

The Hidden Side of Stroke

low mood,
fatigue,
frustration, poor
concentration,
memory
problems

‘me?’



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What is a stroke?

Every five minutes someone in the UK has a stroke.

Each year there are more than 110,000 people in England who have a stroke.

About 300,000 people are living with a moderate or severe disability following a stroke.

Stroke is a major cause of disabilities in adults.

There is an assumption that a stroke is something that happens to older people.

But a stroke can happen to people of all ages, young as well as old, including young children. One in four strokes happens to people who are under 65.

A stroke cuts off the blood supply to part of the brain, either because a clot lodges in a blood vessel or because a blood vessel bursts in the brain. That part of the brain then dies off.

The commonly recognised signs of a stroke include:

- Weakness down one side of the body
 - A facial droop
 - Slurred speech, jumbled words or possibly a total loss of meaningful speech
 - Some people also have problems swallowing
- But this is only part of the experience of having a stroke.
- While the physical effects are devastating, a stroke also has a huge emotional and social impact. Life is turned upside down and the future is suddenly uncertain. Unwanted choices have to be made. Being close to normal again might feel like an impossibility. Surviving a stroke is a highly personal 'journey' for all those affected: the person themselves, their family and close friends and it can touch every corner of life.

Aims

The aim of this project is to raise the level of understanding of the impact of a stroke on someone beyond the obvious physical disabilities.

This will help those who are involved in the care of those affected by stroke to deliver care appropriately and more effectively. This is important in seeing stroke survivors achieve the best possible quality of life for them as individuals and for those around them.

The 'hidden side' of stroke refers to symptoms and experiences which are not immediately obvious to other people, but which represent a very real challenge for the stroke survivor themselves.

The following symptoms and experiences are covered in this module: frustration, self confidence, mood, fatigue and a condition known as emotionalism.

These symptoms may not be mentioned. Information or advice may be hard to find.

The 'hidden side' of stroke is still not well recognised and understood.

Recovery and quality of life for someone who has had a stroke can be improved when others recognise and understand that these are real experiences and difficulties.

Those involved in caring for stroke survivors need to be aware of the hidden side of stroke so that they can give support and care in the best way.

They have a duty of care to understand all problems that can result from a stroke.

They can help stroke survivors to understand, accept and learn to manage their symptoms rather than battling with them. When this happens then they are more likely to make progress towards their goals.

Stroke survivors can be treated with dignity.

An understanding of what the stroke survivor is experiencing will reduce the feeling of isolation and despair. Important instructions and information can be communicated effectively.

This is important to ensure patient safety.

Problems may be recognised for the first time and instead of being dismissed the stroke survivor can be referred on to get the specialist help that they need.

Patient outcomes can improve.

Increased job satisfaction for those involved in caring for stroke survivors.

Meet the stroke survivors

We will now introduce you to the stroke survivors who have volunteered to share their experiences.



Mary

Mary is married with two children. She previously worked as a nurse. She has experienced two strokes and her speech is affected.



Kray

Kray is 14 and had his stroke after head butting a football three years ago. His mother, Sonya, now has her own website and supports other parents with young children who have experienced a stroke



Audrey and Frank

Audrey is 80 and married to Frank. She had her stroke a year ago. She experienced flu like symptoms and went to bed for two days. She then started vomiting. By chance Frank asked her if she knew when her birthday was and Audrey couldn't remember. He took Audrey to hospital where she was informed she had experienced a stroke.



Trevor

Trevor is married and worked as a Legal Advisor before his stroke. Trevor thought he was experiencing hayfever as it was August and had suffered from it since childhood. He started to feel breathless and was unable to drive so called his GP. He was admitted to hospital with an atrial fibrillation. After a short stay he was discharged. Two days after discharge Trevor started vomiting and later collapsed.



Bill

Bill is 80. He lives on his own and is a keen gardener with an allotment. He worked for a brewery for many years. He collapsed in his bedroom after suffering his stroke in August 2010 at the age of 79. His sister found him still on the floor a week later after he wasn't answering his phone. Since his stroke he has had to give up his allotment.



