

Care after stroke in childhood

Information for parents
and families of children
affected by stroke

*Based on Stroke in childhood: clinical
guidelines for diagnosis, management
and rehabilitation*



Royal College
of Physicians



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Who is this booklet for and what does it cover?

This booklet is for parents and families of children who have had a stroke. It is designed to help you understand why children have strokes and how children affected by stroke should be treated and cared for. It will not answer all your questions but it will help you understand what a stroke is, some of the effects of stroke and its treatments, and where to go for more information and advice. The information given here is based on detailed clinical guidelines produced for health professionals which are available from the Royal College of Physicians (see back cover), and on their website at www.rcplondon.ac.uk/pubs/books/stroke

What is a stroke?

A stroke is a sudden disruption to the blood supply to the brain. It affects neurological functions – that is, functions that are controlled by the brain; for example, movement and speech.

There are two major types of stroke:

- ▶ ischaemic – this is caused by a blockage of the blood supply to an area of the brain
- ▶ haemorrhagic – this is caused by blood leaking from blood vessels into the brain.

Both types of stroke cause damage to brain cells. The resulting difficulties experienced by the child depend on which area of the brain is affected.

When a stroke happens, some brain cells are damaged and others die. Brain cells that have died cannot start working again. However, those just outside the area of the dead cells may recover as the swelling caused by the stroke goes down. Recovery can also occur as other parts of the brain take over from areas that have died. Stroke may affect children in different ways, and some of these changes may be longer lasting than others. These changes may vary as the child grows and develops.

What are the signs that a child has had a stroke?

As with adults, the most common effect of stroke in a child is weakness of one side of the body (hemiplegia). A child's face may droop on one side and their speech may be affected. Some strokes affect areas of the brain responsible for balance and coordination. Some children may complain of a headache and others may have fits at the time of the stroke. Signs of a stroke may be difficult to recognise in a young child, depending on the child's age and stage of development.

Are strokes common in children?

In the UK, about five out of every 100,000 children per year have a stroke (a total of several hundred). Ischaemic and haemorrhagic strokes are equally common.

What causes stroke in children?

The causes of ischaemic stroke in children are not the same as in adults. With adults, strokes are often brought on by smoking, high blood pressure or 'furring up' of the arteries. In contrast, there are many possible causes of stroke in children; for example, sickle cell disease or heart problems.

It is common to find narrowing of blood vessels which carry blood to the brain. The cause of this narrowing, despite tests, is often not found; rarely, it may be associated with previous chickenpox infection. In around 10% of children who have a stroke, no cause is identified despite extensive tests. The causes of strokes in children and adults are very different and so the fact that an older member of the family might have had a stroke is usually not relevant.

Haemorrhagic stroke is most commonly due to bleeding from abnormal blood vessels in the brain. There are also other possible causes such as blood-clotting problems.

How is healthcare organised for children affected by stroke?

Most children will be admitted to hospital for initial care and assessment.

A number of tests may be carried out, as finding the cause of the stroke will help the planning of your child's medical treatment. Medical, nursing and therapy assessments will also be made to help plan your child's care.

Immediately after the stroke, your child's healthcare may be provided in your local hospital or at a specialist centre. A consultant paediatric neurologist should be involved in or consulted about your child's care. In the longer term, community child health services should coordinate services according to your child's needs. This may involve health, education and social services and include doctors, nurses, therapists, teachers, social workers and many other professionals.

Investigations and medical treatment

Tests

Depending on your child's needs, the following tests may be done.

▶ *Brain scans*

Magnetic resonance imaging (MRI) or computed tomography (CT) scans will be carried out to identify the area of the brain affected and to examine the blood vessels in the brain. Depending on their age or how well they are, some children may need to be sedated or have a general anaesthetic for this.

▶ *Blood tests*

Blood tests may be carried out to check for any chemical problems, infection or blood-clotting problems, which may have caused the stroke.

▶ *Echocardiogram (ECHO)*

This is an ultrasound scan which looks at the structure of the heart. It is done to check whether a clot travelling from the heart to the brain has caused the stroke. The scanning, which is painless, is usually done by placing a small probe/instrument on the child's chest.

Medical treatment

This will depend on the factors that caused the stroke in the individual child. Drugs that make the blood thinner and therefore less likely to clot (such as aspirin, heparin or warfarin) may be considered for children who have had an ischaemic stroke.

Rehabilitation

Rehabilitation following stroke should begin immediately. In the first few days, assessment of movement and positioning, swallowing, speech and communication may take place. These assessments may involve a number of different health professionals, and they will inform the community health team in your local area so that care can continue once your child goes home. As parents, you should be involved in all these processes and express your concerns.

In the longer term, rehabilitation may take place in a hospital or rehabilitation unit, or at home with community therapy input. Areas to be considered may include:

- ▶ improving abilities affected by the stroke; for example, movement or speech
- ▶ finding ways of adapting to changes in ability
- ▶ developing skills in daily activities such as self-care, leisure, school and play
- ▶ social, emotional and practical support following discharge from hospital.

The exact nature of your child's rehabilitation will vary according to their needs, which should be assessed to see which treatments and therapies are needed to bring about as good a recovery as possible.

Returning to school full-time following a stroke will be a major milestone for your child and needs to be carefully planned. A gradual return may be advisable. Keeping in touch with friends during the recovery period can assist your child in settling back into school. The Local Education Authority (LEA) is responsible for planning your child's return, and you should be a part of this process.

Will the stroke happen again?

This very much depends on the underlying cause of the stroke. Some children, such as those with sickle cell disease, are at relatively higher risk than others. It is difficult to be specific without considering each individual separately. Your child's doctors will be able to discuss this with you.

