

Mums, dads and siblings:

The tremendous impact of childhood stroke on families

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Renée and Nancy are two friends who met through an event organised by their consultant at Great Ormond Street Hospital. For 15 years, they have been raising awareness of childhood stroke and advocating for better care for the families affected by this life-changing event.

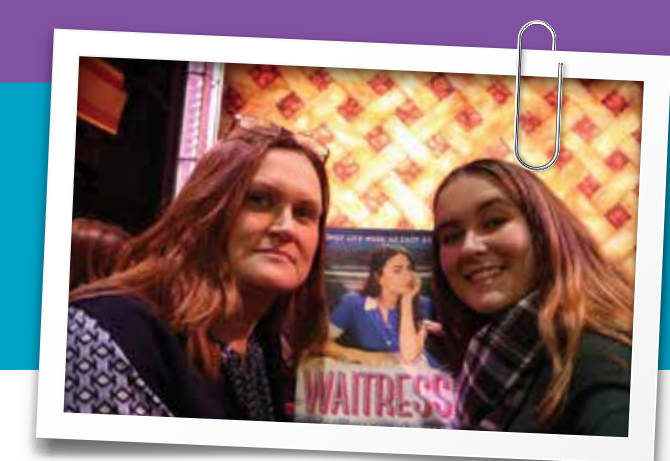
Renée's story



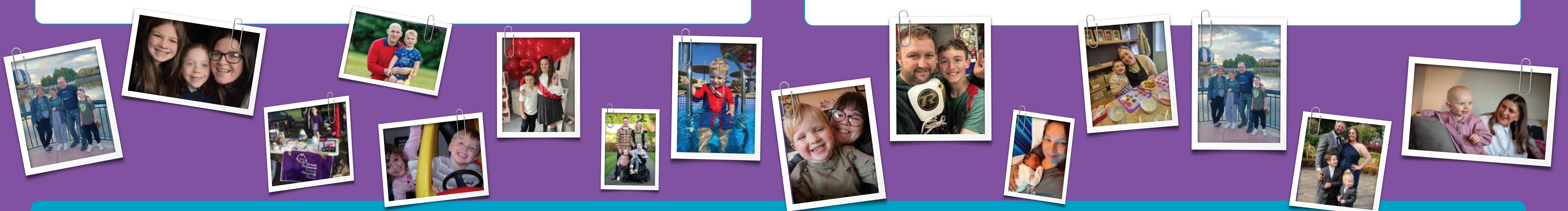
My 13 year old son Oli suffered a stroke in 2009. Although, thankfully, he went on to make a full recovery, our family was placed under immense pressure. We became financially unstable as I stopped work to become a carer and his father lost his job due to taking time off for hospital visits. I was diagnosed with PTSD ten years later. Sadly, our story is not unique.

Since 2010 I've supported over 1300 parents in a safe, online support group: "My Child Had a Stroke." Participants have said that this group provides them with a lifeline, as there is little support available for families.

Nancy's story



At the age of 1 ½ years, my daughter Emily, suffered two strokes. She was one of the lucky ones to have a positive outcome, but the experience had a big impact on the whole family. There was no emotional support from other families, charities or the hospital. We were left alone to try to figure everything out. This had quite a negative impact on the family as a whole – trying to deal with the enormity of the situation. In later years, we sought out therapy to address these issues. While I believe it would have helped if some of the current support measures were in place at that time, a lot more support is needed. Support is needed at the time of the stroke and through the difficult journey that the families live through.



Childhood stroke impacts on the whole family

Over 400 children a year are diagnosed with a stroke in the UK. This has a devastating impact not only on the children, but also on their families. With the fear and anxiety of the child having another stroke, families' lives are changed forever.

Following a childhood stroke, families must adjust to their **child** suffering from a wide range of post-stroke symptoms, including:

- Neurological deficits (75%)
- Hemiplegia (75%)
- ADHD (50%)
- Psychiatric disorders (59%)
- Language problems (30%)

In addition they must cope with issues such as lower levels of social participation, reduced peer acceptance and attention problems.

Family dynamics change. Most parents are of working age, so the experience impacts on their careers / jobs, income and financial stability. As childhood stroke happens in the early stages of life, the effects on everyone can last for many decades.

It's also a deeply emotional and disruptive experience for **siblings**, facing challenges that affect them emotionally, socially and psychologically. Many feel guilty for being healthy or not being able to help. They can suffer confusion, distress, jealousy and

resentment as the young stroke survivor receives more attention from parents. Their needs may be overlooked as the wider family focuses on the care and recovery of their **sibling**.

