Introduction

The Margaret Giffen Charitable Trust has generously supported the Stroke Association over three years to fund the Childhood Stroke Project. The Childhood Stroke Project encompasses a support service, resource development programme and calendar of family support events. This report covers the six month period from February 2017 to July 2017.

The Childhood Stroke Support Service offers information, advice and support to children, families and young people affected by stroke in childhood. The service is based at Evelina London Children’s Hospital, and offers face-to-face support to families in London and the South East. Telephone and email assistance is available on a national basis.

The impact of your support – helping child stroke survivors and their families

The service supports child stroke survivors and their families by:

- providing emotional support, face-to-face, via email or telephone
- signposting to resources and any additional support needed
- advocating for and supporting families to access specialist services
- visiting families at home or in the community (e.g. schools, medical appointments)
- connecting parents to other parents and carers
- organising regular parent support and information days where experts in medical issues, research, rehabilitation and community support are able to provide information directly to families. At these sessions families have an opportunity to ask questions of the expert panels and share their views and experiences.

“The support provided has been a lifeline at a time when there seemed to be no solution to our problems, and we didn’t know where to start to make sense of and alleviate our child’s physical and emotional suffering.

NHS services, however essential to patients’ survival and recovery from stroke, are just not equipped to deal with the complex needs that ensue after a stroke. The Stroke Association service has filled that gap for us.”

Family member supported by the Childhood Stroke Service
The Childhood Stroke Service has successfully launched some new resources over the last six months.

**These include four animations to accompany the content of the Childhood stroke handbook, titled:**

- What is a stroke?
- What happens when you have a stroke?
- Getting better when you have a stroke
- Talking about having a stroke

These animations are a world-first, and have been shared in a range of print and social media settings. They are freely available to view via the Stroke Association and Evelina London websites.

The launch of the animations has also helped to promote the Childhood stroke handbook, resulting in 152 downloads and the distribution of 40 hard copies over the last six months. A psychologist who requested the handbook commented: “...this is a fantastic and valuable contribution to helping children with stroke understand their condition.”

We’ve also launched a new ‘Therapy question and answer’ sheet to help parents prepare for appointments with professionals like physiotherapists or occupational therapists. The content is based on expert guidance from parents, young people and the stroke service delivered at Evelina London Children’s Hospital. It is the third in our freely downloadable ‘Q&A’ series.

Recently, we’ve worked with a group of parents to devise three new posters (displayed on the right) to help raise awareness that stroke happens to babies, children and young people too. The posters are free to download from our website to display in schools, GP surgeries, health centres – wherever families and professionals feel they will have an impact.
Work has started on a guide to stroke for schools, with a scoping document sent out to parents, young people and professionals for comment to ensure the right content and range of information is included.

The service facilitated a parent support and information day in London on 10 June 2017, with about 20 attendees. Topics included the new childhood stroke guidelines, updates on childhood stroke research, and advice accessing rehabilitation and educational support. Information stands were provided by the Children’s Trust and the Child Brain Injury Trust, along with resources from the Childhood Stroke Project.

“Outstanding presenters. All content very relevant. Good balance between clinician, parents, therapists and other professionals. Invaluable sharing of experience with other parents. Excellent day.”

“Thank you for a wonderful day. It is so helpful to meet and talk to other parents who are experiencing similar things.”

“The information provided today will have a significant impact on our confidence in dealing with future appointments and in supporting our child. Thank you.”

Attendees at our childhood stroke parent support day in London

The support service is currently providing active support to 80 families, with 25 new referrals from February 2017 – July 2017.

In addition, there were 17 requests for information or advice from NHS or voluntary sector professionals and Stroke Association colleagues.

The Childhood Stroke Support Service offered support in the following ways:

<table>
<thead>
<tr>
<th>Type of support</th>
<th>Number of contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital visits</td>
<td>16</td>
</tr>
<tr>
<td>Clinic appointments</td>
<td>41</td>
</tr>
<tr>
<td>Home visits</td>
<td>6</td>
</tr>
<tr>
<td>Telephone meetings</td>
<td>123</td>
</tr>
<tr>
<td>Email contacts</td>
<td>272</td>
</tr>
<tr>
<td>Liaison with health and social care</td>
<td>138</td>
</tr>
<tr>
<td>Liaison with educational settings</td>
<td>78</td>
</tr>
<tr>
<td>Stroke Association grants</td>
<td>2</td>
</tr>
</tbody>
</table>
New referrals to the support service have come from a range of locations and through a variety of sources, as shown in the map and table below:

<table>
<thead>
<tr>
<th>New referral source</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family /self-referral</td>
<td>8</td>
</tr>
<tr>
<td>Health professionals</td>
<td>13</td>
</tr>
<tr>
<td>Stroke Association Helpline</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>25</td>
</tr>
</tbody>
</table>

The chart below shows the age ranges of the children and young people who were referred to the service:

- **Within 1 Month Of Birth**: 10 referrals
- **Up to 5 years old**: 7 referrals
- **Up to 15 years old**: 4 referrals
- **Over 15 years old**: 4 referrals
- **> 15 years old**: 9 referrals

The table below gives an overview of when families accessed the service following their diagnosis:

<table>
<thead>
<tr>
<th>Time from stroke to referral</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 4 weeks</td>
<td>8</td>
</tr>
<tr>
<td>1 - 3 months</td>
<td>4</td>
</tr>
<tr>
<td>6 - 12 months</td>
<td>4</td>
</tr>
<tr>
<td>&gt; 12 months</td>
<td>9</td>
</tr>
</tbody>
</table>
The chart below shows the different support needs identified by families:
Case study

Background
Lucy is a nine year old girl, who was born with an underlying heart condition. She lives with her parents. Lucy needed surgery for her heart last year and was admitted to hospital. On waking from her surgery, she was observed to have movement difficulties on one side, and a brain scan revealed she had had a stroke. Lucy’s stroke affected her movement, stamina and vision. She was able to return home within weeks, and was back at school the following term.

