



Health and
Social Care

Stroke
Network



My Stroke Journey

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My Stroke

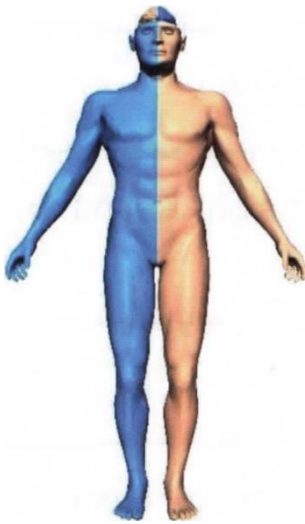


MY STROKE

Stroke affects each person differently. Several factors will impact on your recovery after stroke. These include:

- The type of stroke
- The location of the blocked or ruptured artery
- Which area of your brain is damaged
- How much brain tissue is permanently damaged
- Your general health before the stroke
- Your level of activity before the stroke

The side of the brain that was damaged will also impact on the way your stroke affects you. Each side of the brain controls the opposite side of the body.

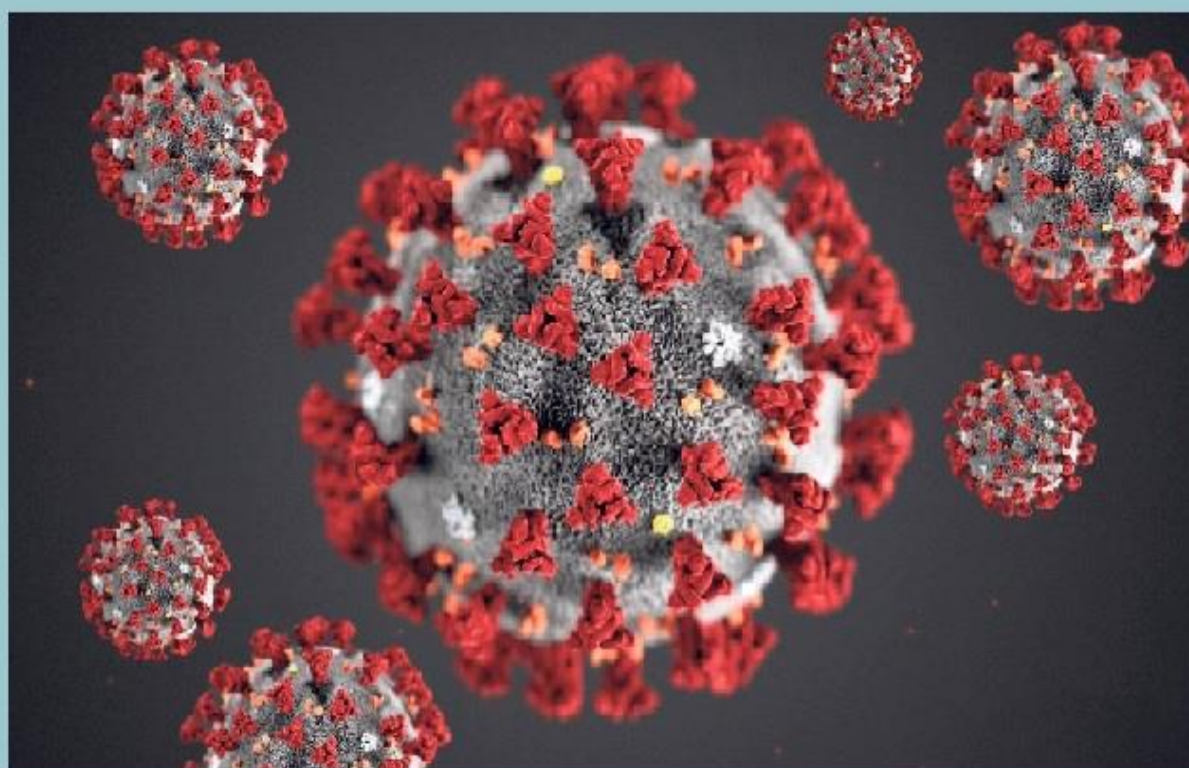


- The left side of your brain controls your right arm and leg.
- The right side of your brain controls your left arm and leg.

The left side of the brain controls reading, writing, speaking and understanding, while the right side controls art, music and mathematics. Sensation, movement, vision, hearing and memory are controlled by both sides of your brain.

The Hospital Stroke Team will determine what type of stroke you have had and assess the severity of your stroke. It is important to note that the investigations, such as CT Scanning, may not be able to determine the exact location of damage within the brain. The diagnosis and prognosis of stroke may be based on your symptoms. Please remember that at the time of diagnosis it is very difficult to predict how your stroke will affect you in the long term. This will be an on-going assessment and the stroke team will work with you to recover as best you can.

Information on Coronavirus for Stroke Survivors



INFORMATION ON CORONAVIRUS FOR STROKE SURVIVORS

Having a stroke means you are at greater risk of getting complications like pneumonia if you have coronavirus (COVID-19). Everyone is different, and if you have other health conditions, you also need to check how this affects you.

At the moment, we are all being asked to stay at home where possible. People in an extremely vulnerable group will need to follow the specific advice about their health condition.

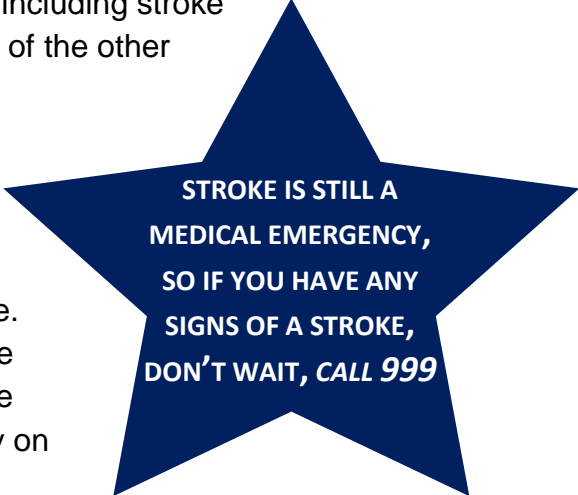
Staying at home and away from others

We all need to follow the latest government guidance on staying home. This tells you how long to stay at home, and what activities you can do outside the home if necessary. This advice will change over the next few weeks and months.

People at increased risk of complications from coronavirus (COVID-19)

Some people are at greater risk from complications, including stroke survivors. Stroke survivors may also belong to some of the other higher-risk groups. These include people aged 70 or over, and people with health conditions like heart disease, diabetes, and respiratory disease.

It's important for stroke survivors to follow the latest advice on staying home and away from other people. People who work are being asked to work from home where possible. If you can't work from home because of the nature of your job, and you are unable to carry on working, help is available. If you are employed, speak to your employer.



