

#### The National Stroke & Heart Charity

# Step by step through stroke

A helpful guide for stroke survivors, families and carers



irishheart.ie

# Step by step through stroke

#### A helpful guide for stroke survivors, families and carers

#### **Produced by the Irish Heart Foundation**

This book is one of the publications in our patient information series. It builds on our first guide for stroke produced by Professor Davis Coakley and Dr Susan Murphy.

This book is a guide for people who have had a stroke, their families and their carers. It cannot replace the advice of your healthcare team.

#### Acknowledgements

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## Introduction



This book is for **stroke survivors**, their **families** and their **carers**.

If you have been told you have had a **brain bleed, brain haemorrhage** or **brain clot**, this book is relevant to you, too.

This book has the information you need to support you as you recover from stroke. It has information about stroke and how it might affect your everyday life. It helps you understand your healthcare team and how they will help you as you go through your stroke journey. It also has tips to help you manage your daily life.

The last chapter contains supportive information for carers of stroke survivors.

You don't need to read the whole book.



Start by reading **14 things to know about stroke** on page 4.

Use the **contents** page on page 7 to find any other information you need.



As you read this information, you can jot down your notes in the **notes section** provided at the end of each chapter.



The **tools and checklists** provided at the end of the book will help you through your recovery journey.

# 14 things to know about stroke



**Irish Heart Foundation** 

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Stroke is a big change. Take the time to re-evaluate what's important to you. With the help of rehabilitation, you will learn to live well after stroke. You may even develop new skills.

In rehabilitation, you'll do exercises and activities to help with the changes you're experiencing after your stroke. Rehabilitation helps you work on your goals and get stronger. Family and friends can help you work on your rehabilitation goals.

After a stroke, your healthcare team will talk with you about reducing your risk of another stroke.

- When you are ready to leave hospital, your healthcare team will develop a care plan for you for after you leave the hospital. They will also point you to community services and support groups in your area.
- **Every stroke is different**. Each person affected by stroke will have different needs. Your rehabilitation and your recovery will be unique to you.
- If you are the carer of a stroke survivor, you play a crucial role in supporting and encouraging their recovery. The best way to achieve this is by talking to the person you are caring for to understand their needs.
- Caring can be challenging and it takes time and energy. If you are the carer of a stroke survivor, it is important you take steps to ease the stress of caring. Make time for rest and play, and ask for help when you need it.











#### **Irish Heart Foundation stroke services**



Stroke Connect Service

Young Stroke Survivor Network

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Nurse Support Line

Face to Face Stroke support groups



Life After Stroke support group

Carers' Support Network Facebook group

Visit <u>irishheart.ie</u> or contact our **Nurse Support Line** on **01 668 5001** for more information.

#### List of abbreviations

Below you will find a list of abbreviations used in this book.

F.A.S.T.	Face, Arms, Speech, Time - an acronym to help you remember the symptoms of stroke.	
ΤΙΑ	Transient ischaemic attack	
ECG	Electrocardiogram	
СТ	Computer tomography	
MRI	Magnetic resonance imaging	
Echo	Echocardiogram	
ОТ	Occupational therapist	
SLT	Speech and language therapist	
HSE	Health Service Executive	
ESD	Early supported discharge	
GP	General practitioner	
СВТ	Cognitive behavioural therapy	
IACP	Irish Association for Counselling and Psychotherapy	
NDLS	National Driver Licence Service	

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# What is stroke?

# 01 What is stroke?

A stroke happens when the blood supply to a part of your brain is interrupted. This can damage some of your brain cells.



About **7,500** strokes happen in Ireland each year.



**1 in 4** strokes occur in people of working age.

Stroke is a brain injury and **must always** be treated as an emergency.

#### **Types of stroke**

There are **two** main types of stroke.



An **ischaemic stroke** occurs when there is a blockage or clot in an artery which cuts off the supply of blood to your brain. These blockages are largely caused by fatty deposits that gather in your arteries over time. This process is called atherosclerosis. A **haemorrhagic stroke** occurs when an artery in your brain bursts and bleeds. This is also known as a brain bleed or a brain haemorrhage. A transient ischaemic attack (TIA) is often called a "mini stroke." This happens when a clot temporarily blocks the supply of blood to your brain. It can last for a few minutes to a few hours, and symptoms fully resolve within 24 hours.

Having a TIA means you are at risk of having a stroke in the future. If you have a TIA, see a doctor urgently to learn how to reduce your risk.

#### What are the symptoms of stroke?

Strokes usually occurs suddenly. The main stroke symptoms can be remembered with the acronym **F.A.S.T.** 

	FACE	The <b>face</b> may have dropped on one side. The person may not be able to smile, or their mouth or eye may have drooped.
	<u>A</u> RM	The person may not be able to lift both arms and keep them raised because of weakness or numbness in one <b>arm</b> .
•	SPEECH	Their <b>speech</b> may be slurred or hard to understand. They may also have problems understanding what you're saying to them.
	TIME	If you experience any of these symptoms, it's <b>time</b> to dial <b>112</b> or <b>999</b> for an ambulance. Even one symptom could mean a stroke. Remember: The faster you get treatment, the more likely you are to have a good recovery.

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Other symptoms of stroke include:

- numbness, weakness or paralysis on one side of the body
- difficulty thinking of words or understanding what other people say or mean
  - confusion

- sudden blurred vision or sight loss
- 🔽 difficulty balancing
- 🔽 severe headache
- vomiting or feeling nauseous
- 🧹 dizziness

## Act F.A.S.T.

Call **112** or **999 immediately** if you see any of these signs or symptoms.



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Thanks to the F.A.S.T. message, I knew what to look out for. Face, arms, speech and time. I spoke to myself out loud and recognised that my speech was slurred and I wasn't making sense. My brain was affected cognitively and my hands were not functioning properly."

Siobhan, young stroke survivor

#### **Treating stroke**

When you have a stroke, first you'll be taken to the hospital's emergency department where you will have tests to find out:

- 1 what **type** of stroke you had
- 2 what **part of your brain** is injured and how badly
- 3 what **caused** your stroke
- 4 if it is safe for you to **eat and** drink

This information helps doctors decide what sort of medication or medical procedures you need. **Ischaemic strokes** can be treated by a medication (thrombolysis) or a procedure (thrombectomy) which helps to break up or remove the clot and restore blood flow. Thrombolysis is not suitable for everyone. Doctors will check if it would be a good treatment for you.

