Ring the Different Strokes helpline on 0845 130 7172 for any further information. It’s available most weekdays between 9am and 5pm and is staffed by people who have personal experience of stroke.

9 Canon Harnett Court, Wolverton Mill, Milton Keynes MK12 5NF
Tel: 0845 130 7172   Fax: 01908 313501
Email: info@differentstrokes.co.uk
Website: www.differentstrokes.co.uk
Who is this booklet for and what does it cover?

This booklet is for parents, carers 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 will help you understand what stroke is, some of the effects of stroke, treatments, and where to go for more information and advice. The information is based on detailed clinical guidelines produced for health professionals which are available from The Royal College of Physicians, and also at their website: www.rcplondon.ac.uk.

What is a stroke?

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, such as a clot, 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 occurs, some brain cells are damaged and others die. Brain cells which die 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 died. Stroke affects different 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 his/her speech may be affected. Some strokes affect areas of the brain responsible for balance and co-ordination. Some children may complain of a headache and others may have fits at the time of the stroke. Some might experience problems seeing clearly. Depending on the child’s age and stage of development, signs of a stroke may be difficult to recognise, especially in a young child.

The signs that somebody may have had a stroke are:

- Sudden weakness or numbness of the face, arm, or leg on one side of the body
- Sudden dimness or loss of vision, particularly in one eye
- Loss of speech, or trouble talking or understanding speech
- Sudden, severe headaches with no known cause
- Unexplained dizziness, unsteadiness or sudden falls especially along with any of the previous symptoms

Are strokes common in children?

Strokes in children are very rare. In the United Kingdom about 5 out of every 100,000 children each year have a stroke\(^2\) (a total of several hundred). Both ischaemic and haemorrhagic strokes are equally common.

What causes stroke in children?

The clinical guidelines produced for professionals mainly deal with ischaemic stroke (clots). So this information concentrates on ischaemic stroke.

The causes of ischaemic stroke in children are not the same as in adults. Adult strokes may be brought on by high blood pressure or “furring” of the arteries. Smoking, excessive alcohol consumption and being overweight are lifestyle risk factors for stroke that affect adults rather than children. In contrast, there are many possible causes of stroke in children for example, sickle cell disease or heart problems.

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It is common to find narrowing of the blood vessels which carry blood to the brain in a child who has had a stroke. Despite tests the cause of this narrowing often is not found. In rare cases, 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 has had a stroke is usually not relevant.

Haemorrhagic stroke (bleeding) is most commonly due to bleeding from abnormal blood vessels in the brain. There are also other possible causes such as problems that cause the blood to fail to clot properly.

**Investigations**

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 its blood vessels. This involves the child lying very still for up to an hour – so, 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 are 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.

The Brain & Spine Foundation produces a range of factsheets about the different types of investigations and tests on its website: [http://www.brainandspine.org](http://www.brainandspine.org). It also has a medical helpline number: 0808 808 1000. This service is staffed by neuroscience nurses and other healthcare professionals.
How is health care organised for children affected by stroke?

Most children will be admitted to hospital for initial care and assessment. The length of hospital stay can vary greatly and depends on individual medical needs. A number of tests may be carried out, as finding the cause of the stroke will help doctors plan 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 health care may be provided in your local hospital or at a specialist centre. A consultant paediatric neurologist will probably be involved in or consulted about your child’s care. In the longer term, Community Child Health Services may coordinate services according to your child’s needs. This may involve health, education and social services and include doctors, nurses, therapists, teachers, social worker and many other professionals.

### Medical Treatment

This will depend on the factors which have 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.

### Rehabilitation

Rehabilitation should begin immediately. In the first few days your child’s movement and positioning, swallowing, speech and communication will be assessed. 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 this process and express any concerns you have.

In the longer term rehabilitation may take place in a hospital or specialised rehabilitation unit, or at home with a community therapist. 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
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. Rehabilitation services may vary around the country. See the NHS Choices website for information about treatments and local services in your area: http://www.nhs.uk/Pages/HomePage.aspx. It is important to be proactive about your child’s rehabilitation and to keep in contact with the health professionals who are in charge of the services.

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 child 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 some other children, long-term blood-thinning medication (e.g. 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.

