Stroke Advice 5

Northern Ireland Chest Heart & Stroke

A Carer's Guide to Stroke

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A Carer's Guide

When someone is **recovering** from a **stroke** they often need a lot of **help** and **support** with everyday activities.

This booklet is designed to help and **advise** anyone who will be **caring** for a person who has survived a stroke.

Recovery starts in hospital but often **continues** at **home** and can take **time. Some** people will make an almost **complete recovery**; others will **recover** enough to be **fairly independent** and able to carry out the **most** everyday **tasks.**

However, some will **improve** only a **little** and will need long term **care.**

If you are a **partner**, a **relative** or a **friend** of someone who has had a stroke then this **information** is for **you.**

You may not **see yourself** as a **carer** but caring for someone who has had a stroke is an **important** role and can be a big undertaking.

The **changes** to your **life** and the **relationship** with the person you are caring for may be very **frightening** and stressful.

You may have mixed **feelings** about being a **carer** and feel **resentful** about the **changes** in your circumstances. These are **normal** feelings and reactions.

No one plans on becoming a **carer** and it is **important** that you get the right **information**, practical help and any emotional support that you need, when you need it.

Every stroke is **different**. Each person affected by stroke will have **different problems** and different needs. Not all of the information in this booklet will **apply** to you so pick out the **information** that is most **useful**.

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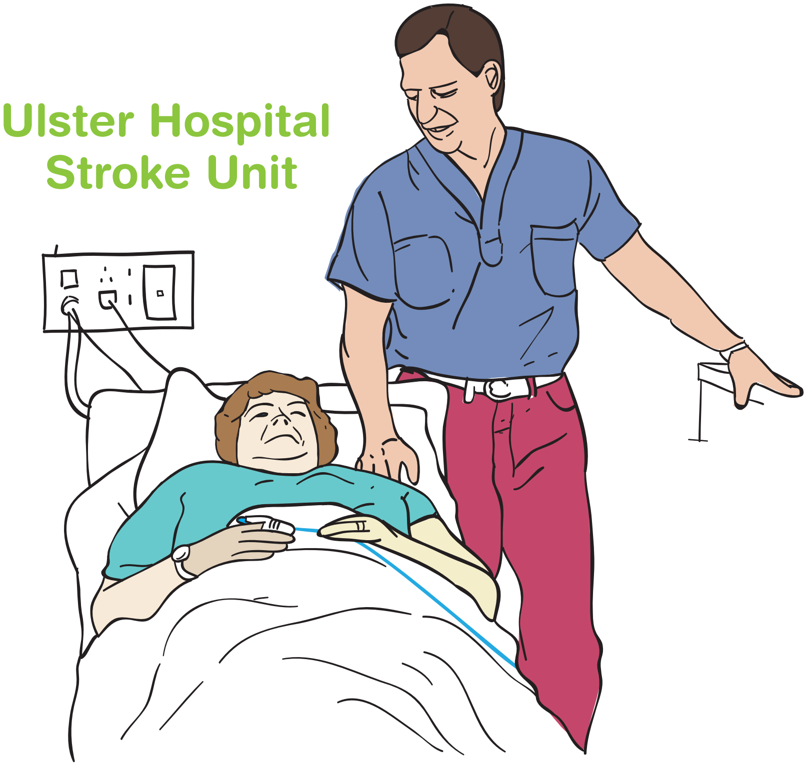


1. The stroke and the immediate impact

A **stroke** is often **sudden.**

Early **treatment** saves lives and **increases** the chance of making a better **recovery.** The main priority for **hospital** staff will be **caring** for the person who has had a **stroke.** This is a **time** of significant emotional distress and **worry** for the **family.**

You may feel **helpless** and that your **questions** are not being **answered.** It will take some **time** for the **severity** of the **stroke** to be fully **assessed.** In the **first** hours it is just too early to **know** what the **outcome** will be.

In the **first** few **days** and **weeks** after a stroke you may then feel **overwhelmed** by the amount of **information** that you are given and the practical **arrangements** you have to make.

Even if you can't take in all the **information**, or don't think you will need it, **keep** all the **information** and contacts that you are given. Your needs and the **needs** of the person you care for are going to **change** over time and the information may come in useful at a **later** date.

It may also be useful to **write down** any **information** you are given verbally so that you can **remember** it at a **later** date.