**STROKE IS STILL A
MEDICAL EMERGENCY,
SO IF YOU HAVE ANY
SIGNS OF A STROKE,
DON'T WAIT, CALL 999**

Extremely vulnerable people and shielding

If you're in an extremely vulnerable group, you will be contacted about what to do. This includes people with severe respiratory disease, people with heart transplants and those on medication that affects your immune system.

You will need to follow the latest government guidance for people in the extremely vulnerable group. This explains the steps you need to take to reduce your risk of infection, known as shielding. If you live with others, you might need to separate yourself and follow advice on how to stay safe at home.

You can register as extremely vulnerable to get extra support such as help with delivery of essential supplies and medicine. If you're not sure if you belong to this group, register to find out if you can get help. If you think you belong to this group and have not been contacted by 30 March, get in touch with your GP or the hospital team treating you.

If you have symptoms of coronavirus (COVID-19)

The main symptoms of coronavirus (COVID-19) are:

- A high temperature.
- A new, continuous cough.

For advice on what to do if you have symptoms, visit NHS online information about coronavirus (COVID-19). This will also tell you what to do if you have been in contact with someone who has the virus.

Help with symptoms

You don't need to contact 111 if you have symptoms. But you should use the NHS online coronavirus service if:

- You feel you cannot cope with your symptoms at home.
- Your condition gets worse.
- Your symptoms do not get better after seven days.

Call 111 if you can't use the online service.

Please do not go to your GP surgery, pharmacy or hospital in person. Look online or phone for advice. In an emergency, **call 999**.

Stroke symptoms and coronavirus (COVID-19)

If you have coronavirus, and you start having stroke symptoms, call 999. Also tell the paramedics that you think you have coronavirus (COVID-19).

Transient Ischaemic Attack (TIA)

If you have stroke symptoms that last a short time, call 999. If the symptoms were a few days ago, call 111. Also tell the call handler that you think you have coronavirus (COVID-19). Read more about symptoms of TIA.

Attending a follow-up appointment for TIA

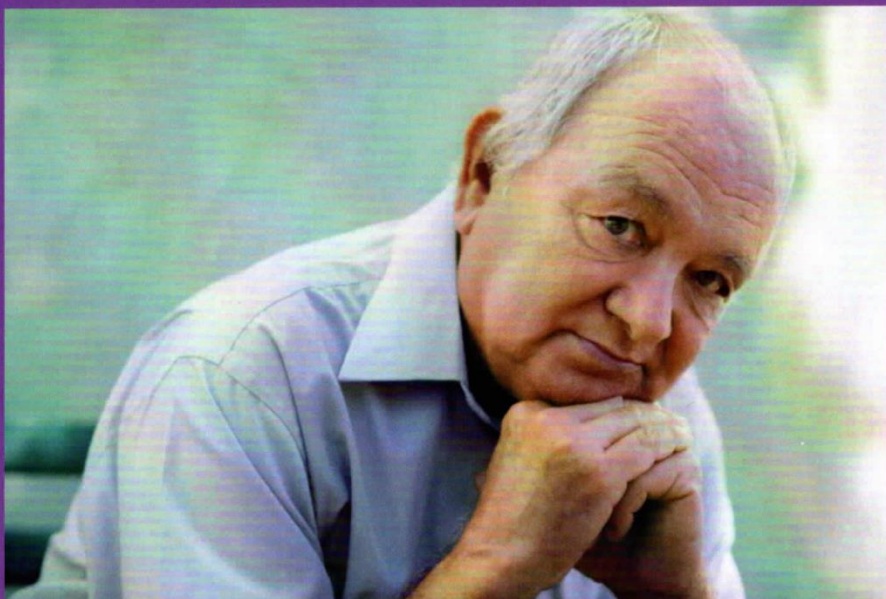
If you start showing signs of coronavirus (COVID-19) before an appointment to assess your TIA symptoms, contact the clinic or GP by phone or email to let them know. Don't go in person. You may be able to have a later appointment. Or you may be able to have a remote appointment by phone or video call.

What help is available for stroke survivors?

Stroke survivors and carers can follow our updates about coronavirus (COVID-19) on this website. If you're in touch with a Stroke Association Coordinator, or being cared for by a community stroke team, contact them for information.

You can find information and practical advice about life and wellbeing after stroke on <https://www.stroke.org.uk>, including tips from Helpline staff on managing loneliness and isolation. An online self-management tool, My Stroke Guide, lets you speak to other stroke survivors and carers online. And if you want someone to talk to, the Stroke Association have a Helpline on **0303 3033 100**.

How might stroke affect me and my life?



HOW MIGHT STROKE AFFECT ME AND MY LIFE?

Inevitably stroke will have an impact on you and your life. A list of the ways stroke might affect you are listed below. You may only experience some of these symptoms and the extent of these will vary for each individual.

POSSIBLE SYMPTOMS THAT YOU MAY EXPERIENCE

Difficulty swallowing (dysphagia)

Difficulty swallowing following stroke due to weakness in the muscles needed for swallowing. This can cause problems with swallowing food, drinks and even your own saliva. This is why most people are not able to eat and drink straight away. Your swallow reflex will need to be assessed first. If a person has swallowing difficulties the extent of this needs to be assessed further. A person may be started on thickened fluids and soft food. Sometimes another form of providing nutrition is required such as through a nasogastric tube.

Slurred speech- difficulty with talking

Where speech becomes slurred or you are unable to say things clearly. It can be caused by either or both of the following:

- **Dysarthria** - a weakness in the muscles used for speaking such as lips and tongue.
- **Verbal dyspraxia** - difficulty planning the movements of the lip and tongue needed for speaking.

Difficulty with communication/language

This can be from difficulty talking, understanding what people have said, reading, writing or a combination of these. This is known as dysphasia or aphasia.

POSSIBLE SYMPTOMS THAT YOU *MAY* EXPERIENCE

<p>Difficulty with body movement (dyspraxia)</p> <p>Where the brain has difficulty planning movement</p>	
<p>Weakness on one side of the body (hemiparesis)</p> <p>This may be in an arm, a leg, one side of your face or on one whole side of your body. You may also feel heaviness, loss of movement and sensation.</p>	
<p>Visual issues (hemianopia)</p> <p>A loss of vision to one part of the visual field. This can cause trouble seeing on one side of your body.</p>	
<p>Issues with muscle tone</p> <ul style="list-style-type: none"> • Hypertonia - affected muscles become stiff or tight. Can also be referred to as spasticity • Hypotonia – affected muscles become floppy 	
<p>Ignoring one side (neglect)</p> <p>Where a stroke causes you to be unaware of things on one side of the body. This is referred to as either ignoring one side or neglect.</p>	
<p>Reduced Sensation</p> <p>Difficulty receiving messages from one or more of your five senses (smell, touch, taste, sight and hearing)</p>	

POSSIBLE SYMPTOMS THAT YOU *MAY* EXPERIENCE

Thinking and memory problems (cognition)

This may be a poor attention span, difficulty remembering things, difficulty planning or organising things or solving everyday problems.

