Psychological effects of stroke



STROKE HELPLINE 0845 3033 100

Stroke can cause many different effects. Most people recognise there can be physical effects such as weakness or speech problems, but stroke can also cause psychological changes. These changes can be expressed in the way people feel or think about things, or in the way they behave. This factsheet explains the different psychological effects that can happen after stroke and the help that is available.

What causes psychological changes?

The emotional, psychological and behavioural changes that take place following a stroke are, in part, caused by physical damage to the brain. When brain cells are damaged, the sensations and parts of the body controlled by these cells no longer function properly.

Each stroke is different and, to a large extent, the psychological problems that someone may experience will **vary** depending on the **part of the brain** affected and the **extent** of the damage. For example, **impulsive behaviour** is associated with damage to the **right half** of the brain, while **tearfulness** and outbursts of **anger** are more common in those with damage to the **left half** of the brain.

Apart from the psychological effects caused by damage to the brain, having a **serious illness** such as a stroke, being in **hospital**, or facing up to the reality of having to live with any **lasting disabilities** can affect emotional health. Someone may feel **anxious** or **depressed**, be **frustrated**, **angry** or **bewildered**. All these feelings are **common** and, although they **usually fade with time**, they may persist in some people.

The most common psychological changes that can happen after stroke are: **depression; apathy; emotional lability;** and **personality changes**.

Depression

Depression is extremely common in people who have had a stroke – it is probably the **most common psychological effect** after stroke. In fact, it is estimated that around **half** of those who survive a stroke **suffer significant depression** within the first year.

Depression after stroke can affect anyone regardless of their age, sex, background, or the severity of their stroke. It can develop immediately after the stroke happens, or weeks or months later. Many people are not routinely assessed for depression after stroke, and only a minority are properly diagnosed and treated. Being assessed and receiving the right help is crucial as managing depression can really make a difference.



FACTSHEET 10

What causes depression?

Having a **stroke** can be a **frightening** experience. Stroke happens very **suddenly** and it can take some time to come to terms with the **shock** of what has happened. Many people feel **frightened**, **anxious**, **frustrated** or **angry** about what has happened to them. These feelings are **normal** and usually **fade** over time, but in some people they develop into **depression**.

Depression often sets in once the initial period of recovery is over, and the person becomes aware of how their lasting disability may affect their everyday life. The person who has had a stroke may have to come to terms with the loss of many of their hopes and plans for the future, as well as having to adapt to a changed role in the family, and possibly the loss of a career.

As many of us value ourselves through everyday activities, the impact of a stroke can result in **loss of confidence** and lowered feelings of **self-worth**. Sometimes the stroke directly **damages** the part of the brain which generates and **controls how we think**, **feel** and **behave**. It may also be the result of the emotional impact of suffering a **serious illness**.

There can also be underlying **physical causes** for the depression. For example, **chronic pain** affects many people after a stroke and is a common cause of depression. Being **isolated** can cause **low mood**, so **having somebody to talk to** is important in reducing the likelihood of depression.

What are the symptoms of depression?

There are a number of symptoms of depression to be aware of. The **most common** include:

- Feeling **sad**, blue or down in the dumps
- A loss of interest in every day activities
- Feelings of worthlessness, hopelessness or despair
- Inability to concentrate or difficulty making decisions
- Anxiety or worry
- Changes in **sleeping** pattern or appetite
- Loss of energy
- Suicidal feelings
- Low self esteem.

Depression after stroke can **range** from **mild** to **severe**, and last for anything from a **few months** to **more than a year**. The most obvious symptom is **low mood**, although occasionally symptoms such as **anxiety** or **irritability** are prominent. Sometimes the emotional symptom is better described as a sort of **flatness** or **inability to feel pleasure**.

Depression can also cause **changes in thinking**, such as trouble concentrating or memory difficulties. Sometimes this negative thinking becomes severe, and the person may develop feelings of **guilt** or **suicidal thoughts**.

What are the treatments for depression?