In the **first** few **weeks** you may **not know** how to **help** the person. Ask **nurses** and other **health professionals** to **show** you **simple ways** to help the **person** feel **comfortable**. You can ask to be **involved** in the patient's **care plan**. Each **health** care **professional** will **assess** the **patient**, set **goals** for **recovery** and **prescribe actions** e.g exercises that will help with their **rehabilitation**. **Carers** play an important role in **assisting** with **recovery** and **rehabilitation**, as you will see in the following sections.

You will not know exactly what **care needs** the person will have once they get **home**, but if you know you are going to be a carer, it is not too early to request a **Carer's Assessment**. You can be assessed even before you start day-to-day caring or at any stage after. A **social worker** will look at your role as a **carer** and how that **affects** other areas of your life such as **work**, **training** or **leisure** activities. You may be **entitled to help** even if the person you will be caring for refuses assessment.

As the **effects** of the stroke become evident **family** members often **feel** a sense of **loss** because the stroke has changed the person they knew and loved.

The main **concern** is to **determine** what level of **recovery** the person might make and **begin** the process of **rehabilitation**.

Across Northern Ireland, **Northern Ireland Chest Heart & Stroke** have a team of **Stroke Family Liaison Co-ordinators** who can provide **support** to the **carers** and **families** of individuals who have experienced a **stroke**.

The Stroke Family Support Service offers advice, **information** as well as practical and emotional **support**. This service is available at hospital, at home or at another place suitable to you.

Telephone **028 9032 0184** for more information.

Northern Ireland Chest Heart & Stroke co-ordinate a number of **Carers' Groups.** For information on the service telephone **028 9032 0184**.

2. Discharge from hospital and getting help and support

It can be a very **worrying** time if you are thinking about **caring** for someone who is coming out of **hospital** and who can **no longer** care for themselves in the same way as before.

You may not have considered yourself a **carer** until **now** and so will need to come to terms with a completely **new situation.** For example, you may be bringing home a **relative** who used to live alone or you may be unsure whether you can provide the **extra care** needed after the stroke. The **decision** to become a **carer** should not be **taken lightly.** It is a role that requires a lot of **determination, patience and energy. Sometimes** it is **not practical** or **economical** to become a person's main carer.

When a **patient** comes out of hospital it can sometimes have a **huge impact** on carers' lives. Your employment, health and relationships may be **affected** and so you need the right **information** to make the right choices.

Social Services

Help for the person affected by stroke

As part of **discharge** from hospital a

referral will often have been made for **Social Services** to **visit** your **home** to provide a Community Care Assessment and/or a Carer's Assessment where appropriate. The person who has had the stroke can also be referred by their GP to Social Services for a **Community Care Assessment**. This assessment will be used to decide if they can receive **community support services** such as:

- A **home help** or **care assistant** to help with practical tasks such as washing and dressing
- **Home services** such as delivery of meals to your home or laundry services
- A place at a **day centre** or community **group**
- **Respite** care

If they are eligible for **services** the Department of Health, Social services and Public Safety (DHSSPS) can provide the services **directly**. As an alternative they may provide **money** in **lieu** of the **services**. This is called a direct payment and it can give people more independence and say in their care. If you accept direct payments you will be responsible for the management of your own services.

Help for Carers

As well as a **community assessment** for the person who has had a stroke, carers also have a legal right to an **assessment** of their needs. The purpose of the

Carer's Assessment is for you as a carer to discuss with **Social Services** what **help you need** with caring, as well as any **help** that will assist you to maintain your own **health** and **balance** caring with other aspects of your **life** such as work and **family** commitments.

The **assessment** can often be done at the **same time** as the Community Care Assessment. If you **prefer,** the assessment can be done **without** the person you care for being present, and at a **location** of your **choice.**

Social Services use the **assessment** to decide what **help** to provide to you in your role as a carer. It is also a good **opportunity to talk** to somebody about how you feel about **caring**. It is **important** you **maintain** your own **health** and **wellbeing.** They can offer **advice** on how to achieve a **balance** between **caring** and other aspects of your life such as **work, family** commitments and **leisure** time.

Before your assessment **think** carefully about what kind of **support** you need. You may find it useful to keep a **diary** for a week to record the **daily needs** of the person who has had the stroke and the **caring tasks** that you do.

Write down what you think would **help** the person you care for to become more **independent.** For example, equipment, adjustments in the home or help with transport. Write down any extra help you need to **assist** you in the role of **caring.**

The **reality** of looking after someone **long term** at home can be very **different** from what was **anticipated** when the person was in hospital. This is particularly the case in the **first** few weeks after the person you care for is **back at home**.

