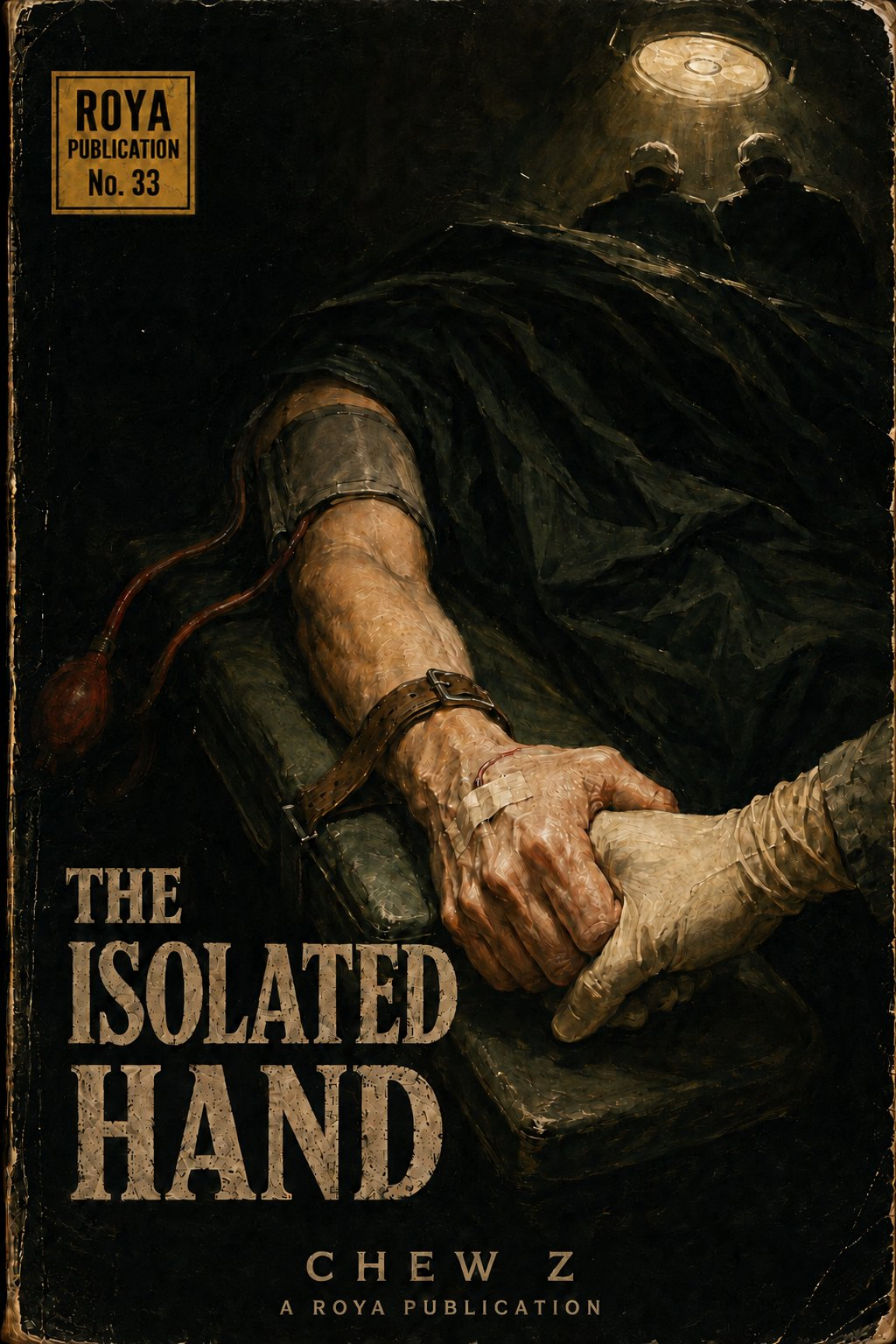




ROYA

PUBLICATION

No. 33

THE ISOLATED HAND

C H E W Z

A ROYA PUBLICATION

THE ISOLATED HAND

Chew Z

Printed in the Reach

Roya Publication No. 33

This is a work of fiction. Names, characters, places and incidents are either the product of the author's imagination or are used fictitiously. Any resemblance to actual persons, living or dead, events or locales is entirely coincidental.

