1

Abnormality

'Every bump is a mystery . . .'

PROFESSOR ANNA DAVID, FETAL MEDICINE CONSULTANT

One muggy August day in 2015, I sat in a large treatment room at the end of a corridor in central London, watching as consultant obstetrician George Attilakos placed a knife in a kidney dish on a small wheeled table. Together with midwives Ignacio Rosas and Georgina Fox, he laid out everything he needed for the invasive procedure he was about to perform on a woman seventeen weeks pregnant with twins: gauze, syringes, needles, large sterile dressings and plastic and metal tubes. The floor around the bed was covered in paper towels.

At three o'clock, the patient walked in, wearing a hospital gown. Emma was twenty-eight, and, in the world outside, a cheerful, robust office manager and mother of a toddler.

The surgery she was here to have – fetoscopic laser treatment, burning the blood vessels in her placenta to disconnect her twins, who had developed twin-to-twin transfusion syndrome – is one of the more intense procedures the fetal medicine unit of University College Hospital (UCH) undertakes, and is not done lightly.

Emma and her partner Tom, a taxi driver, from north London, had had a complicated pregnancy. At four months, a

scan revealed one twin had acrania – the baby was developing without a skull and wouldn't survive after it was born. Emma and Tom were sent here, one of Britain's leading fetal medicine centres, which treat the most problematic pregnancies. Then, on this overcast day, the doctors told them there was a 'time bomb' in Emma's womb.

Blood vessels in the twins' shared placenta were giving one baby too much blood and the other too little, which meant the twin without acrania was likely to die, too. Laser treatment has many risks but gave an 80 per cent chance that the well baby would survive – there was simply no other option. Doctors treat forty cases of twin-to-twin transfusion syndrome each year here, one of only a few hospitals in Britain to do this.

Emma lay on the bed with an absorbent towel tucked into her pants. Naturally a chatty, confident person, she was breathing deeply: 'I'm really nervous.' She was draped from neck to toe, only her belly exposed. The doctor and midwives tried to be reassuring – 'Most women afterwards say it's not as bad as they think,' said Mr Attilakos, gowning up – but Emma radiated anxiety as she was handed a pair of dark glasses to protect her eyes from laser rays. She moaned and sang to herself. Then she sighed: 'I don't want to see anything,' and squeezed her eyes shut.

Georgina said, 'Sweetheart, I know you're scared. You're going to be fine. Nice cup of tea for you afterwards.'

'How many times have you done this before?' Emma asked Mr Attilakos.

'Seventy,' he said.

'Is it tricky for you?'

'No.'

He warned her, though: 'Even if it goes well, you could still miscarry.'

With Tom holding Emma's hand, it was time to start. A local anaesthetic was injected into Emma's belly and Mr Attilakos scanned her using ultrasound, then plunged a needle into her womb, to one side of her belly button. 'Owowowow,' Emma cried. 'It stings.' Georgina held her hand.

Standing at the foot of the bed, observing in my role as a reporter, I thought it looked barbaric. Memories came back from my own similar experience here, five years before, when another specialist, Professor Donald Peebles, pushed a shunt into my unborn baby's thorax to save his life from a deadly condition called hydrops.

I longed to give Emma some words of reassurance, but I couldn't break the concentration and sterile atmosphere surrounding the operation.

*

I'll always remember the ordinariness of the last journey before my own life changed – the feel of the plastic handrails as I calmly sat on the bus, going down Highgate Hill. Later, I found myself wondering how I could not have known that life would never be the same again.

It was a Monday; 4 January 2011. That Christmas, I had been swollen with pregnancy; my mother-in-law seemed amazed by the size of my rock-hard bump for just twenty-seven weeks. We thought I was carrying a big bonny baby. 'He's a little chubster,' my husband Phil laughed.

On Christmas Day, Phil gave me a bottle of eau de parfum. A year later, I would rediscover it, unused. I also wanted a handbag that Christmas – something grown-up, subtle and mature to match the new identity coming my way: 'mother'. I didn't get one, but a few months later I thought about that

wish for a handbag and couldn't imagine how I'd have found any use for it or identified with it in the slightest, just as I didn't get any time or desire to wear perfume. Phil gave me a beautiful sewing box – the wooden kind that folds out – but it stood empty on the living room floor for a year. Another gift of several large candles, from our friends Nina and Kris who came to dinner that last New Year's Eve, was, a year on, still wrapped and sitting by our fireplace where I had put it on New Year's Day, planning to start using the candles later that week.