How can another stroke be prevented?

Various treatments are available to try to reduce the chances of further stroke. In children with sickle cell disease, regular blood transfusions are used. In other children with ischaemic stroke, long-term blood-thinning medication (eg aspirin or warfarin) is recommended. In children with a rare condition called moyamoya, surgery is sometimes possible to try to improve the blood flow to the brain. Recommendations will be made according to your child's individual needs.

Useful organisations

Organisations which may be helpful in offering support and advice to children and families affected by stroke are listed below.

Acquire

Helps children, young people and adults who have an acquired brain injury and face difficulties in learning as a result.

Manor Farm House, Wendlebury, Bicester, Oxfordshire OX25 2PW.

Tel: 01869 324339. Fax: 01869 234683.

Email: info@acquire.org.uk

Website: www.acquire.org.uk

Afasic

Represents children and young adults with communication impairments, works for their inclusion in society and supports their parents and carers.

2nd Floor, 50–52 Great Sutton Street, London EC1V 0DJ.

Helpline: 0845 355 5577. Fax: 020 7251 2834.

Email: info@afasic.org.uk

Website: www.afasic.org.uk

Chest, Heart & Stroke Scotland

Provides advice and support for people in Scotland affected by chest, heart and stroke conditions.

65 North Castle St, Edinburgh EH2 3LT.

Advice line: 0845 077 6000. Fax: 0131 220 6313.

Email: advice@chss.org.uk

Website: www.chss.org.uk

Children's Brain Injury Trust

Aims to improve the quality of life for all children who have an acquired brain injury (ABI) and to enable them to achieve their full potential.

Child Brain Injury Trust, The Radcliffe Infirmary, Woodstock Road,
Oxford OX2 6HE.

Helpline: 0845 601 4939. Tel: 01865 552 467.

Email: helpline@cbituk.org

Website: www.cbituk.org/

Children's Hemiplegia and Stroke Association

Offers support and information for families of children who have hemiplegia, hemiparesis and/or stroke. Based in the USA.

CHASA Foundation, Suite 305, PMB 149, 4101 West Green Oaks,
Arlington TX 76016, USA.

Email: info437@chasa.org

Website: www.chasa.org

Contact a Family

Provides information for families of children with disabilities and/or rare syndromes.

209–211 City Road, London EC1V 1JN.

Tel: 020 7608 8700. Fax: 020 7608 8701.

Freephone: 0808 808 3555.

Email: info@cafamily.org.uk

Website: www.cafamily.org.uk

Department for Education and Skills

Provides advice for parents and teachers of children with special educational needs.

Website: www.dfes.gov.uk/sen

Department for Work and Pensions

Provides information on a range of benefits and services for families.

Public Enquiry Office Tel: 020 7712 2171. Fax: 020 7712 2386.

Website: www.dwp.gov.uk/lifeevent/famchild/index.asp

Different Strokes

For younger people who have had a stroke, mainly young adults. Includes information on access to leisure activities, counselling services, benefits and rights information, and information packs.

Information Officer, Different Strokes, 9 Canon Harnett Court, Wolverton Mill, Milton Keynes MK12 5NF.

Helpline: 0845 130 7172. Fax: 01908 313501.

Email: info@differentstrokes.co.uk

Website: www.differentstrokes.co.uk

Disability Alliance

Provides information and advice to disabled people and their families about entitlement to social security benefits and services. Publications include the *Disability rights handbook*.

Universal House, 88–94 Wentworth St, London E1 7SA.

Tel: 020 7247 8776. Fax: 020 7247 8765.

Website: www.disabilityalliance.org

HemiHelp

Provides information and support for children with hemiplegia and their families.

Unit 1, Wellington Works, Wellington Road, London SW19 8EQ.

Helpline: 0845 123 2372. Fax: 0845 120 3723.

Email: support@hemihelp.org.uk

Website: www.hemihelp.org.uk

Independent Panel for Special Education Advice (IPSEA)

Gives free independent advice on education issues, including appealing to Special Educational Needs Tribunals.

6 Carlow Mews, Woodbridge, Suffolk IP12 1EA.

Tel: 01394 380 518. Freephone: England & Wales: 0800 018 4016;

Scotland: 0131 665 4396.

Website: www.ipsea.org.uk

The Stroke Association

Provides information and support for people who have had a stroke and their families. Produces wide range of publications, supports research and health education. Provides a national Stroke Information Service and helpline.

240 City Rd, London EC1V 2PR.

Helpline: 0845 3033 100 (local rate within UK). Fax: 020 7490 2686.

Email: info@stroke.org.uk

Website: www.stroke.org.uk

Sickle Cell Society

Provides information, counselling and caring for those with sickle cell disorders and their families.

54 Station Road, Harlesden, London NW10 4UA.

Tel: 020 8961 7795. Fax: 020 8961 8346.

Email: sickleinfo.line@btinternet.com.

Website: www.sicklecellsociety.org

Front cover

The cover photograph, of a young boy who suffered a stroke at 15 months but who has made an almost complete recovery, is used by kind permission of Derek and Jane Walker and Different Strokes (see page 13).

The information contained in this booklet was compiled by the Paediatric Stroke Working Group.

Parents and families requiring further copies of this booklet should contact The Stroke Association on 0845 3033 100, or write to:

The Stroke Association, 240 City Rd, London EC1V 2PR.
Email: info@stroke.org.uk

It is also available on the Royal College of Physicians website at
www.rcplondon.ac.uk/pubs/books/stroke/

Physicians and others who wish to purchase copies of the full clinical guideline, *Stroke in childhood: clinical guidelines for diagnosis, management and rehabilitation*, should contact the Publications Department at the Royal College of Physicians.

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