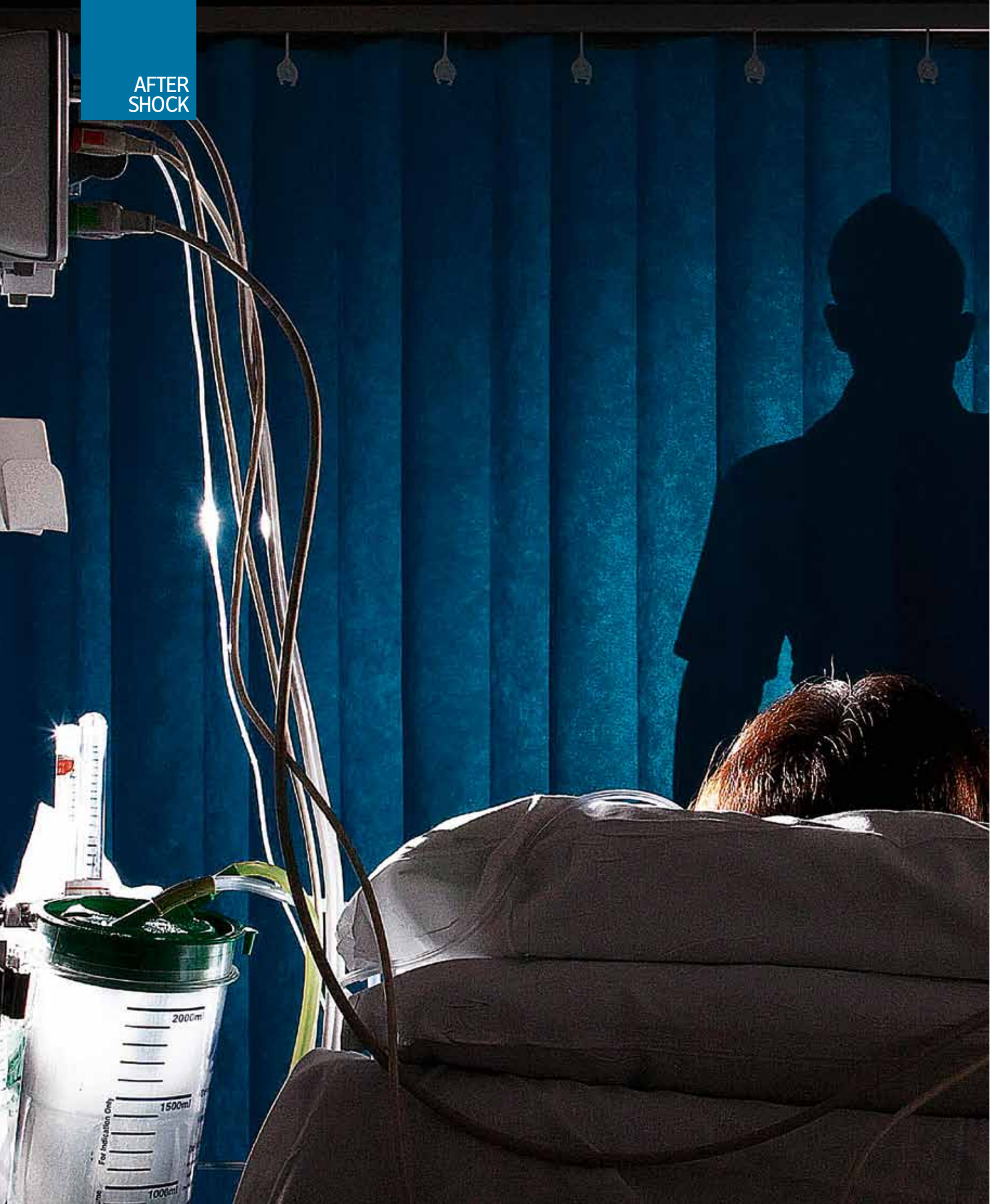
2000ml
1500ml
1000ml
For Indication Only

The demons that can't be warded off

Thousands of patients who have survived critical illness suffer terrifying hallucinations in intensive care, and traumatic flashbacks when they return home. We're only just beginning to understand why, says **Caroline Scott**

PORTRAITS: **MANUEL VAZQUEZ**

‘They had heads, long arms and legs, but no faces’

Barbara Clarke
Believed she was being pursued and confined in a type of concentration camp

Barbara Clarke was admitted to London’s University College Hospital (UCH) in April, for surgery to repair an aortic aneurysm. The next thing she can recall is waking up surrounded by ghostly figures. “They had heads, long arms and legs, but no faces,” she says. “They hovered above the ground and they wouldn’t let me go.”

