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FROM THE INSIDE

Delirium: name it, say it—loud and clear

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The following piece was prepared for From the Inside with the help of section editor Aoife Abbey. Louise Gallie is a former intensive care unit (ICU) patient and now ICU rehabilitation volunteer who previously shared a testimony of her journey through this illness in 'Nursing in Critical Care (NICC)' [1]. Some parts of the story below will resemble that piece. The purpose of working with Louise for this iteration was to disseminate an important patient-led message about delirium to as wide an audience as possible.

When you enter an intensive care unit planned or otherwise, your life and that of your loved ones is turned upside down. The world stops and your 'here and now' is a single bed space and the walls that surround it.

As a former ICU patient, people often ask me what life is like now. My story started with an initially undetected ruptured oesophagus. I have achalasia and had been admitted for an elective 'Heller myotomy'. My post-operative condition deteriorated rapidly and what followed amounted to a large oesophageal tear, severe sepsis, acute kidney injury and later a collapsed lung. I was given life-saving surgery and returned to ICU ventilated. Ten days later, after three failed attempts, I was extubated.

As members of the ICU team, you will know that coming around from a coma is nothing like it is on television. I didn't open my eyes, gently cough a tube out and sit up smiling at my loved ones. Inside my head, I was at a party. There were balloons, people laughing and having fun and yes, that strange pipe in my mouth. Someone kept trying to take the pipe out. But I didn't want to leave, so I kept biting down. I could hear people shouting my name, but when I looked around there were no faces. Then, I suddenly found myself in a room, gagging, with my mum telling me to 'stop fiddling!' I didn't know where or who I was. In reality there was no party.

My time in the ICU was permeated by severe delirium. I don't know if it started during or after extubation, but I know that I had no concept of time or place. My last firm memory is walking into theatre for the original procedure; next would be 3 weeks later and sandwiched in between was a world like no other.

Rationally, I understand that I was surrounded by people who were trying to bring me back to health, but during that period what I experienced was terror. I do not use that word lightly. There was what I experienced as abuse, harassment, humiliation, and torture. Everything that happened to me in my delirious state was real to me and to this day, my memories survive in this way. I can feel, taste, see and hear it all.

My physical rehabilitation began after stepping down from the ICU to a speciality ward. At that time there was no follow-up service available to those transferring from the ICU. My handover to the ward felt tumultuous. It happened at night and moving from the calmer, measured environment of the ICU to the busy ward was terrifying. Nobody spoke to me, nobody seemed to give a thought to where I'd come from. Nobody seemed to care if I felt safe.

You will be anticipating that the role my experiences of delirium would go on to play in my recovery and my life was significant, and you are correct. Knowing what I know now, I find it astonishing that although my family were given updates about my surgeries, my organ failure and what was being done to treat my sepsis, at no point did anyone talk to me or my family about delirium.

As the weeks went by, the physiotherapy and occupational therapy teams were fantastic. They helped me learn to walk again, supported me through the bad days, arranged for my dog to visit, facilitated walks in the fresh air and even a trip home for Christmas day. Following the initial shock of leaving the ICU, the staff on the ward did become the friendly, supportive, and empathetic team I needed. I often say that the ICU team saved my life, but it was the staff on the ward that saved me. For almost

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three months, I became part of the furniture. On the day of discharge, I left to cheers and applause and I felt like a superstar.

But then a new reality hit.

As I walked through the hospital, into the quietness of the night, it struck me that I was now alone. In the weeks that followed I would struggle with everyday things: picking up a kettle, climbing stairs, getting into my own bed. And I slowly became psychologically unwell. I needed to be in bed at the same time as I had gotten used to in hospital. I would set my clock to the schedule the 'nursing observation rounds' had been on. I was expected to 'slot back in' to home life and I just couldn't make myself fit.

The precarious state of my mind became more apparent during outpatient follow-up visits. I crumbled in the waiting room; racing heart, fear and sweat. I then began having flashbacks. Triggering memories were followed by anger and frustration, and I drifted further from who I used to be.

During an outpatient visit, a nurse asked if I'd received any support with my panic attacks and suggested contacting the ICU regarding their follow-up service. At this point, it was two months since I had left hospital and it was my first signpost that this service existed. I had fallen through some cracks in follow-up, and all this culminated in a self-referral and eventually, I received an appointment with the psychologist.

By the time my appointment had arrived, a few weeks more had passed, and things had gotten worse. On the day of the appointment, I stood in the waiting room shaking, crying, and confused. In my appointment, the psychologist informed me that I had experienced severe ICU delirium and now had post-traumatic stress disorder (PTSD). It was a relief to have an explanation, but it was also very confusing. I struggled to understand how a patient could acquire PTSD to such a severe extent, when during my hospital stay, there had been no mention at all of potential aftereffects of delirium or the ICU stay, not even to my family.

Over subsequent months, the professional support of a psychologist helped me decipher how associations had influenced particular delirium events. For example, in one scenario, I was in an underground swimming pool. I believe this materialised after a computed tomography (CT) scan, which I have vague memories of. I discovered recently that the route to that particular radiology-suite passed the hydrotherapy department. There is a very strong smell of chlorine that lingers in the corridor there and I believe that was the trigger. In another memory, I was being tortured by nuns carving a picture of Jesus onto my forearm. I now know that this was the insertion of an arterial line and I have now been told that this can be both difficult and painful. I think the bruise that followed obviously looked like Jesus to me!

Looking back, I know that I couldn't have anticipated such a significant complication after an elective procedure. I couldn't have imagined just how much at 38 years old my life would change. But once the complications happened and I was wheeled through the doors of the ICU, the team around me almost certainly could. They almost certainly did, and I would have liked my family to have been prepared for that. Later, I would have liked to have been prepared too.

Looking back, an opportunity was missed. Not only would early communication have given my family an explanation for my behaviour, but it would also have allowed them to support me better. The same could be applied to the ward team who accepted me post-ICU discharge, because, initially, they didn't seem to comprehend what I was facing at all.

Instead, my family recalled 'funny' anecdotes of things I'd said, while I sat there uncomfortably with little or no memory of any of it, completely in the dark about how challenging my next few months could be.

Rehabilitation for ICU survivors is about body and mind. 'Recovery' can last forever. Even now, I am sometimes faced with a trigger that takes me back to the trauma. Of course, all patients are individuals and because people have their own stories and values, needs will differ. But the right to adequate holistic rehabilitation should be universal and being prepared for what is coming should be the norm.

Table 1 Take home messages; a patient's manifesto

Key lessons
Educate the patient and their family members about delirium and post-ICU psychological morbidity
Explain procedures, journeys, and noises to patients. Even when you're not sure they can take it in
Communicate the reality of what a post-ICU trajectory can look like
Prioritise discharge of long-stay patients to daytime hours only
Communicate the patient's story to the ward. Help them understand delirium, rehab needs and potential for psychological trauma
Signpost ICU follow-up services as soon as appropriate. This is vital to prepare patients not just for transition to home, but for re-integration into homelife

So I ask: Tell your patient about delirium. Tell their family. Warn them that they might leave intensive care and be visited by terror and trauma. And crucially, tell them that they don't have to be alone when that happens.

'Recovery' doesn't end at discharge: it is often just the beginning (Table 1).

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Reference

1. Gallie L (2003) Life after intensive care—a journey into the unknown. Nurs Crit Care 28(4):482–483