If you are **concerned** that you or someone you know is depressed, **do not be afraid to talk about it** and **mention** any **symptoms** to the **doctor**. **Depression** is **best treated** when it is **diagnosed** and **treated early**. The **most effective** treatment is **psychological intervention** or counselling, combined, if appropriate, with **antidepressant medication**. There are also a number of things you can do yourself to help ease depression. See the **Help available** section at the end of this factsheet for details.

Apathy

What is apathy?

Apathy is a lack of motivation or enthusiasm. Someone with apathy may appear listless, passive, lacking spontaneity and motivation, and may not show the variety of expression that they usually display. They are often indifferent to everyday occurrences and unmoved by emotional events that would normally arouse strong feelings. Often there is a loss of interest in things going on around them, such as socialising or previous hobbies.

This can be **difficult** for friends and family who may become **confused** or **frustrated**. The carer or partner may feel **hurt** or **neglected**, as the person with apathy may show less interest in them. This can be particularly frustrating if the individual was **previously active**. People with apathy need **support and encouragement**, and it may be helpful knowing that apathy is **not** the individual **'giving up'** but more often is the result of **damage to the brain**.

What causes apathy?

Post-stroke apathy, like all mood changes after strokes, is caused by a **combination of psychological, biological** and **other factors**. In general, apathy is the result of either **post-stroke depression** or is a symptom of **changes in the brain**.

Many people experience **depression** after stroke and may develop **emotional symptoms**, such as **sadness** or **hopelessness**, and **physical symptoms**, such as **lethargy** or **insomnia**. They may not be confident of their abilities and be unable to feel pleasure. Not surprisingly, they may become **apathetic** and uninterested in mundane concerns or unwilling to initiate actions.

Secondly, post-stroke apathy can be unrelated to depressive episodes, but due to brain changes in critical structures that regulate emotional reactivity. Certain areas of the brain are involved in emotional control. A stroke in those brain areas can produce an emotional disorder.

The **frontal area** is important for such emotional experiences as **energy**, **enthusiasm, productivity**, and **initiative**. A stroke in this area may produce an apathetic state in the way described. Damage in the frontal lobes could be a biological cause of apathy.

Managing apathy

Many people with apathy will take part in tasks and activities as long as they are **prompted** and **encouraged** to do so. This can put additional strain onto carers and therefore if you are caring for someone with apathy, it is important you have support for yourself as well. You may find that joining and attending a **stroke club** together is helpful. Meeting other people in a **similar situation** can be beneficial.

As with many of the after effects of stroke, feelings of apathy often begin to disappear with time. This can be through the **recovery process** or as the depression begins to lift. If however the apathy is linked to depression and shows no sign of lifting, then **antidepressant drugs** and **counselling** may help.

Emotional lability

What is emotional lability?

Emotional lability is the term used when someone is more emotional and/or has difficulty controlling their emotions. It can happen with many neurological conditions and often happens after a stroke. Some people describe the feeling as though all their emotions are "much nearer the surface" or stronger after their stroke. For example some people may become upset more easily, or cry at things they would not have cried at before their stroke. Their emotional response is in line with their feelings, but is much greater than before the stroke. For other people the symptoms can be more **exaggerated**, and some people find that they cry for little or no reason. Less commonly, people **laugh** rather than **cry**, but again the emotion is **out of place** and does not match how they are feeling at the time.

These emotions usually come and go very **quickly**, unlike when someone feels upset and is crying. Some people may even **swing** from **crying to laughing**. Although the individual realises that their crying or laughter doesn't fit the situation, they **cannot control** it and this can be very **upsetting**.

These episodes of crying can often be **misinterpreted** as **depression**. Sometimes people with emotional lability have **depression as well**, but crying because of emotional lability is not necessarily a sign of depression. If there are doubts about whether or not the individual has depression, a **mental health professional** might be able to help by assessing and advising on treatments.

What causes emotional lability?

Emotional lability is caused by the **damage** done by the **stroke**. Frequently, difficulties with **swallowing and tongue movements** coincide with **emotional lability**. If this is the case, a **speech and language therapist** may help to accurately identify emotional lability.

