



Dysphagia & Me



Kate Allatt, Stroke survivor, inspirational speaker, Mum & author of 'Running Free: Breaking Out Of Locked In Syndrome' (2011 Amazon) – @KateAllatt

To us humans, food is so much more than fuel; for most of us eating and drinking is a pleasurable experience.

Acute ill health and chronic conditions can often result in us being robbed of this pleasure, our ability to choose what we want to eat and to be able to feed ourselves – something on a day-to-day basis most of us take for granted.

Appropriate nutrition is key to both recovery and disease management, not just physiologically but psychologically – the choice of what we eat, when we eat and the act of feeding ourselves is empowering.

To highlight how important food is to us all on so many levels, Fresenius Kabi is collaborating with motivational speaker and stroke survivor mentor, Kate Allatt, to support healthcare professionals in caring for neurological patients and their individual needs.

In 2010, Kate – a fit and healthy 39-year-old – suffered a brainstem stroke that resulted in Locked In Syndrome. Here, she shares her experience in hospital, her ongoing journey to recovery and the lengths she went to in her very personal quest to eat and drink again.

Introduction written by Fresenius Kabi

Kate's story

"You need to assemble your family. Sorry."

"What, why? No! Our kids need Kate. No. You can't be right. No. You've made a mistake," said Kate's husband, Mark, as he desperately pleaded with the ICU doctor.

"I'm sorry Mark, Kate's had a huge brainstem stroke – a right vertical artery dissection, occlusion and infarction of the Pons – it's severe. Our brainstem is the control box for our body."

"She's in a medically induced coma on life support. If she survives the night, she will have very little quality of life and we would recommend switching off her life support. I'm so sorry," the doctor said.

Three days later, I slowly emerge from my coma.



'I'm here. Help! Help! Why can't you hear me. Stop ignoring me. Why are you talking about me? I'm right next to you. What are you doing? Why am I here? Take that out of my mouth!

'Where are my kids? I need to hug my kids.'

'I'm so thirsty. I need a drink, look at my eyes, I need water. What's happening to that poor man next to me? My leg cramps, please make it stop. Why can't I move myself? Someone HELP,' the voice in my head was freaking out.

Later Mark explained: *"You've had a stroke."*

'What! Don't be ridiculous, I run 70 miles a week and I'm 39,' said my voice in my head.

"You've also got Locked In Syndrome," Mark said.

"You mean that's why I can think, feel, see and yet move absolutely nothing below my eyelids!"

Mark said: *"The doctors recommend we read The Diving Bell & Butterfly to help us."*

'...he never recovered! Sod you all for trying to lower my recovery expectations. I'll be home to hug our kids, eat again and run to the hills. I'll prove you all wrong. Watch me!

...and please don't eat those McCoy's Cheese and Onion crisps near me!

Nine weeks later, I left my amazing one-to-one care to head for a busy stroke rehabilitation ward. By then, my right thumb had moved three millimetres and I had slight head movement. I'd endured hours of boredom with a ticking clock for company. I had almost no oral hygiene. I had no taste pleasure except for secret teaspoons of Earl Grey tea, until it was stopped.

I experienced a real Code Blue emergency after my PEG insertion; suffered horrific hallucinations that no one warned me about; endured gut-wrenching separation anxiety; and had frequent and frightening trachi pop-offs.

I hoped my rehabilitation might 'save' me, but I was wrong.

Grit & determination

Six weeks into my rehabilitation, I had my formal review. Slobbering like Hooch (the dog in Turner & Hooch), I was told by the multidisciplinary team (MDT) treating me that I hadn't improved significantly. In fact, plans were afoot to discharge me to a nursing care home. What?

I had to be removed from the meeting, hoisted like a sack of potatoes back into bed. I spelt out to my partner-in-crime S-T-A-N-D B-Y M-E.

On top of being written-off in my review, I never got a refund to climb Kilimanjaro via the Western Breach for my 40th birthday, which I'd paid for, and my now ex-husband took our kids on holiday on my actual birthday, as I lay in hospital.

I was fuming, had a point to prove and set about 'willing' every sinew in my body back to life.

I later discovered Dr Robert W Teasell clinically referred to my 'willing' as repetitive, frequent and intensive actions, which he says are necessary to optimise stroke recovery. I'd look at my finger and shout - in my head - at it to move in an attempt to re-wire my broken brain. I had never been average; I was highly motivated and driven to be reunited with my kids, India(10), Harvey(8) and Woody(4).

I also insisted that all my visitors must facilitate lip, tongue and swallow exercises before every social visit with me. They hated doing it because while I could feel flickers happening, they saw no physical movement.

I had an abject fear of not eating ever again. Eating and drinking again mattered to me; as did walking, running and hugging my kids. My MDT would have known how important eating was to me if they'd asked me.

My oral motor exercises included trying to touch a pink lollipop sponge with the tip of my tongue or trying to induce an epiglottis swallow with an ice-chilled teaspoon on the back of my tongue.

