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The Liquid Light

Bibo Keeley & Brian Keeley

DEAR BRIAN
Bibo Keeley

Dear Brian,
I have not written to you for the last few days because I have been unable to find any words to express what has been going on inside me. Instead, I will describe what happened.

Saturday. At 10.30 a.m. Nurse J. called to tell me they might have a donor heart for you. I have not been sleeping well for a long time, and I was exhausted and overwhelmed with so many different emotions that I wasn't as composed as I wanted to be. I hurriedly got out of bed, dressed, and rushed over to the Intensive Care Unit. I had to wait until your special pre-operation bed-bath was finished. Standing outside the ward door I started to cry. Dr S. came round the corner, and when she saw me, she gave me a hug. I tried to pull myself together, but as I entered your room, I still had tears in my eyes. So did you. I realised that we were both scared and I decided to be strong for you.

I told you that I was absolutely convinced that you would make it if your heart transplant were to go ahead. Everything would go well. I told you about the confidence others had shared with me,

too—your aunt, your cousin, one our favourite nurses, and a friend back home. You appreciated that. Then I asked you what you were most scared of. You said, “That it’s a life-or-death situation.” I think what made it extra hard was that we had already been through the experience of our hopes being shattered after your transplant operation was stood down at the last minute two weeks ago.

You had been awake since 6:15a.m. and were so exhausted that you fell asleep a few times amidst all the preparation activity and the different people popping in to inform us about the procedure. Nurse J. made me a cup of tea with milk. The hot drink made me feel less numb.

Later, we had some time to ourselves. I reminded you of the image that had come to my mind when I was sitting by your bed, right at the beginning, when you were in a coma. I had “seen” liquid light flowing through your body; a healing light, full of warmth, love, and energy. “I saw it, so it will happen,” I said, “Your body will heal.” The image seemed to give us both comfort. You told me how much you appreciated everything I had done for you and that I had stood by you all this time.

When it was time for you to be taken to the operating theatre, you said, “I am scared shitless.” You wanted me to come with you. All the machines were still attached to you as they prepared to move you from ICU to the operating theatre. They were looked after by different members of the team. There was a perfusionist, an anaesthetist, and the lovely doctor who had allowed our poodles to come and visit you. There were also

two other members of staff we hadn't met before, nurse J. and me. You seemed anxious and said, "I didn't realize how many people were here to help."

I was only allowed to accompany you to the end of the ward, where the corridor leads to the operating theatre. You asked them to stop at the point where I had to go back. They did. You looked at me with a pained expression and said, "I love you. I will always love you." I kissed you on the mouth and said, "I love you, Brian." I whispered into your ear, reminding you to concentrate on your self-healing powers and the liquid light in your body. Then they took you away. I shouted after you "I love you!" Nurse J. put her arm around me, and we walked back to the ICU ward.

Your old room would have to be cleared, so I collected all your personal belongings. On the way out of the ward, I was introduced to the transplant coordinator. He told me that they had now assessed the donor heart in the other hospital, and it was still looking as if the transplant would go ahead. I think that was at about 12:30 p.m. From then on, he would keep me informed about the progress of the operation by telephone, and I would keep your mum, who was at home, updated by text and phone.

12:56 Brian in theatre now, getting prepared for op. Still looks like it's going ahead. Start of op. in two hours.

16:15 I phoned your mum with the following update: Chest opened up, all parts exposed, heart on its way, ETA 17:45.

18:10 New heart due to arrive within next 20 min.

I then sent the following text to many of our friends: Please create a lot of positive energy for Brian NOW + for the rest of the day + all weekend + all week! Thanks! (Heart transplant op. in progress.)

20:01 All well so far. New heart connected and already beating slowly. Now next phase starting: warming up and weaning off support machine.

22:25 Everything fine so far. Weaning process (off heart-lung support) starting now.

00:09 Brian is off heart-lung support. Heart appears to be beating fine at normal temperature. Now observation for 45 minutes before they close him up to see if any extra support needed.

At 02:00, I got a phone call from the intensive care unit. You had been back on the ward for half an hour and the surgeon wanted to see me for an update. I walked over from my hotel room to the ward. The surgeon told me that you were stable and that you didn't need extracorporeal membrane oxygenation (ECMO). They had expected that you would. The surgeon said that you now had a good strong heart. It all sounded so positive, but I didn't dare be overjoyed or relieved as I know by now that in ICU anything can happen at any time.

