



**Irish Heart
Foundation**

www.irishheart.ie

CARING FOR A PERSON AFFECTED BY STROKE





This booklet aims to tell you where you can find information and advice to help and support you as you care for someone close who has had a stroke. At the Irish Heart Foundation, we recognise that you probably didn't choose this role, and may have received little or no training and support as a carer. Through this booklet we hope we can help you to take care of yourself and give you some help and support in caring for your loved one.

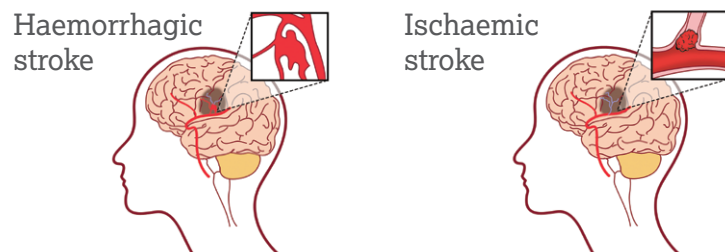
What's inside?

1. Stroke and caring for someone close to you who is affected by stroke.
2. Practical matters, benefits and legal questions.
3. How to look after yourself, other carers, and family members
4. Additional resources

What causes a stroke?

- Over 80 percent of strokes are caused by a blockage in an artery supplying blood to the brain. This is known as an ischaemic stroke. There are three main types of ischaemic stroke:
 1. A blood clot that forms in a main artery to your brain.
 2. A partial clot that may form in your heart or the blood vessels of your neck. This partial clot can be carried in your bloodstream to your brain and get lodged in an artery. This is a cerebral embolism.
 3. A blockage that occurs in the tiny blood vessels deep in your brain. This is a lacunar stroke.
- Up to 20 percent of strokes are caused by a bleed into your brain from a burst blood vessel. This is called a haemorrhagic stroke.
- A transient ischaemic attack (TIA) or mini-stroke is a sudden and brief disturbance of your brain caused by small clots. Stroke symptoms from a TIA last less than 24 hours before going away.

TIAs do not cause any long term damage. However, they are a serious warning sign that you may have a full stroke in the near future. Approximately 10 percent of people with a TIA will have a stroke within a week and 20 percent of people will have a stroke within a month. TIAs should not be ignored and urgent medical attention is required.



Part 1: Stroke and caring for someone affected by stroke.

What is a stroke?

A stroke happens in the brain. Your brain needs a continuous flow of blood to stay healthy. When blood suddenly stops going to the brain, we say this is a “stroke”.

What stops blood going to the brain?

1. A sudden blood clot. Strokes caused by a blood clot are known as ischaemic strokes.

Or

2. A sudden bleed into the brain. Strokes caused by a bleed are known as haemorrhagic strokes.

Who gets a stroke?

Stroke can affect anyone. Most people who have a stroke are over 65, but stroke can occur at any age for example it also happens to young people

Are all strokes the same?

No. Every stroke is different. How a person is affected by stroke and how they recover is different for everyone.

A stroke is always an emergency. Phone 999 or 112 immediately if you think someone is having a stroke.

Watch for:

F – Face: Has their face fallen on one side? Can they smile?

A – Arms: Can they raise both their arms and keep them there?

S – Speech: Is their speech slurred?

T – Time: Time to call 999 or 112 if you see any of these signs.

These are the most common signs of stroke, but there are others, such as blurred vision, severe headache, feeling confused and numbness or weakness on one side of your body. You can find out more in our booklet “What is a stroke and how to treat stroke”.

When you phone 999 or 112, the emergency call-taker may ask you to do some checks with the person you think has had a stroke. They may ask you questions about how the person is responding. Do not panic; make sure to answer the emergency call-taker’s questions as these will help them to establish whether the person is having a stroke or not.

What happens when we get to a hospital?