It is important that you have an opportunity to say how you are **coping** and whether you or the person who has had a stroke needs **extra help**.

Social Services should get **in touch** with you to see if you and the person are **coping** at home and see if you need any **additional help**. After your initial assessments, a **date** should be set to review whether **support** services are sufficient but if your situation changes and the person who has had a stroke needs **more help** ask for a **review** straight away.

Whilst community **care assessments** and carers' assessments are **free**, Social Services can **charge** for **some** community **care** services. The **regulations** about **which** community care services must be **paid** for, and how much can be **charged**, are complicated and will include **financial assessments**. The Citizens Advice Bureau or Carers NI can give you **independent advice**.

It may be helpful to let your **GP** know that you have **caring responsibilities**. Your GP may be able to **offer** or suggest other sources of **help** and support.

Benefits and entitlements

Caring for someone who has had a **stroke** is likely to involve **extra expense**, for example increased **heating bills** or paying someone to help with caring. It can also mean a **drop in income** if you and/or the person who has had the stroke have to **give up work**. You may both be entitled to **benefits**.

Benefits for the person affected by stroke

The table opposite will give you an indication of the benefits that you or the person you are caring for may be entitled to.

Age	Employment situation	Benefit
Under 16 years old	n/a	**Disability Living Allowance** (DLA)
16-64 years old	**Employed** but off work sick	You may be able to claim **Statutory Sick Pay** (SSP) from your employer for up to 28 weeks depending on how long you have been employed, your age, and how much you earn. When your entitlement to SSP ends you may be able to claim **Employment and Support Allowance.**
16-64 years old	Employed and back at work	If you go back to work, you may be entitled to an increase in **Working Tax Credit.**
16-64 years old	**Unable** to return to **work**	**Disability Living Allowance** (DLA).

Over 65 years old	Retired	**Attendance Allowance**, which is for people who need assistance with their personal care and/or supervision.
Over 16 years old (no upper age limit)	**Carer** (at least 35 hours per week)	If the person you are caring for receives DLA (middle or higher rate) or Attendance Allowance, you may be eligible for **Carer's Allowance.** You do not have to be a relative of or live with the person you are caring for.

As a carer, you may be very involved in helping the person who has had the stroke to fill in their claim forms.

You should familiarise yourself with the questions on the forms in advance of filling them in. It can be helpful to keep a **diary** of the person's **difficulties** in performing everyday living activities, any falls or accidents, **supervision** needs and **communication** difficulties over a period of time. You can then refer back to this list when filling in forms to help you remember all the areas that the person has difficulties with and/or requires extra help with.

Benefits for carers

If you are over 16 (there is no upper age limit) and caring for someone for at least 35 hours per week, you may be eligible for **Carer's Allowance.** You may be eligible if the person you are caring for receives DLA (middle or higher rate) or Attendance Allowance. You do not have to be a relative of or live with the person you are caring for.

Carers may also get **Carer's Credits** towards their state pension.

If you qualify for Carer's Allowance or have an underlying entitlement to it, you may also qualify for the **carer premium** in any **Income Support**, **Employment** and Support **Allowance** or **Jobseeker's** Allowance that you are entitled to.

There are **other benefits** such as Working Tax Credit and Housing Benefit which may be affected due to changes in your household income.

The **benefits** system is **complex** and it changes frequently. It is important to get **advice** about what you are entitled to and how to apply. The Social Security Agency will assess and pay any claims you submit. They can give you advice about benefits and how to fill in application forms.

It can be useful to get **independent advice** from the Citizens Advice Bureau.

The website at **NIDirect.gov.uk** provides comprehensive **advice** on financial help and services. It also features a benefits **calculator** that can help you estimate what income you can expect from various benefits and to explore how receiving one benefit may affect another.

Legal Matters

You may find that the person you are looking after has **difficulty managing** their **affairs.** He or she may be unable to sign **cheques**, or may not have the mental capacity to make their own **decisions.** Ask their **bank** if they have measures in place to help the person provide a consistent **signature** or allow you to sign on **their behalf**.

When the **effects** of stroke are more **complicated** and include problems with memory, thinking and understanding, **legal powers** may be needed.

If someone is unable to make their own decisions, they can appoint someone to have an Enduring **Power** of **Attorney** (EPA) to take decisions on property and finances on their behalf. However, a person must be able to make their own decisions to set up a Power of Attorney.

If the person you are caring for has already **lost** the **ability** to **make decisions**, you can apply to take over their finances and **become** a '**deputy**'. A deputy is someone appointed by the Court of Protection to make **decisions for someone** who is **unable** to do so on their own. In Northern Ireland, you apply to the Office for Care and Protection to become a deputy for someone.

