



rejoicing

a patient I learned from

A nurse reflects on a high
dependency patient who
showed her the true meaning
of joy and courage

You go into nursing to make people better, right? Well, what do we imagine that looks like? Have we done our jobs well if our patients leave our care with seemingly greater needs than they had before? Or is that an inevitable, natural progression of illness, injury, and life? Is our role rather to come alongside them in that journey, easing some of the burden?

Sometimes I wonder if I will remember my patient's time with me more than they'll remember my time with them?

Reflecting on a very challenging season for one of our long-term patients on our respiratory High Dependency Unit (HDU), I'm struck again by the qualities I admired in her.

Maya (pseudonym) was joyful and resilient. Many afternoons, I'd sit with her, singing a Mr Tumble song and trying to interpret her Makaton. I'd witness her simultaneously sensing everything around her, whilst maintaining her focus on her video or colouring book – and boogieing in her chair – and I'd think back to the contrastingly scary clinical situations I've also witnessed in her room.

Maya has muscular dystrophy and learning

disabilities. Months before she turned 18, she was admitted to our adult HDU for the first time, to manage her secretions and provide non-invasive ventilatory (NIV) support. Understandably, she hated it when she needed suctioning, nebulisers, 'cough-assist' and her tight mask fitted to her face, especially in a deteriorating situation. If her monitoring screen was beeping and her oxygen level was dropping, the 'tough love' side of nursing would come out as we firmly but gently repeated *'Maya, we need to put this mask on...'*

It must have been terrifying when the beeps and noises got louder, the ITU team rushed in and, amidst serious but focussed voices, laid her flat, inserted lines, tubes, and drugs to put her to sleep, whisked her to ITU before waking her up a few weeks later. Then, the reverse, until eventually she 'stepped down' to us on HDU.

Sadly, this sequence of events happened more than once for Maya, and each time our concern grew. On her final return from ITU, Maya looked winsomely better, but there was one distinct change: she had a permanent tracheostomy. We cheered as she entered our unit, but questions rang in our ears: can we be hopeful? Will we ever wean her off the ventilator? Will she ever be her playful, cheeky self again? Will she survive this admission?

Over the following weeks, and months, Maya made me smile countless times. She showed incredible adaptability to breathing and living with a 'trachy', including many trials and chest physio sessions. But most profoundly, she learnt to adapt to life without an audible voice, communicating with Makaton instead! She used her infectious, warm, hilarious energy to express her emotions and encouraged us to feel them too. She welcomed every visitor to her room with a silent but warm 'hello', asked them their name, and invited them into her activities with an affectionate handhold or a hug.

Despite so many setbacks, Maya showed me what joy and courage are. I can rejoice over her and thank God for the privilege I had to be on this journey with her. And although she may not have looked 'better' than when she came in, she had grown and adapted through the challenges she faced. She had found the strength to face the challenges that lay ahead. I hope I have eased some of the burdens in that journey, as she certainly eased some of mine.

Anon

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