke of luck". Onwards and upwards!

Alec, aged 71, Stroke Survivor.





Irish Heart Foundation Supports for Heart and Stroke Patients

Nurse Support Line

The Irish Heart Foundation have developed a range of resources including online and telephone support services for people living with cardiac conditions, the effects of stroke and their carers, as well as ways to stay active, eat well and keep heart healthy. The nurse support line is available Monday – Friday, 9am – 1pm, **01 6685001** or Email support@irishheart.ie

Stroke Check In Service

Returning home after stroke is difficult at any time, but never more so than during the COVID-19 pandemic. So, stroke patients being discharged from hospital now are likely to need extra support. To deliver this, the Irish Heart Foundation, in association with the HSE has established a phone service providing regular one to one calls to stroke survivors after they leave hospital. The purpose of the phone check-in service is to assist you to live as well as possible at home with the effects of your stroke and to provide you with practical support.

To avail of this free service ask your nurse or a member of the stroke team for a referral form.

Heart and Stroke Groups

All our **heart and stroke support groups** have moved to **telephone and online support**. We have also launched **private Facebook groups** to give you access to **expert information** and allow you to share your thoughts and concerns with similarly affected people. All groups include home-based exercise videos, advice from nurses, tips on diet and peer to peer support which is vital at this time. We are **accepting new members** in all of our groups.

Life After Stroke Facebook Group

This is a closed Facebook group where individuals can ask questions, share stories or watch our Facebook Live guest speakers. <https://www.facebook.com/groups/IHFLifeAfterStroke/?ref=share>

Carers Facebook Group

Becoming a carer for someone affected by stroke is an enormous undertaking physically, mentally, and emotionally. Within this group you will find useful information and resources as well as a safe space to share your thoughts and concerns with others in similar positions.

Contact:

To get involved with any of our heart and stroke support services please contact;

support@irishheart.ie
or call
01 6685001

Living Well

A programme for adults with long-term health conditions
Your toolkit for better health

Self-management is what a person does every day to manage their long-term health condition. A long-term health condition is one which can be treated and managed but usually not cured. Examples of long-term health conditions include (but are not limited to): Stroke, COPD, asthma, diabetes, heart conditions, multiple sclerosis (MS), arthritis, cancer, Crohn's disease, chronic pain, depression. Learning how to manage your condition may help you feel better, stay active and live well. Having the right information and support can help you to do this.

What is the Living Well programme?

Living Well is a free group self-management programme for adults with long-term health conditions.

The programme supports you to develop skills which will help you to live well with a long-term health condition(s). These skills include how to:

- › Set goals to make changes in your life
- › Make plans to achieve these goals
- › Solve problems
- › Manage your medications
- › Cope with difficult emotions, low mood and feelings of depression
- › Communicate well with your family, friends and healthcare team

These skills become your toolkit for better health.

Who is Living Well for?

Living Well is for adults 18 years and over. It is suitable for you, if you are:

- › Living with one or more long-term health conditions
- › Caring for someone with a long-term health condition(s)

What does Living Well involve?

It runs for six weeks. There is one workshop each week that lasts for 2.5 hours.

The programme is usually delivered in a classroom setting. However, during COVID-19 it is available online.

People taking part in the workshops may have the same health condition(s) as you. Others will have different health conditions.

The workshops are delivered in a relaxed and friendly way so that all participants can learn from each other. You can also share experiences of living with your condition(s). Each person who takes part gets a book about self-management. Two trained facilitators or leaders run the workshops each week. At least one of the facilitators lives with a long-term health condition.

What is covered each week?

A key part of Living Well is setting goals that you want to achieve. Each week you learn how to reach these goals by making an action plan. You also get support from the group to problem solve. In addition, the following are covered over the 6 weeks:

Week 1	Using your mind to manage symptoms Fatigue and getting a good night's sleep Introduction to action plans
Week 2	Dealing with difficult emotions Physical activity, exercise, preventing falls
Week 3	Decision making Pain management Healthy eating
Week 4	Breathing techniques Reading food labels Communicating skills
Week 5	Medication management Positive thinking, dealing with low mood and feelings of depression
Week 6	Making informed treatment decisions Planning for the future

How do I register?