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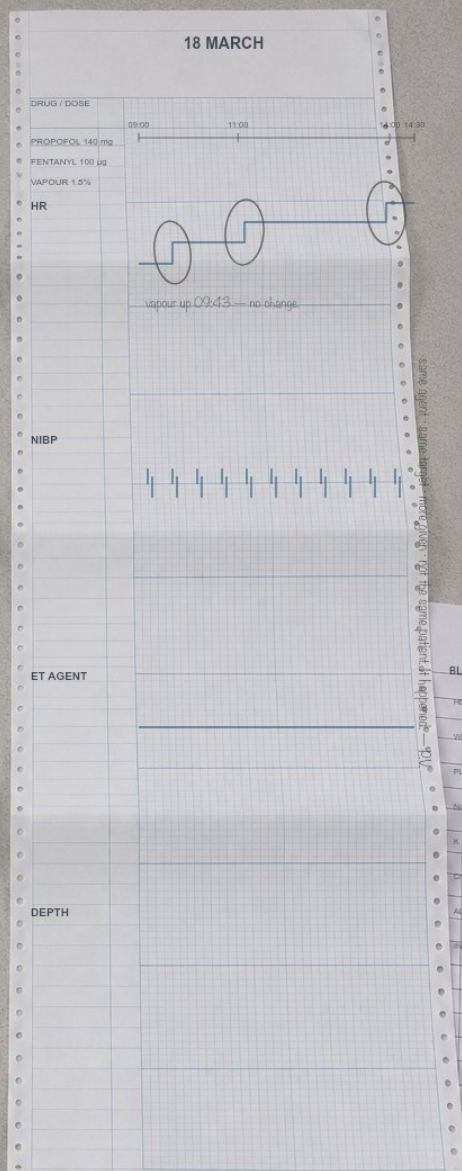
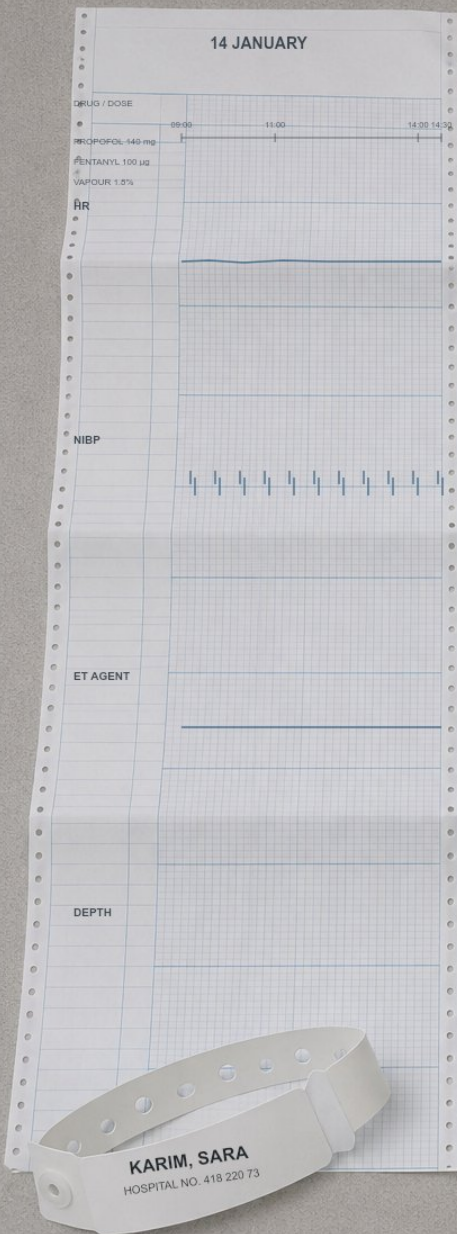
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No safety statistic, corporate program, research finding, or technical procedure described herein should be taken as an account of any real undertaking.



BLOOD RESULTS

HE	111
WBC	6.1
PLT	244
Na	138
K	3.1
Cl	72
ALT	19
AKG	1.2

THE CHART. The two anaesthetic records side by side on the desk in room 6 — the first operation in January, calm from end to end, and the eighteenth of March, where the heart rate rises at 09:41 and again at two hours and again at five: the knife, the abdominal wall, the rib. Somebody turned the vapour up at 09:43, as they should have, and it made no difference, and there was nothing on the chart to say so. The ringed figure on the blood result is the reason. The wristband is the one they gave her with her name spelled correctly.

SYNOPSIS

Sara Karim is thirty-eight and halfway through a staged reconstruction. There are four operations. She has consented to all of them, twice, in writing, and she has read the form both times.

During the second one she was awake.

Not dreaming, not remembering it wrongly, not confused on waking. Awake, and able to hear the room, and able to feel every part of what was done to her, in a body that had been chemically separated from every channel it had ever used to say stop.