3. Adjusting to life at home

Recovery is a very **individual** thing; it can depend on where the **stroke** occurred, the **severity** of the stroke and the person's general **health** beforehand.

It might **not** be **realistic** to expect everything to go back to exactly how it was **before** and the aim of recovery is for the person to become as **independent** as possible within the **limitations** of their stroke.

A **stroke** is likely to **affect** the whole **family** in many different ways. The **person** who has had the stroke may be **unable** to do some of the things they **previously** did and you, and other **family** members, may have to take on **new roles** and responsibilities.

Caring for someone who is no longer independent changes the relationship between you and it can be **stressful**. Many **carers** go through feelings of **loss** and **grief**

for the way their life, and that of the person they care for, has changed.

It is not unusual to have **feelings** of anger, resentment, guilt, anxiety and **depression**.

Finding someone you can **talk** to about how you feel can **help**. Help is available at Northern Ireland Chest Heart & Stroke on **028 9032 0184**.

The stroke may have left the person with physical **disabilities** but a stroke can also cause psychological or emotional changes and these can be more **difficult** to cope with. Common changes can include:

- Depression
- Tiredness
- Loss of concentration
- Personality changes
- Irritability

It is important to realise that these changes are the result of the stroke and that the person has **no control** over them.

Physical recovery from stroke depends to a large extent on the **effort** made by the **person** who has had a stroke and so it is important that **you** are **positive**.

Encourage the person to continue with their **rehabilitation** exercises. As **tiredness** can be a factor, **exercises** should be done during **short** sessions throughout the day. Try to give constant **reassurance** that things will get better and **congratulate** every sign of **progress**.

It will help if you are **familiar** with the **exercises** and so ask to be involved in the initial rehabilitation sessions with the health professionals so that you can learn them too.

It is also important not to be too **over protective**, to get the **balance** between helping and encouraging. **Encourage** the person you care for to do as much as is possible right from the start.

It will probably be a **gradual** process, small steps at a time. It can often be **frustrating** and time consuming but it is the best way for the person you care for to **relearn** skills and regain their confidence and independence.

Getting into a daily **routine** that meets both your **needs** is important. Within this routine try to build in time for any **rehabilitation exercises** that any of the health professionals have advised, for example, physical exercises, speech therapy or **practicing** some of the **skills** that the occupational therapist has taught. It is important that **over-exertion** is **avoided** and so regular rest periods should also be included in the day.

Many **people** who have had strokes are **conscious** of, and sometimes embarrassed, by their **muscle** weakness or **speech** difficulties and can be reluctant to go out or meet people. However it is good to **encourage** the person you care for to continue with **hobbies** or interests that they are still able to do, to ensure that they do **not** become **socially isolated**, and depressed as a result.

You may be able to do sports you enjoyed before your stroke if you are determined enough. Many sports can be adapted to become accessible to people with different abilities. For example, many people play one-handed golf or get involved in wheelchair sports. All ability sports such as Boccia and New Age kurling are also becoming popular.

Your local council will be able to provide information about swimming clubs or exercise classes which cater for people with disabilities.

It can also help them to talk to **other people** who **understand** what they are going through. Northern Ireland Chest Heart & Stroke provides Stroke Schemes for people who have had strokes. Contact Northern Ireland Chest Heart & Stroke on **028 9032 0184** for more information.

It is also important that you get some **time for yourself**. Ask other family members or friends for some help, people often want to help, you just need to let them know how.

Overall **patience** is vital. **Recovery** is a very **individual** thing; it can depend on:

- Where the stroke occurred
- The severity of the stroke
- The person's general health beforehand

Most **recovery** happens within the **first few weeks** after the stroke; however, people can go on **gradually recovering** for a long time after the stroke. It might **not** be **realistic** to expect everything to go back to exactly how it was before and the aim of recovery is to become as **independent** as possible within the limitations of the stroke.

HRT after stroke

Current research shows that if you have had a stroke you should not take HRT (Hormone Replacement Therapy) as it will slightly increase your risk of having another stroke or developing other health problems. If you have been taking HRT before having a stroke, your doctor will recommend that you stop taking it immediately.

Children or Grandchildren

If you have **children** or **grandchildren** it is important to **explain** what has happened to their parent or grandparent and to give them plenty of **opportunities** to ask **questions** as they will be worried too.