That New Year's Day, Phil and I went to one of our favourite cafes and made a list of things we needed for the nursery and baby. When I found that jokey and innocent list again, a few months later, I could hardly bear to look at it. I'd thought I might buy a breast pump to express occasionally. 'Nappies!!' Phil had written playfully, unthinkingly. A musician – a composer-turned-improviser – and writer who had 'escaped' Sunderland in the north of England for a life of concerts and culture in London, Phil had met me when he was thirty-four and I was twenty-eight. I loved his curly red hair, his nerdy kindness and intellect, and the flattened lilt of a northern accent with which he told jokes. We had both always wanted children. That day we were excited to think our baby would be with us at the end of March. We had no idea that I wouldn't be giving birth in March or even in February; that we wouldn't need to buy and use nappies at home for many more months; that small ordinary things like this, which most parents take for granted, would, for us, be gaping absences.

The Sunday afternoon just after New Year, I fell asleep. I woke to hear Phil on the phone to a friend in New York whose wife was due to give birth in late March, like me. They were comparing how big we were. As I got up, I noticed an odd stitch-like sensation in my twenty-nine-weeks-pregnant belly.

The next morning, I was supposed to go back to my work as a freelance journalist – I had a deadline for Tuesday. But the odd feeling was still there. Just a bug or indigestion, for sure, but I supposed I'd better run it past the midwives. They told me to come in and get assessed. I called Phil away from his desk so we could go to our local north London hospital, the Whittington. It was only a half-hour journey on the bus, and we assumed we'd be sent home within two hours to get on with planning our childbirth classes.

Having miscarried my first pregnancy had made me ultra-anxious this time. Throughout the twenty-nine weeks of this, my second pregnancy, I had been exceedingly cautious, even though I realized my fears were excessive. I hadn't painted my nails, stood near a smoker, eaten forbidden foods – not once. It was as if by worrying constantly and following the recommended guidelines to the letter, I could ward off anything truly bad happening. Pregnancy, I was to discover, has no regard for superstition.

It hadn't been a straightforward six months. I had bled on and off through the first trimester and had several early scans. When the midwife told me: 'Go home and put your feet up,' I was so paranoid about not following her advice to the letter that I was afraid to stand up. Then at our thirteen-week antenatal screening, we'd had the nuchal translucency test, a scan which measures the fluid at the back of the baby's neck.

3.01 mm is a number I'll never forget. It was the exact width of a black space at the back of our baby's neck, and the fact that it was over 3 mm, I was told, could be a sign it had Down's syndrome, or another chromosomal condition. Like many, I had accepted the screening test offered to me without much thought, assuming that the result would be normal. I'd had weeks of bleeding and early scans, but the solemn reaction of

the sonographer when she measured the fluid under the skin of our child's neck and found it just a little too much was the first official red flag Phil and I had that this pregnancy wasn't typical.

I'd hit Google and found a world of pregnant women panicking about their numbers. My baby's result was just above the borderline, but along with stories from women who had had high numbers and 'normal' babies, I read many stories of pregnancies with measurements like ours where the fetuses were found to have abnormalities and terminated. It seemed that even being 0.1 mm over the 3 mm cut-off point was cause for concern. Never before in my life had a minute number held such significance. I looked at the scan photo again and again, at that black space deemed just a little too big, wondering how such a small thing could be pinpointed accurately.

Together, the nuchal and blood test results gave every woman a ratio, the chance of her baby having one of the commonest chromosomal syndromes: Down's, Edwards' or Patau's. I read that a high nuchal translucency was also associated with heart conditions and one or two other genetic syndromes – it all sounded obscure and unlikely; a world away. My blood test results turned out unremarkable, so my given chance of a child with a chromosomal condition was only one in several hundred, a relatively high ratio but nothing compared to the women whose ratios were one in three or one in twenty.

For the first time since schoolgirl maths lessons, I thought about probability. Most of the women with high ratios did have invasive tests – chorionic villus sampling (CVS) or amniocentesis – and after anxious posts debating what a chance of one in thirty or one in ten really meant, they returned to the online forums to broadcast their relief – 'Everything's normal, thank God' – and to be congratulated. We

would not have considered ending the pregnancy unless our child had a condition incompatible with life and we chose not to undergo the risk of invasive tests.

Although there was the occasional mention online of a diagnosis with Patau's or Edwards', almost always followed by a termination because these trisomies are generally considered incompatible with life long after birth, most of the talk – and anxiety – surrounded the possibility of having a baby with the far more common Down's syndrome. A few voices crept in saying Down's wasn't something to fear, but they were drowned out by other women reassuring the worried: 'I had a high risk and my baby didn't have Down's – he's a gorgeous, healthy baby.'

Noting how frightened other pregnant women were of Down's, and the NHS offering screening for it to all pregnant women, it was hard not to become frightened, too.

At twenty weeks, after extra scans, including a fetal echocardiogram to examine our baby's heart, we were told he was a boy and everything was 'beautiful'. The cardiologist said, 'Go away and enjoy the rest of your pregnancy.'

At last, I finally felt relatively safe. Every time we had been for scans before, we'd been terrified something was wrong, and rushed to the hospital by Tube. This early day of a new year, it was different. We were in the third trimester; everything was 'beautiful'. So we took the bus, as if to underline that we were in a safe new place now.

