

'I'M BLOODY-MINDED'

Richard Ford with his wife and three sons. 'He's way better than all the other dads,' says Oscar, aged 5



LOCKED IN AND GLAD TO BE ALIVE

Richard has suffered from locked-in syndrome since a stroke left him barely able to move, eat or speak. But he's living life to the full, and, as **Caroline Scott** discovers, he is not alone.

Photographs by **Kate Peters**

A year ago, Richard Ford, a detective constable with West Yorkshire police, and the father of three little boys, was a super-fit, hands-on dad, who managed his sons' football team and thought nothing of running the 20-odd miles home from work in Huddersfield in the evening.

Richard, 42, has tufty hair and serious brown eyes. At work, as an officer with the serious sexual offences unit, Richard was "very highly trained, and very highly regarded", according to his wife, Jude, also a police officer. At home, they divided everything down the middle, from childcare to the endless ferrying between school and clubs, until a massive brain-stem stroke on June 9 last year erased "absolutely everything". Within hours of feeling unwell, though awake and aware, Richard was incapable of

voluntary movement, including breathing and swallowing. All he had left was the ability to blink his eyes.

Two weeks after Richard's stroke, Jude was told by the psychologist at Leeds General Infirmary not to have any long-term goals. "I could have swung for her. I thought: don't tell me what he's capable of doing. You don't know him. Richard regularly ran marathons. He's faced that wall when you think you can't cope, and he's carried on, so don't underestimate him. Make him work."

It was the family's dream to tour Europe over the summer in a motorhome. Jude duly plastered the walls of his hospital room with pictures from travel brochures and the words: "Richard's long-term goal is to tour Europe in a motorhome with his children."

Jude, 41, is impassioned, voluble, half-talking to me — "from day ►►►→

DETERMINED TO LIVE

Left: Christine Wadell goes to gigs and communicates using an alphabet board.

Right: Kate Allatt made an extraordinary recovery after her stroke



LOCKED-IN SYNDROME

two I knew he was still in there” — while wiping Richard’s nose, barking at five-year-old Oscar to come off the Wii and organising a jacket potato for Harry, 8, before he goes swimming. Meanwhile, Richard, with excruciating deliberation, spells out what he wants to say using his eye-gaze computer: “She’ll talk all the time, given half a chance.”

Jude says they talk as they always did, “though it’s not an easy conversation, with Peter, is it?” “Peter” is the name of Richard’s computer voice. “We used to use ‘Graham’ but he was a bit smarmy. Peter’s more of a straight-talking bloke.” Richard suffers from emotional lability, which means he has little control over the way emotions play across his face, greeting every question with what sounds like a howl of despair and occasional tears. But when I ask him if I’m upsetting him, he says emphatically: “Not upset.” Then, through gritted teeth: “Don’t expect to stay like this.”

The late Tony Nicklinson, who suffered a brain-stem stroke in 2005, and last summer fought and lost a very public legal battle for the right to die, described living with locked-in syndrome (LIS) as “dull, miserable, demeaning, undignified and intolerable”. “It’s been seven years and I have zero quality of life.” When he lost his High Court battle, he refused food, and died of pneumonia less than a week later.

Richard has no wish to die; I’ve never met a man more determined to live, but he believes he should have the right to change his mind. The Court of Appeal is now considering three

CHRISTINE HAS HAD A BOYFRIEND. ‘HA, HA, YES, IT WAS PHYSICAL’

more requests; one from Jane Nicklinson who is carrying on her late husband’s battle, and one from Paul Lamb, 57, who was paralysed 23 years ago after a car accident and suffers excruciating pain and what he describes as “daily indignities”, including the manual emptying of his bowels. Another claimant, a 48-year-old, known only as Martin, has been locked in for four years. All want the right to assistance in ending their lives should they wish. The campaigning group Dignity in Dying says 82% of the public support them, while the charity Scope insists the entire debate simply adds weight to the notion that the lives of disabled people are worthless.

Richard describes himself as: “Strong, quiet, fit, stubborn, bloody-minded.” “A hard guy?” he laughs. “Emotionally strong, and patient. People think they couldn’t stand this, but you can and you do. People believe in me. I am determined not to let them or myself down. I have a lot to live for, a lot to look forward to. A lot of memories to make.”

Jude thinks his body may have released endomorphins, which helped him to stay calm.

“I don’t think you were patient at all, before,” she says. “I’d say you were a right hothead.”

It helps that Jude is practical and strong. “I care for his every need, but I don’t really do sympathy — I’ve got to think about the washing!” But Richard finds it painful that the boys no longer listen to him, especially when Jude’s trying to get all three to bed — the youngest, Will, is only 3 — and they’re all playing up. He starts to sob. “But Richard,” Jude says, “you can’t get upset about it. How does an eight-year-old understand that Daddy’s voice now comes out of a computer?”

