

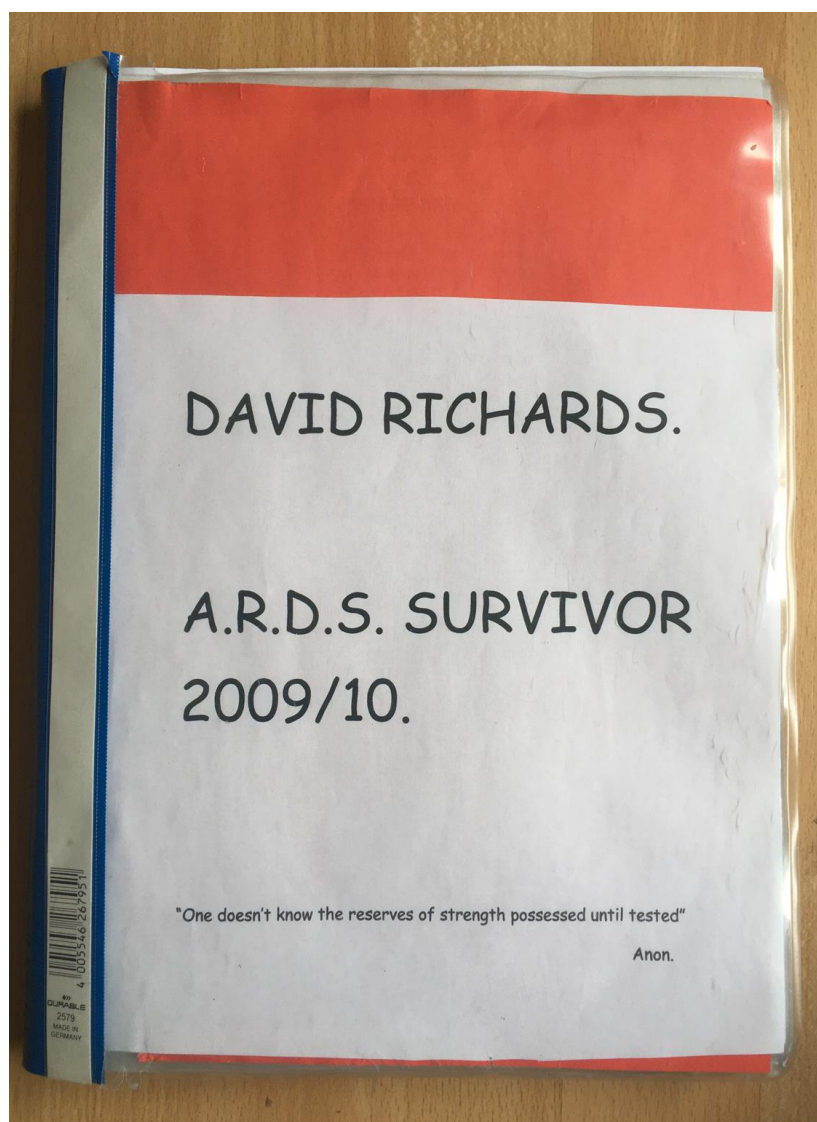
My critical illness journey as told through my ICU diary

I want to highlight the potential benefits of an ICU diary as an aid to help with the patient's psychological recovery.