When we got to triage, where I was examined on a row of couches next to two other pregnant women, the midwives couldn't find anything wrong, apart from the fact their tape measures suggested I was around thirty-five weeks pregnant rather than twenty-nine. But then, it's so easy to mis-measure with a tape measure. They wondered if I might have placental

abruption – a separation of the placenta from the uterus – and decided to keep me in overnight. It was my first ever night on a hospital ward, lying in my little curtained cubicle among twenty other pregnant women, and I couldn't sleep. I emailed my editor to say I'd be back the next day.

The next day, Tuesday, I was told I could go home as soon as they'd scanned me. As we walked down the corridor towards the ultrasound room, I couldn't wait to see our baby again. How lucky to get an extra scan at such a late stage. Phil and I held hands.

I lay there being scanned and I saw the baby on the screen and I was happy and saying, 'Oh wow! He's moving! Look at those legs!' And then I noticed the sonographer was very quiet.

Finally, she said something.

'Er – it looks like there's a lot of amniotic fluid.'

'Oh,' we said. It didn't sound too bad. But it did explain why I hadn't felt much movement the last few hours.

Then she continued, 'These are pleural effusions – fluid around the lungs – and it looks like there's fluid under the scalp.'

'What does that mean?' I asked.

She paused awkwardly.

I asked, 'Is this serious?'

All this time, I'd been worrying about something going wrong, and now it seemed it actually was. This wasn't supposed to happen.

'I'm sorry. I'm not allowed to go into any detail,' she said, her voice withdrawn. There was no smile. 'You'll have to see the consultant.'

'But is it a bad thing?' I asked.

'I'm afraid it's not great news,' she replied, poker-faced.

It was from that moment that everything changed.

We were taken back to the ward, where we waited and

waited for a doctor to come. Night fell; my mother's chicken casserole, waiting at home, grew cold.

A young, anxious-looking junior doctor finally came to my cubicle and pulled the curtain closed. Our baby, he explained, had a rare condition called hydrops fetalis, affecting around one in 3,000 pregnancies, many of which, associated with conditions like Edwards' syndrome or toxoplasmosis, usually end spontaneously, sooner or later during pregnancy. For whatever reason, the body's lymphatic, or drainage, system fails. Our baby was breathing in amniotic fluid but not processing it; it was building up within both of us, crushing his lungs, restricting his growth and filling my womb, putting him at risk of premature birth.

'What's going to happen to him?' I dared to ask. 'What is his chance of living?'

'I can't give you a chance,' the doctor said.

Did he mean there was no chance at all? I couldn't ask this question.

The doctor stumbled over his words, as if he was unsure. He kept saying a consultant would come to see me and would explain everything properly.

From the cubicle next to me, separated by a floaty curtain, I could hear a doctor talking to a mother about her gestational diabetes. She was crying. I was shocked to find myself feeling, of all things, envy. I wished I was having a 'typical' pregnancy hospital conversation.

I asked to be moved from the ward with the other pregnant women. I was sent to the labour ward. Not because I was about to give birth imminently, but so I could have a room of my own. It was much more comfortable than the antenatal ward, although all night I heard the women in labour, doing their thing, screaming, it seemed to me, in a sort of blithe innocence.

New fathers lugged car seats around, looking proud and important. Outside the toilet, one woman dripped pools of bright red blood on the linoleum. I no longer identified with these people. I wouldn't have antenatal care or give birth at this hospital. I was to be transferred to University College Hospital, where there was a specialist fetal medicine unit for pregnancies like mine, where the baby was in trouble.

The Irish midwife was kind, coming in to take my vital signs every few hours. My mother stayed by my side all night. Sometime around 2 a.m., I drifted. Then at eight in the morning, an obstetric consultant came to see me. Sometimes, a gesture of caring when you're really scared in hospital can actually be frightening. When a senior doctor comes to see you – having put you first on his list – with compassion in his eyes and reaches out as he leaves to pat you on the shoulder and says, 'You're being very strong,' you know this is bad. As the day went on, and we were scanned again, we saw the most senior obstetricians the hospital had to offer.

I wasn't being strong; I was just living through this. The first scan had been on Tuesday afternoon; thanks to the NHS, at noon on Friday we, my parents and Phil's mother stepped through the doors of UCH, a glass-walled modern hospital in the centre of London. On the first floor of the obstetric wing, we followed signs which diverted us from the general antenatal care area to a set of closed doors marked Fetal Medicine Unit. I sanitized my hands carefully at the dispenser and called my family back to sanitize theirs, too. There were only a few other pregnant women in the waiting room – two simple rows of chairs and a water dispenser – all of us sitting quietly. No one was being called; every so often a doctor or midwife in blue scrubs walked past. We waited for forty-five minutes, watching the clock ticking. A notice on the wall read: 'Please

be aware you may have a long waiting time due to the nature of the Fetal Medicine Unit'.

