



Supporting children after a stroke

Toolkit for teachers and childcare professionals Part 2

Supporting learning after a stroke

Rebuilding lives after stroke

Stroke
Association

 **Evelina**London

Supporting learning after a stroke

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1. When a child has had a stroke before starting school

When a baby or pre-school child has had a stroke, the impact this may have had on learning, play and social skills may not become clear for some time. They may have a physical disability, or the effects of their brain injury may be more hidden.

Reception or Year 1 may be the first structured opportunity to fully assess and identify their support needs. The school needs to be aware of their early medical history if possible, and will need to communicate with any pre-school services that might be able to provide information and advice, such as therapies or Portage (a home-visiting educational service for pre-school children with additional support needs and their families).

Key things to think about when a child starts in Reception:

- Be aware that some skills may take longer for children to acquire if they've had a stroke at an early age. For example, they may need more support with dressing and changing themselves, using the toilet independently, holding a pen, concentrating in a classroom environment or listening and retaining information.
- Talk to the family about how they have been managing the effects of stroke at home, and the best way to offer support and enable independence.
- Be aware that fatigue and tiredness can still be a factor, even when a stroke has happened some years before. In small children, this may show itself as behavioural difficulties or frustration. Fatigue may not only come from being physically active, but also from being in a noisy and busy environment, and responding to the social demands of the setting. Fatigue can happen regardless of whether or not a child has a physical disability.
- Talk to the family about how they have been managing fatigue at home, and consider a gradual start to school attendance, or building rest breaks into the day.
- Be aware that children may have been discharged from therapies prior to starting school, as they were managing well in the home setting, but that new support needs may emerge in the school environment.
- Be proactive in re-referring to therapies. If the child has any special educational needs, this could mean that an educational psychology assessment is needed.
- Be aware that some of the secondary medical effects of stroke and brain injury may only emerge some years later. For example, the emergence of epilepsy, or the need for medications or therapy to help with muscle control and ease of movement.
- Review the child's support needs, training for school staff, and how to manage missed attendance and appointments on a regular basis.

Parent's story

"In my son's infant school, it was actually the head teacher who wrote the care plan, oversaw the phased start to school, and was our main point of contact. This was fantastic as she ensured that all staff were aware of his needs and all health and safety contacts knew what to do in the event of further strokes. She put playtime strategies in place to ensure he always had friends during the months he was not able to go into the playground."



2. When a school age child/young person has a stroke

When a school age child/young person has a stroke they are likely to be hospitalised for a period of days or weeks. For some children/young people this will extend to months of rehabilitation. Even for those children/young people who return home relatively quickly, they may have continued appointments, and be too unwell or tired to return to school full-time immediately.

To support the child/young person, the school can:

- identify a key point of contact within the school for the family, so they can keep the school updated as to how the child/young person is doing, and timeframes for return to school.
- identify someone from the school who can attend hospital discharge planning meetings. This can be helpful when children/young people have been admitted for some time and will need significant adjustments in the school setting.
- talk to the family about what the child/young person wants their friends and school peers to know about what has happened. Ask if visits from friends and teaching staff would be helpful while the child/young person is in hospital or recovering at home.
- consider if there are any siblings who may have been affected, and discuss with the family.
- talk to the family about the medical and therapy team who are treating their child/young person. Can they identify someone on the team for the school to work with to gather any information they need for their health care plan on return to school?

- acknowledge that the parents and young person may not have all the information or answers ready at this stage. It may be best to seek their permission to liaise directly with health professionals.

As the return to school approaches

Once a child/young person has returned home, they may be keen to return to school and normality as quickly as they can. It's vital to recognise that the return to school may be very important for them emotionally and socially. But it may also be extremely tiring physically and cognitively.x

Returning to school is an important part of their rehabilitation and recovery, and it is helpful to have a planning meeting with members of staff who will be supporting them before they return.

3. Planning a child's support at school

Therapy recommendations and exercises may need to be incorporated within the school timetable. The child/young person may be on medication, and may have to cope with additional medication for conditions such as epilepsy. They have a health condition and so the school nurse should also be notified and included. These are some of the topics to think about when you are planning a child's support at school:

Documentation and communication

- Does the school have all the information it needs to document a health care plan for the child/young person? This could include medical reports, information about medications, therapy reports and recommendations.
- How will they manage any medical recommendations that may differ from usual school policy? For example some children/young people may be advised to drink more frequently or not take part in certain physical activities.
- Establish clear plans from the outset for communication between the school and family, as well as defined plans to review progress and support. Make sure that all staff that need to know about any changes in needs are aware, including supply teachers, playground supervisors and support staff.
- Are there any specific learning support strategies or therapy recommendations that teachers and teaching assistants need to be aware of? How can these be documented in an easily accessible format? (See learning support plan in Part 4.)