Haemorrhagic strokes can be treated with medication that focuses on controlling the bleeding in your brain and reducing the pressure caused by the bleeding. You may also need a procedure to repair the artery that may have been damaged due to the bleeding.



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I was happy to take it [thrombolysis]. Thankfully the medicine returned the blood flow and oxygen to my brain to keep me alive, but too much damage was already done and the left side of my body was paralysed."

Meaghan, young stroke survivor

After the initial tests, you should be cared for in a specialist stroke unit. Some hospitals don't have a specialist stroke unit, so talk to your healthcare team if you have any questions. In a specialist stroke unit you will have a team of healthcare professionals looking after your rehabilitation. This may include:



**Rehabilitation** aims to help you recover and achieve as much independence as possible after a stroke.

#### **Hospital tests**

Blood pressure check	High blood pressure is the most common cause of stroke. Your blood pressure will be checked immediately. Doctors will give you medication to lower your blood pressure if you need it.
Electrocardiogram (ECG)	Irregular heart rhythms can increase your risk of stroke. This test checks your heart for unusual rhythms.
Blood tests	Samples of blood are taken to check your cholesterol levels, your blood's ability to clot and your blood sugar levels.
Brain scan or computerised tomography (CT) scan	This is a specialised x-ray of your brain. You should have a brain scan within a few hours of having a stroke.
Magnetic resonance imaging (MRI)	This scan gives a detailed picture of your brain. You will lie in a large tunnel-shaped scanner for this test. If you are nervous, speak to your doctor or radiographer before the test.
Carotid doppler ultrasound	This scan checks for blockages in the arteries in your neck (carotid arteries).
Echocardiogram (Echo)	A probe is moved over your chest to check the way your heart is working and to look for any problems.
Chest x-ray	This will help show the condition of your heart and lungs.
Videofluoroscopy swallow test	This is an x-ray that looks at the way your swallowing works.

#### Notes...




# Rehabilitation

## 02 Rehabilitation

**Rehabilitation** is when you work on the things that have changed since your stroke. It helps you get stronger so you can do daily activities as independently as possible.

Rehabilitation is called 'rehab' for short.

### Stroke is a life-changing event.

#### It affects everyone differently.



Your healthcare team will:

- do a detailed assessment to understand how you have been affected by stroke
- set realistic goals for you and monitor your progress

You may also wish to take some time to re-evaluate what's important to you. You **CAN** learn to live well after stroke with the help of rehabilitation. You may even develop new skills.

#### When and where will rehab take place?

Your healthcare team will begin your rehab as soon as you are well enough.

Your rehab will usually start in hospital, for example, on the ward, in the physiotherapy gym or in other healthcare team departments.

You may have an early supported discharge to a rehab hospital, or you may continue your rehab at home or in a local rehab centre. Some people also need specialist rehabilitation in the National Rehabilitation Hospital.

In areas where there is no access to early supported discharge teams, you should be looked after by the health services in your community.

Your healthcare team will advise you on what the best pathway is for you. Get information about what services are available for you.

#### What does rehab involve?

In rehab, you'll do a lot of exercises. You'll practise tasks over and over with guidance from your team. Your team will make sure you're aiming for the right number of repetitions and that the task is at the right level of difficulty for you. This repetition process will help your brain adapt and build new pathways.



New synaptic pathways

Your team will also tell you how much time you need to spend on each exercise without getting fatigued. Many people spend about 45 minutes on each exercise 5 days a week, but this may vary from person to person based on their needs.

#### Your healthcare team and how they help

Consultant doctor	This is the doctor who will oversee your care. They may be any of the following:
	<ul> <li>a stroke physician (a doctor specialising in stroke)</li> </ul>
	<ul> <li>a geriatrician (a doctor specialising in the health of older people)</li> </ul>
	<ul> <li>a neurologist (a doctor specialising in illnesses related to the brain, spinal cord and nerves)</li> </ul>
	They will have a team of junior doctors helping them.
Hospital nurses	A team of nurses will care for you in hospital.
	They are the link between you, your consultant and the rest of your healthcare team.
	They help to plan your care, encourage you to practise your exercises and help you with your daily activities.
	Nurses will also help to plan your discharge with you, your family, carers and your healthcare team.
	The clinical nurse manager (CNM) is responsible for supervising nursing staff on your ward.

Stroke care clinical nurse specialist or advanced nurse	A stroke care clinical nurse specialist will help match your needs with members of the stroke team while you are in hospital.
practitioner	They will explain to you about the type of stroke you've had.
	They will identify your risk factors for stroke and give you advice on how to prevent another stroke.
	Like stroke care clinical nurse specialists, advanced nurse practitioners have lots of experience and have undergone extensive training.
Public health nurse	The public health nurse looks after your needs when you leave hospital.
	They will visit you at home and make sure you have the right care and support.
Physiotherapist	The physiotherapist will help you with your physical recovery after stroke — the way you sit, stand, walk and exercise.
	They will help you with your movement and muscle strength, sensation, coordination and fitness.
Occupational therapist (OT)	An occupational therapist (OT) will work with you to help you become as independent as possible in your daily life.
	The OT may also visit your home to see what alterations or equipment you might need.
Speech and language therapist (SLT)	The speech and language therapist (SLT) will assess, diagnose and treat any difficulties you may have with speech, language, voice and swallowing.

Dietitian	If you are at risk of losing too much weight or you are having trouble swallowing, a dietitian will develop a nutrition care plan to help you meet your nutrition and hydration needs. This is important if you need a feeding tube or the thickness or texture of your foods and fluids need to be changed to make them easier and safer to swallow.
Medical social worker	A medical social worker will give you and your family useful information about benefits, entitlements, employment, housing and HSE and voluntary services that are available. They will organise meetings with you and your family to discuss any anxieties you or your family may have. They will also plan your discharge with your team and provide advice and support to your carer.
Psychologist	A psychologist will work with you to help you make sense of the changes a stroke can bring to your life. They may conduct tests to work out your needs and make a plan to support you.

#### How much will I improve?

It's difficult to say, but the majority of people show some improvement.