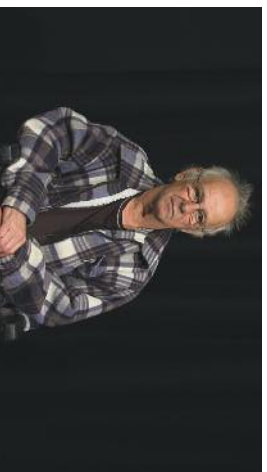
Rose

Rose is married with two children. She had her stroke 10 years ago after having surgery for a brain tumour. When Rose woke up after surgery she thought she had been given too much anaesthetic. Rose worked as a teaching assistant before the stroke.



Peter

Peter is 38 and lives with his partner and two children. He was dropping the children off at nursery when he suddenly began swaying and was physically sick. Someone called an ambulance.



Tommy

In 2011 Tommy went to hospital for a hip operation. On the day he was due to come home, he felt strange and couldn't talk properly. Tommy had had a stroke and lost the use of the left side of his body.

Module one

Mood related problems

Frustration and loss of confidence

Low mood and anxiety

Emotionalism

Fatigue



Introduction

Having a stroke can be emotionally overwhelming.

People are understandably distressed and upset in the days and weeks afterwards. This is absolutely normal. A stroke brings about change, loss and uncertainty, all without warning.

And a stroke affects more than the patient. Family and close friends commonly have their own distress and questions about what has happened to people close to them.



Frustration and loss of confidence

Two very common complaints following a stroke are frustration and loss of self confidence. These are not clinical or medical conditions which need a doctor to diagnose them, but they are significant because:

- They are typical responses to the sudden loss of independence, normality and control brought about by the stroke
- They are natural human reactions and so extremely common following a stroke
- They are part of the early stages of an adjustment process; normally frustration and low self confidence give way to gradual acceptance
- They can be present for many months as someone comes to terms with what they can and can't do

Frustration

Just about every aspect of a stroke can cause frustration, for example difficulties with communicating, preparing or eating meals, getting dressed and going about day to day activities.

Frustration is a natural response to the sudden loss of independence a stroke can bring, and to the fact that progress often feels slow.

In the following clip Peter talks about the frustration he experiences following his stroke



Frustration should gradually lessen as the person comes to terms with what they can and can't do. This takes time. Accepting what has happened is a gradual process.

If acceptance does not happen then continuing frustration may result in a worsening of mood.

Loss of confidence

It is also perfectly natural for someone to lose their self confidence in the first few months after a stroke.

People often use words such as embarrassed, alone, lost, inadequate, different and 'not me' to describe how they feel after their stroke.

As a result ordinary things, that would never have troubled them before, may make people feel vulnerable, daunted and unsure. Things such as going out, answering the telephone, seeing friends or going into shops.



Self confidence should gradually improve as the person comes to terms with what they can and can't do. This takes time. Acceptance is gradual.

If acceptance does not happen then continuing low self confidence may result in a worsening of mood.

The following can be helpful in managing frustration and low self confidence after a stroke

- Tell the stroke survivor that these are normal responses following a stroke and to be expected
- Tell the stroke survivor the adjustment process takes time
- Explain that these feelings are natural and understandable after a stroke
- Be aware that sometimes these can lead to low mood and depression

Which of the following is true of frustration and low self confidence after a stroke?

- Q1** The majority of people who have a stroke complain of frustration and low self confidence
YES/NO
- Q2** They are a form of illness **YES/NO**
- Q3** They improve with anti depressant medication
YES/NO
- Q4** They are linked to the sudden changes imposed by the stroke **YES/NO**
- Q5** They often occur in the early stages as part of the process of acceptance and adjustment after a stroke **YES/NO**
- Q6** They need to be told to pull themselves together **YES/NO**

Low mood and anxiety

An awareness of how mood disturbances present are very important in relation to stroke because so many people are affected by this following a stroke.