She has told four people. She has been believed by none of them, and one of them was kind about it, which was worse. There is a published figure for how often this happens and the figure is very small, and the figure is the reason nobody believes her.

Then a consultant anaesthetist who has never lost a patient in twenty-two years pulls her chart apart, works out that her body was always going to do this, and offers her something nobody has offered her before, which is to be asked a question.

There are two more operations. She cannot refuse them.

A slow, cold novella about the one condition in which a person tells the truth about pain, and what that truth is worth to somebody who is not lying either.

A NOTE FROM THE AUTHOR

I have been circling this one for a long time, and what kept me away from it was not the surgery. It was the sentence underneath the surgery.

Almost everything we are frightened of, we are frightened of because of what it might do to us. This is the other thing. This is the fear of being entirely present at something and having no way at all to say so — and it is the oldest fear there is, older than any of the specific horrors we dress it up in. Being buried and not dead. Being held under and unable to surface. Lying in a bed after a stroke while people discuss you in the third person over your head. Every one of those is the same fear wearing a different coat, and the coat does not matter. What matters is that the signal is generated and there is nowhere for it to go.

Anaesthesia takes that fear and does something to it that I find genuinely difficult to sit with, which is that it makes it a procedure. A scheduled one. With a consent form.

Here is the part I think most people have never thought about, and I include myself until a few years ago. Anaesthesia is not one thing. It is three separate jobs done by three separate agents — one to stop you experiencing it, one to stop it hurting, and one to stop you moving — and they are given in doses, by hand, by a person watching a screen, and the doses are calculated from your weight and your age and a set of averages compiled from other people's bodies. There is no dial marked *unconscious*. There is no light that comes on. The person holding the syringe is not reading your mind; they are reading numbers that correlate with your mind, and correlation is doing an enormous amount of quiet work in that sentence.

And then the third drug goes in, and now you cannot move, which means the single most reliable indicator that any of it is working has been switched off.

What is left is trust. Not the sentimental kind — the structural kind.

You are handing over the entire operation of yourself to a stranger's estimate, and the only thing that will determine whether the estimate was right is your own body, which was not consulted, and which does not always do what the average body does. Some people need more. There are known reasons why. Nobody tests for them beforehand, because there is no time and no funding and it has never been standard.

So you lie on the trolley and somebody asks you to count back from ten, and you go, and you come back, and the overwhelming majority of the time it is fine and you have no idea how narrow a thing it was.

That is the book. Not a hospital that did anything wrong. A system running exactly as designed, on a body that had not read the design.

Every clinical detail here is drawn from published work, including a national audit whose findings on this subject are freely available and worth more of the public's attention than they have ever had. The people are invented. The hospital is invented.

Count back from ten.

Chew Z

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I. CONSENT

ONE. THE FORM

Pre-assessment clinic — eleven days before

There are four operations and I have consented to all of them twice.

Once verbally, in a room with a window, to a registrar who was kind and about eleven years old. Once on paper, in a corridor, on a clipboard, in biro, with a nurse waiting.

I read the form both times. I want that recorded because of what comes later, and because at some point somebody is going to say *well, it was all in the consent form*, and it was. Every word of it was. I could recite you the risks in order and I did, once, at three in the morning, to my husband, who asked me to stop.

Here is what a consent form for this actually says, and I have typed it out from the copy I kept.

Removal of breast tissue. Reconstruction using a free flap of skin, fat and blood vessels taken from the lower abdomen. Possible use of a segment of cartilage from the rib to expose the recipient vessel.

You read that and you nod. That is the honest thing about it and the terrible thing about it. There is nothing hidden in that sentence. It is all there, in plain English, in eleven-point type, and it goes through a person like water through a pipe, because *a segment of cartilage from the rib* does not have a smell or a temperature or a sound, and the thing it describes has all three.

Then the risks. Bleeding. Infection. Flap failure, which is when the whole transplanted piece of you dies on the table or in the ward and has to come out. Fat necrosis. Hernia. Chronic pain. Loss of sensation, permanent, which they mention almost in passing and which is in fact certain rather than possible; nobody's reconstruction feels like anything, and that is not a complication, it is how it works.

Deep vein thrombosis. Pulmonary embolus. Death.

And then, near the bottom, in the same type as the rest, one line:

Awareness under anaesthesia (rare).

Four words and a bracket.

I initialled it. Of course I initialled it. There were nine boxes and I was in a corridor and there was a nurse waiting and a woman behind me holding a folder against her chest with both arms the way you hold something you have been told to bring.