Parent's story

"We made a scrapbook for the secondary school staff room. It explained what had happened, what the effects of the stroke had left her with, things that they could do to help, things they might see that meant she was struggling and photos so staff could identify who she was. This helped staff to understand so many of her issues and she did not have to keep telling them her story. When new staff started they were always asked to read her book."

Parent's story

"Getting to know the Special Needs Manager made our life a lot easier because we just had one person to deal with who then communicated with the relevant people within the school."

Parent's story

"Knowing that he could go to the Head of Year or SENCO (Special Educational Needs Coordinator) with any problem made the return to school much less stressful. The single point of contact was a swift and efficient channel for flagging up and dealing with problems, organising visits and meetings and ensuring support in lessons. Any text or email was answered promptly by the person on the case, avoiding tension for our child and complications for teachers, and allowing us to be kept in the picture and communicate any concerns."

Training

- Does the school understand what to do in the event of a medical emergency, like a suspected stroke, and who to communicate with in the family?
- Does the school require any additional training or support from other professionals around any aspects of the child/young person's health condition? For example epilepsy/seizure training, sickle cell training, stroke or acquired brain injury.
- Does the child/young person use any equipment that staff need to be trained to be familiar with? For example helping with splints or orthotics (a type of brace or support that may be used for hand/wrist/arm and/or lower leg/ankle/foot) in PE lessons, helping with any writing aids or visual support aids.

Timetabling and planning considerations

- Consider missed attendance due to a partial timetable, hospital appointments or illness. How can the child/young person be supported to catch up with schoolwork - while being aware this may be a longer-term goal as fatigue is often an issue after stroke.
- Is the child/young person approaching any exams or assessments where liaison with the examinations board about access arrangements would be appropriate (for example extra time, rest breaks, a scribe or completing the exam in a smaller quiet room).
- Consider any aspects of the school term that may require additional planning. For example, think about trips and events such as sports day, and how the child/young person can be included.
- Are there any other specialist services within the borough/region that the school should consider applying to

for early referral? These might include specialist teachers or visual support services.

- Should the school or the hospital consider starting an Education Health and Care Plan application? What steps do they need to take to put this in place?

Parent's story

"Make it clear to the school that absences are for medical appointments and provide hospital/doctor letters wherever possible."

Parent's story

"School timetables are unavoidably inflexible, and therapists have blocks of appointments on the same days each week so it can be hard to avoid clashes. We managed to arrange a morning only school timetable to ease our son in, freeing up afternoons for most appointments and missing few lessons. He had appointments at least three days a week at the start of his transition to school, often in different places, so it was a challenge to integrate with school."

Young person's advice

"Being given extra time for my exams means I can plan my answers and not lose marks just because I haven't managed to finish the whole paper."

Young person's advice

"It helps if teachers are fun, really kind and they understand what's happened to you."

Fatigue

- Can the child/young person manage a whole day or full week, or does a phased return need to be considered? If a child/young person is only attending for part of each day, consider how you can include opportunities for social activity and catching up with friends as well as academic activity.
- If the child/young person needs rest breaks during the day, where is the best place in the school for them to have them? If some of their subjects require double periods, how can rest breaks be factored in to this?
- Consider the amount of homework and coursework the child or young person may have to do and if they are preparing for any tests or exams. Discuss any flexibility that can be offered in managing this if it may be difficult for them.

Parent's story

"It really helps to have a teacher or learning support assistant who understands how much tiredness and fatigue dominates life for a child following a stroke. My son has had wonderful teachers who have quickly picked up on his cues when he is getting tired (which often appear similar to bad behaviour and being disruptive) and are proactive in giving him the rest breaks he needs and pacing him during the week and school term."

Parent's story

"Fatigue makes it hard to respond in a mature, reflective, sensitive way to emotional pressure."

Parent's story

"An hour long lesson is hugely demanding and distraction or absences of attention can interfere with understanding. Loss of concentration leads to gaps in knowledge and loss of confidence. Trying to pick up the threads of a detailed topic can seem impossible."