Your recovery will depend on:

- the area of the brain that was injured
- how much of it was injured
- how your rehabilitation is going

Not knowing how much you will improve can be frustrating, but every stroke is different and your recovery will be unique to you. It's important to work on overall recovery. This means working on your:





- thinking skills, which help with attention, memory, planning and organising
- emotional skills so you are able to cope with anxiety, sadness or fatigue

#### Focus on your rehabilitation as soon as possible.

The fastest recovery takes place in the days and weeks after stroke but can continue for years.

#### Get the most out of rehabilitation



#### Ask questions

If you don't understand what you're doing or why, ask your team. They are there to help you.



#### Set realistic goals

Ask yourself what you think you can achieve and then break these goals down into smaller steps.



#### Practice makes perfect

Practise the tasks that the therapists have shown you. Doing all your exercises regularly will help you improve your physical, thinking and emotional skills. All these areas are important to work on.



#### Involve your family and friends

Spend time with them. They can help with your exercises.



#### Take your time

Rehab is hard work. Take breaks when you need to. Make sure you're getting enough rest. Be kind to yourself as you work through your rehab.

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#### Celebrate

Progress is not easy. Sometimes you may feel like you are going backwards. Keep a written or video diary to remind you of all the progress you're making.



#### **Connect with other survivors**

This can show you what's possible if you keep working at it.



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Don't give up. We all have down days and when you have a stroke, these down days are even worse. If you can't do your rehabilitation today, you WILL be able to do it tomorrow. Set goals. Let the professionals guide you. They aren't pushing you for their own benefit, they are pushing you so you get better. People tend to forget that."

Michael, 58, Stroke survivor



Call the Irish Heart Foundation Nurse Support Line on **01 668 5001** 

or



Email **referrals@irishheart.ie** to connect with other stroke survivors.

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#### **Discharge from hospital**

When you are ready, your healthcare team will talk to you about leaving hospital. Together you can put together a discharge plan for yourself. A discharge plan relies on good communication between you, your family and your team. Talk to your team about your needs.

Your discharge plan will make sure:

📀 you get the right health care and services after leaving hospital

ᠵ you stay safe and well

Your occupational therapist (OT) will advise you on what changes and equipment you may need in your home. For example, you may need to install shower chairs or raised toilet seats in your bathroom. And you may need to add handrails or ramps in your house.



Check out **My leaving hospital checklist** on page 67. This will help you prepare for life after hospital.



#### After you leave hospital...



You will be looked after by your GP and a public health nurse.

You may need more rehabilitation after you go home. If you do, your healthcare team will be there for you.

#### **Early Supported Discharge**

You may be allowed to leave hospital early and be under the care of a team who will help you with your rehabilitation at home. This is called Early Supported Discharge (ESD). However, this service is only available in a handful of hospitals and areas.



When I left the hospital, it emotionally hit me. I'm not sure that I'm fully back to where I was before my stroke with certain things like my vocabulary but other than that I feel I have made a full recovery."

Siobhan, young stroke survivor

#### **Community support**

Organisations in the community can help you settle into your life after stroke. Talk to your healthcare team to work out what community supports are available in your area.

The Irish Heart Foundation runs stroke support groups, which often meet once a month. It's a good place to come together to meet other stroke survivors and discuss common issues.

Visit **irishheart.ie** or contact our **Nurse Support Line** on **01 668 5001** for information on stroke support groups in your area.

#### Support in your home

You might need extra help around the house or with your personal care. You may be eligible for the **HSE's home support service**. Talk to your healthcare team about it.



Your GP or public health nurse can give you information on services available in your area, such as home help, care assistants or Meals on Wheels.

If you need more care, your medical social worker can help you consider other types of caring arrangements such as sheltered accommodation, residential care in a nursing home or 24-hour nursing care.



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I really encourage people to attend the free talks – from learning about rehabilitation to speech and language therapy, there are lots of really helpful topics that can make a difference to your recovery."

Carrie 42, stroke survivor

#### Notes...




# How will my stroke change me?

## 03 How will my stroke change me?

Stroke affects people in different ways. The impact of stroke depends on:

- 1 the part of your brain that has been injured
- 2 how much of your brain has been injured
- 3 your prior medical history and wellbeing

The fastest recovery takes place in the **days and weeks after stroke**, but can continue for years.

The following image shows the different parts of the brain and what function each part performs. A stroke can affect any of these functions depending on which part of the brain is injured.



#### **Irish Heart Foundation**

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# **Effects of stroke**

Some stroke survivors **do not** have any effects of stroke. But usually, you may have a **combination** of the following effects of stroke.

#### Fatigue

You may feel constantly tired after your stroke. This is called post-stroke fatigue.

Post-stroke fatigue can make it difficult to regain independence and engage in your rehabilitation.

It can affect your quality of life and can be difficult, as family and friends may not understand how exhausted you are.

Many people who suffer from fatigue after stroke also feel anxious or depressed.

You can speed up your recovery if you take steps to manage your fatigue. You can do this by:

- sleeping a little more than you used to before your stroke
- adopting a consistent regime, making sure you sleep and nap at the same times every day

Don't hesitate to ask your **rehab team** about what else you can do to help manage your fatigue.

#### Arms, legs and muscles

Your arms, legs, hands and feet may not work like they used to. This can change how you sit, stand, move, walk or move your arm.

- Your muscles may be weak and floppy.
- You may find it hard to coordinate movements and to balance, putting you at risk of falling.
- Your face and speech may be affected as well. This can cause drooping or drooling.
- You may find it hard to raise the front part of your affected foot. This can make walking a challenge.

#### Spasticity (high muscle tone)

After stroke, your muscles can tighten up, get stiff and resist stretching. This is called **spasticity** (high muscle tone). Spasticity happens when there is a breakdown in communication between your brain and your muscles.

Spasticity can make it difficult to carry out normal tasks.

- You may find it difficult to open your hand, reach for something high or clean under your arm.
- If you have spasticity in your leg, you may find yourself dragging your leg while walking or feel out of balance.
- You may be in pain.
- At times the affected hand or leg can become fixed in one position.



It can begin in the first few weeks after stroke or it can begin months and sometimes years later.

If left untreated, it can get worse over time. But you can get better with rehab and with other treatments if needed.

Speak to your GP and your stroke team for advice and support.