I also had a series of lip sync exercises and tongue gymnastics. I never stopped, well only for 10 minutes when my muscles fatigued. Then I'd start all over again. I was a machine and used to working hard. It's funny to think that my MDT commented that 'I pushed them harder than they pushed me!'

But that does raise an interesting point.

I came into hospital nine stone five pounds of running muscle and was weighed at seven stone six pounds towards the end. I know that my dietitian meticulously calculated my PEG diet, but she never told me that. I wanted to be informed and I am convinced being told this kind of information would have really helped me understand the rationale behind decisions being made about my treatment plan, making me feel more involved and in control.

Knockbacks

Imagine my excitement when I was offered my first videofluoroscopy. Finally, I could stop eating with my eyes watching MasterChef, I thought.

Sadly, I failed the test.

However, I raised my game after the setback. Together with my diligent assistant Speech and Language Therapist (SLT), I worked tirelessly with a straw to improve my lip sync and diaphragm function, with more tongue and epiglottis exercises. She believed in me, actively listened, always looked into my eyes and I trusted her. We had a bond. The relationship between patient and therapist is key to recovery optimisation, in my opinion. Perhaps, a useful lesson for all healthcare professionals involved with patients like me.



I was utterly relentless with my rehab, just like the classic fight-back-to-fitness sequence in Rocky II. I even managed, with the help of my SLT holding the straw, to blow a ping pong ball off the length of my hospital table.

Six weeks passed and I was to have a second videofluoroscopy. We felt very confident that I would pass it. I'd considerably ramped up my oral motor exercises and was so close to eating and drinking again.

My mindset was never 'if' I'd recover but 'when'. I dreamt about once again enjoying my guilty pleasures - a few chilled pints of lager on a summer's day and a Sausage and an Egg McMuffin.

Within 5 minutes of taking my position by the video, having drunk my thickened solution, the rather matter-of-fact doctor behind the glass screen said to her colleague: *"No change."* (I learnt how to lip read in hospital by the way.)

I was utterly floored.

My SLT went white with shock. My whole world imploded. I was devastated and couldn't see how I could ever recover from this massive body blow.

My hospital incarceration had been one step forward and two steps back since my brainstem stroke, but this was 100 steps back to me. I was inconsolable and did lots of ugly crying for a whole week. I refused to go to any of any of my therapy sessions and pretended to be asleep when anyone, apart from my best friend, visited. This was by far the lowest point in my stroke journey.

Then, I had an idea.

What if I 'signed' a disclaimer to say that I accepted all responsibility if I choked to death and died by choosing to eat? I put it to my dietitian and SLT who duly approved a few safer foods to experiment with.

I was ecstatic to be given Petit Filous, huge salad-sized bowls of porridge (me pushing), and blocks of Cadburys Caramel Chocolate to suck on. It's true that the more you chew and swallow real food, the more you improve your swallow. But it is risky.

Walk to a new life

Nine months after my stroke, against all the odds, I walked out of hospital.²

But eating and drinking at home has not been without problems for me. Not least the stone of weight I put on with my

daily Sausage & Egg McMuffin in just one month of leaving hospital.

There have been no less than 15 different hospital visit endoscopies to remove stuck food in my oesophagus over the years. I've since learned is to better self-manage my condition by always cutting up grapes, to tuck my chin when I eat, to eat slower, chew more and don't wait until you are starving to devour a meal.

It seems incredible to me that in the 10 years since my stroke, I now collaborate with NHS Leadership to help survivors improve their swallow issues, functional rehab and all-round holistic health.

I've had the pleasure of working with Fresenius Kabi and I am heartened to see how they genuinely put patients at the very centre of what they do. They listened to my dysphagia journey, they learned from it and improved. They put lifesaving medicines and technologies in the hands of healthcare professionals to help patients with swallow issues be the safest and best versions of themselves.

For me, I did run,³ hug my kids and eat again. I'm lucky, although I do still try to chew food thirty times before I swallow! I even managed to achieve a few more things which no one could have predicted in ICU.⁴

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References: ¹ Teasell R (2019). DocTalks: Dr. Robert Teasell. Recovery after Stroke. St. Joseph's Health Care London. Accessed online: www.youtube.com/watch?v=exBEKlkj2RY (Nov 2020); ² Allatt K (2010). Let me out! (leaving hospital). Accessed online: www.youtube.com/watch?v=zVDMBNr136U (Nov 2020); ³ Allatt K (2011). Percy Pud 2011 (running 1.5 miles in the Percy Pud Race Sheffield just 18 months after my stroke in December 2011). Accessed online: www.youtube.com/watch?v=Sk6qnBVYXbk (Nov 2020); ⁴ Allatt K (2018). How will YOU #ThinkDifferently in the next 8 years? (proving I could have quality of life and they were right not to turn off my life support machine). Accessed online: www.youtube.com/watch?v=GrOFzPkZApE (Nov 2020).