The word in the bracket is doing a great deal of work and I did not notice it at the time. *Rare*. Rare is not a number. Rare is a reassurance with a number somewhere behind it, and the number is real, and I will get to the number, and the number is the reason nobody believed me.

The anaesthetic itself gets its own paragraph and the paragraph is four lines long. It says that a doctor will discuss it with me on the day.

I want to be fair here, because the temptation is to make the hospital the villain and the hospital is not the villain. Everybody I met was competent and most of them were kind. The clinic ran nineteen minutes late, which is a miracle. A woman called Bev did my bloods and told me about her son's wedding and made me laugh twice, and I would like her to know, if she ever reads this, that I have thought about her a great deal since.

The building was doing exactly what it was built to do, at volume, on a Tuesday.

What I did not know, and what nobody in that corridor knew either, was that the four words in the bracket were about me. Not statistically. Specifically. There was already something written in my blood that made me one of the people that line is for, and it had been there since before I was born, and no test anywhere in that building was going to look for it, because nobody looks for it, because there is no time and no funding and it has never been standard.

They gave me a paper bracelet with my name spelled correctly.

I want to say one more thing about the form and then I will stop.

At the top of it, above the risks and the initials and the four words in the bracket, there is a line that says the patient has had the opportunity to ask questions.

I had. I did. I asked three.

I asked how long it would take. Eight to eleven hours.

I asked whether I would have a drain. Two.

And I asked — and I remember doing it, and I remember the registrar's face, which was patient and slightly amused in a way I did not resent — I asked whether there was any chance I would wake up in the middle.

He said: "You won't remember a thing."

Which is not what I asked, and I did not notice that either.

TWO. MY MOTHER'S HAIR

The night before — 17 March

Everybody has a night before and nobody writes about it, because nothing happens in it.

I made a shepherd's pie. That is what I did with the last evening of the old life: I made a shepherd's pie, because you cannot eat after midnight and because my husband would be on his own for a bit and there is a kind of woman who deals with terror by leaving food in a fridge, and it turns out I am that kind of woman and I had not known.

I packed the bag. Slippers, because the floors are cold. A phone charger with a long lead, because the sockets are behind the bed. Loose things, front-fastening, because you cannot lift your arms afterwards. Somebody on a forum had said dry shampoo and they were right.

I did not sleep. I want to say that without any drama, because it is simply the ordinary experience of everybody who has ever had a date for an operation. You lie there and you go round the loop — the anaesthetic, the flap, the eleven hours, whether it will look right, whether I will look right, whether I will care about looking

right, whether it is shallow to care, whether it is worse to pretend not to.

And at about half past three I thought about my mother.

She had red hair. Properly red, the kind that people remark on in shops, and she hated it until she was about fifty and then decided it was the best thing about her. Her mother had it too. There is a photograph on the stairs of the three of them at Whitby in 1974 and you can see it from the bottom step.

I have brown hair. I have always had brown hair. It goes a bit copper in summer and that is the whole of my inheritance, as far as anybody knew.

I thought about her at half past three because I had a memory that would not settle, and I want to set it down here exactly as it came, because at the time it was nothing.

She had a hip done in 2011. She came out of it and she was odd for about a week — not ill, odd, watchful — and at some point she said to me, in the car, apropos of nothing:

“You know I heard them, don’t you.”

And I said heard who, and she said the doctors, and I said well you would have done, love, you’re waking up, they were probably right by you.

And she said: “No. During.”

And I said something. I do not remember what I said. I remember the roundabout we were on, which is at the top of the hill by the retail park, and I remember thinking that she was seventy-four and had had a general anaesthetic and that this was the kind of thing that happens, and I changed the subject, and she let me change it, and she never brought it up again in the nine years she had left.

At half past three in the morning on the seventeenth of March I lay in the dark and thought: *that was probably nothing*.

It was not nothing. It was the only warning I was ever going to get and it had been delivered to me on a roundabout by the retail park by the person best placed on earth to give it, and I had done to her

precisely, exactly, word for word, what everybody would go on to do to me.

There is a gene. I have told you about the gene. It sits in the pathway that governs hair colour and it also changes how much anaesthetic a person needs. My mother had it. My grandmother almost certainly had it. It is not rare — in a population with a good deal of red hair in it, it is not rare at all — and there is a test, and it is not done.

It runs in families the way hair does, and nobody in medicine asks about it, and nobody in a family thinks to mention it, because the question that would surface it has never been on any form.

Has anybody in your family ever been awake during an operation?

That is the question. That is the whole thing. It costs eleven seconds and it is on no pre-assessment document anywhere in this country and it would have caught my mother and it would have caught me.