The exact process by which emotional lability occurs is **not fully understood** but it is thought that damage to the **cortex** in the brain is responsible. Crying is a reflex that we can normally control, but it can become uncontrollable when the cortex is damaged. Consequently the crying reflex can be caused even when the person does not have normal triggers that would usually make them cry (in a similar way that your leg jerks when the doctor uses a hammer to hit your knee to check your reflexes).

What can be done to help?

Emotional lability is often **distressing** and **embarrassing** for the individual and their friends and family. Understanding that the exaggerated (and often uncontrollable) emotional reaction is **due to the stroke**, may help others to accept and adjust to the differences in behaviour.

Emotional lability is often worse **soon after the stroke happens**, but usually **lessens or goes away with time** as the person recovers. If this doesn't happen, the **GP** may be able to help. Some **medications** that are also used to treat depression can help with the **control of emotions** even if the person is not depressed.

Tips for helping someone with emotional lability

Ask the person affected how they would like to be treated when they have an episode of crying. **Some ideas** are:

 Remember being so emotional often causes people to feel upset or embarrassed. Don't tell the person not to cry, this will not help.

- Distraction by changing the subject of conversation, or trying some deep breathing can help some people.
- Some people find it harder to control their emotions when other people are very emotional around them, so it may help to be aware of this.
- **Don't ignore the person**, or leave, unless they say that is what they want.
- Treat it like a **minor inconvenience** and continue the conversation as if it will go away. It usually does.
- Touch can be helpful a touch on the arm or hand or a hug as is appropriate to the relationship. This may increase the crying, but that may be preferred. It's OK to cry, and sometimes it helps people to feel better.
- With genuine crying, or crying full of emotion, **empathy** and **understanding** are usually helpful.

Personality changes

Strokes can cause changes in someone's **behaviour or personality**. They may become **impatient** and **irritable** or **withdrawn** and **introspective**. Sometimes **previous character traits can be reversed**, with a mild-mannered person becoming aggressive, a difficult person becoming more passive, or a once sociable and lively person becoming less sociable and withdrawn. **More commonly**, however, **existing traits are exaggerated**.

Managing personality changes

Family and friends of stroke survivors who are affected in this way often find changes to behaviour and personality **hard to deal with**. People can be **upset** by the things their relative says to them and may find them very **difficult to live with** or to be around.

This is especially true if the stroke survivor becomes **aggressive**. If your partner, friend or family member becomes aggressive (in a way that you find threatening), it is important to remember that, despite the stroke, it can be quite **frightening**. If you find yourself in this situation, then there are **organisations that can help**. These are listed at the end of this factsheet.

Some people find that the **challenging behaviour** is aimed only at **them** and that the person affected by the stroke is **reasonable with other people**. This is really quite **consistent** with **people's behaviour generally**. Most of us are more able to get cross with the people we are actually closest to, as we feel safe in the knowledge that they will probably forgive us and still want to see us.

Some stroke survivors seem **unable to recognise** or understand that their **behaviour or personality has altered**, and feel that there is nothing wrong with them so they have no reason to try and change. This kind of situation is **harder to manage** so it is important to try and get **support** from other members of your family as well. You may also find it helpful to avoid confrontational situations and to **walk away** if a situation is becoming too difficult to manage. Helping the stroke survivor **become aware** of their **actions** and the **effect** it is having on you may help them change their behaviour. It may be that **relationship counselling** can offer support to both of you. The Stroke Association's **Family and Carer Support Co-ordinators** (formerly Family Support Organisers) also support families affected by stroke. Joining a **stroke club** may also help as socialising with other people who have experienced strokes may be beneficial in gaining a deeper understanding of strokes, for you and your partner. See the **Useful organisations** section at the end of this factsheet for more information.

Everybody needs to find their own way of coping with these changes and **often things take time**. As the brain goes through the **healing process**, the changes that have occurred may begin to feel **more manageable** for all concerned.