In nine months, Richard has made huge progress; carers come in for 45 minutes, four times a day, to wash and dress him and put him on the commode, but he’s no longer catheterised and he’s able to swallow. This evening, he’s feeding himself mushed-up Bombay chicken from a red plastic toddler bowl fixed to his tray with a sucker. Oscar surveys his dad, hunched over his dinner, a trail of drool escaping from his mouth, with a mixture of horror and fascination. “Why aren’t you a footballer daddy?” Then, without waiting for an answer: “Anyway, he’s way better than all the other dads.”

Research from Association du Locked-in Syndrome in France indicates that most people with the condition are happy. Out of the 65 people who responded to the questionnaire, 47 reported a good quality of life. Within the LIS community — for there is now a fledgling ►►►

BUILDING HOPE
Eve Anderson, aged
10, is having her home
converted to improve
her quality of life



one, linked by social media — most sufferers believe they should have the right to choose when to die, but that that battle shouldn't occlude the right to live a full life, or place limits on hope for improvement.

Christine Wadell, who once dreamt of a career in childcare, had a brain-stem stroke at 24. She is now 42 and hasn't spoken, eaten, drunk or emptied her own bladder for 16 years. But she doesn't want to die. In fact, she embraces a pretty full life. If Christine wants to say something, she swivels her head to attract her carer Carol's attention. She then uses a clear, plastic E-Tran (eye transfer) alphabet board to spell out words, throwing her eyes up when Carol reaches the right letter. She's far from silent; her conversation is punctuated by raucous laughter, but her body is stock-still, her hands, with their perfectly manicured nails, rest permanently in her lap.

Carol has cared for Christine nine hours a day for 12 years. How many carers did you have before that, Christine? Carol holds up the board, and starts reading. First line: a, b, c, d, e, f... F. Was it five? No? Second line: i, j, k... FI. Fifteen? No? First again, a, b, c, d, e, f... F. FIF... Not fifteen? You sure? Third line: u, v, w, x, y... Ah. Y. Fifty. Was it fifty? Fifty carers, then? Christine nods. It's like playing a Victorian parlour game with a really patient aunt; i-n-c-r-e-d-i-b-l-y slow, but Christine's answers are worth waiting for. Why do you think Carol has stayed so long? First line a, b... B. First line, a, b, c, d, e... E. First line a, b, c... C... "Because she likes picking on me." "Yeah. More like you picking on me," snaps Carol. "You're a right flipping handful, you are."

Christine is dressed in a pink T-shirt and black trousers from Next Directory, and her lips glisten with frosted lip gloss, though she grumbles that nobody does her make-up as she likes it. How do your limbs feel to you? "Just as though I'm sitting still all the time." She feels stiffness, pain, cramp and itching. She makes a face that says: "Don't even get me started on the itching." Sometimes, Carol rubs a rough towel over her back, trying to find the spot. "Hairbrush!" Christine eyeballs. Bliss is a hairbrush scraped through her hair. "It's just one irritation after another, isn't it, pet?" says Carol. Christine rolls her eyes then deadpans. "She's the major irritation."

Christine is fed a greyish liquid five times a day straight into her stomach wall via a gastrostomy (PEG). A urostomy diverts urine from her kidneys, into a bag under her chair. Twice a week, Carol squirts 50ml of vodka

it gives her. Do you feel envious that in the real world, they're able bodied and you're not? She shakes her head. She says she's done her grieving, very quickly letting go of her physicality to survive psychologically. But as the light dims outside, she asks Carol to shut the blinds. She can't bear people staring at her, sitting there in her chair. She'd like to put two fingers up, but, since she can't, she pretends they're not there.

To me, the eye-roll communication looks exhausting, but Christine says she loves talking; she could do it all day. She recently started having two hours of physiotherapy a week, the first she's had in 15 years, with the result that she can now move a thumb; the equivalent, she reckons, in terms

of effort, of me running a marathon. She tells me about a gig she's just been to — Ne-Yo — then laughs when I look baffled. "You need to keep up," she eyeballs. "Funky, young chicks. That's what we are."

EVE IS TOO YOUNG TO UNDERSTAND WHAT HAPPENED TO HER

straight into her PEG. "But she doesn't measure it very carefully. Ha ha ha..." If you're this jolly when you're sober, what are you like when you're drunk? "Ecstatic," she says. "As soon as it goes in, I'm away. I just laugh and laugh." She loves a bit of chocolate pressed to the roof of her mouth, but nothing else passes her lips. What she really wants is a burger. The boredom must be excruciating. "Can you suck," I find myself wondering out loud — there's nothing Christine loves more than a spot of double entendre, and she finds my squirming hilarious. "So what gives you the most pleasure?" "Ooh, ha ha ha," she bellows.