Barbara, 81, remembers being confined to something like a concentration camp. “I’d crouch below a window, thinking: ‘I’ll wait here until they go.’ But they knew what I was thinking and they’d find me. I was completely alone,” she says. “And I was constantly being chased. I can’t tell you how exhausting it was.”

Kevin Beard, 45, was admitted to UCH after a seizure earlier this year. He was in a bad way: over seven weeks in intensive care, Kevin had several heart attacks, a series of mini strokes, and all his main organs shut down. He received 61 blood transfusions. He remembers little of what happened, but knows he suffered “awful dreams, really unpleasant stuff”. He has asked his wife not to tell him what he went through, but he was so agitated, staff bound his hands with foam padding, like soft boxing gloves, to try to stop him pulling his lines out. “I don’t know what I was going through, but it upsets me to think I was so horrifically frightened, I was driven to try to escape in that state.”

Once he had recovered, Kevin’s specialist, consultant haematologist Dr Marie Scully, made a point of taking him back to the unit for a visit. “It was a very, very surreal experience. The nursing staff hugged me and said: ‘Wow, it’s lovely to see you.’ But I recognised nobody, to me they were strangers. It gave me a chance to thank everyone for all their hard work, skill and expertise — I’d been one of the sickest patients they’d ever had. But I felt very bad about the way I’d behaved. My wife crumbled. She broke down and cried because she remembered every moment of it and it was so difficult for her to go back to where she’d had such terrible, dark days.”

Barbara and Kevin’s experience are, surprisingly, not that uncommon. The singer George Michael recently cancelled a tour of Australia, citing stress as a result of a life-threatening bout of pneumonia that saw him hospitalised in Austria for a month last year. In fact, a new study from UCH suggests that more than half of intensive care patients may suffer from psychological trauma three months afterwards. The study, published in the medical journal Critical Care tomorrow, found that 46% of intensive care survivors had depression, 43% had anxiety and 27% suffered post-traumatic stress disorder (PTSD).

“We’ve known for several years that patients suffer flashback memories to the terrifying hallucinations and delusions they had in the ICU [intensive care unit],” says health psychologist Dr Dorothy Wade, who conducted the study with colleagues from University College London (UCL). “But we were surprised at just how many patients were affected by depression and PTSD. It represents a huge amount of psychological suffering, but also means their physical recovery is slower, with a higher risk of death. The evidence is increasing to a point where it can’t be ignored — there’s a real need to find out why it’s happening.”

The main findings of the UCL study are that patients who receive highly potent drugs, undergo a greater number of invasive treatments or experience extreme stress and delirium in intensive care are more likely to bear long-term psychological scars. Wade is trialling a short, simple questionnaire to be used by nurses as soon as patients are conscious, to detect which are suffering “unbearable stress”. If it picks up those who go on to develop depression and PTSD, it could lead to improved psychological therapy in the ICU.

“Patients are often very withdrawn, and it’s difficult for us to assess their psychological

condition," she explains. "Nurses might say: 'She won't let us touch her,' or 'He won't let us give him a wash.'" This is not surprising if you're convinced you're being held captive and people are trying to steal your organs.

Other researchers have found that the sedative drugs, including benzodiazepines, commonly given to help patients tolerate distressing intensive care treatments may make them more delirious. The drugs, along with the effects of illness and infection, may alter the delicate balance of chemicals in the brain. "Some of the drugs given to sedate patients in the ICU were originally designed for short-term use," explains Dr David Howell, critical-care consultant and clinical director at UCH. "When we're forced to use them for longer, they often produce side effects such as agitation and delusions. And as very sick patients can't excrete these drugs from the body so well, the side effects may be prolonged." Better drugs may be in the pipeline, but at the moment, the medics say, there are no viable alternatives.