First, the medical staff need to be sure it is a stroke. If it is a stroke, they need to find out if it is caused by a clot or a bleed. To do this, they will carry out different tests and investigations, including blood tests and brain scans. For more information on hospital investigations, see the Irish Heart Foundation’s booklet “What is a stroke and how to treat stroke”.

What can the doctors do?

If the stroke is caused by a clot, a doctor may use a drug that dissolves clots. Medical staff call this **Thrombolysis**. This can only be used for up to four and a half hours from the time of a stroke. If doctors are not sure about when the person had the stroke, they may not be able to use these drugs. To learn more about thrombolysis, visit our website, www.irishheart.ie.



Another treatment for stroke caused by a clot is called **Thrombectomy**. This is carried out in two hospitals – Beaumont Hospital in Dublin and Cork University Hospital. Doctors use specialist equipment to mechanically remove the clot from the brain. For more information about thrombectomy, visit www.irishheart.ie

If a stroke is caused by bleeding, a doctor may operate to remove the blood and reduce pressure on your brain or to repair a blood vessel.

How long will someone stay in hospital after a stroke?

The length of a hospital stay varies greatly depending on the severity of the stroke and any other health problems the person may have. It can range from two weeks for a mild stroke to a number of months for a more severe stroke

What will happen in hospital?

1. Tests and treatments to stabilise the person.
2. In-hospital rehabilitation
3. Discharge from hospital to go home, to a rehabilitation hospital or to a nursing home.

Tests and treatments to stabilise the person

First, the person affected by stroke undergoes tests and treatments to make sure they are stable and have no other problems.. This can be a difficult time.

You will have many questions. You may want to know how you can help, what the tests showed and what happens next. But, early on, it can be hard for doctors or nurses to give you and your loved one all the answers.

Who treats them?

A **team of stroke professionals** should treat a person after a stroke.

What is a stroke team?

A stroke team can consist of up to 10 people and can include a doctor, nurse, physiotherapist, occupational therapist, dietitian, speech and language therapist, medical social worker, clinical psychologist and orthoptist (eye-care health professional).

Each person on a stroke team looks after different effects of stroke. For example, the speech and language therapist on the stroke team works on speech and helps with swallowing problems. But they all work together as a team for each patient.

If you would like to find more about stroke teams and what each person does, visit our website at www.irishheart.ie

As a carer or family member, you can help by working with the team. You can play an important part in your loved one's treatment. Find out who will speak to you regularly from the team so you know how you can help in looking after your loved one . You may need to speak to a staff member, such as the head nurse, and to plan a time when someone from the stroke team will be there. In most hospitals, you can ask for a family meeting.

A person affected by stroke will make their own decisions, but under a new law from 2020 or 2021, they can appoint someone, like a carer or family member, to support them making certain decisions at certain times. If your loved one is not able to make healthcare decisions, the doctors will discuss treatment options with their next of kin.

What happens next? In-hospital rehabilitation

For the second part of their stay in hospital, if they are well, their rehabilitation starts. Rehabilitation is important after a stroke.





Rehabilitation will be different for everybody. As part of their rehabilitation your loved one may have to learn how to carry out everyday tasks all over again like walking, washing, speaking, standing or swallowing.

What happens after leaving hospital?

Discharge from hospital to go home, to a rehabilitation hospital or to a nursing home

The third stage, if they are well enough, is to leave hospital to go home or to a rehabilitation unit or other facility.

All stroke survivors should get 45 minutes of rehabilitation after their time in hospital, between five and seven days a week. However, this may not be available everywhere.

What is important for them, and you as a carer and for other family members, is to have a copy of the plan for their care. This is called a **discharge plan**.

This plan should cover the person's needs after hospital, including their medicine, any equipment they might need and how they can link into local services.

Discharge planning

Planning ahead in hospital means talking to a medical social worker who will help with information on health and social care services in your area. They can help contact your local health office, to set up visits from healthcare staff, identify rehabilitation needs and other home care supports, and give you information on what benefits your loved one may be entitled to.