It is natural for someone to feel down and worried after having a stroke. This is part of adjusting to the changes caused by the stroke and does not necessarily mean they have a mood disturbance.

Mood disturbances include low mood, which may develop into depression and anxiety.

Low mood occurs in approximately one in three people after a stroke. It may develop immediately, months or even years following a stroke.

Anxiety disorders also occur in about one in three people following a stroke.



In the video clip we heard Trevor and Mary talk about some of the typical symptoms which include:

- Being irritable or short tempered
- Sadness or tearfulness
- Loss of motivation
- Loss of interest
- Mood swings
- Showing anger or aggression
- Loss of enjoyment
- Feeling restless and fidgety
- Avoidance of anxiety-provoking situations

All of these can be seen in someone's behaviour and these observations are important. Do not rely on someone talking about how they are feeling as it can be very difficult for them to describe. In addition, some people affected by stroke can have communication problems.

Typical symptoms

In those who do not have communication problems and are able to talk about what they are feeling, they may describe:

- Hopelessness about the future
- Low self esteem
- Feeling tense, anxious, panicky or 'wound up'
- Constant worrying
- Thoughts of death and suicide

If a number of these symptoms are present most of the time and are interfering with general goals and routine then mood has become a problem.

Apart from the fact that low mood and anxiety are extremely unpleasant conditions to have to experience, they can also make recovery from a stroke much harder. For example someone who has lost interest in the future will be more difficult to motivate to participate in rehabilitation. Similarly, someone who is anxious or feeling worked up about doing something, is more likely to avoid the challenge altogether.

It can make family life harder too. Being with someone who is short tempered and snappier than usual is draining for those around them. The phrase "walking on eggshells" is often quoted. Trying to encourage someone when they aren't willing is also frustrating, and can leave those around them feeling unsupported and alone.

Mood disturbance is an illness and is best treated within two weeks. The first step is to seek medical advice from a doctor who can fully assess mood. For most people this will be the GP.

The doctor may prescribe anti-depressant medication which can be effective in treating low mood after stroke, or they may decide to refer to another service for 'talking therapy'.

But other ways of helping can be just as important and effective in terms of treating mood disturbance.

Regular and appropriate social contact can be helpful in boosting mood, including speaking to other stroke survivors and carers.

As with all aspects of the hidden side of stroke it can be reassuring for stroke survivors and their families to know that mood disturbance is extremely common after a stroke, and that there are effective treatments.

Which of the following would make you think that a stroke survivor may have a mood disturbance?

- Q7** They are noticeably more irritable and short tempered **YES/NO**
- Q8** They look very tired most evenings **YES/NO**
- Q9** They are physically well enough to do most things but don't want to do anything **YES/NO**
- Q10** They avoid going out because it brings on panic attacks **YES/NO**
- Q11** They feel confident and good about themselves **YES/NO**

Emotionalism

Emotionalism is a very common condition after stroke. On the surface, it looks similar to mood disturbance it is easy to confuse the two.

Emotionalism is defined as difficulty with controlling emotions, particularly crying or laughing.

Emotionalism effects about a quarter of people in the first 12 months and may resolve, but it can continue for many years.

Typical symptoms

The symptoms of emotionalism include the very sudden onset of uncontrollable weeping, or the sudden onset of uncontrollable laughter. Sometimes people will swing between the two. This is a pattern which is repeated.

One of the characteristics of emotionalism is that the crying, or occasionally laughing, comes on rapidly, and usually goes just as rapidly.

The trigger for crying or laughing may not be obvious. Or there may be a small trigger - such as a sad film or mention of a family member. Despite the trigger being small the emotional reaction is very visible, certainly much greater than you would normally expect. This is another characteristic of emotionalism. The amount of emotion expressed does not 'fit' the situation.

Here is a clip of Bill showing signs of emotionalism.