If you are interested in taking part in this programme or would like more information, please contact the Programme Coordinator:

Jackie Lynott

Mobile: 087-7185615

Landline: 0949034980

Email: jackielynott@mayocil.ie

Acquired Brain Injury Ireland

If you would like to access the services offered through Acquired Brain Injury Ireland, or if you wish to refer someone to our service, the first step is to complete a referral form. This can be downloaded from the ABI website along with the accompanying Consent for Release of Information Form. The ABI service is for under 65 year olds. If you wish to refer someone to our services, the first step is to complete a referral form and the accompanying Consent for Release of Information Form which can be downloaded from the ABI website.

www.abiireland.ie

About On With Life

Acquired Brain Injury Ireland's 'On With Life' Programme, is a new Brain Injury Family and Friends Support Network. The ambition is to establish a network of support groups all over the country.

This brain injury support network will provide support for family members as they support their family member impacted by an acquired brain injury. We will also provide you with education on brain injury and information on steps to take to keep yourself physically and emotionally healthy.

To find out more information please contact co-ordinator Dolores Gallagher on dgallagher@abiireland.ie or call 086-0102361.

For further details please see the website link : <https://www.abiireland.ie/services/family-carer/on-with-life-project/>

Age and Opportunity



www.ageandopportunity.ie

Changing Gears (online):

An online programme designed to help people who are 50+ to manage health challenges. The programme promotes resilience in later life, facilitating participants to be more self-directive in making life style choices to optimise older age.

Information here: <https://ageandopportunity.ie/event/changing-gears-online-course-helping-those-aged-50-to-manage-health-challenges/>

Physical Activity:

Movement Minutes is a 15 minute seated and standing physical activity class for older people takes place live on Facebook every Monday, Wednesday and Friday at 11am. Check with your GP or physiotherapist if you need advice on whether these classes are suitable for you.

Join the class as it's happening on Facebook here: <https://www.facebook.com/AgeandOpportunity>

or do the class at a time of your own choosing by viewing on YouTube here: <https://www.youtube.com/playlist?list=PLfCQ6OkV7hAiHQ2RIm1iM1TBxNYeUXfqA>

The following is a list of other activities that have taken place during the year which are saved on the Age and Opportunity YouTube channel - a great resource which is free to access:

Go to YouTube and search for Age and Opportunity to see videos below. Subscription to the channel is optional.

Barbara Murphy (movement and walks) Pilates with Margaret O'Keeffe

Arts Activities:

A number of arts activities are available on the Age & Opportunity YouTube channel.

Education/well being:

Enjoy the 5 part series on Resilience on the Age & Opportunity YouTube channel.

Entertainment:

Theatre – The Windy Lady

Music – The Dusk Chorus

Find the entertainment on the Age & Opportunity YouTube channel.

Further information about the work of Age & Opportunity can be found here: <https://ageandopportunity.ie/about-age-and-opportunity/>

Age Action

Age Action information service is open from 9:30am-1:30pm and 2.30pm - 4.00pm Monday to Friday.

Tel: (01) 475 6989

Email: helpline@ageaction.ie

Getting Started Keep In Touch (KIT)

Age Action has launched Getting Started Keep In Touch (KIT) to help older people get online during Covid-19. This is a national learning initiative to help older people improve their digital literacy skills. It includes guides and a video tutorial to help older people to use a smartphone or other device, to get online so that they are more connected, informed and supported.

See Age Actions website for further details.

www.ageaction.ie

Age Action through the University of the Third Age network (U3A) helps bring lifelong learning to those in the 'third age'. This is defined by a period in life in which full time employment has ceased. Members form interest groups covering as wide a range of topics and activities as they desire; by the members, for the members.

No qualifications are sought or offered. Learning is for its own sake, with enjoyment being the prime motive, not qualifications or awards.

There are 30 U3A groups operating throughout Ireland. As a result of COVID-19 none of the U3A groups are holding their regular face to face meetings. Some of the groups have set up meetings using Zoom and continue to engage virtually. Age Action facilitates a series of webinars (using Zoom) for all who can and would like to engage in discussions.

To get further information please contact

u3a@ageaction.ie



ALONE

ALONE offers help to resolve financial and pension difficulties, support engagement with local events and activities, access housing grants and adaptations, navigate the healthcare system, access housing and tenancy support, and resolve any other challenges that may arise.

Alone: Helpline Listening service and supports for older people. The line is open Monday to Friday, 8am to 8pm, during Covid-19 lockdown.

Call: 0818 222 024 for any of ALONEs services.
Email: hello@alone.ie

Find out more about **ALONE's** work coordinating **Befriending Network Ireland**, a national network of befriending and support services for adults by contacting your relevant local centre.