You can also help by making sure your loved one has a list of their medicines. They need to know when and how to take them. Now is the time to ask questions such as: What is this tablet for? Do they take them before or after food? What should they do if they forget to take a tablet?

When a person affected by stroke leaves hospital, the responsibility for their medical care passes to their family doctor (GP), the local public health nurse and the primary care team, but all of these healthcare professionals will also work with the stroke doctor from the hospital.

Support from the Irish Heart Foundation

As a carer or family member, you should also be told about community services and support groups that are available. The Irish Heart Foundation has a national network of stroke support groups and a Facebook support network for carers.

Are there any other discharge services?

There are currently three Early Supported Discharge Teams in Ireland, which are based in Galway, Dublin North and Dublin South.

If someone close to you is in hospital after a stroke and if well enough, would like to leave hospital early, the early supported discharge team will help to setup rehabilitation and recovery goals for them at home.

Is there a risk of a second stroke?

Yes this can happen, particularly in the first year after a stroke. Your stroke team can provide you with advice to help reduce the risk specifically for your loved one.

By making small lifestyle changes, a person can reduce their risk of having another stroke:

- **Control blood pressure** – High blood pressure is the leading cause of stroke. After a stroke, a person’s blood pressure will be monitored carefully. A combination of medicine and lifestyle changes (such as, stopping smoking, being a healthy weight and keeping alcohol intake below the recommended maximum weekly limit) can help reduce and control high blood pressure. Our booklet, “Manage your blood pressure” has more information.
- **Quit smoking** – stopping smoking halves the chance of having a stroke or a repeat stroke. Our booklet, “Quit smoking” has lots of helpful advice and techniques to help you quit.
- **Eat healthily and control your cholesterol** – eat lots of fruit and vegetables, and more unsaturated fats which are found in oily fish, nuts, seeds and most pure vegetable oils; reduce the amount of saturated fat (animal and dairy fats) you eat. If you drink alcohol, keep your intake below the maximum weekly limit of 17 standard drinks for men and 11 standard drinks for women. Our booklets, “Healthy eating” and “Manage your cholesterol” have more information to help you plan healthy meals and control cholesterol.

- **Trying to achieve and maintain a healthy weight** – If you have a higher weight you can gain important health benefits by losing 5-10% of your weight. This can help reduce your risk of diabetes, decrease your blood pressure and help control your cholesterol levels, therefore reducing risk of stroke and heart disease. Eating a nutritious and



balanced diet, looking at portion sizes, getting enough sleep, checking labels, being more active and preparation can all help. Remember even if weight loss progress is slow or you hit a plateau, making these healthy lifestyle changes will be beneficial.

- **Be more physically active** –this depends on a person’s level of disability after a stroke. If your loved one can be physically active, their stroke team will give you advice on suitable rehabilitation activities to re-build strength, coordination and fitness.
- **Manage you stress** – hormones released during stressful times, may damage your blood vessels over time and lead to high blood pressure. When we are stressed, we can drink and smoke more and tend to be less active. All of these increase the risk of stroke. Our booklet, “Manage you stress”, gives advice on how to control stress levels.



- **Atrial fibrillation (AF)** – this is a type of irregular heartbeat that can cause blood clots, which lead to stroke. If a stroke was caused by AF, the person is likely to be prescribed medicine to help prevent blood clots. It is very important to take this medicine according to the doctor’s instructions. Sometimes, a person may have a medical procedure to try and stop this irregular heartbeat. You can learn more about AF and treatment options in our booklet, “AF and You”.

What is life like for someone after a stroke?

When someone close to you has had a stroke, they may face many changes. They can have trouble walking, dressing, moving, swallowing, going to the bathroom or speaking. They may have pain in their muscles or joints. Their eyesight may be poor.