Emotionalism can be very embarrassing and distressing. It might stop some people from wanting to go out and mix socially in case they start crying or laughing in front of others.

It can be reassuring for people to know how common emotionalism is after a stroke.

As a technique for emotionalism, distraction works well. For example changing the topic of conversation to something neutral or switching TV channels to watch a less emotional programme.

Sometimes a small dose of an anti-depressant can be effective in reducing the symptoms.

As noted earlier, it is easy to confuse emotionalism with low mood, and in fact the two often overlap so that it is perfectly possible for people to suffer both conditions at the same time.

An awareness of both emotionalism and mood disturbance is important in stroke, but a more specialist opinion is usually required for a precise diagnosis.

Which of the following would make you think that a stroke survivor may have 'emotionalism'?

- Q12** They look miserable much of the time **YES/NO**
- Q13** They have spells where they suddenly laugh or cry **YES/NO**
- Q14** They cry constantly **YES/NO**
- Q15** They cry but, like everyone, only in very sad situations **YES/NO**
- Q16** They cannot easily control their emotions **YES/NO**

Which of the following is helpful when managing someone with 'emotionalism'?

- Q17** Explain that the condition is common and due to the stroke **YES/NO**
- Q18** Distract them onto another topic or activity **YES/NO**
- Q19** Tell them to stop crying or laughing **YES/NO**
- Q20** Walk away from them and leave them alone **YES/NO**
- Q21** If the symptoms are troublesome and ongoing, consider asking for a specialist opinion **YES/NO**

Fatigue

Feeling exhausted and drained is another common complaint after a stroke. Stroke related fatigue is completely different to the tiredness anyone can feel day to day. It can be absolutely overwhelming, causing the stroke survivor to feel drained, and forcing them to take a rest or nap.

This is not a condition which can be fought with willpower. When the fatigue strikes the individual must rest, both physically and mentally. It is also a condition which can come on quickly and at any time, morning or afternoon. It is perfectly possible some days to wake up tired and un-refreshed.

Sometimes there can be a daily pattern to the fatigue. Rose gives examples of how she manages her fatigue.



Like most aspects following a stroke, fatigue can place demands on the whole family.

If family and friends are not aware of this hidden aspect of stroke it is very easy to think the person affected is just being lazy. Once it is recognised that they need to take time out then it can be a tremendous challenge for everyone else to adjust their routines and expectations.

Fatigue, in the first year, affects more than half of all those who have had a stroke. It can continue to trouble people for many years.

How much someone is affected by fatigue does not seem to be linked to the type of stroke or the size of the stroke. Even a small stroke which does not appear to have caused many other problems can bring about fatigue.

Some people with post stroke fatigue also have mood disturbance.

Low mood can worsen the symptoms of fatigue because energy and motivation levels are already low. When this happens then a specialist opinion may be needed.

As with all aspects of the hidden side of stroke it can be reassuring for stroke survivors and their families to know that fatigue is extremely common after a stroke. Otherwise it is easy to label this difficulty as a sign of not coping.

There is no cure for post stroke fatigue, but there are techniques for managing the symptoms. If everyone accepts the fatigue and works together then it is easier to deal with, and less of a problem on a daily basis.

Feeling tired all the time, is a non-specific symptom. It can be due to physical conditions such as anaemia or thyroid problems. It can also be a side effect of medication. This is a common problem and is not the same as stroke-related fatigue.

Coping strategies to help someone manage their fatigue may include:

- Structuring the day so there are rest periods built in, and alternating those with periods of activity
- Accepting that when the fatigue is overwhelming then it is advisable to take a break rather than fighting it
- Avoid overdoing it even if it is a 'good day' or the exhaustion will be much worse the following day

Which of the following is true of post stroke fatigue?

- Q22** The level of fatigue is dependent on the size of the stroke **YES/NO**
- Q23** It occurs in one in four people in the first year **YES/NO**
- Q24** The symptoms can last up to a year **YES/NO**
- Q25** Fatigue is real and not someone being lazy **YES/NO**

Which of the following is helpful in managing post stroke tiredness?