Then a door opened and a sensible, friendly-looking midwife with straight brown hair and glasses called my name. Phil and I – and my father, a doctor himself – were ushered through the door into an ultrasound suite. There, tall and patrician Professor Donald Peebles shook our hands and told us that hydrops was, frankly, not an everyday problem.

I'd Googled him and found out that he was the hospital's head of research in maternal and fetal medicine and had two grown-up daughters. He divided his time between research into the physiology of unborn babies and clinical practice, in fetal medicine and also as an obstetrician. Professor Peebles would one day tell me that fetal medicine 'poses a completely different set of ethical challenges because there are two patients – mum and fetus. Sometimes they're at odds. And although the focus is on the baby, all the interaction is with the mother.' For now, I was one such mother. The prof was like his online picture – a distinguished-looking man in a suit, smiling reassuringly but, more than anything, cool and matter-of-fact. Doctors working with ill babies can't appear sentimental, I was to learn. Their job is to give the patient the facts, even if they are bad.

I had also Googled hydrops and the word 'fatal' had leaped into my vision again and again; there was line after line and page after page of that word. Most babies, I'd read, die in the womb or don't live long after a premature birth. Phil refused to look at my pages of Google searches and medical journal write-ups about dead hydropic fetuses. He believed that everything would be all right. But I'd kept Googling, unable to look away from the computer screen.

Now I lay on the couch while Professor Peebles scanned me using a state-of-the-art ultrasound machine. I hoped he would

find things weren't so bad, but the fluid all around our baby and inside his scalp and chest was still there and, if anything, was getting worse. Professor Peebles and the midwife looked serious. Our only potential treatment, Peebles told us, was an emergency invasive procedure – draining the excess fluid from the baby and womb, and inserting a plastic 'shunt', a coiled plastic drainage tube, halfway into the baby's chest wall, to drain more fluid from his chest into my amniotic sac.

The shunt treatment, he said, was the only treatment. He had done it before, but not that often – the unit only did this procedure five times a year, since hydrops is rare. The longer we left it, the less chance our baby had. It had to go ahead right now. The shunt could well fail; the risks were many.

No one could tell us why this was happening. Hydrops often develops with no known cause or could be connected to anything from genetic conditions to infections. The unit would do every test available. It was gently mentioned that we had the right to abort this pregnancy if the situation deteriorated. But my thoughts gathered on a different fate: if the baby didn't respond to the fetal procedure and died of hydrops, I would give birth to a stillborn.

Phil and I signed the consent form for the operation and my father returned to the waiting room to update the prospective grandmothers, who were in a state of controlled anxiety. 'We've contacted the neonatal unit and they have a cot ready – there's a one in three chance you'll go into premature labour,' said Peebles.

I'd never seen a neonatal unit. Phil didn't even know what a neonatal unit was. We had no idea what would go on there. It was hard to imagine the creature under my skin as a living baby, but it was reassuring to hear that if he did come early,

the doctors thought they could treat him. He must have some chance, then.

I asked to go to the ladies' while Peebles and the junior doctor and nurse prepared for the procedure. There, I looked in the mirror and steeled myself. 'Is this happening?' I asked. 'Am I going to let them cut into my unborn baby in five minutes?' My answer to myself was 'Yes.' I took a deep breath.

Back in the darkened scanning room, I lay on the examination couch with my belly and baby exposed and vulnerable. They swabbed cold antiseptic onto my abdomen and injected local anaesthetic. At this point I turned my head to the right so I couldn't see any more. Phil sat on my left, holding my hand. The brown-haired nurse, whose name was Nicky, was so gentle, holding my feet and asking, 'Are you all right?' Peebles was going to watch his operation on the ultrasound screen so he could see what he was doing. Phil watched the screen. I didn't want to close my eyes but I stared at the edge of the room.

First Peebles inserted a needle through my abdomen into one side of my womb and drained out – I later saw – several litre bottles of amniotic fluid. There was so much that it splashed into his shoes, making him shout almost comically in surprise. The pressure in my belly relieved, and the baby one step safer, he then moved on to what the doctors called 'shunting'.

Phil later described to me what he had seen. Peebles watched the screen intently as he stood poised over a point on the other side of my bump, holding a cannula (tube) mounted on a sharp, thick needle. At an instant when our baby moved to one side of the womb and grew still, Peebles called 'Now!' and plunged the cannula very quickly into my belly, into my womb, into our baby's chest. I felt the visceral deep force of this plunge and cried out. It was as if Peebles was playing a video game or taking a pot shot at a coconut. Basic.

The 'oooh' groans I was making came instinctively and sounded animal-like. It wasn't so much pain as surprise and strangeness for our unexpecting baby. It felt wrong; the antithesis of every effort I'd made to keep my baby safe in pregnancy.