Pastoral care and psychological wellbeing

- Explore whether the child/young person has any particular worries or concerns around returning to school, and make a plan as to what support or adjustments may need to be implemented to address these.
- Consider how the family and child/young person wants to talk about what has happened to them, and what they want their peers to know. Agree an appropriate way to manage any questions or discussions.
- Can the child/young person have an allocated person to talk to about any concerns or difficulties they are having? How will they know who this person is, and how can they arrange to talk to them if they want to?
Ensure the allocated person knows who to speak to if they have medical questions or significant concerns about the child/young person and/or family's wellbeing.
- Can school staff be educated about signs and behaviours that may indicate difficulties with psychological wellbeing, adjustment or coping? For example, look out for the child/young person appearing tearful, angry or anxious, changes in behaviour, withdrawal or changes in typical class participation, changes in friendships or social interaction.

Parent's story

"The school helped him with his mental wellbeing too. This is so often overlooked, and in teenage years becomes a bigger issue. Mental wellbeing, self-esteem and sense of self can all be affected."

Parent's story

"A good SENCO or head of year is worth their weight in gold to a child facing confusion and coming to terms with a new situation. Timetabled sessions to off-load and escape the busy school environment proved invaluable, and kept school absence to a minimum."

Parent's story

"Although we were told my son's stroke would mainly affect him physically, his personality and emotions have changed too. He is more anxious, depressed and emotionally labile. He's relearning subtle social rules, such as making eye contact or not being overly familiar with strangers that he just implicitly understood prior to his stroke. There are many subtle but significant consequences that go beyond the obvious physical limp and we have to keep reminding ourselves that his brain operates differently now."



Physical access

- Can the child/young person manage their journey to school? Does alternative transport need to be considered?
- Can the child/young person manage physical access to the school? For example, can they reach all the lessons they need to attend, PE, toilets, lunch area, and play area? An occupational therapy or physiotherapy assessment may be required.
- Check the child/young person's timetable during the day and plan where they need to go for each lesson. What do they need to carry, and where are resources like lockers? Consider if they need additional time to move between lessons, or support in carrying equipment or books.
- Can the child/young person access all equipment they need to participate in lessons, PE, games, eating and drinking? Is an equipment assessment required?
- Be sensitive to difficulties that children and young people may find it difficult to talk about - like needing assistance in adjusting clothes and self-care when going to the toilet. They may not feel able to talk about this, so be vigilant for signs of difficulty and include in discussions when care planning.
- Consider talking to the therapy team about how therapy exercises and recommendations can be incorporated into the school day and whole class activity - in a fun and engaging way.'

Parent's story

"Consideration of the physical space from the outset was critical for my son's successful return. Thinking about where his locker was sited, giving him two so he could leave things in school, designating a space for him to retreat to when everything got too much in school, a seat in assembly so he could sit with an adult to support him... small things that made a huge difference. The transport to school was also essential to ensure that he wasn't exhausted even before he had even had the chance to reach a lesson!"

Parent's story

"Small changes can make all the difference such as sitting on the edge during carpet time, not being told to cross their legs or being at the back of the line to avoid being rushed. Also in secondary school thinking about whether a lift pass should be considered".

4. Learning support in class

The child or young person may return to school with a number of therapy assessments completed, and recommendations in place as to how to support their physical participation and learning. They may have spent some time in a hospital school, and therefore feedback may be available from an educational professional. However, it's possible that they will return to school while awaiting some assessments, such as neuropsychology, which might provide more detailed information about skills like attention, language and memory. Some of their capabilities might not have been tested, for example how they will manage in a noisy and busy environment like a school.

The learning support plan that comes with this toolkit can be completed in consultation with parents and professionals who know the child/young person and considered by teaching staff as they observe the child/young person in the school setting. The child or young person should also be actively consulted in completing and reviewing the support plan.

Teaching staff may prefer to allow for a period of observation prior to confirming a new timetabling arrangement or method of support. This allows time to check what works for each individual pupil and gather feedback from the young person and staff.

Download the printable learning support plans in **Part 4** of this toolkit from stroke.org.uk/childhood

Parent's story

"We found a lot of teachers misunderstood the constant fiddling with a pen, eraser etc. They thought this was because our son was distracted but it was actually him desperately trying to maintain his concentration. Get the teacher onside and agree specific 'fidget toys'; blue tack works well."

Parent's story

"She prefers it if a teacher comes to talk and explain individually rather than checking that she is following by interrupting the lesson to ask in front of the whole class."

"She also benefits from teachers who take the time to praise her progress, in whatever area they have taken place – social or academic... and a friendly, approachable SENCO who is consistently positive, does not judge, makes her laugh and engages her on topics other than school."