- Q26** Give it time to sort itself out **YES/NO**
- Q27** Ask for a medical review to look for other possible causes of the tiredness **YES/NO**
- Q28** It tends to come on in the evening **YES/NO**
- Q29** Explain that the condition is common and due to the stroke **YES/NO**
- Q30** Recognise the times of the day when the fatigue affects them and allow for times of rest **YES/NO**
- Q31** Encourage people to push themselves if they are having a good day **YES/NO**

In this module the following problems following a stroke have been described

- Frustration
- Loss of confidence
- Low mood and anxiety
- Emotionalism
- Fatigue

These are common problems in those who have had a stroke

Recognising them will help those who have had a stroke:

- Feel less isolated and maintain their dignity
- Receive the support that they really need
- Receive safer care
- Receive more effective care
- Make more progress in rehabilitation
- Have a better quality of life

This will also help their family and carers.

Enable you to become more effective in helping stroke survivors and their carers, usually family members.

Module two

Cognitive problems

Memory

Attention/concentration

Distraction

Information processing

Planning and sequencing skills

Decision making

Numeracy skills

Personality change

Apathy

Thinking skills

Personal impact

Helpful approaches

Spatial neglect

Introduction

Cognitive problems are another part of The Hidden Side of Stroke, in addition to the emotional and mood disturbances that stroke survivors can experience.

The term cognition refers to the thinking, learning or mental processing skills of the brain. Some examples of these mental skills are memory, attention, communication, perception and orientation.

As humans we rely enormously on our ability to think, speak, understand and reason. Our brains do this automatically without us being aware of these processes. When a stroke damages part of the brain these, and many other mental skills, can be damaged.

In the early days almost everyone who has a stroke is likely to have cognitive damage of some sort, for example confusion or loss of speech. There is usually some improvement over time. However, many stroke survivors will continue to live with some degree of cognitive difficulty in the long term.

Exactly which cognitive problems a person experiences will depend on where the stroke happened in the brain and how much of that part of the brain was damaged.

After a stroke the brain can become quickly overloaded even by the thinking, learning and mental processes needed for simple tasks.

To the stroke survivor it can feel as though the most tremendous effort is going into the smallest of interactions. On the outside this effort is invisible. They may look as though they have 'switched off'.



Because cognitive difficulties are not visible on the outside, stroke survivors often say that they get comments on how well they look in the months after their stroke.

Their personal, internal experience is however, very different.

In addition people often try to hide their cognitive difficulties because they feel embarrassed and ashamed.



Memory

Difficulties with memory will affect almost everyone at some point after a stroke.

The way memory works is extremely complex. Memory is not just one process and can be affected in lots of different ways.

The speed of memory can also slow down. This means that people after a stroke may take longer to remember things and need more prompts to help them.

One of the most common memory problems is short term memory loss.

This is when the ability to remember events which have happened recently or conversations which have just happened. For example, someone may need to be told the same thing more than once.



Difficulties with short term memory make it harder for people to learn new things after a stroke, for example learning a new telephone number.

Longer-term memory, or memory for things which happened long before the stroke, may not be affected.

There are other forms of memory problems that can result from a stroke. Some examples are:

- Difficulty with remembering words and names
- Remembering to do things in the future such as attend an appointment
- Remembering the way around local streets and area. This is a problem of spatial memory
- Recognising someone they know by their face or visual appearance. This is a problem of visual memory

Memory may improve gradually over time, but there is no actual cure. The most useful approach is to learn ways of coping with memory loss, for example

- Keeping a diary
- Writing messages down before they are forgotten
- Using post-it notes as reminders, for example turning off the cooker and locking the door at night
- Keeping a fixed daily routine as this reduces the demands on memory



Which of the following is true of memory after stroke?

