

Please see below for a brief summary of the discussion at the end of today's HIT session. I am sure I didn't capture it all, but hopefully the essence and main points.

Thanks, Gemma

1. When asked if anything had helped anyone with communication someone said that they had used AI tools to help with understanding and being able to explain themselves.
2. When asked about issues that people have, someone said that their timelines have changed. Their perception around time....sometimes thought it was weeks ago when it was yesterday. It was suggested to keep a diary to keep track of things
3. We talked about the cognitive assessment by the neuropsychologists and a number of people had had these. They cover talking, numbers, spelling, letters, understanding. We talked about their experiences:
 - One person said it took 3 hours and was exhausting. He said that afterwards his cognitive fatigue was so much his wife said that he wasn't making any sense when he talked. He also said that he would recommend doing one if you are able although it was fatiguing. He said that results are not shared straight away.
 - One person had to have 7 different sessions of 45 minutes each to complete the assessment as his cognitive fatigue was so prevalent. He said he found it quite difficult as the tests made him realise the extent of his cognitive issues, particularly cognitive fatigue.
4. Cognitive fatigue is like a rollercoaster with lots of variables...could be medication, could be what you have been doing that day, how you are feeling, where you have been and there are no warning signs. ... no warning signs
5. It is hard to explain to kids what cognitive fatigue is...Different Strokes have resources you can order: <https://differentstrokes.co.uk/new-childrens-resources/>

6. Having things in visual format helps with cognition
7. Often people have to pre think about what I'm going to say before they say it, which is tiring in itself
8. There is a big impact of medication on fatigue...any changes can affect you. Discussion on how it is important to ask health professionals about side effects so you can have full understanding. Some medications can affect fatigue and cognitive response times, someone mentioned that they felt morphine and amitriptyline affected them this way. *NB. All medications affect people differently. It is important to talk to medical professionals if you think these are affecting you and they can support you to change to come off them if deemed appropriate. Reminder that medication changes should always be discussed with a health professional first.*
9. One comment that is sometimes a problem to explain to others what you need in a conversation and your needs differ from conversation to conversation – whether its lunch in a café with a friend, work, a group setting, parenting etc
10. Cognitive changes are often missed in an acute setting as don't notice them until you're in context of your life later in your recover. It is felt that the possibility of this happening is not explained in the early days so can come as a shock.
11. Don't always realize things are happening to you or you are acting in a certain way until later on after an event has occurred as when you are in it you are in fight or flight mode
12. BAS wants to focus on the unseen stroke this year and is hoping to support more information giving around this.