There was a pause and then everyone breathed with relief as our baby moved again. Peebles pushed the 'shunt' – a drainage tube – into the cannula, then pulled out the cannula and needle. The shunt seemed to be in place, halfway into the baby's chest and halfway out, though it was hard for Peebles to be sure. The whole procedure had taken half an hour.

The midwife gave me a womb relaxant to reduce the chance of labour and monitored the baby. I was his only link with the world and so I pressed a button every time I felt him move.

Over the next ten days at home, I tried to move as little as possible to avoid miscarrying, and I Googled, reading stories of mothers who had lost child after child to unexplained hydrops. That word, which I had never heard before, and which no one in my non-medical world knew, and which was mentioned in absolutely none of my fifteen pregnancy manuals, was like a portal to a dark new world. I strung together enough words for that article I'd been on deadline for, then stopped work. I lay in the bath and couldn't stop thinking about what I was sure was going to happen, which was that my baby would die in the womb and I would have to give birth to him . . . and that then I would never be able to have another baby; every pregnancy would end in hydrops. From my bedside window, I watched the neighbours in our frosty suburban street coming in and out of their houses with their children; mothers wheeling prams. In my mind, I wasn't properly pregnant any more; I wasn't one of them. I felt an odd embarrassment at my failure to have a healthy baby.

I couldn't sleep and asked my parents to stay day and night. Late one night I crawled into my mother's arms and she held me like a baby. I thought only my husband and family could see me like this; I only group-emailed my friends to let them know what was happening. But Grace, my old schoolfriend since the age of eleven, was determined to speak to me. So, from a Goan beach where she was beginning a six-month career break from her job as a PA, she insisted Phil put me on the phone.

'I'm going to fly home,' she said as she waded in the sea. 'I want to be with you. Call me any time of the night.'

'Oh, it's not necessary,' I replied automatically.

I don't believe in God, but I prayed for half-hours at a time – sometimes to God or Jesus (because he loved children), sometimes to my baby himself, sometimes to a vague idea of some god of motherhood who might save him. I lay on my bed and murmured these prayers to my baby; I hoped he was somehow listening.

One especially dark Sunday afternoon, I found myself driving to my local synagogue in suburban north London. I'd never been before; it was an anonymous, brutalist building in a row of semi-detached houses. I could see the rabbi and a group of people having a small gathering inside. I knocked on the door until someone heard me, and was ushered in, feeling surreal and biblical, with my swollen pregnant belly.

I told my story to the bemused rabbi. 'I know I've never been here before,' I said, 'and I'm not religious, but would you pray for my baby?'

'Of course,' he said. We lit a candle and prayed.

On Tuesday my phone rang. 'The chromosomal result is normal,' the fetal unit midwife had to repeat again and again because I needed endless reassurance. Our baby didn't have

a chromosomal abnormality; this wasn't Edwards', Patau's or Down's syndrome. Tests for serious viral infections – toxoplasmosis and parvovirus – were also negative. More tests could be done at birth, but for now, the cause of the hydrops remained 'unknown'. In one way, that was good – nothing else had been found. In another way, it was bad – unexplained hydrops can repeat in future pregnancies, and in my mind I was already thinking about my lack of ability to have any children. I started Googling adoption.

I also phoned the Down's Syndrome Association and selected the option to make a donation. 'That's very kind of you,' said the woman who processed it. 'May I take your name?'

'Thank you, but I'd like to be anonymous,' I said.

There was a pause before she politely said: 'Oh . . . Well, yes, that's fine.' I knew she was wondering who the hell I was. Little did this nice woman from the charity imagine, I thought, that she was talking to a heavily pregnant woman moved by guilty relief.

A few days after the shunt treatment, Phil and I returned for more scans with the director of the fetal medicine unit, Pranav Pandya, a slim, smiley man I imagined playing carefree games of tennis or yachting in his spare time. We had hoped the fluid in our baby's chest, which appeared on the scan as two black pools – dark and unknown – would have shrunk. We might need to be 'shunted' again if the shunt had ended up totally inside or outside our son's chest rather than halfway in, though of course each operation carried greater risk. And so it turned out – the shunt had ended up lodged all the way in our baby's chest, and so could not drain the amniotic fluid collecting there. But for the moment, Mr Pandya told us in his

reassuringly breezy manner, the overall volume of fluid was much better.†

'When you first came in, your baby's chances of survival were 50–50,' Pandya said at a scan a week after our shunt, 'but now it's gone up to 80 per cent and I'd even say now it's at 90.' Every day the baby could stay inside me now, without needing shunting again, the better.

Three days later, I felt the pressure in my stomach return and I started bleeding. The initial shunt operation had saved my son's life for another few weeks in the womb, but no longer.