#### **Sensation**

Whether you feel a sensory overload or a lack of sensation, stroke can affect how you sense things around you. You may:

- feel less sensitive to touch on the affected side of your body
- feel like your limbs are wrapped in cotton wool
- not be aware if your clothes are too tight or scratchy because your limbs feel numb
- not know if you're too hot or too cold
- feel distressed in loud, crowded places as you may find it difficult to separate the sounds you hear
- find bright lights uncomfortable

- have double vision, blurred vision or partial blindness
- not be able to see to the left or right
- try to move but forget to move your weaker leg and lose your balance
- bump into or trip over objects you can't see on the affected side of your body
- have unusual sensations like pins and needles and tingling in your affected arm or leg



#### Vision

Vision problems are common after stroke, but they may not always be obvious. After stroke you may notice:

- it is difficult to read or watch television
- you are bumping into things
- you are struggling to see things on one side of your body

How much your vision is impacted by stroke will depend on where the stroke happened in your brain. With time, vision problems can improve as you recover.

After stroke, your vision will be checked before you leave hospital and your medical team will talk to you about any treatments you may need. If you cannot remember whether your vision was checked in hospital or not, speak to your GP or medical team.

As you recover, it is important to tell your **healthcare team** if you notice changes to your vision.

#### Seizures

Some stroke survivors have seizures after stroke. They are most likely to happen in the days after a stroke, but they can happen years later.

Having a seizure in the days following a stroke does not mean that you have epilepsy, but some people may be diagnosed with the condition.

Your risk of having a seizure reduces over time. Treatments are available to prevent future seizures. Talk to your healthcare team.
# Swallowing

Stroke can affect the muscles you use for chewing and swallowing, and can make eating and drinking difficult.

A swallow test is one of the first hospital assessments you will have. If you are having trouble swallowing, you should be assessed and treated by a speech and language therapist (SLT).

An SLT will work with you to develop the right strategies to help you improve your ability to swallow safely and comfortably. This will involve swallow rehabilitation exercises and techniques to help you manage and recover.

The good news is that these changes are usually temporary, and most people's swallow improves as they recover from stroke.

Your **dietitian** will help you to meet your nutrition and hydration needs during this time.

# Bladder and bowel control

It is common for people to have difficulty controlling their bladder or bowel after stroke. This is known as incontinence. For many people this control will come back after a few weeks.

You may need a tube (catheter) inserted into your urethra to help empty your bladder. This may need to be done several times to make sure you are comfortable and to avoid a urinary tract infection.

You can get help for continence issues from the **HSE's** continence nurse service.

# Thinking

Stroke can affect your:

- memory: You might be able to remember things from long ago but have trouble with your working (or short-term) memory.
- concentration: You might find it hard to focus on one thing when there are distractions. For example, maintaining a conversation in a noisy room may be difficult. You may find it hard to stay focused, such as when reading a book.
- planning and organising: Some people find it harder to follow the steps involved in everyday tasks, such as dressing, crossing the road, changing television channels using the remote control or making a cup of tea.

# Communicating

After stroke you may find it difficult to speak or understand what others say. This is called **aphasia** and it affects your ability to take part in conversations and share your thoughts with others. Aphasia does not affect your intelligence or your ability to think clearly. Aphasia can affect your ability to:

- express your thoughts in speech and writing
- understand what others say
- recognise and understand written words
- use numbers, tell the time, do calculations and manage money

A sudden change in your ability to communicate can be extremely distressing, especially when you have lots of questions.

Communication problems can be managed using speech and language therapy. A speech and language therapist (SLT) can help you to improve your speech, reading and writing as much as possible. They can also help you to learn other ways to communicate, from the use of gestures to electronic devices.

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## **Behaviour and emotion**

Feeling emotionally overwhelmed is natural after stroke. You may have the following feelings:

- grief and a sense of loss: This may be accompanied by shock, confusion, denial and fear about all the changes in your life.
- frustration and anger: You may be more irritable after stroke, or you may find it hard to control your temper.
- depression and anxiety: You may feel sad or down, lose interest in things you enjoy, feel empty or numb. You may have trouble sleeping. This is all common after stroke. Talk to your psychologist if you feel this way.
- sudden changes in mood: You may feel an anger that seems to come from nowhere. Or you may suddenly start laughing or crying uncontrollably for no reason. This is called 'emotional lability'.

Stroke can leave you feeling very emotional. You may be fatigued, very sleepy or have some side effects from your medication. All this can affect your behaviour. You may:

- struggle with social cues
- interrupt or be blunt in your conversations with others
- stand too close to someone
- act impulsively, spend recklessly or engage in risky activities

Stroke may change how you respond to things, but it does not change who you are as a person. Naming these changes, being aware of them and talking with others about them are the best ways of managing them.

Treatments such as cognitive behavioural therapy (CBT) can help you better understand the link between your thinking and behaviour and how your actions affect other people. Other ways to cope with behavioural changes include:

- making time for rest and play
- taking part in physical activity that is in line with your abilities
- maintaining a daily schedule that balances physical activity, mental activity and everyday activities
- practising mindfulness
- having regular chats with loved ones
- setting daily or weekly behaviour goals and rewarding yourself when you achieve them

Are you struggling with your emotions after stroke? The Irish Heart Foundation offers the following support:

- individual counselling provided by our nationwide panel of Irish Association for Counselling and Psychotherapy (IACP) approved professional counsellors
- peer-to-peer phone support delivered by stroke survivors who understand what you might be going through
- S online mindfulness course
- education to support your mental health



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It's so important for yourself to reflect on your own story and experiences and be able to find some good in them – something positive can come from them, and others can be helped"

Meaghan, young stroke survivor

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# Adjusting to daily life after discharge

# 04 Adjusting to daily life after discharge

Stroke is a **life-changing event**. Transitioning from hospital to home, from patient to person can be a tough and uncertain journey.

Acknowledging the changes in you and being aware that recovery starts with small steps is a good start.

You may have discouraging days. It helps to take a moment, breathe and keep going.

A little step today brings you closer to your goals.

**E** I always told myself 'Today is a new day and things are going to get better."

Carrie, young stroke survivor



In this chapter, we list out **tips** that may help you as you adjust to everyday life after discharge.

- These tips may not all be relevant to you and your needs.
   Pick the ones that work for you.
- Your healthcare team will give you more detailed advice on all these aspects of daily life. If you are unsure about any of these tips, please check with your healthcare team.