Stroke may also impact on the ability to recognise familiar faces and objects or learn new information and skills.

Vision and Perception

Some people have double vision where they see two of everything. Whereas others have issues with seeing things on one side or perceiving how close objects are.

Continence or toileting

Difficulty with controlling your bladder or bowel movements. This may be due to either a reduced ability to sense when you need to go to the toilet or difficulty getting to the toilet on time due to reduced mobility.

Fatigue and Tiredness

Feeling tired and sleepy is very common particularly in the first few weeks after stroke. Some people also experience severe fatigue that can go on for a long time after stroke. Talk to your Stroke Team about the best way to manage your fatigue.

Central Post Stroke Pain (CPSP)

A small number of people experience pain afterwards. They describe it as a burning, shooting and throbbing pain that is not eased by painkillers.

POSSIBLE SYMPTOMS THAT YOU *MAY* EXPERIENCE

Impact on sexual activity

This may be from a worry or concern about having sex or from physical changes that make sexual activity difficult.

Reduced appetite

Stroke can result in not wanting to eat or drink as much as you used to.

Behaviour / Personality changes

You may experience a lack of insight or ability to acknowledge that you have difficulties due to your stroke. Stroke can also lead to poor safety and judgment which can result in impulsive or inappropriate behaviour. Some people experience personality changes as a result of stroke.

Uncontrollable outbursts of emotion (Emotional Lability or Emotionalism)

Some people laugh or cry uncontrollably even though they don't feel happy or sad. It may only last a few weeks, or in some cases longer.

EMOTIONAL SYMPTOMS OF STROKE

"I can't believe I had a stroke. I'm still in shock."

"I get up in the morning and it hits me - I have had a stroke."

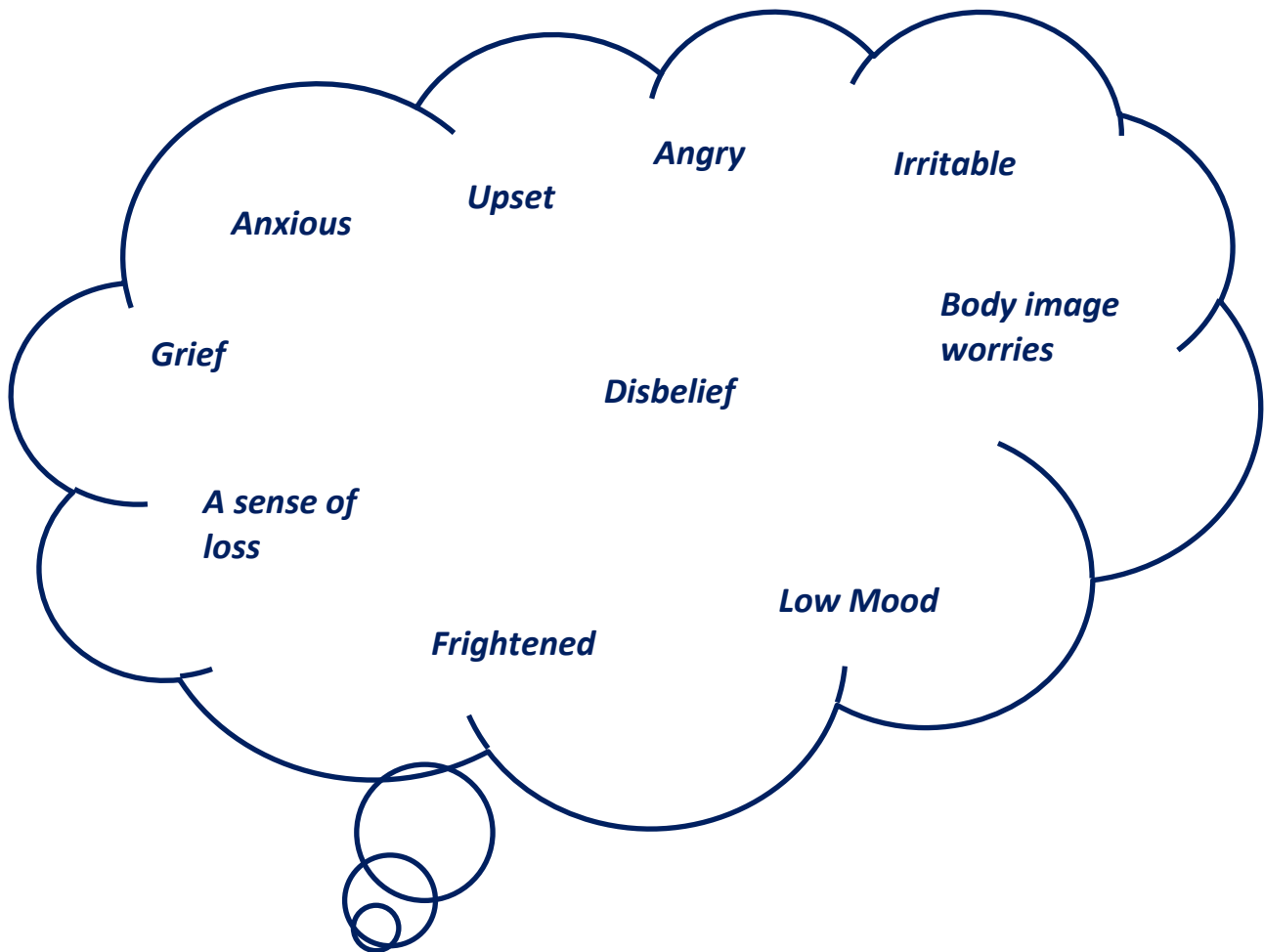
In the early days you will probably feel shock, disbelief and a sense of loss. You and your family may experience a grief reaction initially. This is normal. Stroke can be a life changing event and it does take some time to adjust to the changes.

Your emotional health is just as important as your physical health. Please:

- Give yourself time to adjust.
- Allow yourself to feel emotional after your stroke, it is a natural process and adjustment reaction.
- Seek help and support from your Stroke Team or GP if you or your family is concerned about your emotions or mood.

Everyone will feel differently after their stroke. What is a concern for you may not be a concern for another person. It is important to acknowledge your feelings and accept them as part of your natural emotional process following your stroke.