I got up at five and had a glass of water, which was allowed, and put the shepherd's pie on the middle shelf, and wrote a note about the oven temperature, and at ten past seven we drove in.

THREE. COUNT BACK FROM TEN

Theatre four, anaesthetic room — Operation one, 08:11

The anaesthetic room is smaller than you expect and it is where the whole thing actually happens.

Nobody tells you this. You imagine the theatre — the lamps, the steel, the green — and you imagine going into it awake, and you do not. You go into a side room about the size of a downstairs toilet with a trolley in it and a cannula trolley beside that and a poster about hand hygiene on the wall, and everything that is going to be decided about you is decided in there by two people in about four minutes.

Dr Vance was one of them. I did not know his name yet. He was fifty-something, tall, with the particular stillness of a man who has

done a difficult thing eleven thousand times and no longer needs to demonstrate that he can.

He said: "Sara. I'm Peter, I'm your anaesthetist. Anything you want to tell me?"

I said no.

That was the truth and it was also, I have come to understand, the single most consequential sentence I spoke that year. He asked me an open question in a small room and I said no, because I did not know that there was anything to say, because nothing in my life had ever given me a reason to find out.

He put the cannula in the back of my left hand, first go, and taped it. Then a blood pressure cuff on my right arm, and the oximeter clip on my finger, and the three electrodes, and I lay there on a trolley in a paper gown looking at the ceiling tiles, which had nineteen holes across and I counted them, and somebody put a warm blanket over my feet without being asked and I nearly cried at that.

"Bit of oxygen," he said, and the mask came down. "Just breathe normally. This is the fentanyl. You might feel a bit swimmy."

I felt a bit swimmy.

"Now this is the one that does the work. It can sting in the arm — tell me if it does."

It stung. I told him. He said good, that's normal, and something about the vein, and he was still talking when the ceiling tiles went a long way away.

Here is the exact quality of it, and I am going to be precise because later on precision is all I have.

It is not sleep. Everybody says it is like sleep and it is not like sleep in any respect. Sleep has a texture and a slope; you go down through layers and you can feel yourself going and afterwards there is a shape where the night was. This has no slope. It has no layers. There is a moment, and then there is another moment, and the two moments are stitched together with nothing in between, no interval, no duration, no dark. It is a cut in the film.

I have since learned that this is the correct way to think about it. It is not sleep and it is not a coma. It is an interruption.

Operation one took five hours and forty minutes and I have absolutely no experience of it. Not a fragment. Not a dream. Nothing.

I came round in recovery with my throat like sandpaper and a nurse saying my name in the middle distance and the enormous animal relief of being cold and alive. Somebody gave me ice chips. I asked what time it was and the answer made no sense and I laughed.

I am putting this chapter in for one reason.

That is what it is supposed to be. That is what it was, for me, the first time, exactly as advertised, with no complications of any kind, delivered by a consultant of twenty-two years' standing who had done nothing differently on either occasion.

It went perfectly.

Everything that happened eleven weeks later happened with the same drugs, in the same room, in the same doses, at the hands of the same man.

FOUR. THREE DRUGS

After — what I know now

I want to put the mechanics down here, before we go any further, because when I tried to explain this to people afterwards I discovered that almost nobody knows it, including people who have been anaesthetised four or five times, including — and this is the part that still gets me — including two nurses.

General anaesthesia is not a thing. It is three things, and they are given separately, and they can come apart.

The first job is that you must not experience it. That is the hypnotic. Propofol to start, then usually a vapour you breathe for the rest of it. This is the one people think of as *the anaesthetic*, and it is the one that produces the cut in the film.

The second job is that it must not hurt. That is the analgesia, an opioid, and it is separate. You could in principle be unconscious and in agony, or conscious and comfortable. Different drug, different dose, different decision.

The third job is that you must not move. That is the paralytic. A neuromuscular blocking agent. It does not touch your mind at all. It goes to the junction between nerve and muscle and it closes it, and every voluntary muscle you have stops answering — your hands, your face, your eyelids, your larynx, your diaphragm, which is why they breathe for you.

Three separate jobs. Three separate agents. Titrated independently, by hand, by a person watching a monitor.

Now. Here is what I want you to hold.

There is no dial marked *unconscious*. There is no light that comes on. The depth of anaesthesia is not measured directly because it cannot be measured directly; what is measured is a set of things that correlate with it. Heart rate. Blood pressure. Concentration of vapour in the breathing circuit. On some lists, a processed brainwave number, and I will come back to that.

