

Let me take you back to a morning in March 2012. It's difficult for me to remember the precise date but I know that it was more or less my 13<sup>th</sup> Birthday (ironic, huh?)

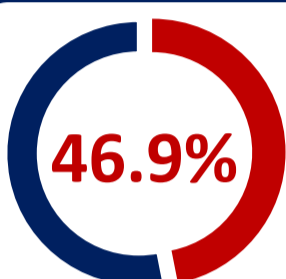
**Sometimes** a tracheostomy is the only way forward. It might seem strange to say this but getting a trachy was a step forward for my daughter Clare, 2 weeks after a severe haemorrhagic stroke.

Clare was intubated. When the ventilator was disconnected, she had no ability to breathe on her own. She was "locked in" and could only move her eyes slightly, and blink one eye. For the first few days in ICU, I was asked whether we should quit. Of course not. By Day 8, Clare had weaned off the drugs that had helped her heart and circulation. The tracheostomy was suggested because "if you're going to carry on, this is the next step".

Being intubated looked brutal. Every day the tube was moved from one side of Clare's mouth to the other to relieve pressure. It was all too easy to imagine damage being inflicted to throat and trachea by intubation. So, the tracheostomy seemed like an improvement, even with a ventilator attached.

**The** children's hospital gave me plenty of information about tracheostomies. A specialist nurse helpfully explained trachy's to me, demonstrating on a baby doll. She also arranged for us to meet a boy with a tracheostomy, who walked into the room. Another good thing about The Children's Hospital was the availability of training and I soon felt confident in tracheostomy care and once Clare moved to HDU I was allowed to perform suction for her. I learned how to change the tracheostomy tube and went on the a Basic Life Support course for people with tracheostomies. I worked through the training packages these until I was 'signed off' allowing me to take Clare out on trips from hospital.

We were out and about every day. I learned about the "emergency kit" to accompany a person with tracheostomy everywhere: this includes a replacement trachy tube in case you have to change it; and a smaller "emergency" trachy tube, in case you can't get the first one back in.



During the ITC Project across 20 UK hospitals we found that 46.9% paediatric inpatients suffer adverse tracheostomy events during their hospital stay.

**Clare** had various different types of tracheostomy tube during this time. After a revision surgery, required because of the heavy ventilator tubing "stretching" her stoma she returned with a "double-lumen" tracheostomy. There are safety advantages. If secretions cause them to block the inner tube can be taken out without removing the whole tube. But it was stiff and bulky and the end stuck up under Clares chin. She preferred a longer more flexible tube so that the ventilator tubing attachments were further away from her chin.

Like many tracheostomy patients, Clare's hospital stay involved a serious incident. One morning the nurses explained to me that Clare's oxygen levels had dropped following a roll overnight. The nurses felt the tracheostomy had blocked and removed it but they'd then struggled to put one of the longer, flexible tubes back in. Clare's oxygen levels continued to drop until a smaller basic tube was re-inserted. To their credit the hospital responded by providing more training for the longer tubes and suggested that emergency procedure should always be to insert the basic and easier to insert tube.

**Everything** is hard to recall clearly after that, but records indicate that in about 2013, I was transferred from critical care to a Rehabilitation Centre. It was great to be a part of and despite my neurologically diverse brain, I succeeded in forming many new memories and making several new friends.

**At** the rehabilitation centre I witnessed the highest level of tracheostomy care. Nurses and support workers were all fully trained and there was a drive to regain physical function as far as possible. This included trial of a speaking valve in-line with the ventilator tubing. Unfortunately, Clare still didn't manage to vocalise, even with hours of trying, and with her improving mouth movement. It took more than 2 years of continuous ventilation before Clare could breathe unaided during the day – and this finally gave her the ability to speak audibly with a speaking valve over the trachy tube.

Without the vent attached in the day, there was no longer a benefit in the longer tube, and the specialist nurse suggested changing to a smaller diameter tube. This gave Clare's voice a powerful boost and we returned the excellent but slow eye-gaze computer system she'd been using at school. She dictated her exams.

Clare's tube required upsizing once again when she spent time in ICU with a virus. A larger diameter tube was helpful in delivering high pressure ventilation during serious respiratory illness.

Sometimes speaking valves can be utilised in ventilated patients. However, this requires clinical stability, specific ventilators and an attentive multidisciplinary team regularly assessing the patient.



**After** 7 months in hospital and 8 months in rehabilitation, I finally went home and met my new carers



The holes in fenestrated tubes allow more airflow through the vocal cords. This can compliment a speaking valve. Each type of tube has its own positives and negatives such as those Jenny addresses here.

**5** years after acquiring the tracheostomy, having transferred to adult services Clare trialled decannulation. The questions were: would night-time ventilation work via a face mask? would it be possible to manage secretions despite with an impaired swallow? It turned out that throat suctioning and use of a Cough Assist were enough to keep on top of secretions. But at night-time, there was an intermittent and dangerous airway collapse. After 2 months of struggle, Clare had her first ever seizure, and went into hospital to get a new tracheostomy.

Clare's new tube was again a bulky, stiff double lumen tube. Speech was not possible until a week after the operation when Clare could have an uncuffed trachy with fenestrations. A drawback of the fenestrated tube is that suction catheters stick in the holes so you have to have two inner tubes. One fenestrated for speaking, one normal for suctioning. I bought a bunch of little boxes for inner tubes to travel around with Clare, but it was far from ideal having carers juggling them in the minibus on the way to college. Without a speaking valve, Clare's voice was non-existent with the bigger trachy, and Clare stopped speaking during morning and evening care routines.

**So** Clare changed back to her paediatric tracheostomy tube and still has one. I'm sure that many adults with tracheostomies find a double lumen tube the best, and standardisation helps with training and the amount of equipment required in hospitals. But, people are different, what works for most people doesn't necessarily work for everybody.

**After** my stroke, I am left feeling both content and guilty at the reason behind my contentment – no matter how terrible and catastrophic your scenario might be, it could always be worse.

**Even** before Clare regained the ability to breathe unaided during the day, the tracheostomy never seemed like one of life's main problems. Clare went to school whilst ventilated via her trachy and even took up climbing. We manage the trachy just fine and have learnt several useful life hacks from the "Tracheostomy UK" Facebook group. The group is a great source of advice for people leaving hospital without all the training and assistance that they would have liked. I'm not sure how I wrote so much on trachys. There are a million more interesting things to write about Clare. Tracheostomies are really not the worst thing in the world. You probably have more to contend with in your life!