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Valerie Page and E. Wesley Ely

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Delirium in Critical Care

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We dedicate this book to our fathers,
both of whom suffered delirium during critical illness.

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FOREWORD

The identification of delirium as an important entity in acutely and critically ill patients has been one of the major advances in intensive care over the last decade. There is increasing recognition that the condition has an important impact on morbidity, health economics and patient outcome, not just in critical care, but also in the perioperative period, during acute medical illness, and at the end of life. However, there has also been a realization that the condition is under diagnosed, and that its prevention and treatment are frequently neglected. Given this context, this book is a welcome resource for clinicians who are involved in treating patients who are at risk of delirium or require treatment for the condition. The authors are practising clinicians with complementary backgrounds in critical care. Professor Wesley Ely is perhaps the best recognized expert in this field worldwide; whose publications have put delirium on the critical care agenda. Dr Valerie Page runs a busy general intensive care unit and brings her experience of everyday critical care to the problem, along with knowledge of the background literature. While this book does provide some information on the clinical science and neurobiology underpinning the condition, this is not its main attraction,

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and there is a refreshing candour about the substantial and large lacunae in knowledge about delirium. Its great strength lies in its practicality, and in the robust clinical sense that it displays in guiding the practising ICU doctor or nurse through the process of detecting, classifying, quantifying, preventing and treating delirium. The resource that it provides should make individual clinicians and ICU teams more aware of the condition, and in doing this, could help improve patient outcomes.

David K. Menon
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DELIRIUM, A PATIENT TESTIMONY

As birthdays go, this one was absolute rubbish. It was 8 o'clock on a May evening in 2007, and where I should have been enjoying an evening out with my husband and friends, here I was sitting in A & E with a broken nose, the result of the most mundane of domestic accidents – falling over some washing while I was completely sober.

Two weeks later I was summoned for day surgery to sort the nose out. My conversation with a porter about the next day's FA Cup final, while making my way down to theatre, is the last memory I have before being plunged into the most terrifying experience of my life.

The next occasion when I had any perception of time was 12 days later, when I found myself being stared at by two middle-aged men in dark suits and bright ties. One was busily explaining to me that I was in the Intensive Care Unit and that I was quite safe.

However, I knew better. I knew they were lying. For me, the reason I was in a bed, on a ventilator, hardly able to move, was that I had been drugged and kidnapped. It had all started in Portugal; at least I thought it was Portugal, where I'd been abducted. At some point I'd managed to escape but was recaptured and taken to a hospital, a few miles from my home.

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I knew that I must have done something wrong, to be held with no hope of escape, but I had no idea what it was. I'd tried on several occasions to pull the tube out of my mouth, but had always been instantly plunged back into darkness.

It never crossed my mind that there might have been a medical reason for my predicament, and I had no knowledge that severe aspiration pneumonia following my routine surgery had landed me in ICU and was putting my family through hell.

What I did know with certainty though was that I would die. One particular doctor would visit me every time I started to wake. He always wore the same clothes and would always speak slowly and deliberately. 'You've been dying to know what that sign on the wall says, haven't you?' he asked one day. He was right; I had wondered what it said but the problem was I could see two of everything and objects and people were frequently blurred so I hadn't been able to read it. 'I'll tell you what it says,' he continued. 'It says "moron". We put it there so every time you open your eyes it's the first thing you see; so that for every minute of every day you know exactly what you are. Unfortunately I'm not allowed to turn your ventilator off, but I want you out of here, and you will leave soon, in a body-bag. You're not going to live, but just remember every time you open your eyes you will see exactly what we think of you - moron.'

From then on, that sign was the only thing I could see that wasn't blurred.

The rest of my stay in ICU was filled with more incidents of despair, humiliation and terror. I saw a patient stabbed

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to death by his wife, and two people committing suicide. I witnessed arguments, in my mind all caused by me, and the pain I felt as my lungs started to recover was all part of a plan to give me pain-inducing drugs – in fact I had seen doctors laughing about it.