Getting through the fetal medicine unit is only the first hurdle for a very sick baby. The worst for our son Joel – and for me – was still to come, during our time in neonatal care. Joel's recovery was to be long and complex. During his first five months as an inpatient, he would be cared for by more than a hundred specialist doctors and nurses in three different hospitals. We were just another family to them, but to us, they were gods.

*

Years passed but I found I couldn't leave that hospital experience behind. It haunted me, as a mother. And I had good reason to believe it haunted my son on some level, too.

I realized I was a member of an increasing band of parents whose children would not have survived, could not have been treated, if born thirty, twenty or even ten years before. Modern medicine had saved our children; we had our 'miracle babies', but beyond the sentimental 'little warrior' clichés, we

† In the UK, senior surgeons (including obstetricians and gynaecologists) often use the title Mr or Miss (or Ms/Mrs) instead of Dr.

faced a reality of children with complex needs and our own uncharted emotions, after our bizarre initiation into parenthood. Saving our children was uncharted territory for the medical staff, too.

A fetus in the womb was unreachable and a mystery to previous generations; today doctors can diagnose illness from the early weeks of pregnancy (and even before implantation) and are saving babies' lives with operations in utero, and intensive care and surgery after birth. My child is one of this new generation. No one knows quite what their lives will be like.

I eventually worked out that I had been lucky, as the shell-shocked mother of a critically ill baby, to live just half an hour away from one of the world's leading centres for fetal medicine, a young, highly specialized and dynamic field of medicine which is saving the lives of unborn babies who aren't growing normally, who will need operations after birth, or with a huge range of disorders. The unit at UCH is one of around seven leading fetal medicine centres in England offering therapies like laser surgery for twin-to-twin transfusion syndrome.[1] Doctors at my hospital, I would later discover, were among the first in the world to treat fetuses and neonates, and in 2018 they became the first in Britain to offer open fetal surgery – in which surgeons open the womb, operate on the fetus, then seal the baby back into the womb for the pregnancy to (hopefully) continue. Parents are referred from hospitals all over the country.

After my son was well, I wanted to go back and see the fetal medicine and neonatal units again, and I wished I could dare to ask the doctors what it had been like for them. I wanted to keep in touch with our doctors. How could I not? They had saved our child's life. When our baby finally came out of hospital, we sent them thank-you cookies; at Christmas we sent

cards we hoped they would display along with all the others on the unit walls, with photos of our own 'miracle baby'. Every now and then, Phil or I sent an email with a photo of Joel to Mr Pandya, or Dr Meek at the neonatal unit. They always replied genially, signing their names as Pran and Judith, but I could still only think of them as Mr Pandya and Dr Meek, mysterious heroic figures. During our time in neonatal care, Dr Meek, in particular, had a way of appearing in the room almost magically, like a fairy godmother materializing in a puff of smoke, just when she was most needed.

I wasn't alone in wanting to revisit the units, perinatal hospital psychologist Dr Claudia De Campos mentioned when I interviewed her for a newspaper. Many former patients like to go back – it's a form of catharsis, of digesting a surreal, sudden past experience. (Others, she said, never want to set foot in the hospital again.) Anyway, when, around a year after Joel came home, I tried to go back to UCH to visit our son's past doctors, the astringent hospital smell and the sight of linoleum corridors and hand-sanitizer dispensers made me feel dizzy, and I turned back at the door.

I was haunted as a journalist, too. As a patient, I used to sit in the waiting room and look at the other pregnant women, some smiley, others tearful. I watched as they were ushered behind the closed doors of the consulting rooms and wondered what was going on in there. Again and again, on hearing my own son's shunting story, people told me they had no idea such procedures were possible, let alone being done. I wanted to know what it was like for other mothers and babies, the first generation for whom life before birth has been highly medicalized, and for these doctors who hold not only life and death but also the possibility of birth in their hands. I needed to explore the strange relationship which grows up between the

doctor and the family in such circumstances – the professional gap between doctor and patient at odds with the intense personal intimacy of treating that most precious thing, a mother's unborn child.

My fascination with fetal and neonatal medicine grew as time passed and the rawness of my own experience damped down. As a journalist, I found myself choosing to write about my own experience and those of others in newspapers and online; interviewing clinicians; following research. Finally, despite my butterflies, I put my queasiness aside and walked back through the unit's doors as a writer, granted unprecedented access to sit in on dozens of consultations behind closed doors to observe and report on procedures like my own. I felt privileged and emotional to be back with all the staff: Nicky, the calm midwife who had held my hand when I was terrified; cool, collected Peebles; and the upbeat force of nature Mr Pandya himself.

I'd grown up the daughter of an Oxford research scientist and doctor, one who studied the immunology of cells. I'd played Consequences on the back of abstruse scientific papers, but never done Biology GCSE. Instead I grew up wanting to be a writer. My father, the kindest man in the world, only ever allowed the slightest frustration to show when I couldn't grasp some basic maths or physics homework. And now I was a mother of a medical curiosity. That gave me a certain worth in doctors' eyes. But I wanted to cross the line and talk to medical people on their own terms. Although this time I was there as a writer – a professional – not a patient, I still felt nervous. I was sure the doctors remembered my own case as utterly insignificant; after all, they see hundreds of women with critically ill babies every year. I wondered if they thought I was weird for wanting to stay in touch.