Castlebar Social Services Limited,
Castlebar,
Co. Mayo.

Tel: (094) 9021378
Email: castlebarvss@gmail.com
Website: www.castlebarvss.com

Offers a confidential and professional telephone befriending service by fully trained volunteers. The aim of the service is to reduce feelings of isolation, insecurity, loneliness and vulnerability. Calls are made 10 am to 12 noon Monday to Friday. No strict age category.

Westport Family & Resource Centre,
The Fairgreen,
Westport,
Co. Mayo.

Tel: (098) 24419
Email: westportfrc@gmail.com
Website: www.westportfrc.ie

The Westport Family & Community Resource Centre operates a telephone befriending service known as 'Befriending Mayo' and a home visitation service called 'Cara Visitation'. The organisation is flexible regarding age.

The organisation covers the Westport Urban and Rural areas but are more flexible with the befriending and visitation services – with some clients in Louisburgh and Newport.

Clár IRD,
Ballyhaunis Road.
Claremorris,
Co. Mayo.

Tel: 094 93 71830
Email: clarird@eircom.net
Website: www.clarird.com

Telephone Befriending Service 'Good Morning Claremorris' for older people and people living alone. The service operates in Claremorris and south west Mayo area. Calls are made every Wednesday and Thursday morning.

Aware



The Aware Support Line service is a free service and is available to anyone, **aged 18 years and over**, who is seeking support and information about issues relating to their own mood or the mood of a friend or family member, or who experiences depression or bipolar disorder.

Freephone 1800 80 48 48
Available Monday – Sunday 10am to 10pm

Website: www.aware.ie

Citizens Information Board

The Citizens Information Board is the national agency responsible for supporting the provision of information, advice and advocacy on social services, and for the provision of the Money Advice and Budgeting Service.

The Citizens Information Board's mandate is:

- › To support individuals, in particular those with disabilities, in identifying and understanding their needs and options
- › To support the provision of, or directly provide, advocacy services for people with a disability
- › To support the provision of advice on personal debt and money management through the Money Advice and Budgeting Service

The Citizens Information Phone Service (CIPS) is funded and supported by the Citizens Information Board to provide a comprehensive and **free** confidential telephone information service.

Citizens Information Centres are currently not open to drop-in callers. You can contact your local centre by phone or email for information and advice. A limited number of face-to-face appointments are available in centres where COVID-19 safety requirements can be met.

These appointments are arranged after a phone or email consultation and are based on client need. Alternatively, you can **Request a call back** or call the Citizens Information Phone Service on **0761 07 4000**, Monday to Friday, 9am-8pm. Website: www.citizensinformationboard.ie

CIPS also operates a **Live Advisor** instant chat service for people with hearing and speech difficulties and others who have difficulty communicating by telephone. Live Advisor allows you to chat directly with an Information Officer in a chat-room-type environment. Live Advisor is available between 9am and 5pm (Monday to Friday) via a link on the home page of the website above.

The following are local Citizens Information Centres:

Ballina CIC

Dillon Terrace, Ballina.
Phone: 0761 07 5990

Belmullet CIC

Main Street, Belmullet.
Phone: 0761 07 6030

Castlebar CIC

Cavendish House, Hopkins Road, Castlebar.
Phone: 0761 07 6040

Claremorris CIC

CURAM Centre, Dalton Street, Claremorris.
Phone: 0761 07 6080

Westport CIC

The Courtyard, James Street, Westport.
Phone: 0761 07 6100

Roscommon CIC

Phone: 0761 07 6380

Exercise: Easy chair based exercises for older adults (HSE)

Research shows that you need to do 30 minutes of moderate intensity physical activity a day to gain many health benefits. However, some of these benefits will be experienced even by doing low intensity gentle exercise, such as the exercises in this booklet.

Go to: <https://www2.hse.ie/file-library/health-eating-active-living/chair-based-exercises-for-older-adults.pdf> or see the Stroke Unit Display Board for the information booklet.

The Family Centre Castlebar

The Family Centre Castlebar offers a wide range of support services for families and individuals through Counselling, Flourish Social Prescribing Service, Mayo Suicide Bereavement Liaison Service, Support Groups, and an Education & Training Programme.

Sometimes after an experience of having a stroke and adjusting to a new way of living it may be helpful to speak with a professional counsellor who can offer a confidential and non-judgemental space just for you to help you adjust and deal with this new change. All change impacts on us and our lives.