Children can be **frightened** by the way the person looks or sounds, or by outbursts of frustration or anger they see or hear. Some are **resentful** of the **time** others spend caring for the person who has had the stroke.

Children can have **misconceptions** eg that they will 'catch' a stroke. It is important to **talk** to your child or grandchild and to **observe** any signs of **worry** or avoidance of the situation. Take the opportunity to **explain** what is happening and to **reassure** them that the person will make realistic **improvements** in time.

It may help to **involve** them, if appropriate, in some of the day to day **tasks**. This will allow them to feel a **part** of the **changes** that have happened in their lives.

You should also set some **quality time** aside to play with children or take them on outings as they need a break from the stresses of home too.

You may need to **ask** family, friends or a social worker for **practical help** with childcare or with entertaining your kids, especially in the first few weeks and months.

Young Carers

If you are a **young carer,** aged under 18, it is important you get the **support** you need. **Social Services** have a duty to provide **support** so that the **education**, **development** and general **well-being** of young carers is not affected by caring responsibilities. Social Services can provide specialised **assessments** and support for young carers.

There are lots of ways your **school** can support you too, such as extra time to complete homework or help with school travel arrangements. They may also be able to put you in touch with a **local** young carers **service** or homework club.

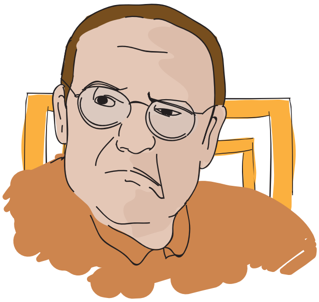
Young people have a **right** to a family life and to **act** as a **carer** for a family member if that is what the young person wants. You also deserve a **childhood**. It is important you are not **tied** down to your role as a carer. You should have enough **help** in place so that you have time for **education**, **play** and **leisure**.

Services including **information**, **respite** and individual **support** for young carers in Northern Ireland are available from Action for Children (telephone 028 9046 0500) and Barnardo's (telephone the Young Carers Service on 028 7963 4402).

4. Coping with physical needs

Every stroke is **different**. Each person affected by stroke will have different **problems** and different **needs**. The way in which they might be affected depends on where in the brain the stroke happens and the **type of stroke**.

The brain **controls** the way we move, think, see, speak, and eat and **everything** we do is controlled by different parts of the brain.



The **left side** of the brain controls the right side of the body and the right side controls the left side of the body. So a stroke on the **right side** of the brain generally causes problems on the left side of the body.

Each side of the brain also has different **functions** and this will also influence what affect the stroke has, or what **symptoms** the person experiences.

The **left side** of the brain normally controls reading, writing, speaking and understanding. So you are more likely to have **speech problems** if the stroke affects the right side of your body.
Movement, sensation and vision are controlled by **both sides** of the brain. Therefore these functions can be affected whichever side of the brain is damaged.

Balance and Movement

During **rehabilitation** the physiotherapist will help the person who has had a stroke with any balance problems, paralysis and muscle weakness.

But it is also important that the health professionals also show you how to **move and handle** the person you care for. For example, helping them in or out of bed so as not to cause injury to them or to yourself. When a person requires extensive moving and handling, **equipment** such as hoists should be provided.

Someone who has **balance problems**, muscle weakness or is learning to walk again is likely to fall more easily. Be prepared for this but do not prevent the person you care for from **being active** as this will slow down recovery. Advice on **using** aids such as **walking frames** or **sticks** should be provided.

A physiotherapist or the occupational therapist can offer advice on making areas **safe**. For example, keep the floor clear of obstacles and loose mats. Avoid uneven surfaces and **encourage** the use of a walking frame or sticks that should have been provided. Stairs should only be used if the person has been **assessed** by a physiotherapist or occupational therapist. Adaptations can be made to rooms eg. bathrooms can be fitted with non-slip floor surfaces, or handrails beside the bath or toilet. **Assessments** for equipment and **adaptations** can be made by a health professional.

Swallowing

After a stroke many people have problems **swallowing** fluids or food (called dysphagia). This may reduce a person's ability to take nutritionally adequate food and drink which can lead to dehydration or weight loss. There is also a **risk** that food or drink will go into the lungs (aspiration) rather than the stomach, which can cause choking and/or a chest infection.

Most people **recover** their swallow within a few weeks. **Some** will take longer, and a few people find that their ability to swallow does not come back.