Help available

Sorting out the **psychological changes** that may occur after a stroke can be **complicated**. Not only can some people suffer a **range** of problems, but it may be difficult to pin down the **exact cause** of a specific problem. If you or your family or carer notice **changes** that are affecting you, **discuss this with your doctor**. Ask to have a **proper examination** so that any **underlying causes** can be correctly **diagnosed and treated**, if possible. It may be that professionals such as **psychologists** and **psychiatrists** can help you find **appropriate solutions** or **coping strategies**. It is important that you are helped to find some way to make your future life as **meaningful** and **fulfilled** as possible. Keeping up your **morale** is a crucial aspect of your psychological well-being. Those around you can contribute greatly to this. They should ensure that they **understand** the reasons for any **changes in your behaviour** or **emotions after a stroke**, so they can **make sense** of what has happened and help as much as possible.

It may help you to **talk to others** who have had similar experiences to yours, for instance in a **stroke club** or **self-help group**. By **sharing your feelings**, and **listening to theirs**, you may be able to help them – as well as yourself.

Counselling

Acknowledging what has happened, and accepting how life has changed is an important step in the recovery process and talking treatments can help with this.

Psychological and counselling services aim to encourage you to talk about your thoughts and feelings and help you to come to terms with what has happened to you. With the guidance of your psychologist or counsellor, you will have the opportunity to look at how the stroke has affected your life and discover ways of moving forward. Having the space to talk things through at your own pace can be very helpful. You will gain a clearer picture of what lies ahead and help you feel more in control of life by working out and trying to find solutions to problems. Many people benefit from talking through their difficulties, but if your stroke has left you with **problems communicating** or **understanding** others, it may not be the best option, or you may require the **specialist skills** of a speech and language therapist.

Your **GP** may be able to refer you to a local **NHS psychology or counselling service**. Often GPs have a counsellor as part of their practice. There are also **community adult mental health**, and **older adult mental health teams** to which you can be referred. However, these services may not be available in all areas, and there may be a **waiting list**.

Therapy is also available **privately** (the cost varies between therapists but can be quite expensive). There may also be **local organisations** which offer counselling, sometimes at a reduced cost, so it is worth checking in your **telephone directory** or at your local **library** for more local contacts.

Medication

Antidepressant medication is usually prescribed to treat depression but is occasionally used if someone has **apathy** or **emotional lability**. It works by acting on the **chemicals** in the brain. Many antidepressants are very effective and about **two thirds** of people who take them **benefit**. As antidepressants take at least **two weeks** to work properly, it is worth **persevering** with them, even if you do not feel better immediately. However, as with any medication, there can be **side effects**, such as fatigue or a dry mouth, so you may need to try **more than one type** of antidepressant before you find one that is effective.

Helping yourself

There are also **many things you can do yourself** to improve your psychological well-being. Not all of these suggestions will suit everyone, but most people find at least one or two helpful.

- Keep informed: A lack of knowledge about stroke can lead to uncertainty, and misunderstandings can arise that can add to worries. Having information about stroke can be reassuring and if there is something you are not sure about, or you do not understand, don't be afraid to ask your doctor or carer to explain. The Stroke Association can also help with information about stroke and its effects.
- Social contact: Meeting people regularly, every day if possible, is an important source of well-being. **Talking to others** can be a big help. If you are able to, keep talking to family and friends, and try not to push people away or assume you are a burden.
- Support groups: Many people find support groups useful. They provide a chance to **meet people** who have been through a **similar experience**, and many arrange social activities. Stroke clubs are support groups for people affected by stroke. Contact us for details of a group near you.
- Hobbies and interests: Returning to hobbies and interests is an important part of the **rehabilitation** process after stroke. You could even look at trying new things. Try not to be put off by thoughts that you

are unable to do things as well as you could before the stroke. Many activities can be **adapted** to enable you to carry on enjoying them.

- **Exercise:** Recent research shows that exercise is very **beneficial** in treating and preventing depression. Doing any physical activity regularly, however gentle, can help.
- Healthy diet: People who are depressed often lose their appetite, and a poor diet can make you feel tired and run down. Try to eat **regular meals** with fresh fruit and vegetables every day.
- There are many self-help books available with further information on living with conditions such as stroke, and depression. They are available from most bookshops and libraries.