Also, when someone close to you has had a stroke, they may have trouble speaking, reading or understanding. This is known as **aphasia**.

You can find out more about the types of disability a person may have after stroke at www.irishheart.ie or in our booklet “Step by step through stroke”.

What other changes does a stroke survivor experience?

A stroke survivor also experiences life changes which may be difficult for you to see. For example, they may have difficulty thinking, knowing where they are or remembering where things are. For some people, this is a short-term effect, for others it may last for a long time.

Many people become depressed after a stroke. They may be anxious or cry for no reason you can see. This may be due to changes caused by the brain injury or from the emotional trauma of having a stroke.

You, your loved one and family members can all struggle to handle these changes but there are organisations that can help

The Irish Heart Foundation

The Irish Heart Foundation can support you and your loved one through this difficult time with a number of services:

Irish Heart Foundation Facebook group for carers

The Irish Heart Foundation hosts a private Facebook group for carers, where you can share experiences and offer support to each other. You can join at www.facebook.com

Irish Heart Foundation stroke support groups

For people who have had a stroke, the Irish Heart Foundation runs 20 local support groups throughout the country. The groups meet weekly and offer their members access to counselling, exercise therapy and other supports. Find your nearest group at www.irishheart.ie/support/stroke-support-groups.

Facebook group for working age stroke survivors

The Irish Heart Foundation hosts a private Facebook group for younger, working age stroke survivors called Life After Stroke. You can join this group at www.facebook.com

How does a stroke affect my relationship with my partner?

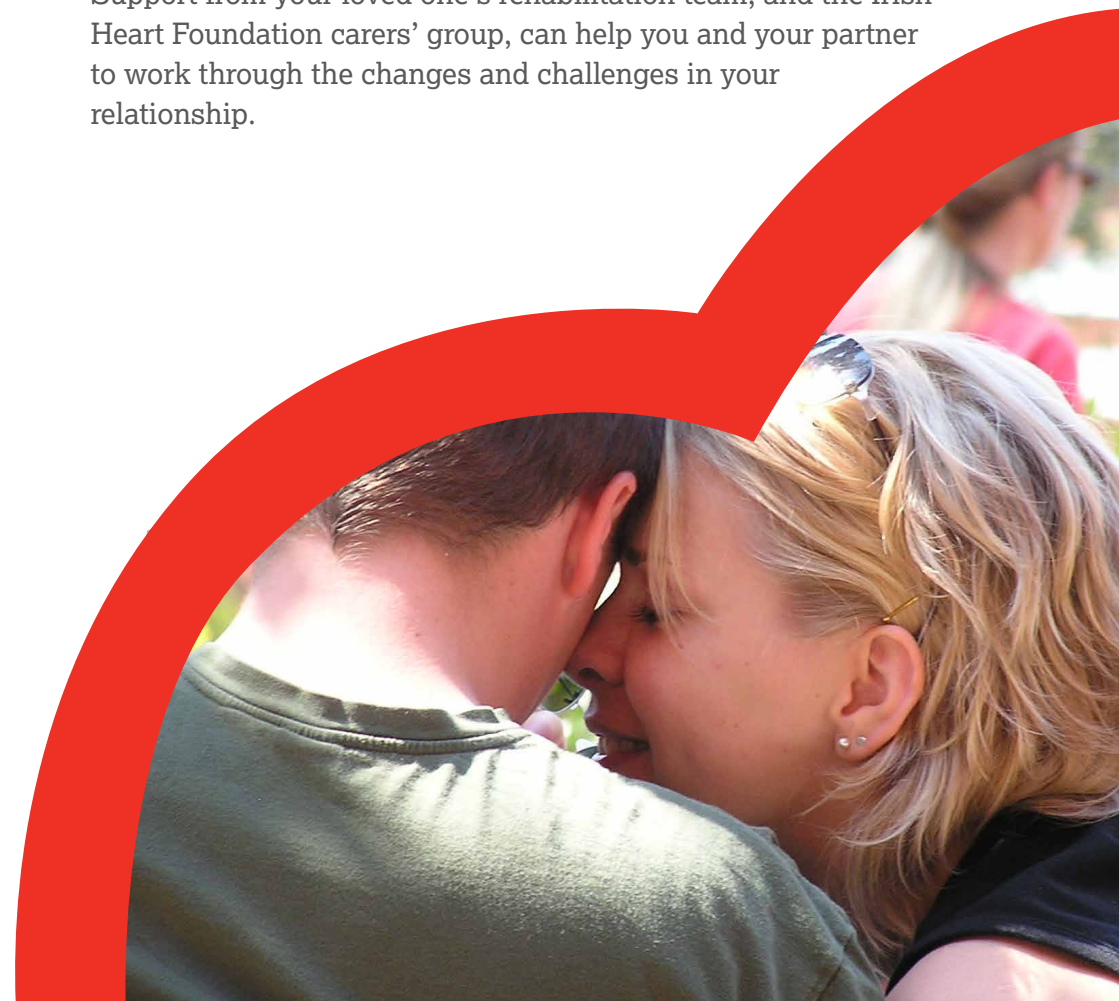
Stroke can have a big impact on relationships and intimacy between partners in many ways.