They may take on more responsibilities at home, which can cause feelings of being overwhelmed. And their performance at school may suffer as a result of the stress. They can become withdrawn and lonely, suffering throughout their childhood and into adulthood.

"Counselling should be offered immediately and available at short notice for 2 years at least"

"The event was very traumatic for myself and my daughter's siblings too. She can't remember anything, but we saw and remember it all, and I still have flashbacks and am panicked by certain noises now"

"My son was in the middle of his GCSEs when our daughter had a stroke and he actually wrote his English speech on the topic, 'A stroke does not only affect the person who had the stroke', it really does have such an impact on the whole family"

"One of my son's therapists told us he thinks it can be just as hard and traumatic for loved ones as it is for the stroke survivor"

"It was the most shocking experience I ever had, and I pay for my support now, and still struggling..."

"My child had a stroke"

Renée's Facebook Group

Parents' contributions highlight the need for more mental health support:

"I have had more help from this group than I've ever had from a Doctor or professional"

"This group has been an incredible source for me over the past 11 years"

"Extremely valuable. We are no longer alone on our journey"

"It has been a lifeline. Despite kindness from my family and friends, I felt so alone. Like no-one understood. Until I found this group."

"Facebook groups like this one saved me! Although we had amazing healthcare professionals and specialists involved in the treatment of our stroke child, there was zero focus on the mental health impact a stroke has on family. Online support, connecting with other parents, sharing personal experiences and feelings - it was crucial to the healing process (physically and mentally)"

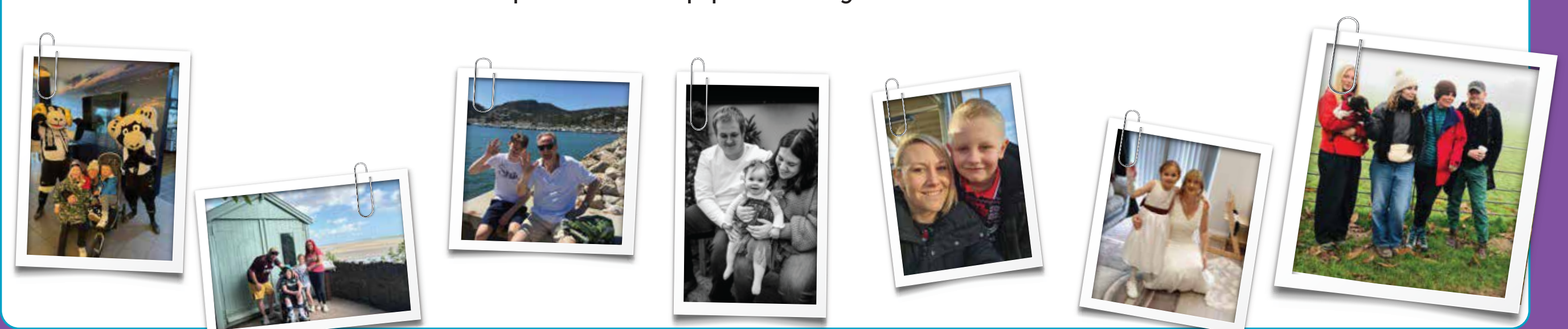
Our involvement with the UK Stroke Association

Working with a small team of other parents, Renée and Nancy have helped to inform childhood stroke services, raised awareness of childhood stroke and promote the charity's work. Between us, we have:

- Spoken in strategy meetings, at Parliament, on the radio and TV
- Helped to recruit dedicated childhood stroke staff
- Assisted in producing clinical guidelines
- Influenced the current national TV campaign
- Developed new resources for paramedics, schools and medical students

The Stroke Association now provides a range of support for parents, incl.:

- Parent-to-parent phone support
- Pre-Covid: Face-to-face parent support days across the UK



Insights

Our work with the Parents' Support Group has shown that more resources are needed for families. By supporting families, they can provide better care for children, improving paediatric stroke outcomes.

We'd like to see...

- **More research** on the effects of childhood stroke on families in the long-term
- **More resources** to meet the unmet emotional needs of families
- **Better communication with healthcare providers** to help siblings understand the situation and express their emotions
- **Counselling/therapy:** Family or individual therapy to help parents and siblings cope with their emotions and reduce feelings of isolation
- **Support groups for siblings:** A safe space that provides understanding and comfort, to process their emotions and help mitigate challenges

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