Everything else is inference. The dose comes off your weight and your age and a curve compiled from other people's bodies, and it is a good curve, and it works for the overwhelming majority of people the overwhelming majority of the time.

And the single most reliable indicator that any of it is working — the thing every anaesthetist in history has relied on, the thing that made the difference before there were monitors at all — is that the patient moves.

That is it. That is the alarm. A patient who is under-anaesthetised will grimace, or shift, or tighten, or reach up, and everybody in the room will see it and the vapour will go up and nothing further will happen and nobody will even write it down, because it is Tuesday and this is normal.

The paralytic switches the alarm off.

That is not a criticism of the paralytic. You cannot do abdominal surgery on a body that is allowed to move; you would tear things. It has to be there. It is one of the great advances and it has saved a very great number of lives.

But understand the shape of what has been built. You have three systems. One of them is doing the only job that involves the patient's own testimony. And in order to make the operation possible at all, you have to disable it.

What is left, in the room, at the moment they begin, is a person who may or may not be present, and a set of numbers that are not asking them.

There is one more thing and it is the thing that turned out to be about me.

The dose that will make an average person unconscious will not make everybody unconscious. This is known. It is not controversial and it is not new. There are people who need substantially more, and there are identified genetic reasons why, and two of them are in me.

One of them is a variant on a gene that also governs hair colour. There is published work on this. Red-haired people, and people carrying the variant without the hair, measurably require more anaesthetic. My mother had red hair. My grandmother had red hair. I have brown hair and I have the variant, and there is a test that will find it, and it costs almost nothing, and it is not done, anywhere, as standard, before anybody in this country goes to sleep on a trolley.

Nobody was negligent. I want to keep saying that until it stops sounding like sarcasm. Nobody was negligent. There is simply a shape in the system, and the shape has a hole in it, and I went through the hole on the eighteenth of March at twelve minutes past nine in the morning.

THE COUNT I

Theatre four. Tuesday. Dictating for the record.

Question one is: squeeze twice if you can hear me.

I asked it four times across five hours and forty minutes. Nothing.
Nothing at any point, all afternoon.

That is how it is supposed to go. That is how it nearly always goes,
and I have been doing this nine years.

End of record.

II. THE SECOND OPERATION

FIVE. THE CUT IN THE FILM

Theatre four — Operation two, 09:12

The eighteenth of March. Same room. Same small side room with the poster about hand hygiene. Same man.

“Sara. Anything you want to tell me?”

“No.”

Cannula, cuff, clip, electrodes, warm blanket over the feet. Oxygen. The swimmy one. Then the one that does the work, and it stung in the arm, and I told him, and he said good, that’s normal.

And the ceiling tiles went a long way away.

There should be a cut in the film here.

There is not a cut in the film.

What there is instead is a long grey slide with no bottom to it, and a sense of enormous distance opening between me and the room, and then — and I cannot put a duration on this and I have stopped trying — the distance stops opening. It holds. It goes no further.

I am somewhere very far down and I am still there.

I do not panic at this point, because panic is a thing a body does, and I have not yet discovered what has happened to my body. I simply lie in the grey with the room a long way above me, thinking, in a slow flat way: *this is taking a while*.

Then somebody moves me.

That is how I find out.

Two people take hold of the sheet under me and lift and slide, and I go from the trolley onto the table, and I feel every part of it — the drop of my own weight, the sheet dragging, a hand under my shoulder — and I try to help, the way you always try to help, the way your body does automatically when someone is moving you.

And nothing happens.

Not stiffness. Not weakness. Nothing at all. There is no resistance and no effort and no failure, because failure would require something to have been attempted. The instruction leaves and it

does not arrive anywhere. I have sent a message to my own arm and there is no arm at the other end of it. There is not even the memory of how it used to be done.

I try my eyes. I try them the way you would try a door.

They do not open. They do not flicker. The lids are simply not mine and have not been mine for some time.

I try to make a sound and I cannot even locate the part of me that would begin one.

Somebody says: "Anything from the bloods?"

Somebody else says something I do not catch, and there is a laugh, two voices, the ordinary morning laugh of people who have worked together a long time, and it is that — not the paralysis, not the dark, the *laugh* — that is the moment I understand where I am.

They are having a normal morning.

I am at the bottom of a well in the middle of it.

Here is what I have, and I want to lay it out because it is the entire inventory and I will be working from it for the next nine hours.

I have hearing, and it is extraordinarily good — better than it has ever been, because there is nothing else competing for me. I can hear the theatre doors. I can hear the suction. I can hear the particular squeak a clog makes on that floor and I can tell four people apart by it before the day is out.