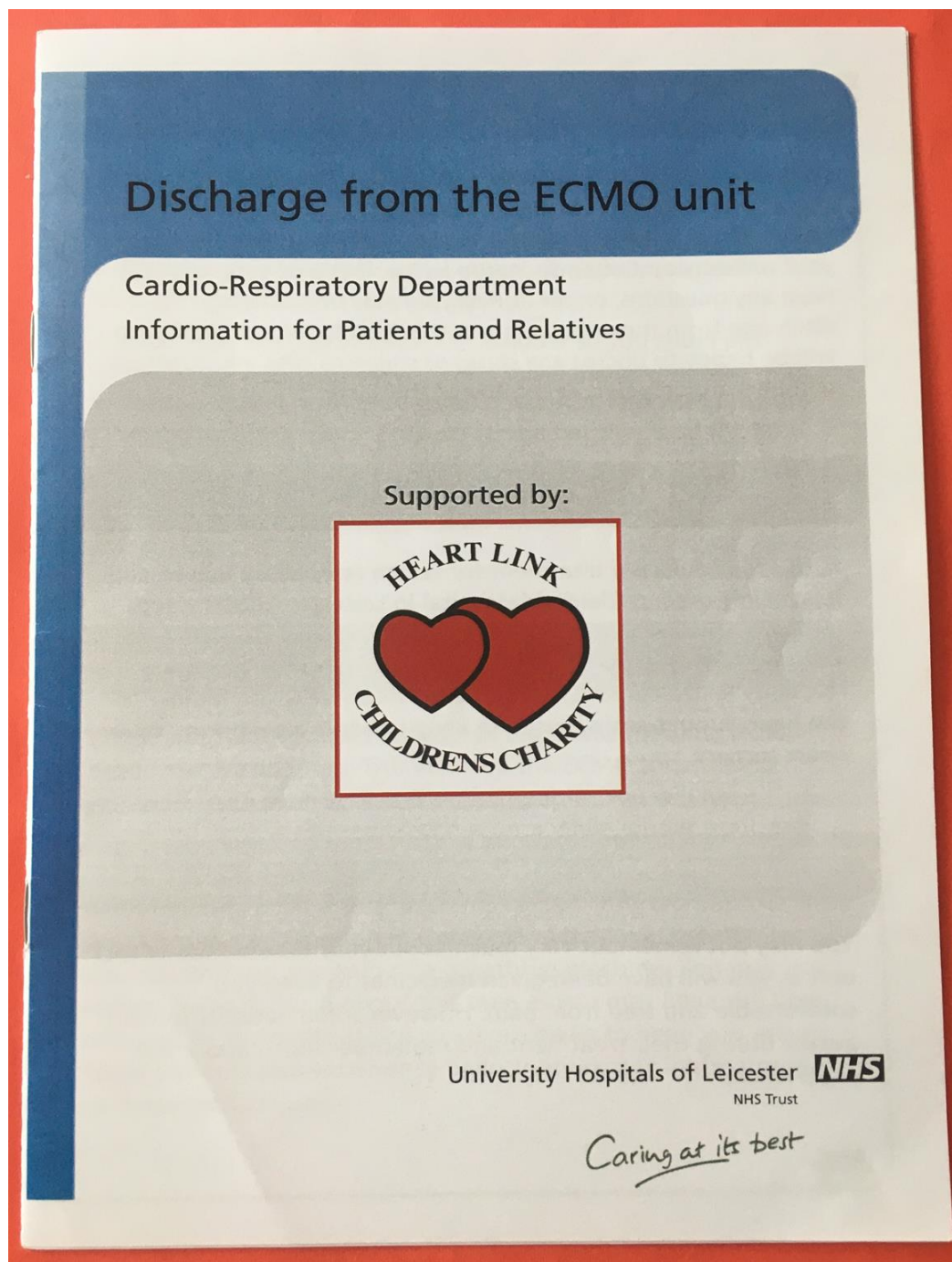
Through my own experience, I believe an ICU diary should be an integral part of intensive care or failing that, the family of a loved one in crisis should be advised to make their own patient journal. I was clinically diagnosed with PTSD following my time in ICU and received eighteen months of weekly counselling, CBT and EMDR therapy to help process my memories. But I believe my best therapy has been provided by my ICU diary and it's value to me as a therapeutic aid in my psychological recovery has been immeasurable.

I will share excerpts and summaries of my time in intensive care, as seen through the eyes of my ICU diary, to show the nature of the information recorded and how it has helped me. I will focus solely on my illness and treatment as some of the entries involving family and friends are too personal to recount here.

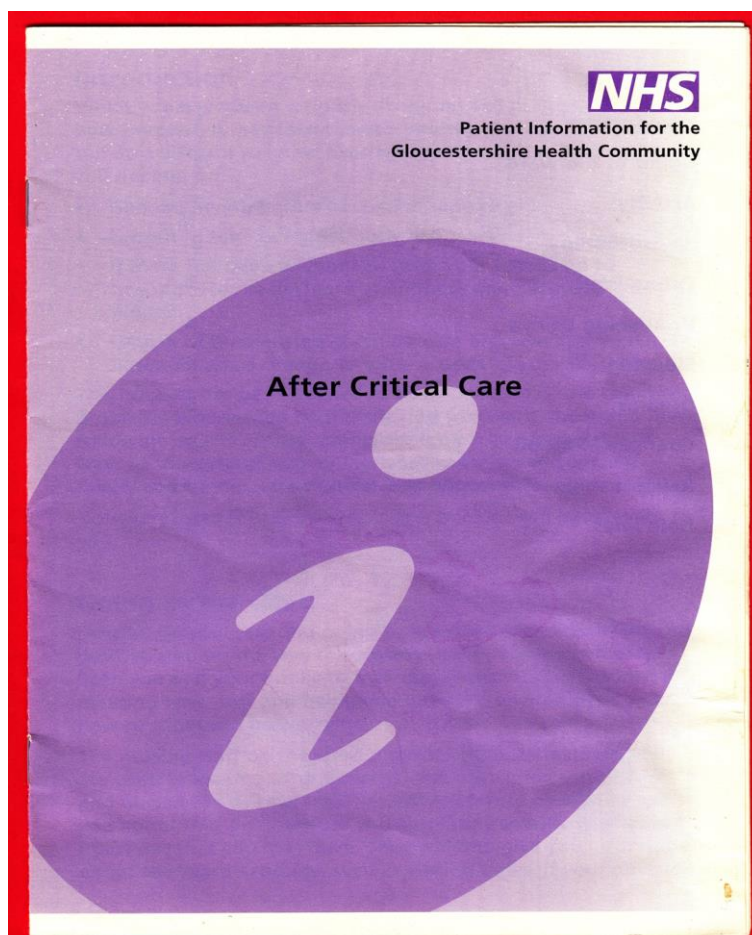
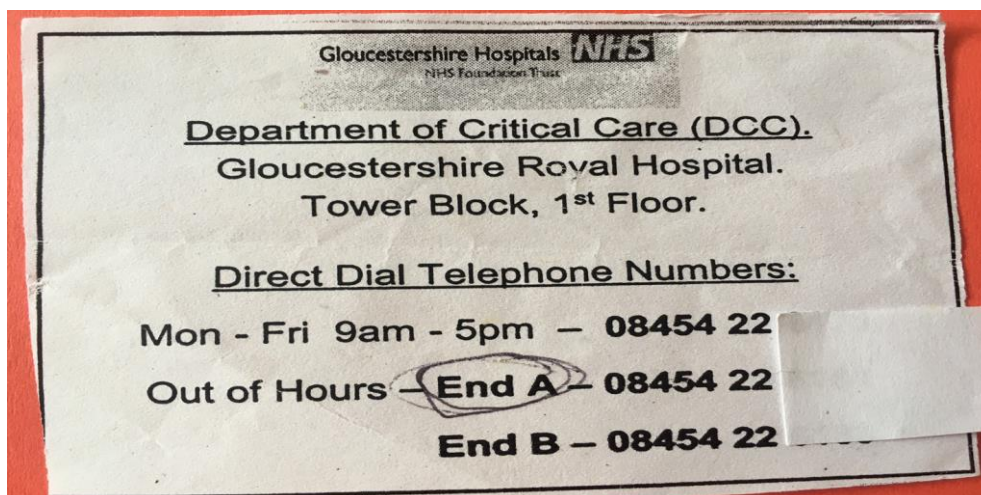
I also hope this document will give families an insight into what their loved one is going through while in a coma and when awake in the ICU, as my experience will not be unique.