A speech and language therapist will have **assessed** whether there are any problems with swallowing and be able to give **advice** on how to deal with them. For example, **sitting** in an upright position whilst eating and **tilting** the head down with the chin slightly tucked in can make swallowing easier. Also making sure food is well **chewed**, small mouthfuls are best. Food and drink shouldn't be mixed in the same mouthful. For some people food may need to be **pureed** or drinks **thickened**. A **dietician** may also provide **advice** on what foods and **consistencies** are appropriate.

It is important that you **encourage** the person affected by stroke to **practise** any **swallow** therapy **exercises** that they have been shown by the physiotherapist or speech and language therapist. It is also important that you, as a carer, are taught to **recognise** the **signs** of **choking** and **learn emergency techniques** in the event that choking occurs.

If there are **long term** problems with swallowing, a **PEG** tube (Percutaneous Endoscopic Gastrostomy) may be needed. A PEG is a flexible fine tube which is inserted, under local anaesthetic, directly into the **stomach** through a small incision in the abdominal wall. This allows liquid supplements and medicines, and even pureed foods can be given through the **tube**. You and the person who has had the stroke will be shown how to use and take care of the PEG and a **dietician** will advise what type of liquid food can be taken.

Incontinence

A stroke can lead to loss of **bladder control** (urinary incontinence), bowel control (faecal incontinence) or both. Most patients regain continence in a few weeks as their body **recovers** from the effects of their stroke. For a small proportion of people, **bladder** or **bowel** problems can be more **long term** but with help and treatment can become more manageable.

Medication can improve continence and exercises can help improve **bladder control**. **Exercises** which help mobility will also help to get to the bathroom on time. **Equipment** and adaptations to bathrooms may also be appropriate to help make it easier to use the toilet. Personal items, such as pads, are also available to help the person remain dry and comfortable. The **continence nurse** will be able to give specific advice.

Communication

Stroke can affect the ability to **speak**, write and **understand** what is being said, this is known as **aphasia**. The effects of the stroke on speech, reading and writing will be fully assessed by a speech and language therapist and they will give advice on how best to **communicate** together.

Using **simple** words and **short** sentences can help the person get **meaning** from what you are saying. You can find out whether someone can use yes or no, or a signal such as thumbs up or thumbs down accurately. If they can do this most of the time, then you can ask questions to which the answer is yes or no.

You can be shown how to **reinforce** your verbal message, using facial expressions, gestures, writing or showing pictures if they are finding it difficult to follow instructions or **understand** what is being said.

It is important not to rush the **conversation**. Give the person **time** to take in what you say and to respond, and don't interrupt them.

There are a number of **computer** aided devices to help a person **communicate** after a stroke. Computers can be adapted to help most people with disabilities to use them. **Text** can be made **larger** or **read aloud** and changes can be made if the person can no longer control a keyboard or mouse with their hands. **Adaptations** can allow the person to use a **computer** using any movement they are able to control, such as eye movements. Your speech and language therapist can make a referral to a **specialist** communication centre who can advise what aids would suit the person's needs and abilities. It is important that both you and the person you care for are involved in the choice of aid and that you both learn how to use it.

Epilepsy

Some people can develop **epilepsy** following a stroke. **Treatment** is the same as for any other kind of epilepsy, and it can usually be well controlled with **medication**.

Coping with an epileptic seizure:

- **Protect** the person from **injury** by removing any sharp or hard objects nearby and cushioning their head

- Do **not move** them unless they are in danger
- **Loosen** any tight **clothing** from around their neck
- **Turn** them onto their **side** to avoid inhalation of **vomit** and to keep their **airway** clear
- Do not force anything into their **mouth** to keep them from biting their **tongue**
- Do **not** give them anything to **drink** after the seizure has stopped

If they have a **second seizure** immediately after the first, contact the **doctor** or call for an ambulance. Try to remember as much detail as possible to tell the doctor.

Memory and understanding

Stroke can also cause problems with functions such as **memory**, learning, understanding, problem solving and perception of space or distance. For example not **remembering** names, not **recognising** familiar objects or bumping into things.

The occupational therapist will have done an **assessment** on how the person who has had a stroke **copes** with a variety of everyday **tasks** and functions and will be able to offer **advice** on how they can learn to adapt.

It is important that you encourage **patience.** Frustration and anger makes it even harder to remember. You also need to be patient, give brief, clear instructions and be prepared to repeat things. **Memory aids** such as diaries, calendars or lists can sometimes help.
If concentration is a problem, removing distractions can help e.g. turn off the TV while the person is eating.