Christine has had a boyfriend since her stroke. So did you, um... "Ha ha, yes, it was a physical relationship. But he couldn't cope with the fact that I couldn't cuddle him during, and was worried in case he strayed to find someone who could... Is that more than you needed to know? Ha ha!" She was heartbroken when it ended; she misses the romance. The audiobook of *Fifty Shades of Grey* sits gathering dust on a shelf. She wasn't gripped then? "Ha ha. Nah... too busy with Facebook."

Social media, which she accesses via her eye-gaze computer, has changed Christine's life; where once she had no contact with the outside world, now she can talk to anyone, on equal terms, and absolutely loves the virtual freedom

Mia Austin, now 24, had a catastrophic stroke aged 21. To begin with, she says, she kept forgetting she was locked in. "When people held up the alphabet board and started reading letters, I looked at them as if they'd gone mad... in my head I'm screaming: 'it's the f***** letter A!'" She can now move her head, thumbs and lower arms, but feels her family has had to fight for everything, including physio ("£60 for half an hour") and a proper mattress to sleep on. Friends have fundraised and her entire street in Heswall, Merseyside, helped decorate a new ground-floor extension so she could come home.

"Once you come out of intensive care, you're just shoved to the side." The speech therapists, she says, have given up on her. She does not want to have her picture taken for this article, and who could blame her. With her sweet face and long dark hair, she looks like Sleeping Beauty. She's conscious of the pathos, and she'd rather not have our pity, thanks very much. Does she want to say anything? "Erm, I don't suppose anything in particular, except maybe determination. I just go out with my friends and do everything as I normally would, and I'm happy — because [inside] I'm just your average 24-year-old."

There is solid evidence to support the concept of neuroplasticity — the capacity to create new neural pathways — but the extent of the brain's ability to rewire itself after a stroke remains unclear. Most stroke patients see some progress, but then reach a plateau. Kate ➤➤➤

Allatt, author of *Running Free*, and *Gonna Fly Now!*, who made an extraordinary recovery after her stroke four years ago, believes this plateau owes more to a lack of NHS funding than patients' own desire, or ability, to move.

Kate, 42, the mother of three children, India, 14, Harvey, 12 and Woody, 9, is locked-in syndrome's poster girl. Following a massive stroke at the age of 39, Kate's x-rays show a white blob, like a child's butterfly print, almost obliterating her brain stem. Kate was completely locked in for eight months, "tube-fed, mute, doubly incontinent. I was pushed about, dribbling, in a baby stroller." Three years on, she's still emotionally fragile — "I was staggered by how many people, including my own sister, thought I'd be better off dead." But there are few physical clues now, bar stalky legs that wobble a little in her high-heeled boots.

Before her stroke, Kate ran her own digital-marketing business and went fell-running in the Peak District, 25 miles at a time, two or three times a week. She ran her last half-marathon in 1 hour 35 minutes. "Was I too fit? I don't know." Afterwards, I was 39, going on 99. I wasn't even capable of letting a nurse know my inco-pad [incontinence pad] needed changing." She says she learnt how to swear with her eyes. "I know I was a right stropmy cow, but it's what helped me survive, and people who've done very well have a similar attitude."

In intensive care, Kate spent every minute willing parts of her body to move. "You think 'white coat' equals 'expert'. But they're not. They're experts in a very narrow field, ie, keeping you alive." She vividly remembers a case-review meeting after seven months: "Not one doctor believed I'd do anything. My husband, Mark, was sitting next to me, wiping up my dribble and talking about putting me in a nursing home." Inside, she was "going beserk". "I was screaming: 'Mark! Mark! What are you saying?'" But the only sound she could muster was a frothing in her tracheostomy tube. Later, she angrily spelt out the words: S-T-A-N-D B-Y M-E.