For background, I was 48 years of age and one of the early Swine Flu victims towards the end of 2009, that rapidly progressed to double viral pneumonia, then severe ARDS (Acute Respiratory Distress Syndrome). I was in excellent health prior to my illness, having been a competitive track and field athlete my entire adult life and won the national masters title (over-40) in my event just three months previously. I was admitted to my local ICU at Gloucestershire Royal Hospital, remained on a ventilator for six weeks and in a coma for four weeks, three of which I spent at Leicester Glenfield Hospital receiving ECMO treatment.



Shortly after returning to the Department of Critical Care (DCC) at Gloucestershire Royal from Leicester Glenfield following my ECMO treatment, I awoke from four weeks of horrific and vivid coma nightmares, only to enter a world of delirium and experience a distorted reality driven by auditory and visual hallucinations over the following weeks. By the time I was discharged to the respiratory ward, I was emerging from the delirium and slowly regaining clarity of thought. While on the respiratory ward, I began to reflect on events during my time in DCC and Glenfield and realised that I had six weeks worth of memories of a life I didn't live. Alongside this, new memories were surfacing every day and I was struggling to determine what was real and what was imagined. My ICU diary would later help me create some sort of time-line and extract the true memories from my fragmented and delusional recall, allowing me to anchor my experience in reality.



From the outset of my illness, my former partner and the mother of my baby son, began chronicling my journey. She was a keen diarist and this became an extension of her daily writings.

She would phone the ICU and ECMO unit daily for updates, often two or three times each day and also speak with my parents who remained at my side throughout my hospitalisation and write down the conversation details. She recorded my progress for the first fifty days of my hospital stay until I was alert and fully aware of my surroundings.

After the final entry, the notes were made into a booklet and presented to me in the weeks following hospital discharge.

The diary records what procedures and treatments were being performed on me, the ups and downs in my condition, how my x-rays were looking, photographs of me both on and off ECMO at Leicester Glenfield (with staff permission), how I reacted when sedation was lowered, the sheets of paper I wrote on for my early attempts at communication and much more.

It has also given me an understanding about how difficult this time was for my family as their thoughts and emotions are recorded in many of the entries.

In addition, it gave me an appreciation and increased respect for the outstanding care I received from the critical care practitioners who saved my life at both hospitals and the support they gave to my family.

It was a few months before I was mentally prepared to start reading the diary. I did find it particularly distressing reading through the entries for the first time and had to stop after a few pages. In the eleven years since, I have never sat down and read it cover to cover as emotions can become overwhelming so I dip in and out of it piecemeal. I mostly get the urge to look at the diary when I'm passing all the major anniversary milestones of my hospitalisation.

The following are partial extracts from the diary entries on the named dates and give an insight to events shortly after my admission to Gloucestershire Royal DCC.

The first entry in the diary is right at the start of my becoming unwell, though no-one could have foreseen what lay ahead for me over the coming weeks and months. I didn't want to pass any bug on to my baby son so I messaged his mother:

Tuesday 1st December 2009

Dave text me to tell me he had the flu and wouldn't be able to visit William. He said "I'm full of flu, have a temperature of 102 and this is my second day off work. Probably not a good idea to see William tonight, I don't want him catching anything off me."

My health declined over the following days, prompting my parents to drive 150 miles from their home in Pembrokeshire in Wales because I had not been responding to phone calls for several days. They found me in a distressed state, struggling to breathe and incoherent. This is the day I was admitted to Gloucestershire Royal Hospital's Department of Critical Care:

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.

