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| Paper | Stroke Association position paper on:**Childhood Stroke** |  |  |
| Date | January 2013 |  |
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| Coverage | England, Northern Ireland, Scotland and Wales |  |  |
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| Taxonomy | **Class:** policy statement **Category:** Papers**Keywords:** Campaigns, policy, influencing |  |  |

1. **Introduction**
* Stroke is a condition often associated with older people but anyone can have a stroke including babies and children.
* Although relatively rare, it is estimated that around 400 children and young people in the UK have a stroke every year and stroke is one of the top ten causes of death in childhood[[1]](#endnote-1).
* The causes of stroke and the recommended treatments for childhood stroke are different from older adults.
* The long term outcomes of paediatric stroke are difficult to predict, but overall place a large burden on childhood stroke survivors, families, and society[[2]](#endnote-2).
* Children are frequently left with significant long term disabilities after stroke. Some are well known like a one-sided paralysis or weakness, or problems with speech and communication. Others are less well known, such as difficulties of perception and awareness and psychological and emotional changes.
* Stroke recurrence is a major concern for children and families. Ischaemic stroke (caused by a clot) recurs in between 6% and 20% of all children and in over 60% of children with sickle cell disease.[[3]](#endnote-3)
* For the purposes of this policy statement the definition of childhood stroke excludes events occurring in the prenatal and perinatal periods and therefore concerns children and young people aged between 1 month and 18 years at the time of presentation.
1. **Summary of the Stroke Association’s position on childhood stroke**
* The improvements that we have seen in recent times in adult stroke care and support have not been matched in the area of childhood stroke.
* We believe that there needs to be more research into the causes, treatment and longer term effects of childhood stroke.
* We believe that there needs to be more work done to raise public and professional awareness of the risk factors, signs and outcomes of childhood stroke.
* We believe that there needs to be refinement and better implementation of national and international guidelines around the diagnosis, treatment and long term management of childhood stroke.
* We believe that there needs to be a particular focus on improving rehabilitation and longer term services for childhood stroke survivors as well as the provision of information and support for survivors and their families.

**c) What are the problems?**

**The causes of childhood stroke are different from adults, more varied and often unknown**

* The causes of childhood stroke are different from older adults where the predominant cause is atherosclerosis, the “furring up” of arteries.
* Strokes in children and young people from 1 month to 18 years occur as a result of a very diverse range of underlying conditions, most commonly congenital heart disease and sickle cell disease. Other underlying causes are infectious diseases, moyamoya syndrome, vasculitis and blood disorders.
* Haemorrhagic strokes are more common in children and young people but UK and international treatment guidelines primarily address ischaemic stroke.
* In around 10% of children who have a stroke, no cause is identified despite extensive tests[[4]](#endnote-4).

**Public and professional awareness of childhood stroke and recognition of stroke symptoms needs improvement**

* Childhood stroke is a neglected area, with both professionals and the general public lacking awareness of the problem and its potential consequences.[[5]](#endnote-5)
* Signs of a stroke (such as weakness or paralysis on one side of the body, facial drooping, speech problems, seizures and headaches) may be difficult to recognise in a young child, depending on age and stage of development. For example in young infants seizures may be the only indication of stroke.
* Stroke is also a relatively rare and unexpected illness in children which can lead to initial misdiagnosis.
* Problems with recognition of stroke symptoms by both parents and health professionals can lead to delays in getting children to hospital and to accessing urgent treatment which could improve outcomes.
* Parents of children who have had a stroke often report their child being discharged from A&E with a misdiagnosis.
* It is particularly important that for those children at higher risk of stroke (eg with Sickle Cell Disease or congenital heart disease) that parents, family members and other people in close contact with the child such as teachers are aware of stroke symptoms and the need for a rapid response.

**Treatment for childhood stroke is under researched and specialist services underdeveloped**

* As with stroke in adults, a quick diagnosis and rapid treatment is essential to save lives and reduce disabilities caused by stroke.
* Children with suspected stroke should be seen by a consultant paediatric neurologist, consultant paediatrician or consultant neurosurgeon and have fast access to a Magnetic Resonance Imaging brain scan to determine if a stroke has occurred and what type of stroke it is.
* There is very little research into the best medical and rehabilitative treatment options in childhood stroke. Most acute management of children with stroke is relatively basic with some clinicians basing their treatment on the evidence for adult stroke care which may, or may not, be of benefit and could even be more risky.
* There is little evidence and knowledge about whether interventions commonly available in adult stroke care such as stroke unit care or the use of thrombolysis (clot busting drugs) in the treatment of ischaemic stroke would be of benefit to children.
* For secondary prevention, drugs that make the blood thinner (such as aspirin, heparin or warfarin) may be considered for children who have had an ischaemic stroke. However, the evidence base for such treatment is limited and current practice varies widely.
* For children with high risk conditions such as Sickle Cell Disease prevention of a first stroke and recurrent strokes is important. The development of accessible screening and transfusion services for children with Sickle Cell Disease is vital and at present not all those who would benefit receive such treatment.
* Guidelines have been produced for the treatment and management of childhood stroke (Royal College of Physicians Stroke in Childhood 2004, American Stroke Association Management of Stroke in Infants and Children 2008) but we are unaware of how well they are used and how well they reflect current evidence.