Tips to help you adjust to life after stroke

# **Get moving**

- Wear comfortable shoes with good support to help you walk.
- 🔽 Talk to your physiotherapist about transfer techniques for getting in and out of chairs and on and off the bed.
- 🗸 Ask your physiotherapist about whether you need a mobility aid like a wheelchair or a walking frame. Aids like walking sticks and splints can help you keep balance.
- Talk to your OT about changes you need in your home, such as handrails and ramps.

# Washing and grooming

- Use a freestanding or walk-in shower instead of a bath or sit at a table with a basin of water and a non-slip mat to wash yourself. Your OT will advise you.
- Get yourself a good mirror and shave with one hand using an electric razor.



## Managing your bladder

- Go to the toilet. This will help to keep your bladder empty and keep you dry.
- Get disposable pads or pull up pants from your local pharmacy.
   You may even be able to get them from the HSE free of charge. Talk to your public health nurse.
- Use absorbent, washable seat pads to protect your furniture.
- Use mattress protectors and absorbent bed pads with tuck-in flaps (known as draw sheets).
- Talk to your nurse or continence advisor about exercises to strengthen your bladder.
- Use a commode. A commode is like a chair with a removable potty under the seat. It can be useful to have in the bedroom, especially at night.



## Managing constipation

- Drink plenty of fluids to soften stools and to avoid constipation.
   Aim for 6-8 cups a day – water, milk, tea, coffee and soup all count.
- Slowly increase the amount of high fibre foods you eat. Choose wholegrain breads, high fibre breakfast cereals, brown rice and pasta, fruit, vegetables, nuts, seeds, beans, peas and lentils. You can add 1 tablespoon per day of milled flaxseed or linseed into cereals, yogurt or soups. Remember to have an extra glass of water for every tablespoon taken.
- Being active can help with constipation. With the help of your physiotherapist, you can gently start adding a little more physical activity into your daily life.
- Your physiotherapist can also support you with bowel retraining.
- If you have tried these suggestions but you are still constipated, speak to your doctor who may prescribe you laxatives, which are medications that make it easier to go to the toilet.

## **Getting dressed**

- Ask a family member or carer to arrange your clothes on the bed for you. Place the items of clothing you need to wear first on top.
- Use your unaffected arm to dress the affected side first. To undress, take the garment off the unaffected side, then remove it from the affected side.
- Choose loose-fitting clothes, clothes with elasticated waistbands, wide neck openings and Velcro closings. This means you don't have to fasten any buttons. Opt for silky fabrics that are easy to slip on.
- Consider slip-on shoes that you can put on with the help of a long shoehorn.

#### Memory

- Write things down. Diaries and lists can help you keep track of appointments and help you remember important things. Use a whiteboard as your daily and weekly planner.
- Use technology. If you're struggling with writing, use your smartphone. You can record voice notes on a voice recorder or note-taking apps on your phone. Set up reminders on your phone to help you remember to take your medication or do your rehab exercises.
- Try prompts. Prompts are a great way to help you remember things. Some people use acronyms or sayings. For example, SLAC could mean: "Set the alarm, lock the door, and close the gate."
- Talk to your OT, psychologist or your doctor. They'll be able to give you more tips to improve your thinking and memory. They may suggest memory exercises and games that you can play with your carer or loved ones.

# **Eating and drinking enough**

Unintended weight loss and dehydration are common after a stroke, especially if your swallow has been affected.

#### You may:

- find that eating and drinking takes longer and is more difficult
- be worried about choking when eating or drinking
- experience less control over your food and drink choices
- feel embarrassed eating or drinking in front of others



If you find it difficult to eat and drink enough or if you are losing weight, ask to be referred to a dietitian for advice. Speak to your healthcare team.

Your **SLT** and **OT** can support you as you develop independence with eating and drinking.

# **Managing fatigue**

- Understand the importance of managing your fatigue for your recovery. When you feel fatigue, it means your brain is not getting enough regular servicing. Getting enough sleep consistently at regular times in the day is your brain's way of healing.
- Get rest in the middle of the day, every day. About 80% of people in recovery from stroke benefit from mid-day rest as part of their daily routine. Try to make sure this is no more than an hour and is at the same time every day. During this time, don't read or play music or use the phone as these can be disruptive. Make sure your phone is on 'Do Not Disturb' mode. Set an alarm to get up if you fall asleep.



Maintain regular rising times and early bedtimes. Rise at the same time every day and go to bed at the same time every night. Keep your phone away from your bed. It is important you have enough sleep so that you wake up feeling rested.

- Pace, plan and prioritise. Try thinking about the '3 Ps' to help you form your own coping strategies:
  - Pace: Think about how you can take things step-by-step at a manageable speed, without triggering your fatigue.
  - Plan: Work out what you want to do and plan when and how you can do it.
  - Prioritise: Decide which activities are important to you and which ones you can leave or get some help with.

Practise these good fatigue management tips. Keep it going. You will start to see benefits after about 7-10 days of doing this.

# Driving

Most people who drove before their stroke will be able to drive again.

If you wish to return to driving:

- Engage with your team to find out when and how you can return to driving.
- Get clearance from your healthcare team.
- You may need an on-road driving assessment. You will be advised by your healthcare team or your OT.

Recovery can take time, so you may be asked to wait longer before you start driving again.

If you're medically cleared and you want to resume driving, let the National Driver Licence Service (NDLS) and your insurance company know.

For more information see ndls.ie

# **Sex and intimacy**

Stroke can affect your sex drive. It can change how your body feels. You may feel different when your partner touches you. Sometimes this may affect your relationship with your partner.

If you're concerned about the effects of stroke on your sex life, talk to your healthcare team. You may want to discuss contraception and family planning with your healthcare team.

The good news is that having sex will not cause another stroke and for many people, getting back to having sex is part of getting better. Take your time and talk to your partner when you feel ready.

# **Returning to work**

How soon you can return to work will depend on:

- the effects of your stroke
- your recovery
- the nature of your work
- the support your employer can give you

Many people only fully realise the impact of their stroke on their concentration, memory and fatigue levels when they return to work.

Talk to your healthcare team about what you can expect.

