

FROM THE INSIDE



Transitioning to reality: the diary of an ARDS survivor

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My name is David Richards. Between 2009 and 2010 I was admitted to intensive care during what a specific generation will vividly remember as the ‘swine flu pandemic’. I was just 48 years when I spent 6 weeks in intensive care unit (ICU); first on mechanical ventilation and later receiving extra-corporeal membrane oxygenation (ECMO) treatment. In time, I became a ‘survivor’ of severe acute respiratory distress syndrome (ARDS). In Fig. 1 you will see a photograph of my ‘ICU diary’, and I would like to share with you what that collection of bound up pages has meant to me.

It was not until I had been discharged from ICU and arrived on the respiratory ward that I truly began to emerge from the fog of my time on ICU. I had awoken from 4 weeks of vivid and terrifying ‘coma nightmares’ only to enter a world of delirium and distorted reality. Now on the ward, I found myself reflecting on the weeks before; 6 weeks of a life I did not live. Alongside this, new memories were surfacing every day. I struggled to understand what was real and what was imagined. My ICU diary would later help me create some sort of timeline and extract the true memories from my fragmented and delusional recall.

Rose, my former partner and mother to my baby son, was already a keen diarist. She fell into chronicling my journey in a way that was an extension of her own daily writing. For 50 days, she recorded clinical updates as well as conversations with those relatives and staff who were by my bedside. The booklet that was eventually handed to me formed a record not just of procedures, treatments and clinical signs but of how I reacted, how I appeared to feel and how I tried to communicate in those days that were so permeated by delirium. The diary presented me

with a record of how difficult this time was for my family; their thoughts and emotions are recorded in many of the entries. It formed a record too which helped me to appreciate the outstanding care both I and my family had received in those weeks.

I did not read it straight away. In fact, it took me months to mentally prepare and even then, I stopped that first time after just a few pages. In the more than a decade since, I have never sat down and read it cover to cover; I dip in and out of it as emotions dictate that the urge is there.

These initial entries came from Rose. She also mentions my son, William and my mother May.

Sunday 13th December 2009

May rang me to say that Dave was on his way to hospital. She had rung the on-call doctor and the paramedics had arrived and taken him.

Dave was taken to the Critical Care unit where he was in a room on his own wearing an oxygen mask. The nurse said they may have to sedate him later for ‘3 or 4 days’ to give his lungs a rest. I rang the hospital before I went to bed. This was the start of many daily and nightly phone calls to see how he was.

Monday 14th December 2009

However, Dr Clayton told me gently that there may come a point where there is nothing more they could do. I asked her “Is there a chance Dave could die?” and she replied, “there is a very good chance Dave could die.”

Tuesday 15th December 2009

Not able to sleep, I rang the hospital early in the morning and they told me Dave was poorly in the night, he had deteriorated.

There was a possibility they were going to reposi-

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tion him to help the lungs. This meant proning him, that is, turning him over so he was lying on his tummy. This takes 6 people to do and is not without risks so the decision to do this was not taken lightly.

Wednesday 16th December 2009

At 6pm I rang the hospital again. Dave had deteriorated and a decision had been made to transfer him to (a tertiary centre) tonight as nothing more could be done for him at this hospital.

An ECMO consultant and a team of special nurses travelled from (ECMO centre) Hospital, to collect Dave. He was going by road in an ambulance under blue flashing lights. It was originally planned that he may go in a helicopter but as it was dark and there was limited room to work on Dave, should they need to in the helicopter, they decided against it.

He said Dave had 3 hurdles to cross. The first was to survive the journey, the second was to survive the ECMO machine being fitted and thirdly, avoid the risk of bleeding and clotting. There were also risks of infection.

The hospital ECMO unit called me around 1.30am to say Dave was safe and in theatre having ECMO fitted. I rang the ECMO centre again at 3am to check Dave had come out of theatre and was ok. When we knew he was safe, stable and in good hands, William and I went to sleep.

The power in these entries lies in their ability to help me understand how dire my prognosis was. When I get frustrated with my life situation and residual health issues, finding myself struggling to move forward, I can look back to these early days and see how far I have travelled in my recovery journey. Reading and reflecting on my diary has often grounded me, helped ease my anxiety and prevented me from slipping further into the grip of depression, proving in my case, the ongoing mental health benefits of the diary.