If the person has problems with perception of **space** or **distance** it can help by ensuring that there is good **lighting** in rooms to make it easier to see everything. Removing unnecessary **clutter** and keep the floor free of obstacles will also help.

Overall, physical **recovery** from stroke depends to a large extent on the **effort** made by the person who has had a stroke and so it is important that you are positive. Try to give constant reassurance that things will get **better** and congratulate every sign of progress.

5. Coping with emotional needs

As well as physical changes a stroke can also cause psychological and **emotional** changes. Damage to the brain can lead to changes in **behaviour** and the changes will depend on the part of the brain **damaged**. There can also be difficulties in coming to terms with having a stroke which may affect behaviour.

Emotional control

Stroke and damage to parts of the brain can affect the ability to control **emotions**. Emotional reactions can be **exaggerated**, unpredictable and sometimes inappropriate to the situation, for example, sudden unprovoked tearfulness, uncontrolled or inappropriate laughter or anger.

These reactions are often **distressing** for both the person who has had the stroke and their family or friends. It can be helpful **not** to **over-react** to these behaviours, both for you and the person who has had a stroke. **Understanding** that they are due to the stroke rather than a reflection of how they feel helps you all to cope with the situation. Equally it is important to reassure the person you care for that this is usually a **temporary** situation and that in time they will have more control and feel more like themselves.

Besides the neurological reasons behind emotional changes, there is also the fact that stroke is a **traumatic** event to come to terms with. Its after effects can be life-changing. Many people affected by stroke go through feelings of loss for the way their life has changed. **Frustration** and **anger** can contribute to emotional outbursts. Quite often struggling to complete an everyday task such as getting dressed can trigger an outburst.

There are some steps you can take to try to **avoid** outbursts associated with **frustration**:

- Try to find ways to offer the person as much **independence** as possible
- Offer as much **choice** as possible, even down to small things like what they want to wear, eat or go.
- **Plan** ahead and break tasks into small achievable steps.
- **Encourage** and praise progress
- Be **patient** and don't rush the person

As a carer you will spend a lot of time taking care of your loved one. The stroke has changed you and your family's life as well as that of the person you care for. Most likely you are feeling tired, frustrated and fed up at times yourself.

You will probably experience **behavior** from your loved one that you find **challenging** at some point. If you are on the receiving end of words or actions that annoy you or hurt your feelings, it can be difficult not to retaliate or take the argument personally. However getting entangled in an argument when emotions are running high rarely helps anyone involved.

Just because someone has had a stroke does not give them a right to **bully** or abuse you. However it is important to remember that a lot of challenging **behaviours** eg rude comments, hitting out or swearing are often the **neurological effects** of stroke rather than a personal attack. Unfortunately it is loved ones and carers who are often on the receiving end of emotional behavior.

There are **techniques** you can use to cope with challenging behaviour:

- **Walk** away
- **Listen** to the person and discuss the issue once tempers have calmed.
- **Explain** firmly but politely that the behavior is not acceptable.
- Explain how it makes you **feel**. Use 'I' rather than 'You'. For example "I feel angry / hurt when you say/do that" rather than "You are making me angry/ hurting my feelings".
- Encourage other family and friends to **reinforce**

the message that such behavior is not acceptable.

- **Repeat** the message and give **encouragement** when the person reacts more appropriately in future.
- Talk to a friend. Sometimes **sharing** a problem with someone, even having a laugh about it, or just getting a break from the house can give you more resilience and ability to cope.

If you notice **changes** in the person's thinking or emotions you can ask the GP for a referral to a **clinical psychologist**. These professionals can often offer helpful advice and techniques to assist with the thinking (cognitive), behavioural and emotional changes after stroke. They can also help the person, or you as a carer, through the process of accepting what has happened and adapting to life after stroke.

Anxiety and Depression

Sometimes anxiety and depression can be the direct result of the **damage** caused by the stroke. Other times it may be as a result of the **emotional** difficulty involved in coming to terms with having a stroke. Feeling down some of the time is natural after a stroke but if you or the person who you are caring for is **feeling low** most of the time it could be depression. Depression can develop soon after having a stroke or **months afterwards.** Common changes can include:

- Tiredness
- Loss of concentration
- Personality changes
- Irritability

Many people who are **depressed** feel unable to do anything about it and so you may have to **encourage** them to **talk** about it or to seek help from health professionals.

It can also help them to talk to **other people** who **understand** what they are going through. Northern Ireland Chest Heart & Stroke provides Stroke Schemes for people who have had strokes. Contact Northern Ireland Chest Heart & Stroke on **028 9032 0184** for more information.