Be kind to yourself. Give yourself time to follow any treatment or rehabilitation therapy you have been given. You know your needs the best, so you decide when you feel ready to return to work. Contact your employer to discuss options for a gradual return to work. Avoid going back to full-time work hours. For many people, a phased return is helpful. For example, you could start with two hours per day, every second day and gradually increase hours from there. The law says employers must make reasonable adjustments to help you return to work after a stroke. Your healthcare team will help you work out your needs.

Returning to work may impact on any social welfare payments and entitlements you receive. Contact your local Social Welfare Office, Citizens Information or your Employee Assistance Programme, if you have one.

Returning to work before you are ready and without all the supports in place can make recovery difficult.

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Contact the Irish Heart Foundation's **Nurse Support Line** on **01 668 5001** for information on returning to work.



Charities like **Headway** and **Acquired Brain Injury Ireland** will also have helpful information for you.

#### What if I can't go back to work?

Going back to work is not possible for everyone.

If you have been advised that you will not be able to go back to a paid job, that can be very hard to adjust to.

Returning to work is not the only marker of recovery. You can use this time to re-evaluate what you want out of life. You may want to:

- do some volunteering
- develop new hobbies
- return to education
- start your own business

You can also receive financial support from the government if you can't go back to work. Citizens Information has lots of useful information for you about the support you can get. See citizensinformation.ie.

# Socialising

It's important to be able to socialise so that you don't feel isolated and lonely. Socialising can be difficult after a stroke, so here are a few tips:

- Spend time with family and friends. This can help to keep your spirits high. Start slowly, with people who know you best. Plan for just an hour or two.
- When planning an outing, choose a place that suits your needs. Many shopping centres, restaurants, churches and museums are easily accessible for those who rely on walkers and wheelchairs.
- Connect with other stroke survivors. Talk to your social worker and the Irish Heart Foundation about stroke support groups in your area. This is a way for you to meet others who have had experiences similar to yours. You can learn a lot from them about new and different ways to live well after stroke.



# **Preventing another stroke**

Over time, your risk of having another stroke goes down. You can reduce the risk of having another stroke by controlling the major risk factors of stroke.



**Move more**. Be more physically active and aim for at least 30 minutes of brisk activity every day – every bit of movement you can do counts.



Aim for a **healthy weight** – your doctor can help you with this.



Try to eat a **healthy, balanced diet**. Aim for 5-7 portions of fruit and vegetables every day.



Cut down on **salt**, especially from ultra-processed foods high in salt, fat and sugar.



If you drink alcohol, keep within the recommended **low-risk alcohol guidelines**.



If you smoke, try to stop. Freetext QUIT to **50100** or freephone **1800 201 203**.



Control your medical conditions, especially high blood pressure, high cholesterol and type two diabetes. **Take your medication** as prescribed by your doctor. No patient should be told they can't do something, they shouldn't give up. Mindset is so important in recovery."

Meaghan, young stroke survivor

# Notes...




# Caring for a stroke survivor

# 05 Caring for a stroke survivor

As the carer of a stroke survivor, you play a crucial role in supporting and encouraging their recovery.

Encourage the person you are caring for to do things for themselves. This may be time-consuming and will require patience, but it will help rebuild their self-confidence and independence.

Use **reassurance** and **praise** for what has been attempted, rather than correction and feedback – it is far more effective!



As a carer, you may:

- provide round the clock care for someone who is ill, frail or has a disability
- take them to their medical appointments
- help them to advocate for their care

- help them with personal hygiene, cleaning and washing
- < help prepare meals for them
- do the housework and the shopping for them
- balance work and caring responsibilities

Caring can be challenging. Ask for help when you need it.

# **Dealing with emotional and behavioural changes**

Stroke can trigger plenty of emotions in the survivor. Many survivors feel shame about not being able to perform basic everyday tasks and they may minimise the effects of their stroke.

As a carer, it will help to create a safe and supportive space where the stroke survivor feels comfortable to express their feelings.

- Encourage them to talk about their frustrations, fears and concerns.
- Listen to them without judgement.
- Validate their emotions, letting them know that it's ok to feel the way they do.

It is helpful to focus on what the person can do rather than what they cannot do. Celebrate the recovery gains they make as that will help build their self-belief and confidence. Share stories of other stroke survivors who have overcome similar obstacles to inspire hope. You can find stories like this on our website: <u>irishheart.ie/real-life-stories</u> or in face-to-face and online carer and stroke support groups.

You can also help by encouraging the person you are caring for to meet with friends, family and support groups and to speak about their experience of stroke and their recovery. This will help them feel connected.

Take the time to understand the impact of stroke on the person you are caring for. Stay in touch with their healthcare team so you are always aware of the needs of the person you are caring for.

Spend some time learning about stroke recovery, rehabilitation techniques and caregiving best practices through training workshops and educational resources. For example, **Family Carers Ireland** has developed a suite of eLearning courses to help carers.

## Communicating with the person you are caring for

Talking to the person you are caring for may not be the same as it used to be. The stroke survivor may be slower to process the information you give and to respond to you. Here are a few tips to help you communicate better:

- Remember that they can understand you even if they can't speak to you the way they used to.
- Try talking, writing, drawing, gesturing and pointing to convey what you want to say to them.
- Allow plenty of time for a response.
- Keep talking naturally as you would to any other person – not louder or in broken English.

- Try to reduce background noise such as television or radio.
- Keep your sentences short, straightforward and simple, and try introducing one idea at a time.
- Repeat important words and write them down to clarify meaning.
- Help them practise the communication exercises recommended by their speech and language therapist (SLT).



# Looking after yourself

Taking on caring responsibilities is a big decision.

It may have fallen on you because you are a close family member. But caring can be challenging and it takes time and energy.

It can sometimes leave you feeling overwhelmed, exhausted and isolated.

You may also feel a sense of loss at the changes in the person and in your relationship with them following the stroke. Sometimes, you may have feelings of resentment, even anger and guilt about having these feelings. This is natural.

It is important you take steps to ease the stress of caring. This will help you and the person you are caring for.  Give yourself time away from your caring duties each week.
 Physical activity such as walking or gardening can help relieve stress.

Many people find that speaking to other carers is helpful. You can find other carers on the Irish Heart Foundation's Carers Support Network page on Facebook. Family Carers Ireland also have a network of carer groups across the country.

Stay in touch with **family and friends**.

