

Mike takes back control

Mike was a police officer of 17 years when, at the age of 32, a brain tumour was discovered and after cancer treatment and an epilepsy diagnosis he was medically discharged in 2003.

In May 2020 after fighting Sepsis and after a huge stroke as a complication of Covid he was left paralysed down one side, unable to communicate either verbally or by written means. Mike's sister, Mandy, tells us about his journey from here and how working with ARCOS had given him back some control of his life.

Before you read on, close your eyes and cover your mouth and imagine what it might be like to be unable to speak whilst I tell you about my amazing brother, Mike.

On 23 December 2020, after his stroke, our family were given the heart-breaking news by professionals that Mike would continue to deteriorate and the only way forward would be Percutaneous Endoscopic Gastrostomy (PEG) feeding through a tube, due to his inability to swallow.

After two years of trauma, we were all struggling to deal with his damning prognosis. There was no speech and language input as all the health professionals had given up. As it appeared had Mike.

It was then a member of staff at his residential care facility mentioned the charity ARCOS to us. In April 2021, Mike had his first assessment with the absolute powerhouse that is Kay Coombes, their Director and founder.

Over a number of months, Kay came to visit Mike every weekend (outside of her working hours) to look at his posture, his cognition, his challenges, and start to develop some solutions. Her first comment to Mike was that "he could take back some control himself and although there were things that he couldn't yet do there was plenty he could do to help himself".

And she was right! Even now, when Kay's name is mentioned he straightaway puts his hand to his throat so that he can hold his own head up and massage his voice box. Mike no longer drools as he is able to stop that himself by using techniques Kay has taught him.

ARCOS loaned Mike a very expensive tablet that 'talks for him' and enables him to communicate with his carers and family. ARCOS provided 1:1 support to Mike to enable him to use it effectively. The tablet allows him to have a choice over what he eats, what he wears, and what music he listens to. He can now sing along with family and carers!

Each of these devices costs around £4000 to purchase and are only offered by the NHS to 0.01% of the population that might need one.

ARCOS also trained family and staff in how to communicate with Mike in order to facilitate better communication on a day to day basis, including the verbal and written word. They've also advised on the purchase of gadgets to help communication, including a dementia clock and an 'about me' book.



The best news is that Mike did not have to have a PEG fitted! Such is the improvement of his swallowing ability that he has moved from having only liquid food in 2020 to normal food today. Just before Christmas, on a family trip out to the local garden centre, Mike had cheesecake as big as a side plate and wolfed it all down! Not only this, but now no one needs to assist him with his eating or drinking as he is able to do it all for himself with adaptations, as suggested by Kay. Last Friday, he had his first fish and chips with mushy peas in two years and thoroughly enjoyed it!

What Kay and ARCOS did was offer Mike and our family hope where there wasn't any. Instead of concentrating on his limitations, they offered solutions.

Mike is now able to laugh and smile and communicate his feelings. When we visit him, he can very often be found with the new friends he has made and you can hear his laughter echoing down the corridor!

We can never thank Kay and ARCOS enough or repay their kindness. Now take your hands away from your mouth and open your eyes and try to recognise the difference that ARCOS has made.