WHAT MIGHT I BE FEELING AFTER MY STROKE?



We encourage you to share your concerns and worries with your family. However, we know that some people find it difficult to share their feelings with their loved ones. If this is the case, you could try speaking to someone outside the family such as a good friend or a health professional.

Another source of emotional support to you will be the voluntary agencies for stroke in Northern Ireland.


- **Northern Ireland Chest Heart and Stroke**
- **Stroke Association**

Contact details for these agencies are included later in this folder.

WHEN SHOULD I SEEK HELP?

It is quite natural to be feeling low in mood after your stroke. However if you are feeling very low for most of the time you may actually be depressed. Some symptoms of depression may be a direct result of your stroke and it can be difficult for you to understand whether you are depressed or not.

If you have any concerns at all, it is important that you seek advice from your Doctor or General Practitioner (GP). If you do have depression it can be treated so it is important that you seek advice early.



"When I came home I just wanted to lie in a dark room. The doctor gave me a tablet for my mood which helped"

Depression after stroke (also known as post-stroke depression) can set in weeks, months, or even years after your stroke. It can be described as a feeling of hopelessness that can stop your progress of recovery and rehabilitation and impact on your quality of life.

Many factors can lead to depression after stroke. The sudden nature of stroke can have a life-changing impact. It can also be a result of damage to your brain, a genetic predisposition and social factors.

Your family, partner and friends can help you to recognise post-stroke depression symptoms and encourage you to see a healthcare professional such as your GP.

SYMPTOMS OF POST-STROKE DEPRESSION

Symptoms will vary in severity, frequency, and duration for each person. Possible signs and symptoms that you may experience include:

- **Persistent sad, anxious or empty feelings**
- **Sleep disturbances**
- **Increase or decrease in appetite and eating patterns**
- **Feelings of helplessness, hopelessness, worthlessness**
- **Social withdrawal**
- **Loss of interest in activities or hobbies**
- **Irritability**
- **Fatigue**
- **Difficulty concentrating or remembering details**
- **Aches, pains, headaches and digestive problems**
- **Suicidal thoughts**

If your depression is left untreated and unmanaged, it can worsen a number of other common post-stroke conditions such as malnutrition, incontinence, pain, fatigue, and sleep issues. Depressive emotions can increase when you are frustrated about not making progress in recovery. Please discuss any concerns with a health professional.

My Goals



MY GOALS

REHABILITATION AFTER YOUR STROKE

As you will have read in the previous section, there are many factors that influence how your stroke may affect you. Your recovery and rehabilitation will depend on what way your stroke has affected you and the extent of those symptoms. The aim of rehabilitation is for you to become as independent as possible, within the limitations of your stroke. Rehabilitation starts as early as possible in the hospital setting and continues once you leave hospital.

The length of time that you will stay in hospital, and where you receive your rehabilitation will depend on your individual symptoms and your unique care needs. If your stroke was quite severe you may need to consider further care in a nursing or residential home. Your stroke team will discuss your rehabilitation options with you and your family.

SETTING GOALS FOR YOUR REHABILITATION

Rehabilitation is centred on you as an individual and your unique needs following your stroke. Setting goals is an important part of the recovery and rehabilitation process.

- It gives you and your family something to aim for
- It helps you to stay motivated
- It helps your stroke rehabilitation team in supporting you
- Helps to keep track of the improvements you make

Goal setting should start in hospital and continue when you go home. It is important for you to think about your own personal goals following your stroke as each person's may be different. The Stroke Team will work with you to help you set and achieve your goals.

KEEPING LIFE AS NORMAL AS POSSIBLE

How your stroke affects you and your life will also depend on your general health before the stroke and your level of activity before the stroke. A few questions to

think about are:

- What were you able to do before your stroke?
- Did you work?
- What activities did you enjoy?
- What were you able to do around your home?
- Did you need help with daily tasks?
- Did you have any hobbies?
- Did you have any personal goals that you were working towards?

These questions will help you to think about goals for your rehabilitation. It will also help you to stay true to yourself and what was important to you before your stroke so that your life after stroke is as normal for you as possible.

KEEP GOALS REALISTIC AND ACHIEVABLE

Some people may think of a large and overall goal such as: *"to get better"*. While this is quite natural, it is better to break an overall goal down into specific and achievable steps. This way you and your stroke team will be able to measure your progress.

- e.g. *"to be able to dress myself"* or *"to get from the chair to bed"*

We encourage you to keep your goals realistic and achievable. When thinking about your personal goals, ask yourself the following questions: *what would I like to do?* Followed by, *is this realistic?*

It might help you to break your goals down into short, medium and long term goals. The stroke team will help you with this.

GOALS – YOU AND YOUR FAMILY

We strongly encourage you to include your family in your rehabilitation and in helping you to achieve your goals. You and your family should feel confident when the time comes to go home from hospital so we encourage you to ask questions and practice rehabilitation strategies throughout your hospital stay.

Your rehabilitation will become part of your daily life after stroke and the stroke team will provide you with strategies for managing your daily tasks once you go home. You will also be asked to practice specific exercise or movements between therapy sessions. It is important to remember that you may experience fatigue after your stroke,

so we would recommend that you practice your exercise for short periods several times a day rather than in one long session.

POSITIVITY AND PERSEVERANCE

Rehabilitation following stroke can be exhausting and it can be slow. Please remember that it is often a very gradual process so keep a positive mind-set and persevere. It can be hard to stay motivated, but working towards an achievable and realistic short-term goal can help you stay focused.

It is important to recognize that there will be times when the effects of your stroke will limit you from progressing beyond a certain point. This is another reason why it is important to set small and achievable goals. You will be able to look back and be proud of how far you have come in your stroke journey.

PLANNING FOR GOING HOME

It can be daunting leaving hospital after a stroke. This is why we encourage you and your family to make the most of your time in hospital to prepare yourselves for being at home. Think about your home environment, your lifestyle, your social life, your family life and your community. Picture yourself being at home after your stroke: Some questions you might consider are:

- Will anyone be around during the first few weeks?
- What can you do by yourself?
- What do you need help with?
- Will you be able to move around your house?
- Are adaptations required?
- What will you spend your days doing?
- What social activities would you like to do?

These are just some suggestions to help you plan your goals. It is important that you take the time to do this while you are in hospital so that you feel confident for going home.





TAKING OWNERSHIP OF YOUR REHABILITATION

There will come a time when your 'formal' rehabilitation therapy ends and you will no longer be seen by health care professionals. In preparation for this time, it is important that you take ownership of your rehabilitation as early as possible. The health professionals will help you to set your goals and will teach strategies to help with your rehabilitation.