Don't be afraid to **ask for help** if you need it. People around you may be able to do some practical things like shopping or spend time with the stroke survivor.

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Talk to your GP, public health nurse or your local HSE health office about getting **respite care**. Respite care is when someone else or an organisation cares for the person while you take a break. This can be for a short or long period of time.



You can apply for the **Carer's Support Grant** (formerly called the Respite Care Grant). This is a payment you can get every year from the Department of Social Protection.

# Supports for you

#### **Irish Heart Foundation Carers Support Network**

This is a private Facebook group for carers to share their experiences and support each other. Find us on Facebook or **via irishheart.ie/support-for-you** 

#### Irish Heart Foundation Nurse Support Line

As a carer of someone with heart disease or stroke, you can call our Nurse Support Line on **01 668 5001** with any questions or concerns.

#### **Family Carers Ireland**

Family Carers Ireland provides a range of services such as support groups, a national freephone careline and helpful information and guidance. Visit **familycarers.ie.** 

#### **Young Carers**

Young carers face particular challenges and can find it difficult to balance life and study. Young Carers is part of Family Carers Ireland. They offer support through young carer groups, training and respite breaks for carers under 18 years of age. Visit **youngcarers.ie** to find out more.



When things are difficult, I find this quote from Thich Nhat Hann a source of comfort:

'Smile, breathe and go slowly.'"

Majella, carer

# Appendix My stroke and recovery

Stroke is when a part of your brain loses blood supply. When this happens, your brain can be affected. Tick the box that applies to you:

Ischaemic stroke:	an artery is blocked
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Haemorrhagic stroke: an artery in the brain bursts and bleeds

Transient ischaemic attack (TIA): a ministroke

**Other** (e.g. brain injury, brain haemorrhage, brain clot). You may have been given another name for your condition.

Adapted from Stroke Foundation (2024) My Stroke Journey.

# My healthcare team

Write down the names of the members of your healthcare team.

Health care professional	Name and contact details
Consultant doctor	
Hospital nurses	
Public health nurse	
Physiotherapist	
Occupational therapist (OT)	
Speech and language therapist (SLT)	
Dietitian	
Medical social worker	
Clinical psychologist	
Others	

Adapted from Stroke Foundation (2024) My Stroke Journey.

# My risk factors

Talk to your healthcare team to identify which of these risk factors affect you.

Tick the risk factors that apply to you and check if you have taken the right steps to manage your risk factors.

<b>Risk factors</b>	What I need to do	Notes
High blood pressure	Take medication as prescribed by my doctor.	
	Ask my GP or pharmacist to check my blood pressure regularly.	
	Eat well, move more and aim to maintain a healthy weight.	
	Reduce my salt intake.	
High cholesterol	Take medication as prescribed by my doctor.	
	Ask my GP to check my cholesterol regularly.	
	Eat well, move more and maintain a healthy weight.	
	Eat less saturated fat.	
	Don't smoke.	

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Risk factors	What I need to do	Notes
Type 2 diabetes	Take medication prescribed by my doctor.	
	Check my blood sugar when I'm supposed to.	
	Eat well, move more and maintain a healthy weight.	
	Don't smoke and avoid alcohol.	
Atrial fibrillation	<ul> <li>Report any potential symptoms to my hospital team</li> <li>racing heart, palpitations, dizziness.</li> </ul>	
	Take medication prescribed by my doctor.	
	Eat well, move more and maintain a healthy weight.	
	Don't smoke.	
	Avoid alcohol.	

Risk factors	What I need to do	Notes
Not eating healthily	Reduce my salt intake, especially from ultra- processed foods.	
	Include 5-7 portions of fruit and vegetables every day.	
	Choose wholegrains, for example, brown rice and pasta, wholegrain bread and wholegrain cereals.	
	Make heart healthy fat swaps. Switch butter, cream, fatty meats and coconut oil for healthier oils like olive oils, lean meats and oily fish.	
Move as much as I can	Ask my healthcare team about ways to move more that will work for me.	
throughout my day	Move as much as I can throughout my day.	
	Do at least 30 minutes of moderate activity at least 5 days a week.	
	Reduce the time spent sitting or not moving. Break it up as much as I can.	

Risk factors	What I need to do	Notes
Unhealthy weight	Ask my healthcare team what a healthy weight is for me.	
	Eat a healthy balanced diet.	
	Be physically active.	
	Get enough good quality sleep.	
	Seek help from my GP or a CORU-registered dietitian.	
Smoking	<ul> <li>Call the National Smokers'</li> <li>Quitline on 1800 201 203</li> <li>(free) or freetext QUIT to 50100.</li> </ul>	
	Go to quit.ie for more support on quitting smoking.	
High alcohol intake	Talk with my healthcare team or GP about alcohol and my risk of stroke.	
	Visit <u>AskAboutAlcohol.ie</u> for information and support.	
Stress and grief	Talk to my healthcare team or GP.	

Adapted from Stroke Foundation (2024) My Stroke Journey.

# My leaving hospital checklist

Fill this in when you are getting ready to leave hospital. Ask your team about anything you're not sure about.

My stroke	I know who to talk to if I'm worried about something to do with my stroke.
Medication	I know what medication I need to take.
	I know the amount I need to take.
	I know how often I need to take my medication.
	I have enough medication to last until I see my GP.
Follow-up	I know what appointments I need.
appointments	I know how these will be organised.
Services	I know what services I need.
	I know how these will be organised.
Daily life	I know how to do things safely.
	The people helping me know how to help me.
Changes to my	I know what changes I need to make to my home.
home	I know how these will be organised.
Equipment	I know what equipment I need.
	I know how this will be organised.
Rehabilitation	I know what rehabilitation I need.
	I know how this will be organised.
Risk factors	I have discussed my risk factors with my healthcare team.
	I know how to control my stroke risk factors.
Signs of stroke	I know the <b>F.A.S.T.</b> signs of stroke - Face. Arms. Speech. Time.
	I know to call <b>112</b> or <b>999</b> if I have any signs of stroke.

Adapted from Stroke Foundation (2024) My Stroke Journey.

# My goals

Jot down your short-term, medium-term and long-term rehabilitation goals. Make sure your goals are SMART (Specific, Measurable, Achievable, Realistic, Timebound).