Useful organisations

The Stroke Association provides information about stroke and its effects, and has details of support groups and our Family and Carer Support Service (formerly known as Family Support Service). You can call our Helpline on 0845 3033 100 or email us at info@stroke.org.uk

British Association for Counselling and Psychotherapy (BACP)

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB Tel: 01455 883 316 Email: bacp@bacp.co.uk Website: www.bacp.co.uk Publish the Counselling & Psychotherapy Resources Directory. This lists organisations, counsellors and psychotherapists in the UK. Some counsellors operate a sliding scale of charges according to income.

British Psychological Society (BPS)

St Andrews House, 48 Princess Road East, Leicester LE1 7DR Tel: 0116 254 9568 Fax: 0116 227 1314 Email: enquiry@bps.org.uk Website: www.bps.org.uk Holds lists of counselling psychologists.

Carers UK

20 Great Dover Street, London, SE1 4LX Carersline: 0808 808 7777 (open Wed & Thur 10–12pm & 2–4pm) Email: info@carersuk.org Website: www.carersuk.org Provides information and support to carers.

CONNECT

16–18 Marshalsea Road. London SE1 1HL Tel: 020 7367 0840 Email: info@ukconnect.org Website: www.ukconnect.org Has counsellors with personal experience of aphasia who are trained to help counsel people with communication problems.

Cruse Bereavement Care

PO Box 800, Richmond, Surrey TW9 1RG Tel: 0844 477 9400 Email: helpline@cruse.org.uk Website: www.cruse.org.uk Provides support, information and advice to anyone who has been bereaved.

Depression Alliance

212 Spitfire Studios, 63–71 Collier St, London N1 9BE Tel (to request an information pack): 0845 123 2320 Email: information@depressionalliance.org Website: www.depressionalliance.org Has publications and information and also coordinates a national network of self-help groups.

Different Strokes

9 Canon Harnett Court, Wolverton Mill, Milton Keynes MK12 5NF Tel: 0845 130 7172 Fax: 01908 313 501 Email: info@differentstrokes.co.uk Website: www.differentstrokes.co.uk A charity for younger people affected by stroke. They are developing a national referrals network of professionally qualified counsellors.

Medical Advisory Service

PO Box 3087, London W4 4ZP Tel: 020 8994 9874 (Mon–Sun 6pm–8pm) Email: info@medicaladvisoryservice.org.uk Website: www.medicaladvisoryservice.org.uk A registered charity you can contact regarding medical problems. Gives information and advice on health services, charities, self-help groups and general counselling.

MIND

15–19 Broadway, London E15 4BQ Tel: 0845 766 0163 (Mon-Fri 9am-5pm) Email: info@mind.org.uk Website: www.mind.org.uk Mind is a national mental health charity offering a range of publications and information on local services and support groups.

Anxiety UK

Zion Community Resource Centre, 339 Stretford Road Hulme, Manchester M15 4ZY Tel: 08444 775 774 (Mon – Fri 9.30am – 5.30pm) Email: info@anxietyuk.org.uk Website: www.anxietyuk.org.uk A national charity for people suffering from anxiety disorders. Provides counselling services, email support and details of self-help groups.

RELATE

Premier House, Carolina Court, Lakeside, Doncaster, DN4 5RA Tel: 0300 100 1234 Email: enquiries@relate.org.uk Website: www.relate.org.uk Relate has local branches and provides counselling for couples and individuals with relationship problems.

Womens Aid

Head Office, PO Box 391, Bristol BS99 7WS Tel: 0808 2000 247 (Freephone 24 Hour National Domestic Violence Helpline run in partnership between

For further information, phone the Stroke Helpline on 0845 3033 100, email info@stroke.org.uk or visit our website www.stroke.org.uk If you are unhappy about any aspect of The Stroke Association, please make your views known to us immediately. We will happily discuss any issues and how they can best be resolved.



CUSTOMER SERVICE EXCELLENCE

Women's Aid and Refuge) Email: helpline@womensaid.org.uk Website: www.womensaid.org.uk Information and support for women experiencing domestic abuse or friends/relatives/professionals seeking information on their behalf.