The information on pages 1-5 above is based on information that was compiled in November 2004 by the Paediatric Stroke Working Group at the Royal College of Physicians, of which Different Strokes is a member. Permission has been given for its inclusion here. It has been checked for ongoing accuracy in November 2010 with Professor Tony Rudd, Stroke Associate Director at the Royal College of Physicians. Copies of the full clinical guidelines on which this information is based, are available at http://www.rcplondon.ac.uk/pubs/books/childstroke/childstroke_guidelines.pdf.
Coping with stroke in the family

Feedback from members tells us that ...

When your child has a stroke, depending on how it has affected them, you may experience some or all of the following:

1. you find yourself grieving for the child you have lost
2. you feel scared and alone
3. you are in denial that your child is brain injured
4. you are trying to understand “stroke”
5. you experience trauma to your body as the shock sets in
6. you start to learn to cope with a brain injured child
7. you feel that nobody understands
8. you ask yourself, “where do I go next?”

Stroke affects all family members, including other children.

Tips from other members

You may need to be proactive in making sure your child receives the services they are entitled to:

1. “Now that you have a list of professional people who will be involved in the aftercare, chase them if they don’t get in touch! I had to wait 6 weeks for physio to start in my son’s case. Keep calling and asking when your child will be seen. The NHS doesn’t hurry things.”

2. “I’ve had to take the initiative in accessing most of the support my daughter has had along the line, particularly as regards the LEA for the initial school statement and application for support in GCSE exams.”

“Even if you think your child is doing well at home, it’s important to let the school know about what has happened. Your child may look fine but their
concentration might still be affected. Making the teacher aware takes some pressure off the parents."

“Getting help with statementing is also very important.”

The Advisory Centre for Education provides information on the statementing process. See http://www.ace-ed.org.uk/Resources/ACE/advice%20booklets/Asking-Statutory-Assessment-Sep09LR.pdf or call 0808 800 5793.

Parent Partnership Services (PPS) also offer information, advice and support to parents and carers of children with special educational needs. They can provide information about how special educational needs are identified and assessed by schools and the local authority and who parents can talk to in a school or Local Authority about their concerns. See http://www.parentpartnership.org.uk/ or call 0207 843 6058.

3. It may be useful to “seek an assessment from a neuro-psychologist.”

The Encephalitis Society has a factsheet about how to obtain a Neuropsychological Assessment. See http://www.encephalitis.info/Info/Recovery/SpecialistServices/NPA.aspx.

4. “It would be useful to know who to contact if you’re not happy about the treatment your child is getting.”

The Patient Advice Liaison Service (PALS) should be able to help with any queries relating to NHS services. See http://www.pals.nhs.uk/cmsContentView.aspx?ItemID=932 to find the contact details for your local office. It is also worth speaking to your GP. If you’d like advice on making a complaint, contact the Patients Association for help. See http://www.patients-association.com/About-Us or call 0845 608 4455.

Feedback from members who had their strokes as children and are now adults:

"As a young stroke survivor, it is vital that you never allow yourself to give up the fight for your recovery. As each day passes and with hope and a positive attitude, every little achievement brings you one step closer to rebuilding your life and achieving your dreams"

Mark, stroke at 14, now aged 30
“I now accept that what happened to me happened for a reason, and I can appreciate the person I am today because of it. I wouldn’t want to be any other way and I can finally say, after years of struggling, I am happy and confident and looking forward to a healthy future.”

Laura, stroke at 17, now in her early 20s

To read more stories about some of our members who experienced stroke as children, go to the Survivors Stories section of our website: www.differentstrokes.co.uk

**Different Strokes** has several services available to support you:

1. The Different Strokes ‘Strokeline’ allows you to speak to stroke survivors about your experiences. We can also possible to put you in touch with other parents to share coping tips and strategies. The number is 0845 130 7172 or 01908 317618 and it is open 9am to 5pm Monday to Friday (answerphone outside of these times). We are happy to call people back. Queries can also be sent by email to info@differentstrokes.co.uk.

2. The Different Strokes Message Board at www.differentstrokes.co.uk is an open forum where you can share your questions, queries and feelings with other parents of young stroke survivors or with stroke survivors themselves. There is a section entitled “Stroke in Childhood – For parents of children who have had a stroke”.