Having to be cared for all of a sudden can affect a stroke survivor's self-esteem and self-confidence. This can, in turn, affect a relationship.

A stroke survivor may also have physical disabilities that make sex and intimacy more challenging. They may also be worried that their disabilities and changes in appearance will make them less attractive to their partner.

After a stroke, people can suffer low mood, anxiety and depression and simply may not feel like being intimate.

A person's personality can change after a stroke, meaning that partners have to learn to live with and love a changed person. Support from your loved one's rehabilitation team, and the Irish Heart Foundation carers' group, can help you and your partner to work through the changes and challenges in your relationship.



The rehabilitation team can suggest practical steps to help make intimacy more comfortable. They can look at the medicines your partner is taking and see if adjusting or prescribing different medicines would help energy levels or sexual activity.

They may also be able to prescribe new medicines to help depression and anxiety and to improve sexual performance.

For more information on sex after stroke visit www.irishheart.ie/news/heart-of-the-matter-sex-after-a-stroke/

Part 2: Practical matters, benefits and legal questions.

Am I entitled to any payments as a carer?

There are **two main social welfare schemes** which carers are entitled to. These are Carer's Benefit and Carer's Allowance.

If you have been in work, you may be eligible for **Carer's Benefit** for up to two years.

- If you are working and want to care for someone, you may also be eligible for **unpaid Carer's Leave** from your place of employment for up to two years.
- For more information, visit www.citizensinformation.ie



- If you are on a low income and want to care full time for someone who has had a stroke, you may be eligible for Carer’s Allowance. This payment is means tested.
- Two people can share **Carer’s Allowance**, each caring full-time Monday to Sunday, every second week.
- With Carer’s Allowance, you may also qualify for a free travel pass and, if you are living with the person you care for, free household benefits for electricity or gas and a free television licence.
- Both the Carer’s Benefit and Carer’s Allowance schemes allow you to work or train for up to 15 hours a week as a carer and still receive your payments.
- A half-rate Carer’s Allowance is paid with some other social welfare payments. This allows you to keep your main social welfare payment and half-rate Carer’s Allowance.
- Domiciliary Care Allowance is paid every month to the carer of a child who lives at home and has a severe disability.

The other payment, under both the Carer’s Benefit and Carer’s Allowance schemes, is the **Carer’s Support Grant** of €1,700. This is paid once a year, usually in June.

Also, Since 1 September 2018, all carers getting full or half-rate Carer’s Benefit or Carer’s Allowance can get a **GP visit card**. The card lets you visit your GP for free.