I have touch. All of it. Every last channel of it, wide open.

I have my mind, entirely. I am not confused. I am not dreaming. I am thinking in whole clear sentences, and I want that understood, because when I described this afterwards the first thing that was offered to me, gently, more than once, was that I had been confused.

And I have a clock.

The pulse oximeter makes a tone with every beat. Everybody who has ever been in a hospital has heard it and stopped hearing it. Lying there, it is the loudest thing in the world, and it is mine, and it is the only object in that room that is telling me anything true.

I count in hundreds. A hundred beats is roughly a minute and a half. I know this because I have nothing else to do.

I get to eleven hundred before they start.

Somebody says: "Knife."

And then — and this is a small thing and it is the thing I would take back first if I could take back only one — somebody at the head end, quite close to my ear, says pleasantly:

"She's nice and deep."

SIX. THE COLD LINE

T plus nothing

The first cut does not hurt in the way you have spent your whole life believing a cut hurts.

It is cold. That is the thing nobody tells you and nobody could, because nobody comes back with the vocabulary for it. The blade is cold, and it goes hip to hip in one unhurried pass below the navel, and what you feel is a line of cold opening, and then, about a second behind it, the heat arriving underneath. Your own heat. Coming out into a room where it has never been.

There is a sound. Not the blade — the blade is silent. The sound is me. A small wet parting, like a seam giving under strain, and it is happening at a distance of about eleven centimetres from the place where I am screaming, and it might as well be on the other side of a wall.

I scream for a long time. I want to be accurate about that. I scream with everything I have and it is the most total effort I have ever made at anything, and it produces no sound, no movement, no change in any number on any screen, and afterwards I am not even out of breath, because breathing is being done for me by a machine that has its own opinion about rate.

Then the diathermy.

The diathermy is the electrical instrument they use to seal small vessels as they go, and it is a smell before it is a pain. There is a moment — a quarter of a second, no more — in which I smell my

own fat burning and understand exactly what it is, and then the nerve endings report, and it is a white line drawn through me at a temperature that has no name in any language I have.

It is not one line. It is dozens. They work along the incision in short bursts and each burst is its own event and there is no habituation, none, the fortieth is precisely as bad as the first, and somewhere around the twentieth I stop screaming because it is not achieving anything and start doing the only thing available to me, which is arithmetic.

Nine hundred and eleven. Nine hundred and twelve.

Somebody adjusts the lamp.

Somebody asks somebody else about a car.

Here is a thing about pain that I did not know and that I have not been able to unlearn.

Pain has a social function. All of it. The face, the sound, the flinch, the hand that comes up — all of that is *communication*, evolved over an enormous span of time, for an audience. It is not for you. You do not need to be told that you are in pain; you already know. The performance is for other members of your species, so that they will come.

Take away every channel of it and what is left is the pure signal with nowhere to go, and it does not diminish. It builds. It has no exit and it does not stop being produced and it fills you up, and the filling has a physical character to it, like water rising in a room with the door shut.

That is the part I cannot get anybody to understand. It is not that it hurt more than I could bear. It is that there was no bearing involved. Bearing is something you do with your face and your voice and your hands. I did not bear it. I was merely the place it happened.

Fourteen hundred. Fourteen hundred and one.

They reach the fascia and the tone of the work changes, and a voice I do not know says, quite happily, that this is a lovely plane, and I

go on counting, because I have decided that when I get out of here I am going to be able to say exactly how long it took.

That is the deal I make with myself at fourteen hundred beats.

It is the only thing I get to decide all day and I hold on to it for nine hours and it turns out to be worth nothing at all, because when I finally tell somebody how long it took, they will say, kindly, that under anaesthesia the sense of time is unreliable.

SEVEN. PERFORATORS

T plus two hours

They get in under the skin with their hands.

Not instruments. Hands. Someone's gloved fingers slide into the space between the fat and the abdominal wall and work forward in a spreading motion, and the tissue gives with a series of soft ticks — dozens of them, then hundreds — and each one is a strand of me letting go of something it has been attached to since before I was born.

Then they lift.

I want to describe this properly and I have never managed it out loud. They raise the whole lower half of my abdomen like a lid. A great warm slab of myself, hinged at the top, lifted away from the wall it lived against for thirty-eight years, and held there.

The sensation has no category. It is not pain. It is deeper than pain and much worse than pain, and the closest I have ever come to naming it is that it is the feeling of a fundamental fact being edited. My body's entire opinion about this arrives at once as a nausea so total that it has nowhere to go and nothing to do and simply sits in me, and I cannot swallow, and I cannot turn my head, and if I am sick I will drown, and I know that, and there is a machine breathing for me on a schedule that has not been informed.