I was then allowed to see you, but only through the door of the adjacent room. You were sedated, with lots of tubes, cables, and lines attached to you, and there were several machines. Your face was yellowish, but you looked peaceful, which was reassuring. There was quite a bit of activity in the room with various doctors and nurses, so I didn't stay long. Back in the hotel, I phoned your mum. The call woke her up. She sounded startled, but I told her that everything was fine and looking positive and that I had seen you. She was relieved. Afterwards, I finally got some sleep.

I love you,
Bibo

COMING ROUND
Brian Keeley

I am gasping for air after frantically swimming back to the surface of some deep, dark water and suddenly breaking out into the fresh air. As I emerge into the light, I feel a hard tube getting pulled out of my throat through my mouth. I wake up coughing and choking at the same time. I am disorientated, but as things start to become clearer, I realise that I am on the other side of the surgery and recovering from the operation. This is a different room from the one I was in before. My mother and Bibo are here, and the nurses too. Apparently, everything went well.

I watch the choreography of people coming into my room, checking the monitors and the medications which are being administered to me intravenously, asking me questions and making small talk.

The clock on the wall says that an hour has passed since I last checked, but I am confused because the same procedure is repeating. The same nurse who came in an hour ago does so again and asks me the same questions. Other members of staff come in and repeat what has been done already, and in exactly the same order. I tell them all to stop because this has already happened, but they don't believe me. Then I notice that I know what they are going to say next, because they said the same thing previously. I continually protest that they are wasting time because I want to move forward. I feel overwhelmed by everyone in my room moving around and repeating things. I feel they are not helping me to move out of this continuous present. I point to the clock to prove that time is passing, and we are still repeating the same routines. A nurse comes in and says the same thing to me for a third time. I sink back into my pillow, knowing that I will have to lie here and watch another hour of the same repeated activity. This time I will be ready for them. I ask for a pen and paper so that I can write down what each person will say next, but I can't quite remember far back enough into the multiple conversations to transcribe what is going to be said. By the time I start to write something down, it has been said once again. It makes me want to shout: "See? I knew you were going to say that because you've said it already."

Sometimes, a whole day passes without a repeat and then I recognise one of the nurses saying and doing something they said and did much earlier in the day. I have to wait another full day before I can move on from the moment. All during these long sessions, I just hope that I can get through to the end of the day without a repeat. Maybe if I can get a good night's sleep, this time-loop will be broken. In the meantime, however, I am so frustrated. I know this is not right, and nobody believes me when I tell them that is actually happening. The operation has apparently been a success, but I wonder if I have become brain-damaged, and that's why my memory is all messed up. The thought of ending up like this makes me so despondent. All I want to do is to move on and get better.

The hallucinations began to fade as the effects of the anaesthetics slowly wore off, and after a few days the time-loops stopped without me even noticing.

What made me most aware of what I had actually been through was that I was now disconnected from the VAD (ventricular assist device). This was the whirring machine at my bedside, which had been pumping my blood for the previous 101 days. It was now gone, and there were no longer heavy tubes leading from it and buried into my chest. Instead, I could feel my new heart beating within me, all by itself. When I was left alone, I found myself staring at the display on the monitor which was mounted on a trolley to my left. Amid the array of information, one area on the screen held my gaze for long periods. A two-digit num-

ber would increase and decrease slightly, next to a flashing heart symbol. It was my heart-rate. My pulse.

I was still in the intensive care unit, and I knew that the first days after a heart transplant are the most risky. When I look back, however, I was more focused on the basic things like being able to eat and drink properly. The relief on the faces of Bibo and my mother gave me great strength. I also felt a huge sense of relief at this time. Despite the fact that I was very weak and in a lot of pain and discomfort, I dared to hope that I was in the early stages of beginning to return to the world.

SHARING TRAUMA

Bibo Keeley & Brian Keeley

Bibo: My contemporaneous account from 2013 was written in the form of diary letters to Brian when he was in intensive care. I wrote them not knowing if he would survive to read them. He had suffered a massive heart attack while we were on holiday in the Western Isles of Scotland. He was airlifted to a specialist hospital in Glasgow, where he went into cardiac arrest, and subsequently had a stroke and suffered kidney and respiratory failure. Brian was put into a coma, and he had a five percent chance of survival. I refused to accept his death as an option, and this had a strong influence on the way I supported him in the months that followed. It enabled me to bring a very different energy to Brian's bedside than if I had accepted the high likelihood that he might die.