Do this in consultation with your healthcare team. Remember, every stroke is different so your recovery will be unique.

Short-term goals	Medium-term goals	Long-term goals

Adapted from Stroke Foundation (2024) My Stroke Journey.

# More information – useful addresses and websites

#### **Acquired Brain Injury Ireland**

Supporting people with brain injury and their families to return to leading independent lives with confidence.

web: <u>abiireland.ie</u> email: hello@abiireland.ie

#### Age Action Ireland

Ireland's leading advocacy organisation for older people and ageing. Also provides practical programmes to support older people to age in place.

web: <u>ageaction.ie</u> email: info@ageaction.ie

#### Age & Opportunity

A national development organisation that offers opportunities for older people to be more active, more visible, more creative, more connected and more confident.

web: <u>ageandopportunity.ie</u> email: info@ageandopportunity.ie

#### ALONE

A national organisation that enables older people to age at home.

#### web: alone.ie

National support line: 0818 222 024

#### **American Stroke Association**

A division of the American Heart Association.

web: stroke.org

#### **Aphasia Ireland**

Raises awareness of aphasia and offers support to people with aphasia and those around them.

web: <u>aphasiaireland.ie</u> email: aphasia.ireland@gmail.com

### Association of Occupational Therapists of Ireland (AOTI)

A professional body serving, promoting and representing occupational therapists in the Republic of Ireland.

web: <u>aoti.ie</u> email: info@aoti.ie

#### Aware

A national organisation providing free support, education and information services to people impacted by anxiety, depression, bipolar disorder and related mood conditions.

#### web: aware.ie

National support line: 1800 804 848

#### **British Heart Foundation**

A UK-based charity that supports people living with heart and circulatory diseases.

web: <u>bhf.org.uk</u>

# British and Irish Association of Stroke Physicians

An organisation that provides leadership in advancing clinical standards, promoting research and improving training across the United Kingdom and the Republic of Ireland.

web: biasp.org

#### **Care Alliance Ireland**

Works with organisations to provide better information and supports to family carers, while also commissioning research and delivering a number of carer-specific projects.

web: <u>carealliance.ie</u> email: info@carealliance.ie

#### **Citizens Information Centres**

Offers information on your rights and entitlements. **web: citizensinformation.ie** 

#### Croí

A heart and stroke charity with a particular focus on the west of Ireland. web: croi.ie email: info@croi.ie

#### **Different Strokes**

A UK-based charity that helps younger stroke survivors and their families to reclaim their lives through active peer support.

web: differentstrokes.co.uk

#### **Disability Federation of Ireland**

A federation of member organisations working with people with disabilities to implement the United Nations Convention on the Rights of Persons with Disabilities and ensure their equal participation in society.

web: <u>disability-federation.ie</u> email: info@disability-federation.ie

#### **European Stroke Organisation**

A pan-European society of stroke researchers and physicians, national and regional stroke societies and lay organisations working to change the way that stroke is viewed and treated.

web: <u>eso-stroke.org</u> email: esoinfo@eso-stroke.org

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#### **Family Carers Ireland**

The national charity supporting the 500,000+ family and young carers across the country who care for loved ones.

web: <u>familycarers.ie</u> National freephone careline: 1800 240 724

#### Headway

Irish registered charity and an internationally accredited brain injury services organisation that supports adults (18+) who are affected by a brain injury, including stroke.

web: headwayireland.ie

email: <u>helpline@headway.ie</u>

#### Irish Association of Social Workers

National professional body for social workers in the Republic of Ireland.

web: <u>iasw.ie</u> email: <u>office@iasw.ie</u>

#### Irish Association of Speech and Language Therapists (IASLT)

The recognised professional body representing speech and language therapists in Ireland.

web: <u>iaslt.ie</u> email: <u>info@iaslt.ie</u>

#### Irish Men's Sheds Association

Provides support, information and resources to member sheds on the island of Ireland. You can also find your nearest men's shed via the website.

web: <u>menssheds.ie</u> email: info@menssheds.ie

# Irish Nutrition and Dietetic Institute (INDI)

The professional body for registered dieticians in the Republic of Ireland.

web: <u>indi.ie</u> email: info@indi.ie

#### Irish Society of Chartered Physiotherapists (ISCP)

The national professional body representing chartered physiotherapists in Ireland. web: iscp.ie email: info@iscp.ie

#### Irish Wheelchair Association (IWA)

One of Ireland's leading representative organisations and service providers for people with physical disabilities.

web: <u>iwa.ie</u> email: info@iwa.ie

#### National Disability Authority (NDA)

Independent statutory body providing evidence-based advice and research to Government on disability policy and practice and promoting Universal Design.

web: <u>nda.ie</u> email: info@nda.ie

#### **National Rehabilitation Hospital**

Delivers complex specialist rehabilitation services in Ireland. **web:** <u>nrh.ie</u>

#### **Neurological Alliance of Ireland**

A group of non-profit organisations who advocate for the rights of people in Ireland living with a neurological condition.

web: nai.ie

#### **Rehab Group**

Empowers people with disabilities to lead more independent lives and play an active and meaningful role in their communities through care services, learning, training and education, employment-skills and opportunities.

web: <u>rehab.ie</u> email: <u>info@rehab.ie</u>

#### The Samaritans

Charity offering emotional support 24-hours a day, 365 days a year, to anyone who is in distress, lonely, struggling to cope or feeling suicidal. web: samaritans.org email: jo@samaritans.org Samaritans' 24-hour Helpline: 116 123

#### The Stroke Association (UK)

A UK-based charity that supports people to rebuild their lives after stroke.

web: stroke.org.uk

#### **Vision Ireland**

Ireland's national sight loss agency. Offers programmes for adults and children who are blind or vision impaired so they can live life confidently and independently.

web: <u>vi.ie</u> InfoLine: 1800 911 250

#### Volunteer Stroke Scheme (VSS)

The Volunteer Stroke Scheme was set up in 1983 to cater for stroke patients and their families.

web: <u>strokescheme.ie</u> email: help@strokescheme.ie

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The National Stroke & Heart Charity

The Irish Heart Foundation is a community of people who fight to protect the cardiovascular health of everyone in Ireland.

Irish Heart Foundation 17-19 Rathmines Road Lower, Dublin 6, D06 C780.

№ 01 668 5001⋈ info@irishheart.ie

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