Discuss any concerns or queries that you may have with the health professionals while they are available to you. Ask them to go over any points that are unclear to you or to explain things in a simpler way. Involve your family and friends as well so that you are all clear on how to incorporate rehabilitation strategies and skills into your daily life.

GOALS SETTING FORM

This questionnaire makes suggestions about areas of your life which you may consider important. Please circle each area to state its importance to you as a goal within rehabilitation. Use the following scale to guide your response:

NOT IMPORTANT	VERY IMPORTANT
1 2 3	4 5
<p>1. Washing / Dressing Shaving / Grooming</p> <div style="display: flex; justify-content: space-around; align-items: center;">  </div>	<div style="display: flex; justify-content: space-between; margin-bottom: 10px;"> 1 2 3 4 5 N/A </div> <p>Comments: _____ _____ _____</p>
<p>2. Transfers (bed, chair toilet, shower/bath, car)</p> <div style="text-align: center; margin: 10px 0;">  </div>	<div style="display: flex; justify-content: space-between; margin-bottom: 10px;"> 1 2 3 4 5 N/A </div> <p>Comments: _____ _____ _____</p>
<p>3. Getting around – Inside the home including the stairs and outdoors</p> <div style="text-align: center; margin: 10px 0;">  </div>	<div style="display: flex; justify-content: space-between; margin-bottom: 10px;"> 1 2 3 4 5 N/A </div> <p>Comments: _____ _____ _____</p>
<p>4. Preparing a meal</p> <div style="text-align: center; margin: 10px 0;">  </div>	<div style="display: flex; justify-content: space-between; margin-bottom: 10px;"> 1 2 3 4 5 N/A </div> <p>Comments: _____ _____ _____</p>

5. Having a conversation – reading and writing

1 2 3 4 5 N/A



Comments: _____

6. Returning to Leisure / Going out of the home / Shopping / Interests

1 2 3 4 5 N/A



Comments: _____

7. Close relationships e.g. family, partner, friends

1 2 3 4 5 N/A



Comments: _____

8. Driving

1 2 3 4 5 N/A



Comments: _____

9. Employment

1 2 3 4 5 N/A



Comments: _____

10. Advice regarding healthy lifestyle

1 2 3 4 5 N/A



Comments: _____

11. Money management / benefits

1 2 3 4 5 N/A



Comments: _____

12. Any others

In your own words, what three things would you like to achieve during rehabilitation?

1. _____
2. _____
3. _____

Completed with: _____

Signed: _____

Date: _____

REVIEW

How satisfied are you that you have achieved your three goals (as above)?

NOT SATISFIED					VERY SATISFIED	
1	2	3	4	5		
1. 1	2	3	4	5		
Comments: _____ _____						
2. 1	2	3	4	5		
Comments: _____ _____						
3. 1	2	3	4	5		
Comments: _____ _____						

Moving on from hospital



MOVING ON FROM HOSPITAL

REVIEW / FOLLOW-UP APPOINTMENTS

Your review appointments will depend on your own individual needs following your stroke. The Stroke Nurse Specialist will discuss any follow up appointments with you. You can use the box below to take any notes of these.



MOVING ON FROM HOSPITAL

Hopefully you have used the 'My Goals' section to set some goals for going home. Working towards these goals should help you, and your family, to feel more prepared and confident when you leave hospital.

While in hospital the Stroke Team will work with you and your family to help you prepare for going home. This is known as 'discharge planning' and should start as early as possible. However, we will also need to see how you progress during your hospital stay. We encourage you to ask questions so that we can help to address your concerns and ease the transition home.

DISCHARGE PLANNING

The Stroke Team may use the term discharge planning or planning for your discharge- this refers to a plan for you to leave hospital.

Before you go home we will need to consider the following:

- What are your individual care needs after your stroke?
- What services will you need?
- How much help will you need?
- Who can provide this support?
- Does your home environment need any adjustments?

Some of the questions that the stroke team will consider to ensure you are safe at home are:

- Can you stand and/or move between furniture/equipment (e.g. from a chair to a bed, or from a chair to a wheelchair) safely?
- Do you need any additional equipment, i.e. rails etc.? Would it be best to rearrange furniture or lift loose mats to keep you and your family members safe?
- Are you at risk of falls?
- Do you need someone to help you get out of a chair, get to the toilet, remind you to use a walking aid or make meals?
- Will you be safe to stay at home alone if /when your family needs to go out?

The services available to you after you go home from hospital will depend on your discharge assessment and will be unique to each individual. The hospital stroke team will complete referrals to services that may be of benefit to you. If appropriate, you may be referred to:

- **Community Stroke Team (C.S.T)**

This is a community based multi-professional team which can be involved alongside other hospital and community services in providing home care, day centre, out-patient appointments etc.

- **Rapid Access Department for Assessment and Rehabilitation of Older People (RADAR)**

This department provides assessment, diagnosis rehabilitation and treatment of a wide range of medical conditions including stroke.

- **Pavestone Centre**

This service provides preparation and assessment for vocation (work) and leisure activities.

- **Physiotherapy / Occupational Therapy / Speech & Language Therapy / Dietetics – Outpatient clinics**

Some stroke patients may be referred for follow up treatment with any of the above therapists.

VOLUNTARY ORGANISATIONS WHO CAN HELP YOU

There are 2 main voluntary organisations that will be able to offer you support. These are:

- **Northern Ireland Chest, Heart and Stroke**



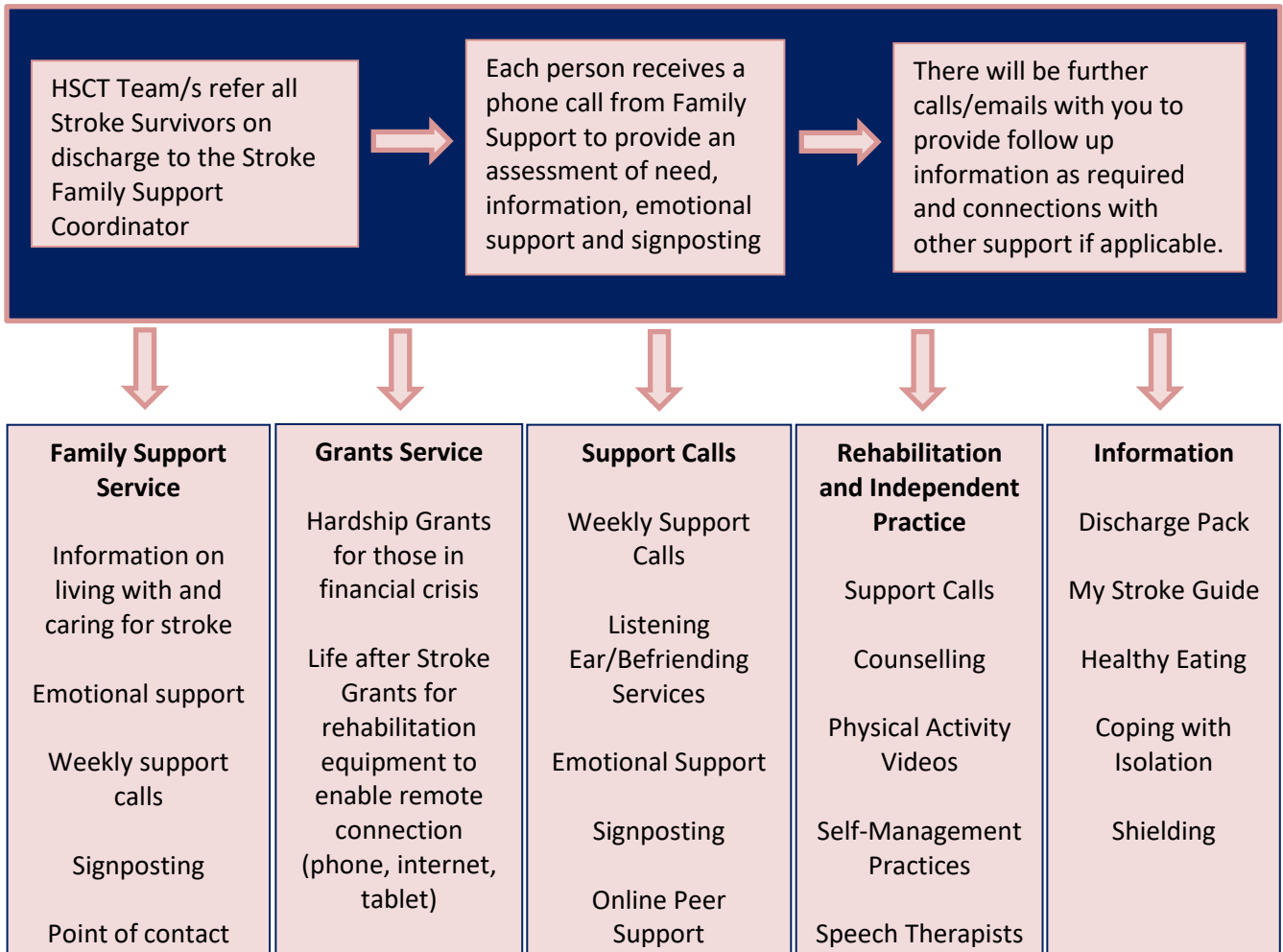
- **Stroke Association**



THE VOLUNTARY SECTOR'S COMMITMENT TO PEOPLE AFFECTED BY STROKE

- Because of Covid-19, people affected by stroke are potentially being discharged from hospital quicker than ever before in the wake of a life changing event.
- Stroke Association and Northern Ireland Chest, Heart & Stroke want to ensure that they continue to do all they can to support people affected by stroke throughout the Covid-19 period, whilst taking measures to reduce any risk to them and to their own staff and volunteers.
- By proactively reaching out, they can offer you a lifeline and essential emotional support and reassurance. They can connect you to their joint package of ongoing support, as well as support from others, to help you rebuild your life and have a more positive experience of care.

The below flowchart shows what these voluntary organisations can offer you and how the referral process will work:



WHAT CAN THE VOLUNTARY SECTOR OFFER ME?

With your consent you will be referred to a NEW Interim Stroke Support Service delivered in collaboration between Northern Ireland Chest Heart & Stroke and the Stroke Association in direct response to the Covid-19 crisis. This jointly delivered service is available for all stroke survivors, their carer's and other family members.

The Service Offer

1. Family Support Service

You will receive an initial phone call to assess your needs and to see how the service can help you. They will provide:

- Information and advice on living with/caring for stroke
- Listening ear and Emotional Support
- Signposting to other local services who can help
- A Point of contact
- Fast Track Referral to Advice Space for support with benefits
- Support liaising with your health professionals
 - Contact **02890320184** or email **strokesupportni.org.uk**

2. Grants Service (Means Tested- Details upon Request)

If you are eligible you will receive a phone call to ascertain suitability to receive a grant and they will help you go through the application process.

- **Hardship Grants** These grants (up to £100) are restricted to providing food, clothes and energy to stroke survivors in **urgent critical need**.
- **Life after Stroke Grants** These grants are to aid recovery (up to £300) and can be spent on items like rehab equipment or to enable you to have better connection (phone or tablet)

3. Weekly Support Calls

You will then have an option on receiving further telephone/online support on a weekly on- going basis with a regular review of how it is going.

- From your Family Support Coordinator each week
- Emotional Support in coping with stroke/caring for stroke
- Signposting to other local services
- Liaison between your health service professionals if needed

4. Access to ongoing other services (including Peer Support)

The Stroke Association and Northern Ireland Chest, Heart and Stroke have adapted their existing services to reach out to stroke survivors, their families and carers, and will continue to look at new ways of providing support during this crisis.

- Stroke Specific Counselling (Via Telephone) - In certain geographical areas (SE Trust & Northern Trust)
- Access to Videos on safe chair based exercises to try home
- Taking Control – an accredited self-management programme adapted to be delivered on-line
- Speech Therapists- Telephone based support regarding communication

difficulties (Ursula to modify)

- Volunteers- Contact and Chat volunteer to call you for a friendly chat
- Volunteers- Lived Experience volunteer (Stroke Survivor) will offer lived experience peer support
- My Stroke Guide- An online platform hosting information and connection to other stroke survivors and carers
- Online support group meetings via Zoom

5. Access to useful Information including:

Additional information that you may find helpful will be provided on an ongoing basis.

- Discharge Pack- Information regarding Life After Stroke and Covid-19 (To be delivered by the Stroke Network)
- Keeping well during isolation (Covered in regular support calls)
- Choosing Healthy Food (Covered in regular support calls)
- Links to updated Public Health Agency advice
- **Stroke Helpline** is run across the UK and is a place for information about stroke and its effects, what happens after a stroke, or what help and support is available.
 - **0303 3033 100** or email helpline@stroke.org.uk

WHAT IF I WANT TO TALK TO SOMEONE ABOUT STROKE?