My diary came with twelve photographs, taken between Christmas and New Year. I had already been in a coma for 3 weeks when they were taken and would spend another 3 weeks on ICU. Those photos added a layer of reality, augmenting the written word and emphasising the severity of my illness.

I have no definitive memory of the weeks I spent at the ECMO centre. I was never 'awake' there. But the diary allowed me to extract a narrative.

16–22 December 2009

The first week of my time on ECMO followed a similar pattern of lung suctioning every two hours and regular periods of being put in the prone position.

I remained stable. On the seventh day, I was medically paralysed because I was shivering uncontrollably, and I received my first blood transfusion.

23 December 2009

On day eight of ECMO, I received a tracheostomy and the rest of my time on ECMO would be disrupted by bleeding complications that would eventually lead to my emergency removal from the machine.

24 December 2009

There was bleeding from my trach through the previous night. Also, the first mention of my receiving passive range of motion physio.

25–28 December 2009

I remained stable but daily entries centred around blood loss and controlling the bleeding.

29 December 2009

I had chest drains inserted on both sides of my chest after suffering a double pneumothorax.

On the 30th of December, the entries allowed me to understand the 'two steps forward, one step back' scenarios that were a common part of ICU and of my family's experience. The diary allowed me to take on board what had happened in a way that would not have been possible had I relied on any single third-party retrospective telling.

30 December 2009

I was due to visit Dave at 2pm but about 12.30pm, the nurse looking after Dave rang my mobile to say that Dave had been bleeding heavily from one of his drains and the doctors had decided to remove Dave from the ECMO machine today. She suggested that I visit now. I went straight up to see him, he looked so frail, very pale, gaunt and oozing blood from his right drain.

The nurse explained he was having a blood transfusion as he had been losing blood at quite a rate (300mls every 1hr–1.5hr). Their hands were forced into making the decision to remove him from the ECMO machine as the drug Heparin that they were using was thinning his blood and the blood loss was concerning them.

I asked the nurse if I could take some photos of Dave as his parents had asked me to and I wanted to put them in Dave's diary that I have been keeping for him. She agreed and I took photos of him on the ECMO machine. The nurse said he looked like a crash test dummy and I could see what she meant. It

was so sad to see him so poorly.

I left Dave at 2pm so the doctor could work on him. The doctor put in two new lines into his groin to prevent infection from the existing lines that had been in there for a while. He also put a tube in his arm to enable them to check his blood pressure. I had to wait until 5.30pm before I could see him again. At 5.30pm I went back in to see Dave and was able to take photos of him off the machine. He looked relaxed and comfortable. The bleeding had stopped from the drain but had started in his neck.

By the 5th of January, I had been returned from the ECMO centre and began to resurface from my coma. I was incredibly and expectedly weak and still tracheostomised, I could not yet speak. Progression from raising my arms to point at letters on a board, to spelling words, to attempting to write, was painstaking. My efforts to communicate were recorded and constitute another important part of my diary (Fig. 1A) It is important to realise how keeping records of my own communication efforts was pivotal to the functionality of this diary.

These entries tell of the nightmares that carried forward into my first days without sedation. While lying in my ICU bed, I thought I was being treated for gunshot wounds and that my two young daughters had been kidnapped. That had been the world I inhabited during my coma and it remained more real to me than the world I was now awake in. My experiences were driven by auditory and visual hallucinations Fig. 1B shows how I tried to communicate this to my family.

The diary also tells of the realisation that I was so weak and dependent on others for my care (Fig. 1C).

Later, the entries in Fig. 1D show some early signs that delirium was taking hold. I was convinced I had been treated back in my home country of Wales. I repeatedly asked my parents, daughters, Rose and nursing staff separately whether I had been in hospital in Cardiff, Wales. Each of them in turn told me I had not, but I did not believe them and became suspicious of their motives. When I received answers that did not concur with my delusions, it only intensified my paranoia.

The warning signs that I was struggling to retain information came early too (Fig. 1E). This challenge continued, levelling out at about 2 years.

We know that orientation of the patient while in ICU is important. When I came round from my coma, the nurse had written a date on the whiteboard near my bed, but that date was never changed. It remained January 9th for the rest of my ICU stay (Fig. 1F).