And even as Mr Pandya – the friendliest of consultants – hugged me and welcomed me and asked after Joel, there was something about the past relationship between us as doctor and patient that I couldn't quite bridge. I wondered if he felt it too. Patients don't usually go back as reporters. As a journalist trying to research the medical science behind my own experiences, I felt intimidated at the very idea of approaching doctors and scientists to speak to me as some sort of equal; a constant fear that they would raise their eyebrows at my ignorance and tell me I'd written up their work completely wrongly. Or that they'd feel I was after their trade secrets – the inner workings of the hospital, the private backstage protocols that patients, like the audience of a play or the customers of a business, aren't meant to see.

*

That stifling August day in the treatment room, on the surface of Emma's belly, I saw a drop of blood seep out around the needle. Mr Attilakos cut into her stomach with a knife. 'This is the bit that will hurt a little,' he said. The local anaesthetic numbs the skin and the tissue beneath, but sometimes the mother still feels pain from this procedure. He fed a long tube attached to both a laser and a camera down into the needle in Emma's womb, and as he repeatedly jabbed, she shouted: 'Ow, oh fuck, it really hurts.'

'Stay still!' he implored her.

Tom was quietly crying.

'I feel faint,' Emma said. She was burning hot; Georgina fanned her with a cardboard sick basin.

Mr Attilakos was watching the camera's view intently on a large screen. He was looking at the placenta with its lethal

shared blood vessels connecting the babies, and he fired on each blood vessel with the laser. On the screen he could see a light flash with each zap, and the tissue evaporating in puffs of smoke as red vessels burned to white. The camera moved slightly and we saw a baby's hand in its silken webbing.

'Try to breathe less deeply,' Mr Attilakos urged Emma. 'When you do a deep breath, it moves everything.' He added: 'You may feel popping; it's a bit alarming.'

'I can feel it in my throat,' Emma said, but Mr Attilakos thought that was sheer anxiety. Georgina tried to lighten the tension: 'These sick bowls come in handy for all sorts of things.'

After forty minutes of laser zapping, they drained nearly a litre of excess amniotic fluid from Emma using the tube in her belly – it would also be checked for chromosomal abnormalities. Mr Attilakos's hands were dripping with amniotic fluid as he pulled the tube out sharply and joked, 'After this you mustn't do any housework for three months!'

The relief that it was over was palpable. Emma and Tom hugged and kissed as they slowly walked to the recovery room. Tomorrow they were to have another scan. 'It's your worst nightmare,' Emma told me. 'You never think this is going to happen to you. We've channelled all our hopes into our well baby.'

The doctors, I saw, felt their pain, and hope, too. Everyone who works at the fetal medicine unit is passionately committed to saving pregnancies – from the team of consultants to the specialist midwives, researchers and receptionists.

Over a few days observing, I watched nervous couples stream into the fetal medicine unit. Sometimes siblings come too, and it is odd to see children, even though children are what this unit is all about, because the world of fetal medicine is a world of black and white scans. As one fetal medicine

consultant here, Professor Anna David, put it to me: 'Scanning is like meeting a new person each time – every bump is a mystery and you're like Sherlock Holmes trying to find out what's wrong.'

One average day in the unit started with a twenty-eight-week termination for lethal skeletal dysplasia – a small chest that would leave the baby unable to breathe. 'You just have to do it,' the doctor told me beforehand. 'I don't like to do it but it's far worse for the patient.' The same morning, there was good news for a couple with twins suspected of having cytomegalovirus (a common virus which can cause great damage in pregnancy). Their scan was normal, and Mr Pandya felt the blood test that flagged up the virus was probably a false positive, though they would have further tests. 'I think this is good news – and we really know what we're doing,' he assured the parents as they cried with relief.

Then there was dark news again – a twenty-four-weeker with congenital diaphragmatic hernia: the abdominal organs in the chest, compressing the unformed lungs. Before the mother, accompanied by grandmother-to-be, came in, Dr Fred Ushakov, another leading doctor in the unit, said: 'This is serious. There's a one in three chance the baby will die; more in this case.' The mother, a twenty-five-year-old having her first baby, walked in smiling and despite Mr Pandya explaining after their scan that the baby had a 50–50 chance and gently touching her arm, they left laughing and upbeat. 'Glass half-full,' the grandmother said.

After the door closed behind them, Mr Pandya said, compassionately, 'Tough . . . she was naive, she has no idea. It didn't seem to me she completely comprehended.' Hilary Hewitt, the midwife attending, added: 'Some parents are completely risk-averse; others are blindly optimistic. Others

have: "God will get us through". You just have to lay the evidence in front of them.'