**Services for the rehabilitation and longer term needs of children who have had a stroke are underdeveloped**

* Children who have had a stroke should receive multidisciplinary assessment and early rehabilitation such as physiotherapy, occupational therapy and speech therapy.
* The Royal College of Physicians (RCP) have said that there is little evidence on the effectiveness of rehabilitation interventions specifically for children affected by stroke and that services for the rehabilitation and longer-term needs of children with any acquired brain injury, including stroke, are relatively underdeveloped in the UK.[[6]](#endnote-6) Neurological rehabilitation services for children are virtually non-existent.
* There are significant problems in accessing therapy following childhood stroke in some geographical areas.[[7]](#endnote-7)
* Parents report issues around the frequency and intensity of contact with therapists and particular delays in access to physiotherapy and occupational therapy services**.** Parents also report a significant need for improved psychological and emotional support for both childhood stroke survivors and their families.
* “Invisible” impairments (such as cognitive problems and fatigue) are also under-recognised and a source of significant morbidity in children affected by stroke.[[8]](#endnote-8)
* The lack of awareness of childhood stroke amongst professionals means that it is often left to the child and family to pursue treatment, rehabilitation and appropriate educational support[[9]](#endnote-9).
* Too many parents say that they have to constantly fight so their child can receive the care and treatment that they feel they should be getting.
* Childhood stroke has an impact on the whole family, including parents, siblings and grandparents. Childhood stroke has been shown to have an adverse impact on parents’ emotional and physical health[[10]](#endnote-10).
* The needs of childhood stroke survivors and their parents can change. Some effects such as cognitive problems may only emerge over time. The challenges of school, socialising and accessing leisure opportunities will also lead to changes in the demands on and the needs of childhood stroke survivors and their families. This means that on-going multidisciplinary assessment must be offered.
	1. **Quotes (taken from RCP Paediatric Stroke Workshop 2004)**

Parents reported feeling concerned and frightened at the amount of time they had to wait for diagnosis, treatment and information about their child’s condition:

*‘Sitting for hours in the emergency department, with ———, before it was finally acknowledged she had had a stroke’*

Parents feel abandoned when their child leaves hospital:

*‘When we came home from hospital it was as if you’re home now “Goodbye and get on with it”. That’s the way I feel and still feel. There’s been no physio or occupational therapy yet and she’s been home about eight weeks now. All I’ve had is phone numbers and names which are no help to me as there’s very little for younger people with strokes. They don’t cater for younger children only adults. So it feels as if you’re forgotten.’*

**e) The changes the Stroke Association want to see**

**Increased research into childhood stroke**

* We call on the UK Government, devolved national governments and other research funding bodies to make research into childhood stroke a higher priority. Paediatric researchers should also be encouraged to conduct more work in this area.
* Lack of knowledge in this area means health professionals are not able to give parents accurate predictions about prognosis, they do not know where to target scarce rehabilitation resources, and they do not know which children are at most risk of complications.
* There is a need for research to help provide clarity about the best model of care, for example, whether children should be managed at regional paediatric neurology centres, and whether additional training in stroke for paediatric neurologists would improve care.

**Audit of childhood stroke care and establishment of a registry of stroke in children**

* There should be an audit of stroke care for children in the UK and the introduction of a registration system for childhood stroke.
* This would create a better knowledge base of the true impact of childhood stroke; give a clearer view of services needs for children who have experienced stroke and provide the springboard for on-going research into the treatment of childhood stroke.

**Greater awareness of childhood stroke**

* The lack of knowledge that stroke can occur in this age group means it is vital to raise awareness of childhood stroke, especially amongst health professionals, parents and those working with children.
* There is a particular need to improve health professionals knowledge of childhood stroke to help avoid delayed or wrong diagnoses.
* The FAST (Face, Arm, Speech, Time to call 999) has been very successful in raising awareness of stroke in adults and efforts now need to be made to raise public and professional awareness of childhood stroke.
* Within education it essential that teachers and other school staff are aware of the potential signs of stroke particularly amongst children with underlying conditions of higher risk such as Sickle Cell Disease. On return of a child to school, teachers and other school staff must also be aware of the “invisible” impairments associated with stroke (such as cognitive problems and fatigue).