6. Looking after yourself

Caring for someone who is **dependent** on you is a big responsibility. It is realistic, not selfish, to think carefully about **taking care** of your own health and organising support for yourself. If you don't look after **yourself**, you run the risk of becoming so stressed or exhausted that you are no longer able to care for the person who has had the stroke.

Think about what you can do to look after your health. Common problems are:

- Back strain from lifting or moving the person needing care
- Tiredness
- Stress

Back pain

The physiotherapist can teach you how to move and **lift** someone so that you don't strain your back. If a person requires actual lifting, **equipment** such as hoists should be provided.

Stress and tiredness

Stress can cause symptoms including:

- Sleeplessness
- Loss of appetite
- Intense anxiety
- Depression

To **reduce** stress levels and tiredness it is important that you get some time for yourself, that you get a break from caring.

Many **carers** say that getting a regular **break** is invaluable. Plan some time for yourself into the daily routine that you develop. Ask other **family** members or friends for some help.

People often want to help, you just need to let them know how.

Taking regular **exercise** also combats stress. It is a good way to get time to yourself and will help maintain your physical health.

It is also important to get enough **sleep** and **rest.** If you are having difficulties sleeping or staying asleep, it may be a sign of anxiety or depression, so always consult your GP with any concerns.

Many carers feel **isolated**. The practicalities of caring can take up a lot of time and you may feel restricted to the home. Carers often feel that they no longer have much in common with friends and colleagues.

However, you should not neglect your own **social life**. Having **hobbies** and **interests** outside the home and having people to talk to can be very helpful in preventing isolation and depression.

It is also worth finding out what **respite** care services are available in your local area. The Health and Social Services Trusts and some voluntary organisations run day centres for the care of adults with disabilities. Centres arrange **social activities**, craftwork clubs or outings. Most can arrange **transport** to and from the centre.

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In some circumstances **residential care** homes and nursing homes can provide **short-term** care for the person you look after so that you can get a break. There may be a **cost** to this type of care. It is important to note that if Social Services help pay towards short term breaks in residential care, benefits may be affected. **Information** and advice can be obtained from Social Services or the local Citizens Advice Bureau can give you independent advice.

Depression

Many **carers** go through feelings of loss and **grief** for the way their life, and that of the person they care for, has changed. It is not unusual to have feelings of anger, resentment, guilt, anxiety and depression. Finding someone you can **talk** to about how you feel can help. Every carer is an **individual**, and each caring situation is unique.

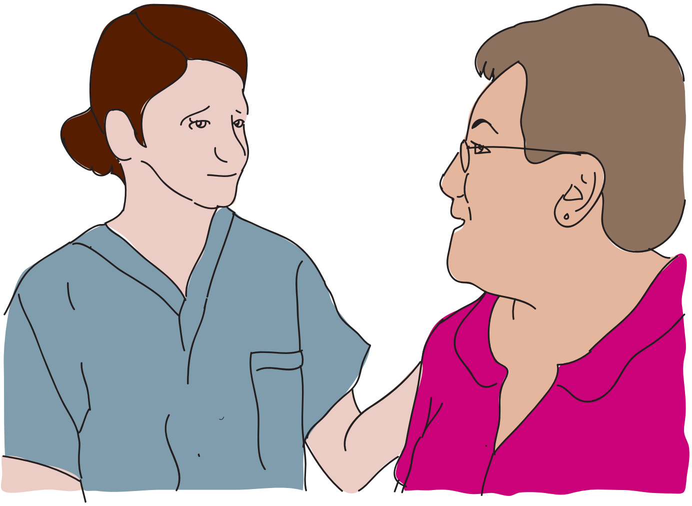
But, you are likely to find that most people who do not have **experience** of caring for another adult have no idea what it involves. Carers do have a lot in **common** and it can be very helpful to meet and talk to other people who understand exactly what you're going through.

Northern Ireland Chest Heart & Stroke have a team of Stroke Family Support Co-ordinators across Northern Ireland who can offer **support** to the carers and families of individuals who have experienced a stroke.

Stroke Family Support offers advice, information as well as practical and emotional support. Telephone **028 9032 0184** for more information.

It is worth finding out if there are any **Carers' Groups** in your area. Northern Ireland Chest Heart & Stroke provide a number of Carers' Groups in Northern Ireland. Contact Northern Ireland Chest Heart & Stroke on **028 9032 0184** for more information.

Recognise that the stroke will change your lives but that this need not prevent you from having new hopes and goals for the future.



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