If you would like to talk to someone about stroke in general, please contact:

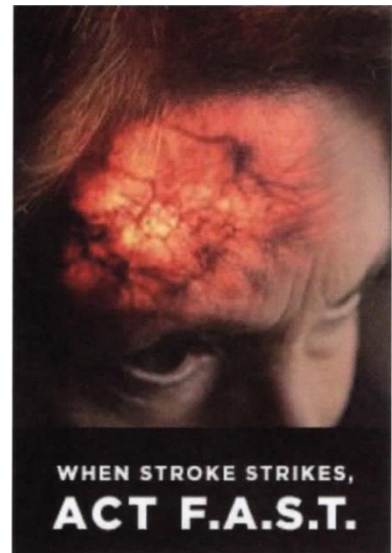
- **NORTHERN IRELAND CHEST HEART AND STROKE :**
Telephone 028 9032 0184
- **STROKE ASSOCIATION :**
Telephone 0303 303 3100

WHAT IF I HAVE ANOTHER STROKE?

If you or your family notices any of the below symptoms - **Think: FAST**

FAST requires an assessment of three specific symptoms of stroke:

- ❖ **Facial weakness** - can the person smile?
Has their mouth or eye drooped?
- ❖ **Arm** - can the person raise both arms?
- ❖ **Speech problems** - can the person speak clearly and understand what you say?
- ❖ **Time to call 999**



 FACE	 ARMS	 SPEECH	 TIME
FACE. HAS THEIR FACE FALLEN ON ONE SIDE? CAN THEY SMILE?	ARMS. CAN THEY RAISE BOTH ARMS AND KEEP THEM THERE?	SPEECH. IS THEIR SPEECH SLURRED?	TIME. TIME TO CALL 999 IF YOU SEE ANY SINGLE ONE OF THESE SIGNS

WHAT IF I HAVE ANOTHER MEDICAL EMERGENCY?

If you have a medical emergency please call an ambulance on 999 to assess your medical situation.

If your situation does not require an ambulance, you may consider your nearest Emergency Department.

EPILEPSY AFTER STROKE

A small percentage of people experience epileptic type seizures following stroke. This is because the scar resulting from the stroke can irritate the brain. This can happen weeks, months or even years later.

Most people who experience seizures are prescribed medication to control this.

If someone has a seizure:

- Clear a space around the person
- Loosen tight clothing
- Place the person in the recovery position once the seizure has run its course.



Don't:

- Lift or move the person unless they are in danger
- Try to restrain or put anything in their mouth
- Offer anything to drink until the person is fully recovered

You should phone 999 if:

- It is the person's first seizure
- The jerking phase lasts more than five minutes
- There are repeated seizures without recovery in between
- The person has been badly injured.

ADJUSTING TO LIFE AFTER STROKE

Although your stroke may have changed certain aspects of your life, it is important to find new ways to help you get the most out of life following your stroke.

Initially you may be focused on learning new skills and how to manage the effects of your stroke. It is also important to put in place strategies to help you enjoy life as much as possible. This will be good for your emotional health, your overall recovery and life in general.

Some suggestions of how to do this are included below:

Network of Support

Try to involve your partner, family or friends in your rehabilitation and care. This will provide you with both emotional support and motivation to reach your goals.

Independence

Try to be as independent as you can after your stroke. This will boost your confidence and your motivation. Learn what you can and cannot do on your own and only ask for help when you need it.

Staying Active

Build in short, but frequent periods in your day to stay active by practicing the movements, exercises and skills that you have learned.

Rest

Ensure that you have set yourself regular time to rest. Don't overdo it. Sometimes if you do too much when you are feeling well, you might be too tired the following day. This might make you feel like you aren't progressing as you wanted to. Be sure to pace yourself.

Daily Routine

After you have figured out the tasks that you need help with, you could plan a daily routine with your family. Consider your goals for rehabilitation and ensure that you have included these into your daily routine.

If a family member helps to take care of you, make sure to include rest for you both within your daily routine. It will be beneficial if you both have time to yourselves as well.

Social Interactions

Learning to socialise again is an important part of your stroke recovery. It is recommended that you try to continue with your hobbies, interests, social and other commitments as best you can.

Friendships

Try to maintain your existing friendships, perhaps you will find new activities to fit around the effects of your stroke. You may also find benefit in meeting new people in a similar situation to yourself. The voluntary agencies that we have talked about can help you to find other people in your area who have had a stroke. (Northern Ireland Chest Heart and Stroke and the Stroke Association)

Returning to Work

If you want to and are able to return to work after your stroke your health care team will discuss this with you. This should be addressed within the 'My Goals' section of this folder. Further information will be provided to you if this is one of your goals.

Gradually reintroduce yourself to crowded places

Some people find that the noise of a crowded place and background noise can be difficult to deal with after a stroke. Take a gradual approach to busier places over short periods.

Getting out and about after your stroke

The practicality of getting out and about after your stroke can seem daunting. You may feel that it would be easier to stay at home in your safe comfort zone, but this can lead to isolation and can set you back with your recovery and rehabilitation. Try to get out and about as much as you are able.

Driving Restrictions

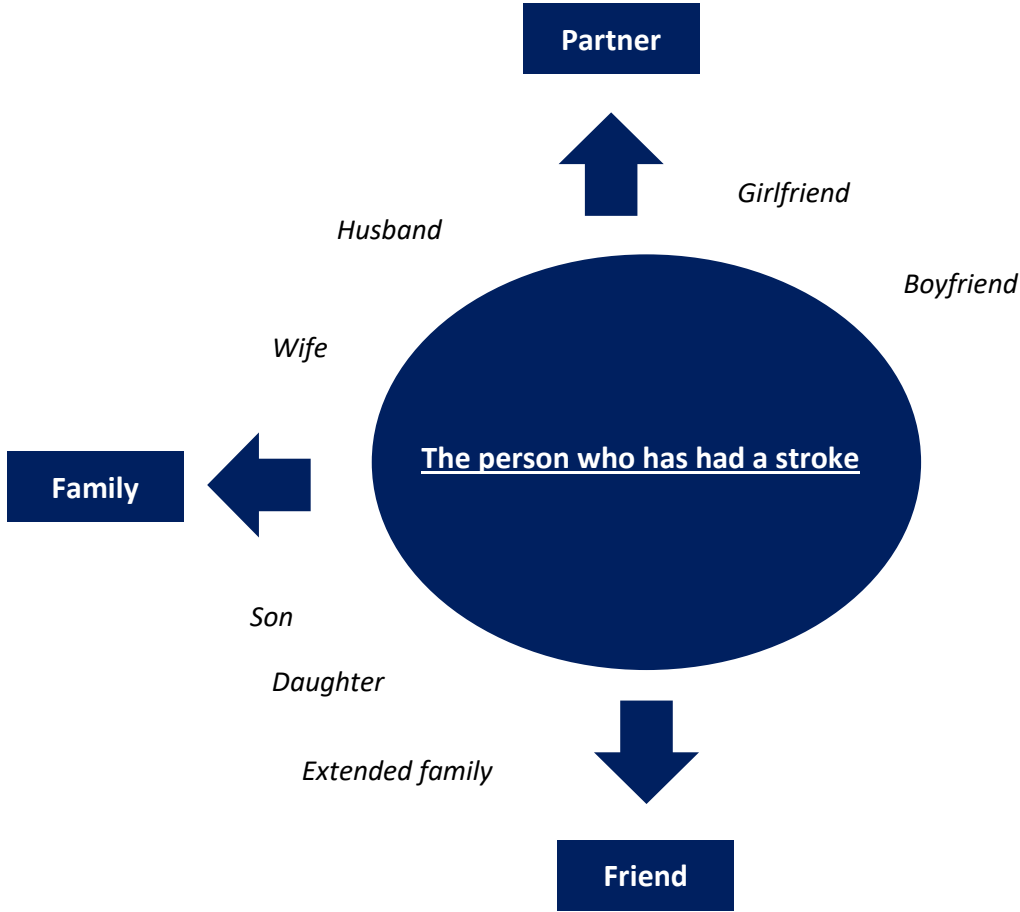
You may not be able to drive after your stroke. Discuss any possible driving restrictions with your Stroke Team.