   See also the “Survivors Stories” section of our website which features stories that have been submitted by people who suffered a stroke in childhood or adolescence. Telling your story in your own words and reading the experiences of others in a similar situation can be a helpful and calming experience as it can validate your experiences and help you process your emotions³. If you or your child would like to submit your story for inclusion on our website or newsletter, please email info@differentstrokes.co.uk or call 0845 130 7172 or 01908 317618.

3. The Different Strokes Facebook Group at http://www.facebook.com/?ref=logo#!/group.php?gid=2364892925 is also a place where you can share your thoughts and feelings with other people who are having similar experiences to you.

4. The Different Strokes exercise groups provide an opportunity to meet other stroke survivors in person. The sessions are aimed at adults, but children are welcome. You will have a chance to share your experiences with other people who understand. It can help to remove the sense of isolation which living with stroke often causes. Contact us on 0845 130 7172 or 01908 317618 for details of your nearest group.

5. “The Invisible Side of Stroke” leaflet which forms part of the Care After Stroke In Childhood information pack contains information on finding a counsellor for any member of the family to help them talk through and cope with their feelings. Different Strokes can help with finding out what is available in your area. Please read this booklet, or contact us on 0845 130 7172 or 01908 317618 to discuss counselling options in your area.
Book Review

Managing Stress for Carers by Dr Ann Edworthy

Available free of charge to parents from Cerebra - a charity set up to help improve the lives of children under 16 years with brain related conditions.

This book is intended for any parents dealing with the pressures of caring for a disabled child. Filled with practical tips that are easy to understand, it aims to show parents how to deal with stress before they experience “burn out”.

“I was so impressed by the book - wow!!! The book was so helpful and it was amazing to read about other parents who are going through the same thing. We all seem to be in the same boat!

I really wish I had had this book when we came home from hospital as it would have been extremely valuable to our family. Even finding out about the helpline was amazing - my God we could have really done with that sooner! We didn’t even know that we were entitled to Carers Allowance...15 months later I have now applied! This book is a total bible and should be given to every family!”

Review by Soniya Mundy, mum to Kray who had an AVM (Arteriovenous malformation – tangle of abnormal blood vessels) at the age of 11

Visit www.cerebra.org.uk for more information or contact 0800 328 1159.

Benefits Advice

Cerebra also has a free step-by-step guide to claiming Disability Living Allowance (DLA) for children under 16 with brain-related conditions. The guide is available to download from their website at http://www.cerebra.org.uk/parent_support/DLA_guide.

Speak to your local Citizens Advice Bureau or a local welfare rights worker for assistance on benefit entitlements. They will also be able to help you with filling in the forms. DIAL UK has a network of disability and advice centres around the UK which are often able to help. See http://www.dialuk.info/ to find out what is available in your local area.

4 For more information on Carers Allowance, go to http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/CarersAllowance/index.htm
5 For more information on Disabled Living Allowance, go to http://www.direct.gov.uk/en/disabledpeople/financialsupport/dg_10011731
USEFUL ORGANISATIONS

There are a number of organisations that are helpful in offering support and advice to children and families affected by stroke. These include:

**Advisory Centre for Education**
A national charity that provides independent advice for parents and carers of children aged 5-16 in state-funded education.
1c Aberdeen Studios, 22 Highbury Grove, London, N5 2DQ
General Advice Line: 0808 800 5793  Exclusion Advice Line: 0808 800 0327
Email: enquiries@ace-ed.org.uk  Website: www.ace-ed.org.uk

**Afasic England – unlocking speech and language**
UK charity representing children and young adults with communication impairments, working for their inclusion in society and supporting their parents and carers.
20 Bowling Green Lane, London, EC1R 0BD
Helpline: 0845 3 55 55 77  Tel: (admin) 020 7490 9410
Website: www.afasicengland.org.uk

**All About ABI (Acquired Brain Injury)**
A website from the Brain & Spine Foundation specifically for children, providing information and explaining about what to expect after an ABI.
c/o The Brain & Spine Foundation, 3.31 Canterbury Court, Kennington Park, 1-3 Brixton Road, London, SW9 6DE  Helpline: 0808 808 1000  Tel: 020 7793 5900
Email: helpline@brainandspine.org.uk  Website: www.aboutbraininjury.org.uk

**Action for Rehabilitation from Neurological Injury (ARNI)**
A registered charity. The ARNI programme is a training regime that was designed by a stroke survivor as a working structure to help people with partial paralysis who want to make as full recovery as possible.
The ARNI Trust, PO Box 68, Lingfield, Surrey RH7 6QQ
Tel: 07712 211378 or 07710 407021
Email: support@arni.uk.com  Website: www.arni.uk.com