To enquire about the counselling service or any one of the other services and supports telephone **094 9025900**, email info@thefamilycentre.com or feel free to have a look at the website www.thefamilycentre.com



flourish Prescribing Service at the Family Centre Castlebar.

The Flourish Service based at the Family Centre in Castlebar, with outreach services currently planned to open in Claremorris and in Ballina in 2021, offers a support service for adults to link with hobbies and interests and self care practices as a means of enhancing their health and wellbeing.

Flourish is ideal for anyone who finds themselves needing that support to reconnect to the community or in need of self-care. You may be wondering how to begin to adjust to a new phase in life after a stroke, and what activities might be suitable for you. Flourish offer a one to one confidential session where you can begin to explore this.

Some people like to consider our Discover Your Interests group programme which offers a supportive group setting to build up social and self- confidence to link with new interests and people in the community. Flourish also offer a weekly Mindful Monday session, a fortnightly Music Circle and many other programmes all designed to offer ways to connect with your community at your pace.

For an appointment for a one to one session or to hear about the range of courses and social options Telephone **094 9025900** or Email Flourish@thefamilycentre.com

Headway



Headway operates a dedicated Information and Support Helpline and Chat Service to help you with any questions you have or support you may need. Everyone copes in their own way – Headway are there for you.

Contact the National Freephone Helpline:
1800 400 478

The Headway team is available to you Monday to Friday, 9am – 1 pm, and 2pm- 5pm. They will answer your questions on all aspects of your stroke or provide you with a listening ear if you need one, both for the stroke survivor and their family members. Headway also provide a respite service.

You can also contact the Information and Support Team through email on helpline@headway.ie

You can even leave a message for Headway on their website, using the “Leave a message” function.

Click here for more information:
www.headway.ie

Stroke Headway Information Booklets which cover a range of relevant topics on recovering and coping with changes following acquired brain injury e.g. fatigue, memory, concentration, communication are available for free access and download/print from Headway's website above.

Irish Men's Sheds Association

The Irish Men's Sheds Association (IMSA) exists to support the development of Ireland's network of over 450 men's sheds.

All sheds are independent and self-autonomous, and the range of activities carried out by sheds differs from the next. Most sheds engage in activities such as woodwork, gardening, carpentry and community work. However, there are more special interests sheds that focus on things like music, fishing and restoration work.

There are many reasons to join a men's shed. If you are someone who still has a lot to offer, you might want to share your skills with other men. Or if you have found yourself in need of a friend, there are countless reasons for joining a shed, but whatever your reason is; you can bet there's a shed close by.

Men's sheds are more than just woodwork or gardening, they are places where men can find meaning and purpose, where a friend is always there. In a men's shed we always say the greatest tool we have is the kettle, because there's nothing more powerful than a cup of tea and a chat.

While all men's sheds across Ireland are temporarily closed, they continue to connect with one another through alternative means such as checking in through phone, text and WhatsApp. The sheds are also operating a 'buddy system', whereby one member is responsible for checking in with another, ensuring that shedders are not isolated during this difficult time.

For more information:
Tel: 01 891 6150
Website: www.menssheds.ie

Irish Wheelchair Association

The Irish Wheelchair Association (IWA) is a national organisation dedicated to the achievement of full social, economic and educational integration of people with disability as equal, independent and participative members of the community.

The IWA services include Assisted Living Service which provides Personal assistance with daily tasks. Resource and Outreach Centres which are centres that provide for IWA activities and services, which currently comprise of (due to COVID-19) home visits, transport to medical appointments, Zoom calls that incorporate Yoga, Music and Wellbeing sessions as well as quizzes, music sessions and Bingo.

The transport fleet is fully adapted to facilitate people to travel safely. Irish Wheelchair Association also provides Motoring advice, Housing support Services, Wheelchair Services, Holiday Services Advocacy and Rehabilitative Training.

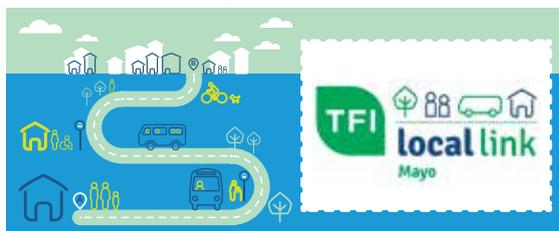
Irish Wheelchair Association, Newport Road, Castlebar, Co. Mayo.

