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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Ulster Hospital Stroke Unit
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.
<table>
<thead>
<tr>
<th>Age</th>
<th>Employment situation</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 16 years old</td>
<td>n/a</td>
<td>Disability Living Allowance (DLA)</td>
</tr>
<tr>
<td>16-64 years old</td>
<td>Employed but off work sick</td>
<td>You may be able to claim <strong>Statutory Sick Pay</strong> (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 <strong>Employment and Support Allowance</strong>.</td>
</tr>
<tr>
<td>16-64 years old</td>
<td>Employed and back at work</td>
<td>If you go back to work, you may be entitled to an increase in <strong>Working Tax Credit</strong>.</td>
</tr>
<tr>
<td>16-64 years old</td>
<td>Unable to return to work</td>
<td>Disability Living Allowance (DLA).</td>
</tr>
<tr>
<td>Over 65 years old</td>
<td>Retired</td>
<td>Attendance Allowance, which is for people who need assistance with their personal care and/or supervision.</td>
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</tr>
<tr>
<td>Over 16 years old (no upper age limit)</td>
<td>Carer (at least 35 hours per week)</td>
<td>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.</td>
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</tbody>
</table>

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:
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.