**Brain & Spine Foundation**
Helps the 10 million people affected by brain and spine conditions in the UK by providing information and resources on its website and via its helpline.
3.36 Canterbury Court, Kennington Park, 1-3 Brixton Road, London, SW9 6DE
Helpline (staffed by neuro science nurses & health professionals): 0808 808 1000
Tel: 020 7793 5900  Email: helpline@brainandspine.org.uk  Website: www.brainandspine.org.uk
The British Institute for Brain Injured Children
Practical help to families caring for children with conditions including brain injury.
Knowle Hall, Bath Rd, Knowle, Bridgwater, Somerset TA7 8PJ
Tel: 01278 684 060   Website: www.bibic.org.uk

Cerebra
Funds research on brain conditions and provides support to parents, carers and professionals.
Cerebra (Parent Support), FREEPOST SWC3360, Carmarthen, SA31 1ZY
Parent Support Helpline: 0800 328 1159
Email: info@cerebra.org.uk   Website: www.cerebra.org.uk

Chest, Heart & Stroke Scotland
Advice and support for people in Scotland affected by chest, heart and stroke conditions.
3rd floor, Rosebery House, 9 Haymarket Terrace, Edinburgh, EH12 5EZ
Advice Line 0845 077 6000   Head Office Tel: 0131 225 6963
Email: admin@chss.org.uk   Website: www.chss.org.uk

Child Stroke Support
An interactive message board set up by the mother of one of our members for parents of children who have suffered a stroke or AVMs. It aims to raise awareness, provide advice, help or just a place to come for an online chat.
Website: www.childstrokesupport.com

CBIT Children’s Brain Injury Trust
Aims to improve the quality of life for all children who have an acquired brain injury, enabling them to achieve their full potential.
Unit 1, The Great Barn, Baynards Green Farm, Nr Bicester, Oxon OX27 7SG
Helpline: 0845 601 4939   Head Office Tel: 01869 341075
Email: helpline@cbituk.org or info@cbituk.org   Website: www.cbituk.org

Contact a Family
Source of information for families of children with disabilities and/or rare syndromes.
209-211 City Road, London EC1V 1JN.
Helpline: 0808 808 3555   Textphone: 0808 808 3556   Tel: 020 7608 8700.
Email: helpline@cafamily.org.uk   Website: www.cafamily.org.uk

Council for Disabled Children
An organisation for disabled children in England, with links to the other UK nations.
8 Wakley St, London EC1V 7QE.
Tel: 020 7843 6000.   Email: enquiries@ncb.org.uk   Website: www.ncb.org.uk
Department for Education
Advice for parents and teachers of children with special educational needs. May not reflect Government policy.
http://www.education.gov.uk/schools/pupilsupport/sen

Department for Work and Pensions and DirectGov
Information regarding a range of benefits and services for families.
http://www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/index.htm

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  This is not an advice line, please look at the website for advice
Email: office@disabilityalliance.org  Website: www.disabilityalliance.org

Disabilities Trust
Provides quality care, rehabilitation and support for people with complex disabilities across the UK.
First Floor, 32 Market Place, Burgess Hill, West Sussex RH15 9NP
Tel: 01444 239 123  Email: info@thedtgroup.org  Website: www.thedtgroup.org

Epilepsy Action
Provides information about coping with epilepsy and seizures.
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
Helpline: 0808 800 5050
Email: epilepsy@epilepsy.org.uk  Website: www.epilepsy.org.uk

The Family Fund
Helps families with severely disabled children to have choices and the opportunity to enjoy ordinary life by giving grants.
4, Alpha Court, Monks Cross Drive, York, YO32 9WN
Tel: 0845 130 4542  Textphone 01904 658085
Email: info@familyfund.org.uk  Website: www.familyfund.org.uk

Family Rights Group
Provide specialist advice to families who are raising children involved with, or who need, social care services. They promote policies and practises that help children to live safely and securely within their families.
Second Floor, The Print House, 18 Ashwin Street London E8 3DL
Advice Line: 0808 801 0366  (10.00 am to 3.30 pm)  Tel: 020 7923 2628
Email: advice@frg.org.uk  Website: www.frg.org.uk
HemiHelp
Information and support for children with hemiplegia and their families.
HemiHelp, 6 Market Road, London. N7 9PW
Helpline: 0845 123 2372 (10am to 1pm, Monday to Friday, during term time)
Office Tel: 0845 120 3713
Email: info@hemihelp.org.uk  Website: www.hemihelp.org.uk