Day two in DCC, when the seriousness of my situation was made clear to my family:

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."

Day three in DCC, things continue to get worse:

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 reposition 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.

Day four in DCC. A major development in my treatment plan and the following are just a few extracts from a large diary entry for that day:

Wednesday 16th December 2009

At 6pm I rang the hospital again. Dave had deteriorated and a decision had been made to transfer him to Leicester tonight as nothing more could be done for him in Gloucester.

An ECMO consultant (Chris Harvey) and a team of special nurses travelled from Glenfield Hospital, Leicester 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 from Staverton 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 Leicester 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.

As difficult as these entries are to read, they give me an understanding of 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 and realise that maybe things are not as bad as I perceive. 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.

It took me many months to piece together a time-line and make sense of my experience by repeatedly reading extracts from the diary, speaking with family members and meeting some of the DCC and Glenfield staff who cared for me.

The photographs in the diary add a layer of reality that augments the written words and emphasises the severity of my illness.

The diary contains twelve photographs and the two below were taken between Christmas 2009 and New Year at Leicester Glenfield Hospital, with staff permission, when I had already been in a coma on life support for nearly three weeks at this point.

The dark looking tubes at the side of my neck (they are actually clear, that is my blood making them look dark) are the size of a hosepipe and go down to the chambers of my heart, through which blood exits my body and passes through an external machine that adds oxygen and removes carbon dioxide, before returning the blood to my body, a process called ECMO (Extra Corporeal Membrane Oxygenation).

The tracheostomy tube into the front of my neck connects to a ventilator which breathes for me.

The large abrasion on my chin is a pressure sore from being placed in the prone position (face down) for around eight hours a day to move around secretions in my lungs.

The tubes into my sides are removing fluid and air which is preventing my lungs from expanding.

The yellow tube into my nose passes down into my stomach and is how I received nutrition.

After this picture was taken, I remained in a coma for a further eight days and on life support for another three weeks.





I have no memory of my three weeks at Leicester Glenfield, as I arrived there in a coma and was returned to Gloucester in the same state. Fortunately, the diary records each day of my stay there and allows me to create a narrative.

16 - 22 December 2009

The first week of my time on ECMO at Leicester Glenfield 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.

The following extract is part of a lengthy diary entry for this day. I suffered a major setback in my recovery process when I had to be removed from the ECMO circuit because I had been bleeding out through several cannulation sites for a number of days.

This was typical of the 'two steps forward, one step back' scenarios that are common in the ICU, though this complication was quite serious and of great concern to my family who were once again facing the possibility that I may not survive.

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.

31 December 2009 – 04 January 2010

The five days following my removal from the ECMO circuit were mainly monitoring the bleeding, observing how I coped being removed from ECMO and seeing how I responded when sedation was lowered. I remained in a coma and when it was considered that I was stable enough to be moved, I was repatriated to Gloucestershire Royal Hospital on the evening of Monday 4th January 2010.

Before departing Leicester Glenfield, my family left messages on the hospital charity Christmas tree to thank the doctors and nurses on the ECMO unit for caring for me and saving my life.



05 January 2010 onwards

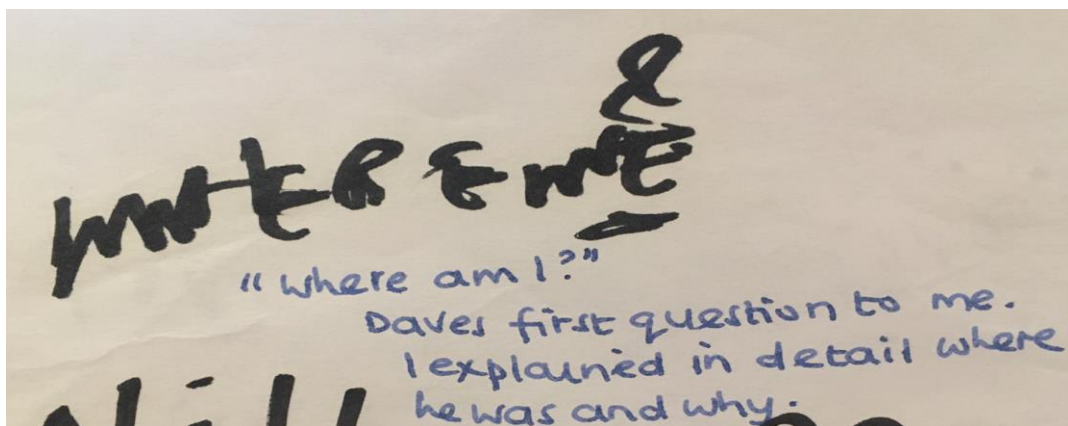
I awoke from my coma in the days after returning to Gloucestershire Royal. I found myself unable to talk due to the trach and with no movement in my limbs. Initially, I was only able to communicate by mouthing words and hoping people could lip read what I was trying to say. As the effects of the paralytics wore off, I could raise my arms to point at letters on an alphabet board to spell words, then progressed to attempting to write.