Young person's advice

"It helps me if teachers plan the session and I'm clear what we are doing and what I have to do, and they tell me what is happening and why."

"Keep things practical: too much talking early on and I've switched off."

5. Planning regular reviews

The return to school is an important part of a young person's recovery, and while planning and preparation are important, it will be difficult to fully predict how the transition will go until the young person starts. Flexibility and communication need to be built into planning as much as possible, with reviews of how things are progressing on a regular basis. It can be helpful to consider:

- who is the best first point of contact for the family: special educational needs coordinator (SENCO), a class teacher, or year tutor?
- how is communication going to be managed: verbal updates, communication books, email?
- how are formal reviews of care plans and support plans going to be managed: termly meetings?
- what happens if the young person is not managing with the agreed level of support? How can this be addressed? When would additional external assessment/consideration of EHCP application be considered?
- are there any school events, like trips, activities or examinations or tests approaching that need advance planning?

Parent's story

"School were able to identify that after PE she would not be as sharp on the next lesson or even the afternoon, it was later agreed she could drop PE in order to work on other lessons."



6. Transitions and transfers

Transitions and transfers can be challenging and stressful for children and families affected by stroke in childhood, particularly when there may be concern about how well-prepared a new school or educational setting might be.

There can be a misconception that if a stroke has happened early in a child's history, for example around the time of birth or pre-school, that it will no longer be having an impact by the time they are in primary school, or moving into a secondary setting.

In fact, it may be that some of the consequences of early stroke only become apparent over time, as the more complex aspects of brain function develop during adolescence. The effects of stroke may also change over time. It can be helpful to:

- carefully plan for each transition – from nursery to primary, primary to secondary, and secondary to tertiary education. Additionally, think about inter-school transitions between years, class groups and class teachers. Ensure good handover to each new setting, and that families have an agreed point of contact. Ensure young people are involved in transition planning, and are informed about who will be supporting them in each new setting.
- anticipate that moving to secondary may be difficult. Young people have to navigate more complex timetables, there is a heavier workload, and a greater number of teaching staff. There is also a higher expectation of independent learning and organisation at this educational stage, and greater challenge in navigating social relationships. Parents and professionals involved in the child's education and wellbeing should ensure

that adequate pastoral support is in place, and that the child is monitored so you know how well they're managing.

- be aware that brain injury could be a factor if a pupil starts to experience difficulties in an educational setting, such as learning, social and behavioural problems. Discuss re-accessing specialist assessment and support if needed, such as neuropsychology, psychology, and family support.
- consider that transitions for a young person might include a permanent or temporary change of class teacher or teaching assistant. Ensure good handover to any new staff working with young people, with explanation of both the visible and hidden effects of brain injury in each case.

Parent's story

"Not all children who have had a stroke will find transitions and changes difficult. But it is really important to anticipate they might do, and meet with SENCOs and pastoral care staff before each move.

"When my son moved to junior school, we only met the SENCO a couple of times: the emphasis was firmly on ensuring the class teacher was providing the necessary support.

Tips from a Special Educational Needs Coordinator (SENCO)

- Liaising with other specialists is a must for schools and making time to talk to them is vital. This can be either away from school, or, if possible, in school with time given for the SENCO to do this.
- Timetable some 'free' periods so the student can have some downtime to have a chat with the SENCO about anything (not just school work), or listen to music or have a snack. It gives time for the brain to re-charge before going into intensive concentration again.
- Get the Key Stage senior staff to fully understand the student's needs. Meet them regularly to update them so they are aware of progress and any issues, and feel included. This means they can be more receptive when you ask for timetable changes or time out of lessons.

- Keep parents informed and respond quickly when they contact you: a good relationship is vital.
- Get to know the student personally whenever possible. Don't just keep conversations to school related issues: if you know they have been to the cinema, ask them about it. Often a chat about something outside school will lead to a chat about any concerns or worries in school.

Parent's story

"Now he is in secondary school I ensured that I filled out all the relevant medical forms and had a meeting with his Form Teacher and SENCO to raise their awareness. He knows who he needs to talk to during the day if he has a problem, which is reassuring."



7. School special educational needs support, and education, health and care planning

Children and young people who have had a stroke may need special educational needs (SEN) support from within school resource, and they may need an Education Health and Care Plan (EHCP) to be put in place. It is possible that special educational needs may have been identified soon after the stroke, but also likely that the full impact of a brain injury on educational attainment may only become clear over time.

Families value the involvement of the SENCO and pastoral support teams from the start of returning to school, to help them monitor progress and be quick to respond to signs of difficulty. It is also helpful to engage specialist teachers, educational psychologists and neuropsychologists as early as possible in the assessment process.