**Implementation and updating of childhood stroke guidelines**

* Progress should be made towards the full implementation of the current RCP guidance on childhood stroke.
* Progress should also be made on the full implementation of the NHS Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care
* The Royal College of Physicians and the Royal College of Paediatrics and Child Health with support from organisations such as the Stroke Association should consider producing new, updated guidelines for the management of childhood stroke to take into account advances in technology and treatments since 2004.

**A bigger focus on the longer term and community needs of childhood stroke survivors**

* There needs to be more effective discharge planning for children who have had a stroke and improved assessment of their on-going needs post hospital. Key transitions in childhood, for example starting school or moving from primary to secondary school are frequently times where support and planning is needed to meet a child’s individual needs.
* Equipment which is appropriate in meeting rehabilitation aims should be assessed on an individual basis, provided in a timely manner and regularly monitored.
* Return to school is a major milestone in a child’s recovery after stroke and must be managed as effectively as possible. An individually tailored reintegration plan, with multi agency engagement, must be in place before children return. Support must be offered for children with special education needs as a result of their stroke to allow them to participate as fully as possible in school life.
* Childhood stroke may result in lifelong physical and cognitive impairments. A coordinated approach to the transition between paediatric and adult services is critical and advance planning essential to ensure smooth handover of any and all aspects of care.[[11]](#endnote-11)
* There needs to be greater recognition of the short and long term impact of childhood stroke on parents and family members. The health needs (in particular psychological well being) of both the child and family need to be addressed by health professionals working with these children[[12]](#endnote-12)

**Better information, advice and support around childhood stroke**

* Children, family members or carers must be supported with both factual and practical information at various stages presented in a format appropriate to their needs.[[13]](#endnote-13)
* Parents and carers of children affected by stroke welcome support from those who have had similar experiences. Children also welcome meetings with those in their own age group affected by stroke. More must be done to help establish networks of support for children and families affected by childhood stroke.
* Organisations such as the Stroke Association, Different Strokes and Hemihelp UK provide information, support and advice to parents and families of children who have experienced stroke but there needs to be more funding to support the establishment of support services and networks for those affected.
1. **What the Stroke Association is doing around childhood stroke**

**The Stroke Association provides funding to increase research on childhood stroke**

This includes funding of over £140,000 to a team at the University of Bristol for research into the incidence and outcomes of childhood stroke. This is the biggest ever UK study into childhood stroke and is likely to be the largest population-based cohort of children with stroke in the world.

**The Stroke Association provides information and advice around childhood stroke**

We have a factsheet written for parents whose child has had a stroke <http://www.stroke.org.uk/factsheet/childhood-stroke> and an information sheet explaining stroke for children <http://www.stroke.org.uk/resourcesheet/stroke-explanation-children>.

A booklet for parents of children with sickle cell is available for download, produced in partnership with the Sickle Cell and Young Stroke Survivors organisation. <http://www.dmu.ac.uk/documents/health-and-life-sciences-documents/sickle-cell/scyssstroke.pdf>

We have a section on our website providing information about childhood stroke and useful links <http://www.stroke.org.uk/about/childhood-stroke>

**The Stroke Association provides and is developing childhood stroke support services**

Staff in our Stroke Information Service are trained to offer practical and emotional support to people affected by childhood stroke.

Our Information Advice and Support Services, where these exist, aim to help the families of children affected by stroke, offering such support as they are able including signposting and system navigation to other specialist organisations.

We have helped secure over £200,000 to help develop the UK’s first dedicated community support service for childhood stroke survivors and their families.

Working with the Evelina Children’s Hospital we will develop a new service to give children and their families in London and the South East the long term support they need after a child has suffered a stroke.

The project will see the recruitment of a specialist childhood stroke coordinator to work across the Evelina and the Stroke Association to develop and deliver the new service. The intention is then to roll out a similar service across the country.

The service will provide direct information, advice and support to children who have experienced a stroke and their families while in hospital, during the transition from hospital to home and over the longer term with help receiving rehabilitation and returning to school.

The service will work with health professionals to raise awareness of childhood stroke and produce new information materials. The service will also will aim to create a network for families affected by childhood stroke, enabling them to meet, forge bonds and create friendships with one another so that they can reach out and support each other.

1. **What you can do to help?**
* If you are a childhood stroke survivor – tell us about your experiences good or bad, by emailing us at campaigns@stroke.org.uk
* If you are a parent, friend or relative of a childhood stroke survivor – tell us how they have recovered and what the experience has been like for you by emailing us at campaigns@stroke.org.uk
* If you are a medical professional working in the field of childhood stroke – tell us what you think needs to change, by emailing us at campaigns@stroke.org.uk
* Join the Campaigners' Network at [www.stroke.org.uk/campaigns](http://www.stroke.org.uk/campaigns) and together we can help more stroke survivors get the social care they need to make their best possible recovery.
* Donate – <http://www.stroke.org.uk/webform/make-donation>
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