The diary incorporates all the loose pages containing my written communications while I was unable to speak. My early attempts at writing are unintelligible, though I thought at the time I was producing perfect hand-writing but family members have written the translation alongside the unreadable parts after lip reading what I was trying to say.

I will look at my time back at Gloucestershire Royal DCC through a selection of my written communications.

Clearly in a state of confusion, the first comment I wrote after waking from the coma was:

“Where am I?”

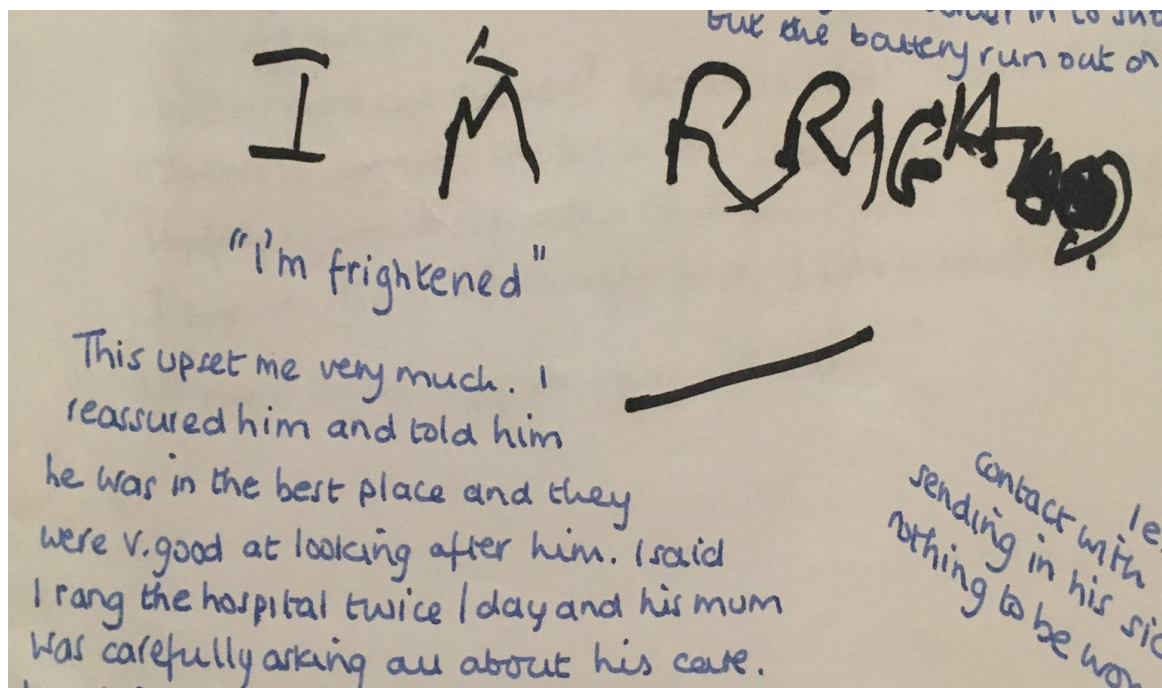


The nightmares I experienced carried forward after I woke from the coma. While lying in my ICU bed, I thought I was being treated for gunshot wounds and that my two young daughters had been kidnapped, as that was my reality in the world I inhabited during my coma, which was more real to me than the world I was now awake in.

I was experiencing a distorted reality driven by auditory and visual hallucinations.

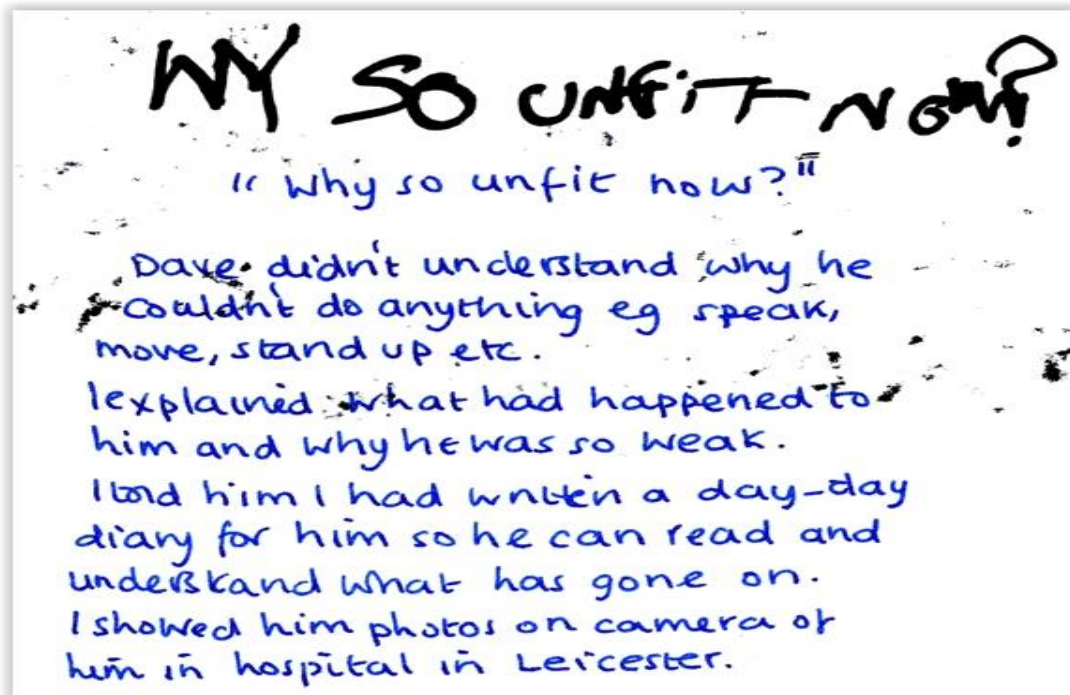
Being a patient in the ICU can be a terrifying and miserable experience, no matter how good the support and care, as the following comment I wrote to my family shortly after waking from the coma illustrates:

"I'm frightened."



I was trach'd and immobile because of the effects of paralytics and acquired weakness, and struggling to comprehend what had happened to me. I was effectively an adult baby, unable to talk, unable to stand, unable to eat solid food, bathed in bed and toileted and cleaned in bed. I was totally dependant on the nursing staff and would remain so for many weeks, even after discharge from the ICU to the respiratory ward. This is also when I first learned that a daily diary was being kept for me.

“Why so unfit now?”



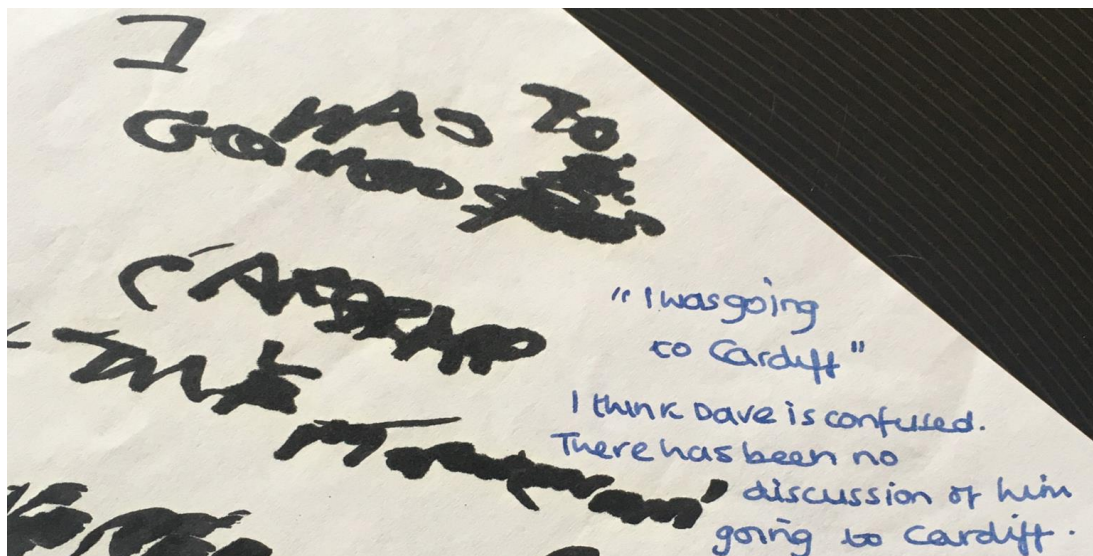
Early signs that delirium was taking hold of me appeared when I was convinced I had been treated back in my home country of Wales. I asked my parents, my daughters, my baby's mother and nursing staff separately and away from each other whether I had been in hospital in Cardiff, Wales. Each of them in turn told me I had not but I didn't believe them and became suspicious of their motives. When I asked questions and received answers that didn't concur with my delusions, it only intensified my paranoia.

"I was going to Cardiff."

"I was going to C/Diff"

"I know C/D Diff"

"How many different hosp Cardiff"



WAS GOING TO: C/D DIFF

I know C/DIFF

HOW MANY DIFFERENT HOSP
CARDIFF.

The warning signs that I was struggling to retain information. When I was finally discharged home months later, problems with my short-term memory became apparent immediately. My GP referred me to neurology at Gloucestershire Royal and I was passed on to their brain injury team. I performed very badly in a memory evaluation and spent around eighteen months under their outpatient services being taught coping strategies.

It's hard to put an accurate time-frame on it looking back but I would guess that any memory improvements from the time of my hospital discharge probably levelled out around the two year mark. After that, it was adapting to the memory and cognitive deficits and introducing strategies to help deal with them. It's no exaggeration to say that more than eleven years later, every day I use a timer or alarm to remind myself of tasks.

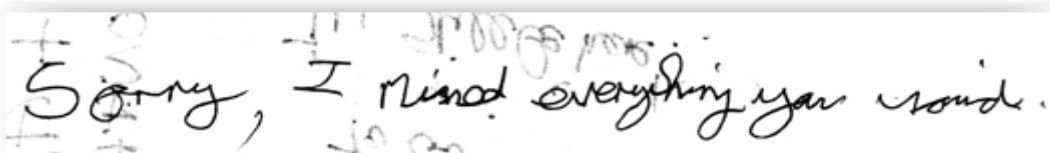
"I can't remember anything."