Educational settings are sometimes unsure when to start SEN support planning or EHCP applications, if a child has a medical condition, or is in the process of recovery and rehabilitation. However, early intervention with a clear support plan in place is helpful for families and young people. It also provides evidence of progress or difficulty that can be extremely helpful if an EHCP application is required at a later stage.

Parents should be told about Local Information Advice and Support Services (also known as SEN Support Services) for support in understanding processes around SEN and EHCP applications. Resources are also available to explain the EHCP process in more detail to educational professionals, and in the context of acquired brain injury such as stroke.

Parent's story

"We found the pupil passport very helpful. Our son filled it out really thoughtfully, and it is a really useful document."

8. Where to find support and information

Below is a list of information and resources that may be useful when supporting a young stroke survivor.

For further details visit stroke.org.uk/childhood

Explaining stroke to children and young people

Childhood stroke – a handbook for families

This handbook is suitable for independent readers in Key Stages 1 and 2. It will help a child to understand their stroke, and provide information about emotions, therapy and fatigue. Parents and carers can read and talk about it with the child. It can help family members to understand the support a child needs.

Published by the Stroke Association and Evelina London. Download free from stroke.org.uk/childhood

Animations explaining stroke to children

These animations about childhood stroke are based on the Childhood stroke handbook. They can be used by parents or in the classroom to help children understand stroke in themselves or others.

View them on stroke.org.uk/childhood

Me and my brain

Handbook for teenagers with acquired brain injury, looking at the issues young people can face with education and relationships.

Published by The Children's Trust. Order free online from shop.thechildrenstrust.org.uk

All about my brain

This book helps young people learn about acquired brain injury, and strategies for dealing with some common difficulties.

Published by the Child Brain Injury Trust.

Buy online from

childbraininjurytrust.org.uk/shop.

All about stroke: information for children

This is a general guide about stroke in people of all ages. It is suitable for independent readers in Key Stages 1 and 2, and parents and carers of younger children can use the guide to help answer questions from a child or their siblings.

Download or order a free print copy from stroke.org.uk/childhood.

Information about medical conditions, disabilities and special educational needs for parents, carers and professionals

Stroke Association Childhood Stroke Support Service

Offers information, advice and support to parents and professionals. It also provides access to peer support networks and events.

Please signpost families to the service and find out more at

stroke.org.uk/childhoodstroke

Sickle cell and thalassemia: A guide to school policy

A detailed guide for schools supporting children who have sickle cell disease, a condition linked to stroke.

Download it from

sicklecellanaemia.org/policy

Understanding and managing fatigue

A guide to support children and young people with fatigue, at home and in education.

Download it for free from

childbraininjurytrust.org.uk.

Brain Injury Hub

This website for families and educational professionals includes information, support and resources, as well as personal stories and practical advice.

Visit braininjuryhub.co.uk

Stroke in childhood: Clinical guideline for diagnosis, management and rehabilitation

This is the main information for professionals on diagnosing stroke and treating the effects of stroke. There is a clinicians' version and a parents' version on the same page.

Download it from rcpch.ac.uk/resources

Teaching and training resources

Must try harder: Returning to school after brain injury

This is a video for educational professionals about children returning to school after a stroke or brain injury, with information about the emotional impact.

To view it, search for the title on youtube.com

Acquired Brain Injury and Education

Factsheet about acquired brain injury (ABI) in children, produced by the Child Brain Injury Trust:

View or download it from

childbraininjurytrust.org.uk/wp-content/uploads/2018/07/Education-Acquired-Brain-Injury-and-Education.pdf

Information for teachers supporting young people with hemiplegia

Advice tailored for pre-school, primary and secondary age children, produced by HemiHelp.

Access it from hemihelp.org.uk/professionals/education

Statutory guidance

Special educational needs and disability code of practice: 0 to 25 years

This is the code of practice for schools in England, published by the Department for Education and Department for Health.

Download it from gov.uk.

Supporting pupils at school with medical conditions

This guide is published by the Department for Education.

Download it from gov.uk

Council for Disabled Children online resources

This is a resource hub for educational staff, other professionals and parents supporting children with disabilities.

Visit councilfordisabledchildren.org.uk/resources-and-help.

When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

We're here for you. If you'd like to know more please get in touch.
Stroke Helpline: **0333 567 0841**
Website: stroke.org.uk/gethelp
Email: info@stroke.org.uk
From a textphone: **18001 0303 3033 100**

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