The study also found a connection between anxiety and the use of inotropes and vasopressors, cardiac drugs that boost blood pressure and heart function. Monty Mythen, an experienced professor of critical-care medicine at UCL, acknowledges there is a good deal he and his contemporaries don't understand. "We use various techniques we know are good in the short term, and we pat ourselves on the back when patients survive, but we haven't addressed the other factors. The question is: how are they three years later? Increasingly, we need to wake up to the fact that we may not have made the right judgment about the quality of life we're giving back."

Howell admits there has not been enough focus on patients' long-term mental health. "People might think critical-care medicine is all about inserting tubes and lines and jumping on people's chests — and we do all that dramatic stuff," he says. "But we'd be mad not to see that psychological recovery is really important too."

Last year, an Italian study found that having clinical psychologists in an ICU reduced PTSD a year later from 50% to 20%. Now UCH and other hospitals have begun to provide psychological support for critically ill patients using everything from simple cognitive-behavioural methods — which could be as basic as discussing with the patient what they've seen, and trying to explain what might have caused them — to relaxation and music therapy. "The aim is to reduce patients' drugs and do whatever we can to make them feel safe," ⟩⟩→

'I saw a lady put her hand in her bag and knew she was reaching for a gun'

Nicole Als

Thought nurses were trying to kill her and her baby

On September 30, 2011, Nicole Als became both a mother and a patient in critical care. When her daughter, Z'Niah, was born by emergency Caesarean at 36 weeks, she weighed 4lb 6oz and was whisked away to the special-care baby unit at UCH. Nicole became unstable and remembers very little after this: a lady in a spotty dress, her family's concern, an oxygen mask and a feeling of "slipping away". "I kept saying: 'If you put me to sleep, I'll die...' I felt that ill. But I'm not sure if I actually said this or not because, at the time, I was standing at the end of the bed looking down on myself."

Nicole, 36, was in an ICU for 12 days. She thought she was being held prisoner in a blue room. "In my mind, I was sitting up, asking questions, trying to find out why I was being held but no one would answer. I was in a constant state of stress and fury."

One patient cried continually, she thought she heard another being murdered and was certain she'd be next. She stayed awake for four days trying to foil attempts by nurses to poison her, planning her escape on a commode on the basis that it had wheels, although she couldn't sit up, let alone walk. She was very angry that her husband seemed not to be listening to her. "I couldn't get him to understand that if he brought the baby to the ICU, the nurses would kill her. I thought I'd heard them talking about it. They were going: 'Hmm. Is it an African baby or a Caribbean baby? Because we're going to kill it.' Then I saw a lady put her hand in her bag and I knew she was reaching for a gun."

Nicole replays conversations with nurses in her mind, trying to work out what was real and what wasn't. "I talked about my career [as a drama practitioner], a miscarriage, the loss of a family member. Then I thought I heard a nurse saying: 'Who cares about her and her stupid career.' I was so upset. They told me I was suffering from paranoia, but I was convinced I was lucid. I didn't know who I could trust. I didn't feel like Nicole, I lost myself completely."

She says she apologised to one of the nurses she thought she'd been rude to, then admits she can't be sure that happened either. "Later I thought I heard her say: 'That cripple is faking it.' I would not knowingly be rude to anyone and I can't get over the image of myself so completely vulnerable and out of control."

When she first came home to her mother's house in West Hampstead, with a now four-week-old baby, she couldn't stop crying and couldn't sleep. She's been given self-help strategies and found that writing everything down has helped. The flashbacks are far less frequent now, but no less vivid. "Each time, I'm transported back there and each time, I think: 'Did that really happen?' My daughter grounds me and forces me to get on with my life, but I can't forget. I still feel responsible for upsetting so many people."

says Wade. "It might be simple reassurance or physical contact. Sometimes patients say, 'I just needed someone to hold my hand.'"

In 2009, a guideline issued by the National Institute for Health and Clinical Excellence suggested all patients leaving an ICU should be assessed psychologically as well as physically, and offered rehabilitation. At Whiston Hospital on Merseyside, nurse consultant Christina Jones has introduced the Scandinavian concept of patient diaries, which provide patients with "surrogate memories", as well as a long-term counselling programme. Peter Gibb, secretary of ICUsteps, a support network for ICU survivors, points out: "Patients worry that it sounds ungrateful to say to a consultant: 'Saving my life wasn't enough.' But people can be derailed by their experiences and then feel worried and guilty about not getting better."