Q32 Memory difficulties are extremely common
YES/NO

Q33 Memory is a very straightforward process
YES/NO

Q34 Problems with short term memory make it harder to learn YES/NO

Q35 Memory for things which happened before the stroke is usually poor YES/NO

Q36 It often takes longer to remember things
YES/NO

Which of the following is helpful in managing memory after stroke?

Q37 Keep a varied routine YES/NO

Q38 Keep a diary YES/NO

Q39 Medication is a good cure YES/NO

Q40 Write notes as reminders for things such as taking medication YES/NO

Q41 Write down any messages a bit later if there is time YES/NO

Attention/concentration

Attention is another part of cognition which can be a problem after a stroke. This may be a difficulty in being able to pay attention or concentrate for a period of time. Not being able to concentrate can be an embarrassing nuisance and also cause problems doing daily activities.

It can also be dangerous, for example when driving or crossing busy roads.



Distraction

Usually we are able to focus on what we are doing because the brain filters out background noises. After a stroke however it can feel as though background noises are taking over so that sticking to the task in hand is a real challenge. This distraction can happen however hard the person is trying.

Peter and Trevor both share their experiences of distraction and concentration.



Another common complaint after a stroke is losing the ability to do two things at once, or multi-tasking. Generally people are only able to do one task at a time.



Attention and concentration can improve gradually with time, although there is no actual cure. The most useful approach is to learn ways of coping with attention problems, such as:

- Asking anyone giving information to keep it simple
- Telling them about the difficulty – asking for help
- Taking frequent breaks/rests
- Dealing with important things before getting tired in the day
- Reducing any background noise or distractions

Which of the following is true of attention, concentration and multi-tasking after a stroke?

Q42 The brain commonly finds it harder to screen out background noise YES/NO

Q43 It is possible to improve attention by trying harder YES/NO

Q44 Performing one task at a time, or two tasks at once, are both equally achievable YES/NO

Q45 Difficulties in these areas can put people at risk of danger YES/NO

Q46 People cannot concentrate for as long YES/NO

Information processing

Processing information is another type of thinking skill. After a stroke people may be slower at processing information. They may also take in less information than they used to.

Difficulties with information processing, together with concentration and memory difficulties, can turn normal conversation into a huge challenge. This is the case even when language is largely unaffected.



Planning and sequencing skills

Planning and sequencing skills are needed for daily tasks. Most tasks are made up of a number of steps, e.g. getting dressed. In order to work out which steps are needed, and in what order, requires these planning and sequencing skills. These skills can sometimes be lost or reduced after a stroke.



Decision making

Decision making involves:

- Being able to recall the possible options
- Weigh up and reason through the pros and cons of each option
- Prioritise which are most important
- Then make an overall judgement

This is a very complicated cognitive skill.

If decision making is impaired after a stroke then people may find it much harder to think things through. They may become impulsive and jump to conclusions. Or they may be unable to make plans and decisions at all.



Numeracy skills

The cognitive difficulties that a stroke survivor can have will be unique to them, most people have never considered what it is like to find noise unbearable, to be unable to recognise familiar faces, to have difficulty getting words out. To be unable to relate to numbers and figures.

Here is a clip of Many demonstrating dysphasia and difficulties with numbers.



Personality change

When thinking skills are affected it can seem to those who know them well that the individual's personality has changed.

Personality change may be linked not only to changes in cognition, but also to mood problems.

As humans we have the ability to consider the impact of our behaviour on others. We think twice before saying something in case we are rude or blunt. After a stroke this ability to self monitor can be lost, and thinking can become more black and white.

Stroke survivors may no longer be able to imagine how what they are saying will come across, and so they can appear blunt, thoughtless, ignorant and even rude.

There may also be a change in their sense of humour or they may lose it completely.



Relatives and friends often find this very upsetting. Although it may not be intentional, for relatives these personality changes can feel very personal.

Gentle feedback to the stroke survivor about how they are coming across can improve their awareness of the ways they are behaving, and the impact this is having. This may need to be repeated over time.