Another midwife rushed out to the waiting area where a man was kicking up a fuss about the waiting time. 'Sometimes people can be angry,' Hilary said. 'It's just stress.' Parents come to the business of bad news in different ways, Pran told me. For him, the human interaction in fetal medicine – managing the families through the maze and empathizing with how they feel – was what made him love going to work on a Monday morning.

There were women having reassurance scans after previous pregnancies went wrong; a fetus with sickle-cell anaemia; another whose blood group was incompatible with its mother; conjoined twins; babies with various heart conditions. Some patients came in smiling and shaking hands; others were withdrawn and taciturn.

The decisions the doctors made for parents and babies at such critical moments were difficult. Sarah and Peter, in their thirties, had been coming to the unit every week after their twenty-week scan showed the baby wasn't growing. I listened to senior fetal medicine and neonatal consultants privately discussing this tiny baby. He was twenty-six weeks old and weighed 500g, which made him just viable, but, Peebles sighed, 'It's not good.' Last week the doctors thought he couldn't be saved, but now he had gained this crucial bit of weight, there was some hope. Then again, Peebles had spotted the baby had ascites: worrying fluid around the abdomen, collecting because his heart was struggling.

In the staff room, the doctors and midwives spent a long time deciding what to say to the couple. Finally, neonatologist Sian Harding brought the parents into a quiet room and carefully told them: 'The baby's condition is deteriorating . . .

things may well get worse. If we wait, there's quite a high risk your baby could die in the next few days.'

Sarah and Peter were calm in the way people are in a crisis, speaking through adrenaline. Sarah said stoically, 'Yeah, sure, OK,' as Dr Harding explained that the best option, in her view, was to deliver the baby in the next few days. His chance of survival, then, would be 30 per cent and his chance of lifelong disability would be 50–50. Peter said: 'I'm quite worried, to be honest.' Dr Harding replied, in a sensitively measured, neutral tone, that his response was appropriate. Sarah said: 'I'm a more positive person,' and managed a laugh – she was trying to be strong.

I saw several women referred by local hospitals who had been told their babies had a low chance of surviving. Here, they were expertly scanned for the first time and reassured things were not so bad after all. The doctors understood how upset couples can be during scans for anomalies and murmured comfort: 'The heart is beautiful,' Mr Pandya told a mother whose baby had pleural effusions, the same potentially lethal fluid around the lungs which my son had had. Pandya, I saw, was simply brilliant at assessing, making decisions and explaining situations to parents, despite the prognosis of fetal medicine cases being especially hard to judge. 'I'm very confident your baby's going to be fine,' he told the couple. Pandya told me: 'Things are often unclear. A good consultant is just someone who is good at guessing.' He was right. Non-medical people, especially those of us who have studied and worked in the arts, tend to have a naive idea that medicine is an exact science. But a little exposure to medicine had taught Phil and me that it is quite the opposite: vague. And of all areas of medicine, the stakes of fetal medicine – saving a whole life which hasn't even

begun, in the body of another living being – are arguably the highest.

I left the fetal medicine unit that week feeling as if I had experienced space travel for the first time. It had been eerie to come so close to death before birth – but I was humbled by medicine's triumph in offering life, at least to some, where there was almost no hope.

Later, I asked Mr Pandya about the outcome for Emma and Tom. One of their twins had acrania and had no hope of living. It was to save the other baby's life that they had undergone the laser surgery for twin-to-twin transfusion syndrome. But this twin also didn't survive, in the end.

Pandya had remarked to me in the unit one morning, 'When the outcome isn't good, it's life-changing for the family, but for the team involved, it's significant too. You get to know them, and to see the parent holding the baby as it's about to die is devastating. You question whether you did the right thing.' The thank-you cards he and his colleagues get after even these terrible experiences mean everything.

This amiable doctor, I learned, wasn't the carefree sportsman I had once imagined him to be when I was his patient. He and his wife had been fetal medicine patients too, when they went through two pregnancies which he described to me as 'harrowing'. He was a father who felt deeply for patients in dire circumstances.

As for me, it's strange to know that my child would not have lived if he had not been born here and now, in a first-rate hospital with access to the latest, greatest technology in modern science. Joel would have had no chance of survival had he been born before the modern era. In one early neonatology textbook, published in 1945, hydrops fetalis was simply described as a condition 'incompatible with life . . . the infant is either

still-born or dies shortly after birth'.[2] Even if Joel had been conceived in the year I was born, 1978, he would still have died a fetus, his lungs crushed by amniotic fluid.

Yet here I am writing this, the mother of a cuddly, whimsical little chatterbox who asks for sausages for dinner every day and can't quite decide which snake he prefers, the boomslang or the inland taipan.

I decided to find out how, exactly, modern medicine got my son here.