"Sorry, I missed everything you said"

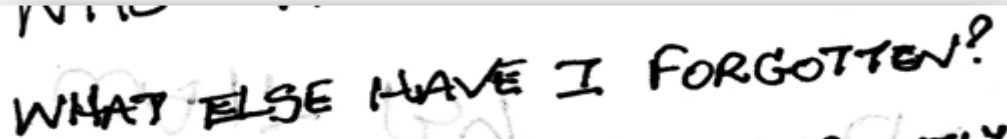
"What else have I forgotten?"



I CANT REMEMBER
ANYTHING.



Sorry, I missed everything you said.



WHAT ELSE HAVE I FORGOTTEN?

Orientation of the patient in the ICU is very important. When I woke from the coma, a nurse wrote the date on a white-board near the side of my bed but it was never changed and showed the same date when I was discharged weeks later. My first question to my family on their daily visits would usually be to ask what the date was.

Also, I had a clock in view above my bed so for the most part, I knew what the time of day was. However because it was a standard 12 hour clock-face there were certain times of the day, like the 6 to 9 period, where I didn't know whether that was morning or evening and there were no windows near my bed to see how light or dark it was outside.

These are minor details when looked at in isolation but they all feed into the confusion that fuels delirium.

"What is date today?"



WHAT IS DATE TODAY?

For much of my time in the ICU after waking from the coma, I was in a distorted reality driven by visual and auditory hallucinations. What I was seeing and hearing was creating a lot of anxiety and I became paranoid and mistrustful, and I could not be persuaded that I was safe and what I was experiencing was not real.


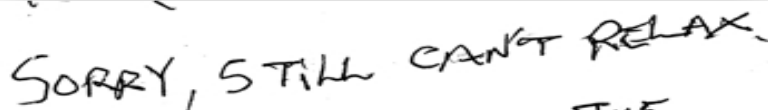
This is known as ICU delirium and affects many patients.

Several of the nurses and doctors involved in my care entered into my hallucinations in a negative way, making me very wary of them. One male doctor attacked me doing Kung-Fu, a female nurse mistreated me by pulling me around by my NG tube and I repeatedly heard nurses having sex at the side of my bed. Of course, none of this happened but it was my reality at the time and nobody could tell me any different.

"Not imagining it."

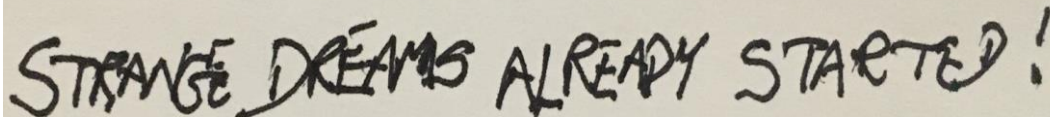
"Too aware of what's going on to relax."

"Sorry, still can't relax."

A rectangular box containing the handwritten text "NOT IMAGINING IT." in a dark, slightly shaky script.A rectangular box containing the handwritten text "TOO AWARE OF WHAT'S GOING ON TO RELAX" in a dark, slightly shaky script.A rectangular box containing the handwritten text "SORRY, STILL CAN'T RELAX." in a dark, slightly shaky script.

Both ICU's I was treated in were aware of the effects of delirium on the patient and when a senior nurse spoke to me about how I may experience nightmares and hallucinations, I responded with:

"Strange dreams already started!"

A rectangular box containing the handwritten text "STRANGE DREAMS ALREADY STARTED!" in a dark, slightly shaky script.

On being asked if I would like a speaking valve (Passy-Muir) attached to my trach to allow my voice to be heard, showing that my mind was still clouded, I thought it would make me sound like a Dalek from the television show Doctor Who:

“What is a speaking valve?”

“Like a Dalek?”

A photograph of a piece of light-colored paper with handwritten text in dark ink. The text is written in a cursive, somewhat shaky hand. It reads: "What is a speaking valve?" on the first line, and "Like a DALEK?" on the second line. The word "DALEK" is written in all caps.

I became attached to the primary nurse assigned to my care (Emma), who I grew to trust and whose compassionate and assured manner made me feel safe when she was on shift but the following comments show how anxious I would be when she was not working:

“Who is looking after me the next two shifts?”

“Is Emma around?”

“Who is looking after me tonight?”

A photograph of a piece of light-colored paper with handwritten text in dark ink. The text is written in a cursive, somewhat shaky hand. It reads: "JUST FIRE" on the first line, "WHO IS LOOKING AFTER ME" on the second line, and "THE NEXT 2 shifts" on the third line. Below "THE NEXT 2 shifts" is a circled phrase: "(12 hour shifts?)".

A photograph of a piece of light-colored paper with handwritten text in dark ink. The text is written in a cursive, somewhat shaky hand. It reads: "Is EMMA around?" The word "EMMA" is written in all caps.

A photograph of a piece of light-colored paper with handwritten text in dark ink. The text is written in a cursive, somewhat shaky hand. It reads: "WHO IS LOOKING AFTER ME TONIGHT". The word "TONIGHT" is written in all caps.