Apathy

A condition known as apathy can result from problems with thinking, learning and mental processing.

Apathy shows itself as an extreme lack of interest and drive, both in getting going with an activity, and then in keeping going.

Apathy can result in another form of personality change.

Those who know them may notice that the stroke survivor may seem to be:

- Switched off and unresponsive
- Emotionally distant and cold
- No longer caring and cannot be bothered



Some features of apathy may be similar to low mood and mood disturbances. They are two different problems with different causes.

It is important to find out what the problem is and this may best be done by an expert. The treatment and help that the stroke survivor needs will be different for apathy compared to mood disturbance problems.



Thinking skills

The thinking skills we use for everyday life are complex. The problems that can result from a stroke can be complicated.

A key characteristic, however, is how much less flexible the brain becomes when thinking skills don't work properly. The brain finds it much harder to:

- Grasp complex ideas
- See two sides of the story
- Come up with suggestions for ways to tackle problems
- Reason through a problem
- Learn new ways of doing things
- Switch between tasks rather than focusing on one thing



As with all aspects of the hidden side of stroke it can be reassuring for stroke survivors and their families to know that difficulties with thinking, learning and mental processes are very common after a stroke.

The first step is often to work on recognising and acknowledging these problems if they exist.

This will help to avoid the stroke survivor being misunderstood and unfairly blamed for the way they behave and respond to people and situations.

Which of the following is true of difficulties with thinking, learning and mental processing after a stroke?

Q47 Personality change can be due to difficulties with thinking and mental processes as well as mood disturbance **YES/NO**

Q48 Processing information can be often faster after a stroke **YES/NO**

Q49 Most activities require the ability to plan and sequence **YES/NO**

Q50 There is only one stage involved in decision making **YES/NO**

Q51 Cognitive apathy relates to an extreme loss of drive and motivation to take action **YES/NO**

Which of the following is helpful in managing difficulties with thinking, learning and mental processing skills after a stroke?

Q52 Stroke survivors and their families will find it helpful to know that executive difficulties are very common after a stroke **YES/NO**

Q53 Recognising and acknowledging problems related to cognitive skills difficulties does not help the person **YES/NO**

Q54 Gentle feedback from people who are trusted can improve the stroke survivor's awareness of their behaviour and its impact **YES/NO**

Q55 There is no point in finding out if someone is having problems due to apathy rather than mood disturbance **YES/NO**

Q56 The stroke survivor should take the blame and responsibility for their rude and blunt behaviour due to problems with their thinking skills **YES/NO**

Personal impact

Difficulties with thinking and cognition can be very frustrating and embarrassing for stroke survivors.

They avoid 'showing themselves up' because they can't remember the thread of a conversation, or because they have drifted off half way through.

People will often try to hide the fact they are struggling with memory, attention or doing a series of tasks involved in a supposedly everyday activity.

These problems can lead those who are affected to lose confidence, withdraw socially and become anxious or low in mood.

Low mood and anxiety can then make the thinking, learning and mental processing problems worse, which then can create a vicious cycle.



Thinking difficulties in a stroke survivor may be interpreted as a lack of willingness.

But the person who has had a stroke may be unable to contribute because they:

- Have not fully understood the question
- Have problems with apathy
- Can no longer able to generate ideas
- Are not able to think logically like they did before the stroke

A lot more patience, support and guidance is needed to help them make improvements following their stroke.

Helpful approaches

The most successful approach is a very structured one

- Keep everything simple
- Give clear messages
- Avoid overloading and don't do too much at once
- Break down information into small steps
- Write things down
- Keep the level of background noise to a minimum
- Give plenty of time to practise
- Involve family and friends as back up
- Allow frequent breaks
- Show understanding and interest
- Giving them things to do



Which of the following is true of the personal impact of cognitive difficulties after a stroke?

