

Living Space London - Saturday 22nd September 2018

Summary of the day

The day was introduced by Anna Panton, Childhood Stroke Project Manager for the Stroke Association. Anna and her colleague Rachel offer a Childhood Stroke Support Service for families affected by stroke in childhood. The service offers information, advice and support for families – and more details are available on the [Stroke Association website](#).

The day was co-facilitated by Renée Wallen, parent of a childhood stroke survivor. She runs a Facebook group for parents and carers – [My child had a stroke](#).



My experience of stroke in childhood

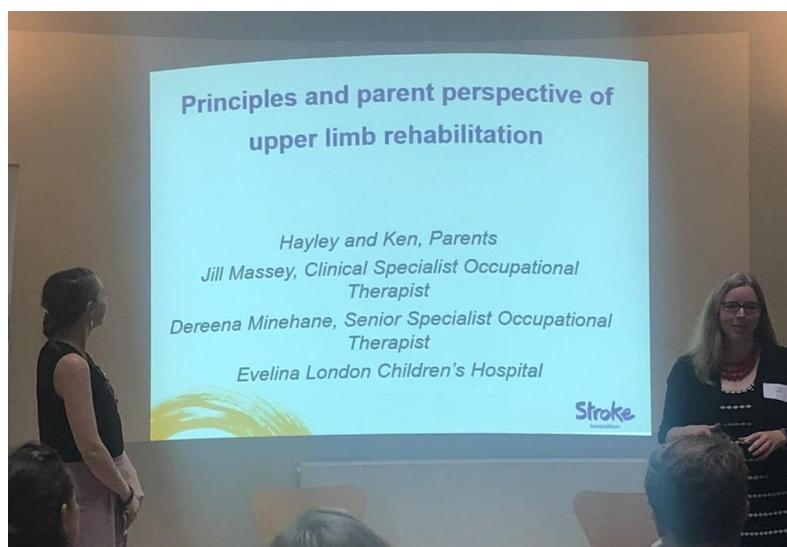
Stroke survivor Kat opened the day by talking about her personal experiences of stroke in childhood, and taking questions from parents who were present.

Kat reflected on her personal journey “I’ve had it forever, so it’s normal for me – I thought it was normal to only use one side and I adapted.

People are often impressed by what I am able to do.”

Principles and parent perspective of upper limb rehabilitation

Jill Massey and Dereena Minehane from the Occupational Therapy Team at Evelina London Children's Hospital spoke about upper limb rehabilitation in their therapy service.



Jill and Dereena were joined by parents Hayley and Ken – who talked about their families experiences in accessing different types of therapy.

Pushing the boundaries - the intensive upper limb rehab service at Queen Square

Will Chegwidan, a Senior Occupational Therapist from the Neuro Rehab Unit at University College London Hospital talked about their intensive upper limb rehabilitation service for stroke survivors over 16.

Will was joined by Harry, a young stroke survivor who has accessed the programme, and reflected on his experiences.

Childhood stroke

Parent support and information day

Accessing sport with additional needs

Katie Page from Access Sport CIO talked about the range of sports and volunteering opportunities available to young people through their services in London, Bristol, Manchester and Oxford. Their website can be accessed at www.accesssport.org.uk/ignite.

Liferaft – Do I have to say it again?

Clare Brooke-Little talked about a new online product called MyLiferaft.

MyLiferaft provides a secure online place where you can keep and update all the details about the person you care for; all their health, care and well-being needs. To find out more about MyLiferaft, visit their website www.myliferaft.com



Working with schools to support young people after stroke

Anna Panton from the Stroke Association and Sharon Richardson, SENCO from Dartford Grammar School talked about support in educational settings. Anna introduced the new Stroke Association [toolkit for schools](#) and discussed some key themes and questions with Sharon.

Childhood stroke

Parent support and information day

Stroke
association

Supporting emotional and psychological wellbeing after stroke in childhood

Sophie Dewar from the Psychology team at Evelina London talked about emotional and psychological support after stroke – and answered specific queries from attendees.

Parents talked about books to help children understand feeling different – and one family referenced a book they had found helpful called [Odd Dog Out](#)



Information stands and resources provided by:

[Brain Injury Hub](#)

[Child Brain Injury Trust](#)

[Contact](#)

[HemiChat](#)

[MyLifeRaft](#)

[Special Effect](#)

[Stroke Association/Evelina London Childhood Stroke Project](#)

[Young Minds](#)

Thank you to everyone who supported the day.

Slides for each of the speakers can be found on the [website](#).