It can be difficult to find out what payments or grants you qualify for and are right for you as a carer. You may be entitled to other allowances and benefits, depending on the scheme you are on. A good place to start finding out about your rights is **Citizens Information**.

You can contact them by phone on 0761 074 000, call into your local centre or visit their website, www.citizensinformation.ie.

With over 200 Citizens Information centres around the country, there is at least one centre in each county. You can talk to Citizens Information about your situation, as well as benefits and rights for someone who has had a stroke. Their service is free and confidential.

If you would like more information about your rights as a carer, **Family Carers** has a useful booklet, “**Rights & Entitlements for Family Carers**” on its website www.familycarers.ie. They offer a free personal advocacy service to family carers. A member of their organisation can accompany you and assist you in dealing with enquiries, appeals and other appointments with health or social service professionals. You can also speak to them on their national freephone careline on Tel: 1800 240724.

The **Health Service Executive** (HSE) website has lots of useful information for carers – visit www.hse.ie. The “Carers” section of the HSE website has a useful Carer’s Emergency Card which ensures that if you have an accident or are taken ill, the person you care for will be looked after.

Home aids and equipment

If someone close to you has had a stroke, they may qualify for home aids or equipment such as a wheelchair, grab rails in the bathroom or tap turners in the kitchen. The HSE is the agency to go to for this. You will need to submit an application to your local health office and an occupational therapist or other healthcare professional will assess the need for appliances, medical equipment or aids. A list of local health offices is available on the HSE website at www.hse.ie.

Finance and grants

Grants to make a house easier to live in for someone who has had a stroke are also available and are administered by local authorities (city and county councils). The grants depend on many different conditions such as household income, the age of the house, medical need, etc. For more information on grants, and who is eligible, contact your local authority, or speak to Citizens Information for information about how to apply.

The Department of Employment Affairs and Social Protection also has a list of social welfare benefits including benefits for carers on its website, www.welfare.ie.

If someone close to you has a stroke, it will be sudden and can mean loss of income and other money problems. If you and your family are in debt or worried you are getting into debt, **the Money Advice and Budgeting Services (MABS)** can help you. MABS has 53 offices around the country or you can phone them on their helpline at 0761 072 000

Legal Matters

What do I need to know as a carer?

There may come a time when it is difficult for a stroke survivor to make important decisions about his or her life.

For them, for family members and for you as a carer, it will help you and your loved one to know about a new law aimed at supporting people to make certain decisions at certain times when they need extra help..

The main parts of the new law, which is called the Assisted Decision-Making Act, are expected to come into force during 2020-2021.

The new law says we all make our own decisions. But if we find it difficult to make certain decisions at certain times, we can choose a second person to support us. This could be someone like a carer, friend or family member,

Or, if we need more formal support we can have a “co decision maker” to help us make certain decisions jointly. The second person would be registered with a new decision support service as our “co decision maker”.

And, lastly, if we need even greater support at any time with certain decisions, a court will appoint a “decision-making representative”. The court will outline what the decision-making representative’s role will be in decision making.

What is an Enduring Power of Attorney? Does that help with making decisions?

An Enduring Power of Attorney allows us, when we are fit and well, to choose who we would like to make certain decisions for us in the future, if the time comes when we cannot do so ourselves.

Currently, the person we choose can make decisions about our personal care but not our healthcare. When the new law comes in, it will bring another change. The person we choose for an Enduring Power of Attorney will also be able to make some decisions on our medical care.

Is there anything else we need to know about the new law?

The other major change is that this law will allow us to record, in law, what we want, and do not want for our future healthcare and treatment.

This is to give doctors, and other healthcare staff, information about how we want to be cared for in the future.

This is called an Advance Healthcare Directive.

We are being encouraged to record an advance healthcare directive, starting now, by the **Irish Hospice Foundation** campaign “Think Ahead”. The Foundation has published a useful form to record future care preferences which you can sign and keep in one place. If you are interested in more information and a copy of the form, the Irish Hospice Foundation website is www.hospicefoundation.ie. Go to the “Programmes” drop down menu and click on “Think Ahead.”