I had only been out of the coma for a week but my mood was already getting low. My daughters aged 12 and 13 were able to visit me throughout my hospital stay, though visiting times were limited and fixed back then. I was also father to a four month old baby boy when I fell ill but he was not allowed in the ICU or the respiratory ward. It would be over two 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 eight months old when I finally came home and 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 rehab facility and insisting on going home after the respiratory ward and requesting out-patient rehab. I felt that any physical gains would have been nullified by the damage to my mental health.

“Miss my children and baby 6 months”

“Want to go home”

“Miss my children!”

MISS MY CHILDREN AND BABY 6 MONTHS

WANT TO GO HOME

MISS MY CHILDREN!

My first photograph after waking from the coma at Gloucestershire Royal DCC, still with a trach and on the ventilator, about to receive a manicure having been hoisted from the bed on to a chair. I hated being put in the chair and the whole process of moving me there. I had lost a lot of weight and my joints were so stiff that it made sitting in the chair very uncomfortable which would rapidly become painful. I would be scooped out of the bed in what seemed like a fisherman's net and placed on the seat. I found it a humiliating experience especially when the power pack would go flat and I would be left suspended in the air while the nurses looked for a replacement. It is difficult to convey and expect people to understand how sitting in a chair can be such an unpleasant ordeal.



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 wasn't able to process or interpret, like the vent alarm, sending my thoughts spinning off on a whole new tangent and creating terrifying and bizarre scenarios.

The assault my body was under through procedures like ECMO cannulation into my neck and groin, tracheostomy, regular proning, catheterisation, chest drains inserted and so on, manifested in the torment and mayhem I experienced in the nightmares.

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 and entering my body as I fell to the floor dying. Was this triggered by having chest drains inserted into my sides when I suffered a double 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.

The nightmares clearly didn't happen, no matter how real they felt. The difficulty for me is determining what was real or imagined in the days after waking from the coma, when I was in the grip of delirium and hallucinating.

The extreme and bizarre memories I can disregard as not being true but I'm left with a big grey area of memory where maybe certain events did happen or maybe they didn't.

Eleven years on, I still have many memories from my time in DCC that I don't know whether they are true or false. I have memories that I discounted as being false that turned out to be true and others I was convinced were true that turned out to be false.

So unless I can relate a memory to my ICU diary or have someone who was present corroborate it, I can not truly trust my recollection of events.

ICU diaries by their very nature are not what you would call light reading because they are journaling what is probably the worst time of your life but they can also contain humorous and positive entries.

I am a lifelong Swansea City football supporter and during my time at Leicester Glenfield, Swansea were playing Leicester in an FA Cup match just three miles from the hospital where I lay in a coma and this is taken from the diary entry for that day:

Saturday 02 January 2010

I asked the nurse to give him the FA Cup footie score – Leicester 2-1 Swansea!! She laughed and I said that's almost worth waking him up to tell him, but please don't do that!

In the following entry, now on the respiratory ward (8b), I am becoming more confident walking with a frame and setting goals:

Tuesday 26 January 2010

However, Dave looked ok, he had been for a longer walk today and was pleased he had made it to the fire hydrant in the corridor and back. Each day he was setting himself a new target that was just a little bit further each time.

I have added to the diary in the years since and some of the extra entries include:

Notes from my follow-up meeting and health review at Leicester Glenfield ECMO centre.

My e-mail exchanges with Dr Robert Bartlett, the man who created ECMO as we recognise it today, including the personal invite from Dr Bartlett to help establish a patient and family ECMO support group for ELSO, the guiding body for ECMO centres world-wide, which is one of my greatest honours.

My ECMO story in the ELSO 2020 Annual Report.

In summary, my ICU diary has benefited me in the following ways:

- a) Allowed me to create a time-line of events so I can anchor my experience in reality.
- b) Filtered out many of the false memories.
- c) Allowed me to identify the source of many of my nightmares and delusions by relating them to events recorded in the diary.
- d) Emphasised how much my family endured during this time through their love and support for me.
- e) Elevated my respect and admiration for the critical care teams who cared for me at Gloucestershire Royal and Leicester Glenfield hospitals.
- f) Addressed the memories and questions that continued to emerge for many months and even years after my critical illness event.
- g) Continues to serve as a grounding mechanism when anxiety and depression tightens it's grip, by reminding me how far I have travelled in my recovery journey from the darkest days and in turn, uplifting my mental health.

The cost to benefit ratio of an ICU diary or patient journal is immense.

Cost to hospital/ICU: pen, notepad, a written sentence or two at the end of a shift.

Benefit to patient: Immeasurable.

The onus doesn't have to be fully on ICU staff either, a journal can also be kept by a family member or a combination of both.

I will sign off with the closing paragraphs from the last entry in the diary, shortly after I was discharged from ICU to the respiratory ward and thank my former partner Rose for having the foresight and perseverance to compile the diary, which is now 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.”

David Richards
(2009 ARDS survivor and ECMO patient)
Gloucestershire Royal Hospital, England.
Leicester Glenfield Hospital, England.