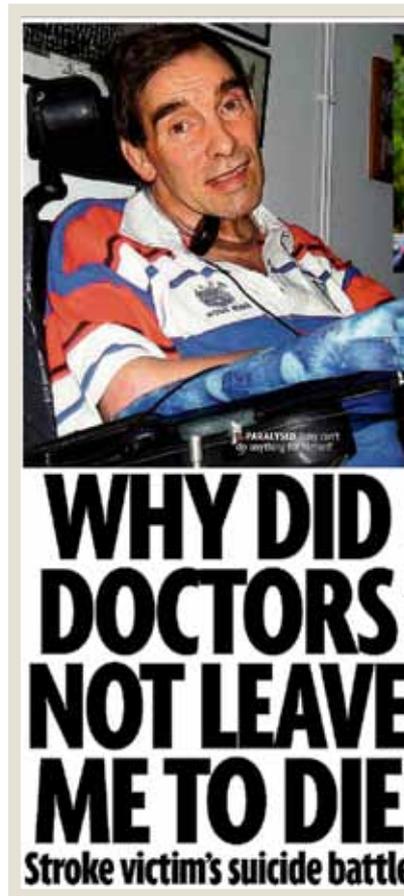
All of this still hurts. The experience left her seriously depressed, with a restless need to advocate for others: her way of turning torment into something positive. She knows that her case is exceptional, but believes passionately that everyone can progress. "Depending on the damage, you could be Tony Nicklinson or me — or anywhere in between. Progress might mean learning to walk — or not to dribble. If there's even a tiny part of your brain stem not screwed, you've got hope, and nobody should be left

without hope."

At 10 years old, Eve Anderson is too young to understand what has happened to her. Aged 8, she was feisty and headstrong, mad on horse riding and, according to her mum, Lee, "always had to have her own way". Eve was at her grandma's when she suddenly felt a pain behind her eye and started slurring her words as if she was drunk. She never spoke again. Lee, 34 and Eve's stepfather, Peter, 32, are articulate, organised, and pro-active; fundraising tirelessly to buy Eve the expensive equipment she needs.

Cognitively, doctors say Eve is unaffected, but it's difficult to tell because, along with her motor skills, she's lost the ability to communicate. The family's house in Northumberland is in the process of being converted. Her bedroom, all pink paint with butterfly stencils, is immaculate. "We wanted it to be a normal little girl's bedroom, not a hospital room," says Peter. A winch runs on a rail between the bathroom and bed, and a lift allows Eve to be lowered into the living room.

To begin with, Eve returned to her old primary school, which her brother, Jed, 3, and sister, Mia, 5, also attend. At break, she'd sit, watching her friends running round. "It was cruel," says Lee. "Absolutely heart-breaking." She now goes to a special school where she shares a bright, modern classroom with eight others, mostly children on the autistic spectrum. This term, they're learning about pirates and dinosaurs. It's Key Stage 1, aimed at six- to seven-year-olds, while other children her age are learning about the First World War. I wonder if Eve might be bored to tears. No one knows. Eve has good days when she responds to YES and NO cards by moving her head, and days when she doesn't. But she evidently understands everything that's going on. When a therapist she clearly doesn't like approaches, she simply closes her eyes. Talk to her about her fabulous blue nail varnish, and they flash open. Recently, school sent a photograph home of Eve "cooking", presumably to show she was accessing all areas of the curriculum. Eve has her motionless hands draped over a rolling pin,



THE FIGHT GOES ON
Tony Nicklinson's widow is still waging a court battle for her husband's right to die

and a snarl on her face which indicates pure disgust. "That attitude is so Eve," chortles Peter.

The couple has fought tooth and nail to have her moved to a school where she'll receive more sensory input, but, as Peter points out, locked-in syndrome is so rare nobody knows what Eve needs. "The honest answer is, we don't know whether Eve enjoys her life now. I imagine she must feel incredibly frustrated, because she was such an active little girl who loved the outdoors. But we hold on to the fact that she also

loved films, TV, music and her family. When she has a smile on her face, or we see her sleeping soundly and comfortably, we have to believe that she still enjoys life, and wants to live it to the best of her capabilities."

For the Fords, acceptance comes in stages. A winch has been installed in the playroom and the boys hang off Richard's high hospital bed, playing the Wii. "My family's always been important, but this has made us rethink," says Richard. "The sports cars are sold. In their place is a static caravan on the east coast, which the boys adore." Jude looks back at their old life and wonders how they managed. "There was way too much going on. Richard and I worked shifts; we'd hand the children over in the dark, we were knackered most of the time. In many ways, we have more quality time now than we've ever had."

In a few months, Jude will take up a new post as a welfare officer in a secondary school, so she'll have the long holidays free. They may not have been around Europe in a motorhome, but Jude firmly believes this summer they'll be together in a caravan at the seaside.

I asked Richard if he felt less of a human being or more since his stroke. He said: "Definitely less." Yet Richard, in essence, is the man he always was. His biggest fear is he will become invisible. "The most important thing is you're heard, your opinion still counts and you're entitled to change your mind. I never wanted this and I might just prove everyone wrong, but I've never stopped wanting to go on living." ■