Phone: 094 90 60937

The **IWA Ability Programme** is a National individualized coaching service for young people with physical disabilities (18-29) who want to get closer to the labour market. The Programme aims to support individuals at every stage of their job-seeking journey, whether they are "job-ready" or not. The coaching method used for programme delivery allows for a very personalized and individualized support structure to enable the participant to develop into a confident and independent jobseeker at their own pace. This involves working with the person one-to-one to identify the barriers to the individual's progression and supporting the person to overcome these barriers in whatever way and whatever timescale they see fit.

Ability is currently funded until the end of June 2021. Please see <https://www.iwa.ie/services/young-adults/employment-skills-programme/> for more details or contact us using ability@iwa.ie

Local Link Mayo



Providing responsive, integrated and accessible transport to the population of County Mayo.

Local Link is offering a collect and delivery service from pharmacies and local shops for passengers delivering critical medical supplies to the elderly, the vulnerable and sick within rural areas. Those in need of such support should contact their Local Link provider. They are also providing additional trips where possible for essential travel to purchase provisions.

Local Link Mayo, Castlebar, Co. Mayo.

Tel: 094 9005150

Email: mayo@locallink.ie

Web: www.locallinkmayo.ie

Local Authority: Covid-19 Community Call

Each local Authority has set up a Covid-19 Community Response Forum. Each forum has a phone line for high risk people or those asked to cocoon.

You can ring the phone line to get help with deliveries of groceries, medicine and fuel or help with any other necessities of daily life. An Information booklet has been made available and includes all local contacts details.

Call: 0818 222 024

This number is available from 8am to 8pm, Monday to Sunday.

Or Call

Mayo County Council Covid-19 Helpline

Tel: 094 906 4660

Email: covidsupport@mayococo.ie

For General Enquiries Go to:

https://www.citizensinformation.ie/en/health/covid19/community_support_during_covid19.html

Memory Technology Resource Room

This HSE service is suitable for anyone with a memory difficulty or diagnosis of dementia and their family/carers. It gives them an opportunity to view and trial resources which will assist them to remain independent and safe at home and in the community.

The service is free of charge to anyone over the age of 18 years.

Contact:
Mairead Bradley,
Occupational Therapist,
Memory Technology Resource Room,
Castlebar,
Co. Mayo.

Tel: 087 1187883 or 087 7514428

Email: MemoryResourceRoom.Mayo@hse.ie

National Council of the Blind


NCBI
**Working for People
with Sight Loss**

NCBI offers community based services countrywide to help people to adapt to sight loss and maintain their independence.

These services include emotional support to the individual experiencing loss of vision following a stroke and to their families, advice and information on all aspects of vision loss as well as practical and rehabilitative support to the daily challenges encountered by people with vision loss. Their services are offered to people of all ages, from birth through to older age.

All services can be accessed by calling InfoLine 1850 33 43 53 or www.ncbi.ie





Quest Brain Injury Services

Part of National Learning Network

Quest Brain Injury Services offer a free, community based rehabilitation programme, to survivors of Acquired Brain Injury (ABI), under 65 years of age, and their families.

Survivors of ABI often make a good physical recovery but find themselves left with residual, more subtle, secondary deficits. These are referred to as the 'hidden disabilities', which may include personality changes, memory deficits, impaired thinking, fatigue issues, or simply feeling less efficient than before. This often results in people becoming isolated or withdrawn, as a result of not knowing how best to deal with the difficulties arising.

Quest is funded by the HSE West, and the service is delivered to Galway, Mayo and Roscommon. Quest offer services to survivors of brain injury within the community setting from the main centre in Galway. Within Mayo and Roscommon, the service is delivered on an Outreach basis, with support from the main team.

The programme in Mayo addresses such areas as brain injury education, memory, general cognitive (thinking) skills, attention and concentration, daily living skills.

The Quest Team aims to assist individuals to re-acclimate themselves post injury, often enabling a return to work, education, maximisation of independence, and an overall improvement in general function.

Further information and application forms can be obtained by contacting Quest:

Tel: 091 778850

Email: quest@nl.n.ie

Website: www.rehab.ie

The Samaritans

For immediate support, about whatever's getting to you, please call Samaritans' 24-hour Helpline **116 123**

This number is free to call from both landlines and mobiles, including pay-as-you-go mobiles. You do not need to have any credit or call allowance on your plan to call 116 123.

Via Email

Emailing us on jo@samaritans.org is free.

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