Brian: When I began to emerge into a blurred and confused consciousness, I had no idea that I had been in a coma for several weeks. I could remember the terrifying pain of the heart attack, which had felt like my whole torso was being crushed in a vice, and I had flashback images of being in an ambulance: the bright orange of the paramedics' jackets, an oxygen mask approaching my face, the sound of velcro.

Very gradually, I began to be aware of my immediate surroundings. A VAD was taking over my heart function outside my body. I was on kidney dialysis, and a ventilator was supporting my breathing through a tracheostomy tube in my neck. This meant that I was unable to communicate verbally, so I could not share my thoughts. I had a profound sense of isolation and helplessness, and I was afraid that I would die without ever making it home with Bibo. I firmly believe that without Bibo's determined positivity and support throughout, I would not have survived.

Bibo: In my diaries, I wrote many things that I couldn't share with Brian at the time due to his fragile condition. I had had no preparation for the events that brought our lives to a standstill. During this time, I started to connect with the strength that lies in surrendering to the present moment, and from this grew my determination to try and manifest Brian's survival. At the same time, I felt scared, and I was exhausted.

Brian: After three months in intensive care, my lungs and kidneys had improved enough for me to be put on the urgent list for a heart transplant, and I received a new heart two weeks later. During the entire experience, I felt numb and somehow detached from real life. I had been confined to a bed, tethered to a myriad of machines and IV lines, unable to move, speak, eat, or drink. I was in constant pain and discomfort. After the transplant, I was so underweight and weak that I could not support my own weight, and I would slowly have to learn to walk again. One month after the transplant, I was discharged from the hospital and Bibo and I began the long road to recovery together.

In early 2014, when I was still recovering, I wrote an account of my experiences, an extract from that appears above, in which I was able to articulate the thoughts I could not share at the time. I knew that Bibo had written letters to me almost daily when I wasn't able to communicate, but neither of us would read each other's words until some years later. The two accounts show our experiences from two distinct perspectives, and in retrospect they offer some insight into the emotions and fears that we both experienced, and the differing ways in which we lived through precarious and unpredictable times.

Bibo: Our shared trauma is only one part of our continually evolving narrative—both as individuals and as artists—as we live a life that will always pivot around Brian's heart transplant: his lifelong dependence of medication just to stay alive, a

heightened awareness of potential side effects, and other risks, which could lead to fatal complications, ongoing medical supervision and interventions, physical impairments, and the impact on our mental wellbeing.

Brian: The pandemic has intensified the uncertainty and fear for me and others who are immunocompromised and more vulnerable to Covid. Despite the worldwide success of the vaccination programmes, there has been little, or no support offered (particularly in the U.K.) to the many for whom the vaccinations have no effect, and who have been simply left behind. After six vaccinations by the end of 2022, a test showed that I had developed no antibodies, so I still feel that I need to live life as if I had never been vaccinated at all.

Brian and Bibo: As a practising artist-duo, we take a number of approaches to expressing the shared narratives of our trauma, emotions, memory, and the subconscious, all of which are rooted in lived experience. Our collaborative work in recent years has largely been produced in the isolation that Covid shielding, and our continued sense of vulnerability, necessitates. It is multilayered and multidisciplinary, interweaving autobiographical elements with themes around compassion, mindfulness, and environmental issues.

Our film *Aware* (2022) explores our experience of the uncertainties of living during the Covid pandemic, and the sense of detachment we felt from the rest of society at a time when the precautions designed to protect the most vul-

nerable were being phased out. The film raises questions of belonging and not belonging, inclusion and exclusion, and being unwillingly “transplanted” into a frightening reality that requires new coping strategies. In our short film *Breathe* (2021), we merge the individual and the universal through references to breathing, fear, and death. Nightmarish memories of Brian’s struggle to come off the ventilator and to be able to breathe again are juxtaposed with imagery of Bibo singing and screaming underwater. This underwater imagery represents the time when Bibo would go swimming in the pool of the hotel she stayed in during Brian’s long critical illness, Bibo would swim up and down for long periods, singing and screaming underwater as a way of releasing her emotions. The surrounding natural setting points to aspects of rootedness, isolation, and perhaps friction.

About the Artists

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