The day after I was extubated I found myself in the High Dependency Unit, where the sheer terror of the execution attempts began. Initially I thought I was in the morgue as I was lying flat and was extremely cold. There was a plain clothes policeman watching me because I'd witnessed a murder on ICU. Someone spoke to me. 'I can control your mind' they said, and then proceeded to demonstrate they had power over me by causing me pain and by interrupting my supply of oxygen at will.

The following morning a tall and distinguished-looking man sat down and explained to me that I had Pershing's Disease. This was a rare congenital heart condition that can lie dormant for many years. Once a sufferer shows symptoms, however, their life expectancy is less than a year. In my mind I might as well just die where I was, and the doctor encouraged me to do exactly that. Pershing's Disease of course, does not exist, but just like everything else that happened to me, the hallucination I had where it was explained was so convincing that I was still trying to find evidence of its existence weeks later.

I was put into a side room in the High Dependency Unit, allegedly for infection control, but I knew it was for my execution. I'd heard the nurses talk about CTO, which was a Compulsory Termination Order, and one had been issued for

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me. As the blinds were pulled down over the room's windows and door, smoke appeared through every vent. A voice told me it was cyanide and I would die more quickly if I relaxed and inhaled it. I watched it creep closer paralysed with terror, and all I could think about was that I would never see my family again.

Having somehow survived, the execution attempts continued. They included suffocation, poisoning, drug overdoses and being forced to hold my breath until four lights went out on my monitor. By the time I moved down to a respiratory ward I had given up trying to convince my family that the hospital staff were trying to kill me. I still had no idea of what was wrong with me, and when my husband explained, I was sure that all my problems had been induced and had not simply happened. It was then that I decided to keep quiet about my views as no-one believed me or was prepared to help me, so I planned my escape alone. By this time I could take some of my medications orally, so this gave me some element of control, as I would wait until the nurse left the room, then would throw the pills containing poison into the medical waste. I ate nothing at mealtimes, but instead stole pieces of cutlery that would help me prise my window open. I was utterly oblivious to the fact that I was four floors up. The hallucinations had stopped by now but were replaced by paranoia and deviousness. The day I planned to leave via the window was the day I was discharged. That might seem lucky, but I spent the next few months wishing that I had died that day.

My physical recovery once I was home moved forward very quickly, but inside I was in meltdown. I couldn't tell anyone

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how I really felt – my family and friends had been through so much already. My delirium and its consequences caused me to believe that I was still being poisoned, even after leaving hospital, so I stopped taking my medication.

What do I wish had been different for me? Well, when I received a copy of my medical notes following a suggestion that it would help me to make some sense of what had happened, I read through the hundreds of pages that comprised a file 6 inches thick. Only once did I find a relevant reference. It was one about me being severely paranoid, and that note was made by a physiotherapist. Although I have no doubts whatsoever that the care I received was of the highest order, I still feel today that my delirium was seen as an acceptable side effect of my illness and treatment. Months later, during my ICU follow-up appointment, they were not at all surprised that I had suffered prolonged and extreme delirium; in fact they appeared to know I had. To them it was ‘normal’. To me it was anything but.

Two years have now passed since my experience of delirium. In that time I’ve been able to make sense of at least some of what happened to me. My mother reminded me that my belief I’d been kidnapped could well have been my brain confusing my situation with something that had been constantly in the news. Unfortunately, I’d shared my birthday, the day of my accident, with the day that Madeleine McCann was taken from her family’s holiday apartment in Portugal, and the tragedy had been at the top of every news bulletin leading up to the day of my surgery.

I know too that my almost total lack of memory for the routine events you would expect to experience on a hospital

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ward, and which would have reassured me about where I was and what was happening, stopped me from challenging my warped and terrifying perception of the world.

Whatever the future holds though, I'm never doing the washing on my birthday again.