For the nurses who have to deal with patients suffering from ICU psychosis, it can be almost equally harrowing. "If a patient is hurling abuse, it is difficult not to take it personally," says senior critical-care nurse Elaine Thorpe. "I try to lead by example so the junior nurses are empowered to do the same, talking to patients, making eye contact, touching them, if they can stand it. You just have to be terribly patient and kind — what can take seconds to explain to a patient can take an hour to explain to someone who is in a delusional state."

Six months after she was released from hospital, Barbara Clarke is still haunted by the spectres that dominated her three-day stay in ICU. Recently, she was loading her shopping into the car after a trip to Waitrose with her daughter Deborah, when she saw a lady sitting in the front seat. "Late fifties, plump, dressed in a green coat. Plain as you're sat there, she was, with her bag on her lap."

Barbara is exasperated by her inability to move on. She has received two psychological follow-up sessions at UCH, but chose not to have full psychotherapy for PTSD. "In my day, you just got on with things," she says, "but I don't seem to be able to put this behind me." A couple of months ago, she adopted a dog, Charlie, who she talks to. It helps. "We'll work it out, won't we Charlie?" she says, without much conviction. "The worst thing is feeling so alone."

In the ICU follow-up clinic at UCH, patients who have suffered, both physically and emotionally, spend time with Dr Howell, nurse specialist Wendy Harris and counselling psychologist Dr Anthony Hazzard. Howell recalls a former patient, a young girl he had attended to but had not expected to live. "I thought we'd done really well, but she said, 'Every day is a living nightmare. I wish I was dead.' It made me realise that we have to get better at avoiding this."

Some patients are able to deconstruct their own delusions and move on, others need longer-term help, but as Howell points out, the legacy of critical care is not yet fully understood by himself and his peers — let alone GPs, who have to pick up the pieces. Upsetting experiences in ICUs can open the floodgates on long-buried emotional trauma, such as abandonment, loss and grief. The work that Howell, Harris and Hazzard are doing continues. The hope is simply that, as Hazzard says, "ultimately, the patient may feel containment of the unbearable is possible" ■

'Bombs were exploding. I thought I was being shot at'

Alistair Drummond

Could not talk and suffered severe hallucinations

Alistair Drummond was taken ill on the 7.20am Hemel Hempstead to Euston train and admitted to UCH on February 9 this year. His appendix burst at 9.45am the following morning and he remembers little for four weeks. He was in a single room in ICU, with big doors. "The one on the right was a Japanese golfer. Each time the door opened, he'd swing his club."

Alistair, 61, became "utterly fixated by time. I was tube-fed, covered in wires, a ventilator was breathing for me. I just watched the clock on the wall going round". A whiteboard was updated daily. "It said: 'Today is February 20, it's the 10th day in intensive care.' It helped, because I had a lot of trouble believing I was in hospital."

He suffered brutal nightmares. On once occasion he was in New York, a place he'd visited with his wife, Sue. He was on a sailing boat, struggling with the rigging. "I said to Sue: 'Are you coming with me?' And she said: 'I've got to go home.' So I spent the night alone, scared witless, in this awful boat. Lights were going on and off, bombs exploding. I thought I was being shot at."

He was unable to talk for three weeks. "Some nurses were good at lip-reading, some couldn't understand a word, and that was really frustrating." Sue has kept the pieces of paper covered in scrawled red felt-tip that he used to communicate: "I have had problems with sleep. I do not know who I am. If I wake up anxious, can you say: 'Alistair, don't worry, you are in UCH, Room 4.'"

"The nurses and psychologist suggested different ways of managing the hallucinations, so I watched what they did and kept a diary," says Sue. "Partly, I thought Alistair might want to know."

In fact, he hasn't felt like looking back. He was taken off the ventilator on March 5, to say happy 50th birthday to Sue. "From then on, I focused on getting out." His goal was to volunteer at the Olympics in August — which he managed — and after five months is back at work in IT. He has not experienced depression or flashbacks since leaving the unit. On the whole, he believes Sue had a far worse time than he did. "It was a nightmare for both of us," she says, "but we've come out the other side."