Information for the family, partner or friend



INFORMATION FOR THE FAMILY, PARTNER OR FRIEND

WHO DOES THIS SECTION APPLY TO?



Your loved one/friend has had a stroke and this will also impact on you and your life. The degree of this impact will depend on the severity of the stroke and your relationship prior to the stroke. This will be a journey for you too and we understand that it can be overwhelming. We have included this section for you so that you also feel supported along the way.

How can you help?

You can also provide physical, practical and emotional support throughout the stroke journey. You will also be a great source of support, encouragement and acceptance for your loved one/friend

Other ways that you can help is by:

- Talking to health professionals about the stroke, the effects of stroke and plans for recovery / rehabilitation
- Helping to set goals and to achieve them
- Learning about the skills and strategies required to prepare for leaving hospital
- Joining in with therapy sessions
- Providing encouragement and support with rehabilitation exercises and activities
- Acknowledging and celebrating progress
- Using and completing this folder with your loved one/friend

Another very important way you can help is to be their advocate. Tell us what their special needs and interests are and making sure we remember these throughout the care process.

Information and Training

We strongly encourage you to use this folder to learn about stroke and familiarise yourself with the individual care needs of your loved one/friend. The better informed you are, the better you will be able to help your loved one/friend and yourself.

- We want you to raise any concerns or fears that you might have about the stroke and rehabilitation process.
- We want you get involved with learning skills, strategies, activities and exercises that will help after the stroke.
- We hope you will feel prepared and confident when the time comes to leave hospital.
- We need you to take an active role and to feel empowered to learn what you need to in order to manage and cope once at home.

We are here to support you too. Please ask us any questions as you go along. No question is silly. If it is concerning you, it is important to you and therefore it is important to us.

Plan Ahead

Think about what life will be like once your loved one/friend is discharged. What will they be able to do themselves and what will you need to do to help them?

Think about the following needs and whether you will need to learn new ways to help them with these:

- Personal Care (showering, dressing)
- Moving around the house (such as from bed to chair, or room to room)
- Communication (verbal, written)
- Eating and drinking (can they swallow safely and do they need additional measures in place?)
- Food preparation (can they prepare food or drinks safely?)
- Behaviours (do they express challenging behaviours as a result of stroke?)

Relationships and Roles

Before the stroke you had the role of 'partner', 'family member' or 'friend'. You should try to maintain this relationship as best you can, despite the stroke. This will help you and your loved one/friend to adjust to life after their stroke.

Depending on the level of stroke care required, you may adopt an additional role, which some people refer to as a 'carer'. While this title is a great way to acknowledge your additional roles and responsibilities, it is important that it does not take away from your first role in the relationship which was 'partner', 'family' or 'friend'. This will help you both to maintain as normal a relationship as possible.

You may find that you are spending more time with each other with less sleep. This can put a strain on relationships. Try to share your concerns with each other. It takes time to adjust to life after stroke and it can be stressful for you both.

Look after Yourself

Some strokes are very complex and if this is the case, your loved one/friend may be very dependent on you. Remember to take care of yourself. Try to get enough sleep, eat nutritious foods, and do some gentle exercise. It is important to maintain your strength and energy.

The role of carer can lead to exhaustion and fatigue. It is important that you take time to yourself and away from any caring responsibilities to do something that you enjoy. This is very important and will help prevent 'burnout'. This will help you manage your emotions, reduce your own fatigue and it will be good for your relationship to do your own thing for a while.

Your Emotions

It is normal that you will feel a range of emotions in response to the stroke also. These may include:

Anger- at the fact that your loved one / friend has had a stroke and maybe on the impact it will have on your life.

Resentment- at the changes the stroke will cause to your life and possibly at your new role, if you are taking on the role as carer.

Guilt -sometimes this can be feeling guilty about being resentful, some feel that they should have noticed the symptoms of stroke earlier or done something to prevent it. Please remember that you are not to blame for the stroke.

Frustration -you may feel frustrated or impatient if your loved one/friend is not able to do things they used to, or not as quickly as they used to.

Depression -initially it is normal to feel sadness or grief about the stroke and the impact it has had on your lives. If these feelings do not go away after a few weeks please discuss it with your doctor in case you have developed depression.

Further Information and Contact Details



FURTHER INFORMATION AND CONTACT DETAILS

INFORMATION ON THE INTERNET

Don't believe everything you read online.

The internet can be a great resource with readily accessible information, but you do need to be wary of the type of information as the quality can vary. A lot of information online is not based on evidence and is not reliable. Here are some tips to help you find reliable and accurate health information online.

Health information should be:

Health information should not:

Approved by a clinical expert Reviewed and updated regularly Unbiased Non-commercial (not trying to sell you anything).	Claim to replace the advice given by a doctor Ask you to pay for a full emailed diagnosis.
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Look for sites which end in:

- .org (not for profit organisations)
- .gov (government run websites)
- .nhs.uk (NHS websites)
- .hscni.net (Northern Ireland health service websites)

Reliable and informative websites on Stroke include the two local charities:

Northern Ireland Chest Heart & Stroke: www.nichs.org.uk

&

Stroke Association: www.stroke.org.uk

CREDITS:

NORTHERN HEALTH AND SOCIAL CARE TRUST / THE QUEEN'S NURSING INSTITUTE: *My Stroke Journey*

STROKE ASSOCIATION: *Information on coronavirus for stroke survivors*
<https://www.stroke.org.uk/finding-support/information-coronavirus-stroke-survivors>