- Q57 They can lead to frustration, embarrassment and low self confidence **YES/NO**
- Q58 People are generally very open and honest about their cognitive difficulties after stroke **YES/NO**
- Q59 Professionals working with stroke survivors could misinterpret cognitive difficulties as a lack of willingness **YES/NO**
- Q60 Cognitive difficulties have no impact on mood **YES/NO**

Which of the following are helpful in working with someone with cognitive difficulties?

- Q61 Extra support and guidance should not be needed **YES/NO**
- Q62 Giving them to do things won't help **YES/NO**
- Q63 Try not to mention the cognitive difficulties **YES/NO**
- Q64 Keep instructions simple and straightforward **YES/NO**
- Q65 Show interest and reinforce any progress **YES/NO**

Spatial neglect

When a stroke survivor has spatial neglect, (sometimes called inattention), it means that they cannot 'take in' information coming from one side of their body or one side of the space around them. This is not because they have a problem with their eyesight.

Someone with spatial neglect may not be aware of things on that side of their body, almost always the left. That space is literally non-existent for them.

- The person with this problem may walk down a corridor colliding with objects and furniture to their left because they do not register anything on that side of them
- They may be completely unaware of people approaching from their left
- They may only shave or apply make-up to the right side of their face

Drink or food placed on the left side of someone with spatial neglect, may well be ignored simply because the individual has absolutely no knowledge that it is there, no matter how hungry or thirsty they are.

Those affected usually do not realise they have this problem.

They need to be taught how to compensate for this lack of awareness by drawing attention to the affected side.

For example encouraging the individual to repeatedly look to the left when washing, dressing and walking about.

Tommy has spatial neglect and he explains how he copes in the next clip.



Spatial neglect can continue long term.

Those involved in looking after those who have this problem must be aware and continue to encourage them to deliberately look to their affected side.

Drinks, food and medication must be put on their right side where they will be aware of it.

Try to make sure that when someone is saying something important they are on the stroke survivor's right side.

Which of the following is true of spatial neglect?

- Q66 The person has problems with their eyesight **YES/NO**
- Q67 The person may not realise they have the condition **YES/NO**
- Q68 It involves not processing or registering information about the space all around the body **YES/NO**
- Q69 It affects one side, usually the left side **YES/NO**

Which of the following is helpful in managing spatial neglect?

- Q70 The problem will improve without any help **YES/NO**
- Q71 Repeatedly drawing the person's attention to their neglected side helps **YES/NO**
- Q72 Teaching people to be aware of their neglected side during self care activities doesn't make a difference **YES/NO**
- Q73 Food or drinks and medicine should be placed on the neglected side **YES/NO**

Once you have answered ALL questions in Modules one and two correctly you may go to the following website to print a certificate: www.gmhcc.org.uk/projects/view/stroke

ON 67Q	SEA 65Q	SEA 54Q	ON 22Q	ON 11Q
SEA 72Q	ON 85Q	ON 44Q	SEA 12Q	SEA 10Q
SEA 17Q	SEA 45Q	ON 64Q	ON 61Q	ON 8Q
ON 07Q	ON 95Q	SEA 24Q	SEA 81Q	SEA 7Q
SEA 69Q	ON 55Q	ON 14Q	ON 28Q	ON 9Q
ON 89Q	SEA 55Q	SEA 04Q	SEA 91Q	SEA 5Q
SEA 76Q	ON 35Q	ON 63Q	ON 26Q	ON 15Q
ON 96Q	SEA 25Q	SEA 83Q	ON 14Q	ON 14Q
SEA 56Q	SEA 15Q	ON 63Q	SEA 25Q	ON 24Q
SEA 46Q	ON 05Q	SEA 93Q	ON 27Q	SEA 13Q
ON 63Q	SEA 49Q	ON 33Q	ON 15Q	ON 12Q
ON 26Q	ON 48Q	SEA 43Q	SEA 25Q	ON 3Q
ON 19Q	SEA 47Q	ON 33Q	ON 24Q	ON 2Q
ON 09Q	SEA 94Q	SEA 23Q	ON 27Q	SEA 1Q