While we wait for the new law to come into force, clear and up to date information on the legal changes is available on Inclusion Ireland’s website at www.inclusionireland.ie. Click on “Assisted Decision-Making (Capacity) Act”. Watch a video about the new Act or read their “Updates”.

Another way to learn more is by going to the Free Legal Aid (FLAC) website www.flac.ie. They have an information leaflet on Enduring Power of Attorney under their “Resources” menu. Type the word “Enduring” in the title box and this will find it for you.

Someone who has suffered a stroke may be keen to make a will. **FLAC** also have advice on “Wills and Intestacy”. You can phone lo-call 1890 350250 or 01 8745690 for basic information. FLAC also runs legal advice clinics. If your loved one has their own solicitor, she or he will be able to advise them further.

Part 3. Looking after yourself, other carers and family members

“No one at the hospital asked if I was qualified or able to be a carer, I was just expected to take on the role without any help or guidance”. (Carer of a stroke survivor)

Most carers of stroke survivors never expected to find themselves in this role, but take it on selflessly. Caring for a stroke survivor is a huge undertaking physically, mentally and emotionally. It is important not to underestimate the impact this new role will have on you as a carer. It is important that you take care of your own mental and physical health so that you can have a reasonable quality of life, provide the care your loved one needs and can cope with the demands of life as a carer.

Who can help me with advice on how to look after myself?

Support group and respite care for your loved one are important for you as a carer. You need to think about staying healthy and looking after yourself to be able to care for your loved one. Finding ways to relax, reduce your stress and minding your diet and sleep will all stand to you as a carer.

“I would just like to be able to meet and talk to other carers”. (Carer of a stroke survivor)

Formal and informal support

Carers who we have spoken to all talk about the strain they feel on their mental and emotional health. Sometimes just having someone to talk to, who is in a similar situation, can be enough to help.

The Irish Heart Foundation has a **private Facebook group for carers** who simply want to contact each other, share their experiences and support each other. You can join the group at www.facebook.com/

For people who have had a stroke, the Irish Heart Foundation runs 20 local support groups throughout the country. The groups meet weekly and offer their members access to counselling, exercise therapy and other supports. Find your nearest group at www.irishheart.ie/support/stroke-support-groups.

Directory of further links and information

Irish Heart Foundation www.irishheart.ie

We fight for better health and care for stroke survivors, for you as a carer and for family members. You can contact us by calling 01 668 5001 or emailing carers@irishheart.ie.

Family Carers Ireland www.familycarers.ie

This organisation supports carers and families. You can contact them through their national freephone careline 1800 240 724 or by email at info@familycarers.ie.

Young carers www.youngcarers.ie

Young carers face particular challenges and can find life and study difficult. Young Carers is part of the Family Carers Ireland organisation and offers support through Young Carer Groups, training and respite breaks for carers under 18 years of age. Visit www.youngcarers.ie to find out more.

ABI Ireland www.abiireland.ie

ABI Ireland works with the person with a brain injury and their carers and medical team to help provide the most effective neuro-rehabilitation therapies.

Headway www.headway.ie

Headway supports people with a brain injury, their carers and family. They provide a range of community-based rehabilitation supports and services.

HSE www.hse.ie

The HSE operates the hospitals and many of the rehabilitation facilities your loved one will be treated in. Its website has lots of helpful resources and contact information. The HSE runs a quality of life programme run for carers of stroke survivors in Donegal see: www.hse.ie



IRISH HEART FOUNDATION

The Irish Heart Foundation is Ireland's national charity fighting heart disease and stroke through advocacy, research, prevention and care. For more information, visit www.irisheart.ie



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Charity Regulator Number: 200008376

Charity Registration Number: CHY 5507

Published December 2019