Headway (The Brain Injury Association)
Aims to promote understanding of all aspects of head injury and to provide
information, support and services to people who have suffered a head injury, their
family and carers.
Bradbury House, 190 Bagnall Road, Old Basford, Nottingham, NG6 8SF
Helpline: 0808 800 2244  Tel: 0115 924 0800
Email: helpline@headway.org.uk  Website: www.headway.org.uk

IPSEA (Independent Panel for Special Education Advice)
Free independent advice on education issues including appealing to Special
Educational Needs Tribunal.
Hunters Court, Debden Road, Saffron Walden, CB11 4AA
Advice Line: 0800 018 4016  Office Tel: 01799 582030
Website: www.ipsea.org.uk

National Parent Partnership Network
Parent Partnership Services (PPS) are statutory services offering information advice
and support to parents and carers of children and young people with special
educational needs (SEN).  8 Wakley Street, London, EC1V 7QE
Telephone: 0207 843 6058
Email: nppn@ncb.org.uk  Website: www.parentpartnership.org.uk

Northern Ireland Chest Heart & Stroke
Offers support and advice to stroke survivors and their families throughout Northern
Ireland.
21 Dublin Rd, Belfast BT2 7HB
Advice Line: 08457 697 299  Tel: 028 9032 0184
Email: mail@nichsa.com  Website: www.nichsa.com

Parentline Plus
Offers a parents-to-parents support to work through problems and find practical
solutions. The Parentline helpline is open 24 hours a day, seven days a week.
Parentline Plus, CAN Mezzanine, 49-51 East Road, London, N1 6AH
Parentline 0808 800 2222  Tel: 020 7553 3080  Textphone: 0800 783 6783
Website: www.parentlineplus.org.uk
Patients Association
An independent charity that highlights the concerns and needs of patients. They can provide booklets on issues such as include Pain Management, How to Obtain Access to your Medical Records and How to Make a Complaint. The Patients Association, PO Box 935, Harrow, Middlesex, HA1 3YJ
Helpline: 0845 608 4455
Email: helpline@patients-association.com  Website: www.patients-association.com

Relate for Parents
Relate has created a new online Live Chat service so that parents can talk to a trained Relate consultant in real time about problems in any area of family life. See website for availability times.
Premier House, Carolina Court, Lakeside, Doncaster, DN4 5RA
Tel: 0300 100 1234
Email: relateforparents@relate.org.uk  Website: www.relateforparents.org.uk

Sibs
Aims to make growing up with a brother or sister with special needs, disability or chronic illness a little bit easier. Meadowfield, Oxenhope, West Yorkshire, BD22 9JD
Tel: 01535 645453. Website: www.sibs.org.uk

Sickle cell society
Information, counselling and caring for those with Sickle Cell Disorders and their families. 54 Station Road, Harlesden, London, NW10 4UA
Tel: 020 8961 7795
Email: info@sicklecellsociety.org  Website: www.sicklecellsociety.org

The Stroke Association
Provide information and support for people who have had a stroke and their families throughout the UK. Produces a wide range of publications, supports research and health education. Stroke House, 240 City Rd, London EC1V 2PR
Tel: 0303 3033 100  Email: info@stroke.org.uk  Website: www.stroke.org.uk

Young Minds
A national charity committed to improving the mental health and emotional wellbeing of all children and young people, offering information and advice to parents on these issues and the services that are available to them.
48-50 St John Street, London, EC1M 4DG
Parents Helpline: 0808 802 5544 Tel: 020 7336 8445
Website: www.youngminds.org.uk

Please note that this list is for guidance only. Inclusion in this list does not constitute endorsement by Different Strokes.
Contact us:

If you have any queries, require any further information, or wish to provide feedback on how this information could be improved, please contact us using the details below:

Different Strokes
9 Canon Harnett Court
Wolverton Mill
Milton Keynes MK12 5NF
Tel: 0845 1307172 / 01908 317618 (9am to 5pm)
info@differentstrokes.co.uk
www.differentstrokes.co.uk