When delirium came, several of the doctors and nurses involved in my care entered into my hallucinations in a

negative way. One male doctor attacked me, doing martial arts. I heard nurses having sex by the side of my bed. My diary reminds me how real this was to me at the time (Fig. 1G) When a senior nurse came and spoke to me about how I may experience nightmares and hallucinations I told her they had already started.

I have always believed that my coma nightmares and hallucinations after waking were driven by events happening in my immediate environment. Sounds that my brain could not process or interpret, like the ventilator alarm, sent my thoughts spinning off on tangents that created terrifying and bizarre scenarios.

The assault my body was under through procedures like ECMO cannulation, tracheostomy, regular prone positioning, catheterisation, chest drains insertion also manifested in the torment I experienced.

In one nightmare, I was in a hospital being hunted down by gunmen shooting at me and as I ran for my life, I felt the bullets hitting me, entering my body as I fell to the floor dying. Was this triggered by having chest drains inserted into my sides when I suffered bilateral pneumothorax? Were the nightmares of a sexual nature a result of having a catheter fitted?

Most of my nightmares, if not all, I have been able to relate to events recorded in the diary.

My diary also reminds me what it felt like to try and understand what it would be like to use a speaking valve for the first time. 'What is a speaking valve? Is it like a Dalek?' (from Doctor Who) I asked! (Fig. 1H).

As time went on, I became attached to the staff that helped me feel secure. Emma was a nurse whose compassionate and assured manner made me feel safe. I felt anxious when she was not on shift (Fig. 1H).

At the end of my first week off sedation, my diary shows how my mind steadily drifted to the need to see my children. My daughters aged 12 and 13 were able to visit me throughout my hospital stay, though visiting times were limited and fixed back then. But I was also father to a 4-month-old boy who was not allowed in the ICU or respiratory ward. It would be over 2 months before I would see him again and that was only when I was well enough to be put in a wheelchair and taken down to a hospital coffee shop. These visits would be short as I fatigued quickly. He was 4 months when I left him and 8 months when I finally came home. He had developed a lot in that time. I had become a stranger and it took a long time to re-build my bond with him.

The psychological impact of missing my children was the primary factor in my refusing to go to a rehabilitation facility and insisted on going home after the respiratory ward, instead requesting out-patient rehab. I felt that any physical gains would have been nullified by the damage to my mental health. My diary demonstrates

how early in my journey I began to express and prioritise these needs (Fig. 11).

It has been more than a decade since this ordeal and yet the benefit my ICU diary holds for me remain tangible. My ICU diary:

- Created a timeline of events so I can anchor my experiences in reality.
- Filtered out many false memories.



Fig. 1 My 'ICU diary'

- Identified the source of many of my nightmares and delusions by relating them to events recorded in the diary.
- Emphasised how much my family endured during this time through their love and support for me.
- Elevated my respect and admiration for the critical care teams who cared for me
- Addressed the memories and questions that continued to emerge for many months and even years after my critical illness event.
- Continues to serve as a grounding mechanism when anxiety and depression tighten their grip, by reminding me how far I have travelled in my recovery journey from the darkest days and in turn, uplifting my mental health.

In a world where intensive care is provided at huge expense, an 'ICU diary' costs a small amount of time, the price of paper and a pen and a moderate amount of teamwork. I hope I have demonstrated that the cost to benefit ratio for your patient is undoubtedly in its favour.

I will sign off with the closing paragraph of my diary and with thanks to Rose, for having the perseverance to compile so much of what has become one of my most treasured possessions.

Sunday 31st January 2010

"This is where I finish writing Dave's diary and I give him a notebook to continue jotting notes for himself. It was always my intention, whilst Dave was so

poorly and unconscious, to record the series of events that surrounded Dave's illness so that I could help him fill the gaps in his memory when he got better.

I am so delighted that today he is well enough to continue with this diary and for him to put in his own words how life feels for him now he has recovered from such a serious illness and has started on his journey of rehabilitation.

I thank everyone who has supported and cared for Dave and who have helped me with the detail of the diary but most especially I thank God for listening to all our prayers and for being there for us all when we were at our lowest and darkest moments of our life."

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