Lucy and her mother met the Childhood Stroke Support Service Coordinator in an outpatient clinic shortly after the stroke. They reported that although her movement had improved – she was still tired, and not able to do things as easily as before. Lucy’s mother also expressed concern about her memory and attention, and was aware her mood and behaviour varied from day to day. Lucy’s mother had some questions about the risk of further strokes, and also expressed a request for support in working with school to ensure they were informed about how to manage her medical condition, and how to monitor and support her progress.

Lucy explained that she would like her classmates to have a better understanding of what had happened to her, why she gets tired, and how to help her.

Identified needs and desired outcomes:
- Support in asking questions and raising concerns with professionals
- Support in liaising with school to ensure therapy and educational needs being monitored, and plans being documented and communicated
- Information for school on how to support the needs of children affected by stroke
- Information for Lucy’s classmates.

Support provided by the Childhood Stroke Support Service:
- Liaison and discussion with Lucy’s mother to help her clarify her questions and concerns and support in identifying the appropriate professional to provide answers/feedback
- Set up a meeting at school – for Lucy’s mother, SENCO, school nurse and local therapists
- Provided childhood stroke training and resources for school staff
- Provided childhood stroke classroom session for classmates
- Ongoing phone and email support as new queries and concerns were identified.

Outcomes:
- Increased safety in the school environment – with medical history and support needs clearly documented
- Increased understanding of stroke in childhood – through provision of information and resources
- Increased feelings of reassurance for Lucy and her family – in having questions answered and local support put in place
- Reduced family/carer stress and isolation by providing a consistent point of contact going forwards.

Service feedback:

“Excellent resources – tailored perfectly for both child and teacher session. It will make me more aware of what to look out for with children who have suffered from a stroke within school.”

Feedback from school staff after session

Note: some detail and identifying information has been removed or altered within these case studies to ensure anonymity and to respect the confidentiality we offer our clients. Each case study does, however, represent a genuine case example of our work and the results we have achieved with individuals and families supported by the service.
The support service evaluates its effectiveness by looking at recorded aims and outcomes, and by asking for user feedback. Over 160 outcomes were recorded over the last six months.

- Reduced isolation
- Increased safety and dignity
- Increased confidence to engage in activity
- Increased understanding of stroke
- Improved physical well-being
- Increased ability to self-manage
- Increased independence
- Reduced emotional distress
- Increased knowledge of communication disability
- Reduced carer stress
- Increased confidence to care
- Reduced carer isolation
- Increased feelings of reassurance
- Increased access to financial support
Families who received the service for three or more months were also sent an online survey to complete. Twelve responses were received with all respondents reporting they would recommend the service to other families. Participants described having accessed and made use of the full range of support available – including advice, resources, peer support networks and parent days.

**The top four most highly rated elements of the service were:**
1. time to talk, discuss concerns or ask questions
2. advice or information
3. advocacy or practical help to access a service/assessment/support for their child
4. emotional support.

When families were asked to rate how the service had helped them, they gave the following feedback:
Going forward

Following the success of the childhood stroke support day held in June 2017, we will be holding another event later in the year. We are looking forward to expanding the reach of the day to the north-west, and are working with a new group of parents and professionals to help plan the day. We will hold a further two days in 2018.

The support service will continue to develop the guide to stroke for schools, with a plan to complete a first draft and receive feedback within the next six months. Work will also start on looking into additional peer support options that can be piloted within the service, in addition to signposting to social media support, and delivering the support days.

The new childhood stroke guidelines were launched by the Royal College of Paediatrics and Child Health (RCPCH) and the Stroke Association in May 2017. The Childhood Stroke Support Service has been supporting their dissemination by sharing with parent and professional networks, discussing at parent days, and highlighting related resources via the childhood stroke section of our website.

The RCPCH shared Childhood Stroke Support Service resources at their launch event, and also features our new awareness raising posters on their website. The important work of promoting and sharing these guidelines will continue in the next phase of the project.

Anna Panton
Childhood Stroke Project Manager
anna.panton@stroke.org.uk
07715 065925

“We knew nothing about childhood strokes – our worker has gone above and beyond. Training my child’s school with more information. Having someone to turn to for advice and support.”

“Initially we felt very isolated as it’s so unusual to have a child who has had a stroke – none of the local professionals really knew what to say to us and had nothing to offer us in terms of their support or in our community. Childhood Stroke Support Service has given us that and understood when we are ready to have it.”

“I like that we experienced a very gentle and understanding level of support that suited us. I felt I could ask for as little or as much as I wanted or needed. I never felt rushed and always felt listened to. Absolutely invaluable at a time when friends and family don’t really understand what is happening to you or your child.”

Service user feedback
We are the Stroke Association

The Stroke Association is the leading stroke charity in the UK. We believe in the power of research to save lives, prevent stroke and ensure that people make the best recovery they can after a stroke.

We’re here for you. If you’d like to know more, please get in touch.

**Stroke Helpline:** 0303 3033 100  
**Website:** stroke.org.uk  
**Email:** info@stroke.org.uk  
**From a textphone:** 18001 0303 3033 100

Our research programme relies on voluntary donations.

Please help us to fund more vital research.

Call our Donations line on **0300 3300740**,  
or visit **stroke.org.uk**

Together we can conquer stroke

© Stroke Association, September 2017