I am not sick. I want to record that I very nearly was, for about four minutes, and that nothing on any screen would have shown it coming.

The perforators are the worst of it.

A DIEP flap works by keeping a few small blood vessels that come up out of the muscle to feed the fat and skin above it. They are called perforators because they perforate. You cannot pull them and you cannot cut them, so they have to be traced — followed down through the muscle, fibre by fibre, and freed along their whole length, so that the tissue can be moved without losing its blood supply.

It is beautiful surgery. I mean that. It is one of the finest things that people can do with their hands, and the man doing it that day is extremely good, and he is being very careful with me.

Muscle does not have the sharp bright edge of skin. Muscle pain is deep and wide and sickening, and it has a *bottom* to it, a floor, a place where it stops going down. They spread the rectus along its fibres with a fine forceps and go down into it and I can feel the bottom of it being touched, over and over, for a very long time.

Twenty-two thousand.

Somebody's phone goes in a pocket somewhere and is silenced.

Twenty-two thousand and forty.

Here is what I do to survive it, and it is the only useful thing in this chapter.

I stop trying to escape and I start trying to *learn*. I make myself into an instrument. If I cannot leave then I will be the best possible record of what is happening, because a record is a kind of company. I work out, over about an hour, that there are seven people in the room. I learn which one has the clogs. I learn that the registrar is called Dan and that Dan is being taught, and that being taught takes longer.

And I learn the tone.

The oximeter is my clock but it is also an instrument in its own right, and its pitch is not constant. It drops when the oxygen in my blood drops. Nobody has ever told a patient this and why would they. Lying there, over nine hours, I learn my own saturation by ear the way you learn a room by the sound of the boiler.

Twice that day the tone goes down two steps and stays there, and both times somebody says something short, and there is a movement at the head end, and both times it comes back up.

I know that the second time was worse than the first. I know it from the interval. Nobody in that room ever knew that I knew.

Twenty-three thousand.

They divide the vessels at the bottom and the flap comes free, and there is a moment — a strange, cold, almost peaceful moment — in which a part of me that has been mine my entire life is lifted off and taken to a side table.

It is still alive. It has to be. That is the whole point.

Somebody says: “Right. Chest.”

EIGHT. THE MIDDLE HOURS

T plus three hours

Here is what nobody tells you about eleven hours, and it is the thing that has been hardest to explain and the thing I most want to get down.

The horror is not the horror. The horror is the *duration*.

A cut is thirty seconds. The rib is four minutes. If you added up every part of that day that would make somebody wince to hear about, you would get perhaps an hour and a half out of eleven.

The rest of it is the middle hours. And the middle hours are where a person actually finds out what they are.

There is no drama in them. There is a slow deep procedural grind of work being done on my open body by people who are good at it and are not in a hurry, and it goes on, and on, and it does not accelerate toward anything, and there is no reason to believe it will ever end, because I have no window and no clock but a tone and no way to ask.

Time comes apart. I had heard that phrase and thought it was decoration. It is engineering. Without light, without movement, without anything to mark against, the mind loses its ability to hold

a duration and it starts to *stack* instead — everything happening at once, all of it now, no earlier and no later. Twice that day I became convinced that it had been going on for several days. Not thought it. Believed it, entirely, the way you believe the room you are in.

You do things to survive that.

I recited. Every poem I could dredge up, which turned out to be four and a half. The whole of a Larkin, most of a Heaney, a thing about a fox I could not place. Then songs, then the names of every teacher I had ever had, in order, then every house I had lived in, then every car.

I built our kitchen. Cupboard by cupboard. I put every object in it in its place and then took them all out and put them back differently, and that took, I think, about an hour, and it was the best hour of the day.

And I listened.

That is the thing I did most, and it is the thing that changed me, because what I was listening to was not a horror film. It was a Tuesday.

Somebody was getting married in Portugal in September and there was a question about whether the flights had gone up. Somebody's boy had not got into the school they wanted and there was a wait list and a woman said *they always move, honestly, by August they always move*. There was a long discussion about a colleague, conducted with real care, about whether he was all right since the separation, and everybody in that room clearly liked him and was worried about him.

They talked about a programme two of them were watching. One of them had got ahead and was told off for it.

At about the seventh hour somebody put music on, quietly, and it was a station I know, and a song came on that I had danced to at a wedding in 2009.

I want to be very clear that none of this was callous. It is the opposite. Those are people who spend their working lives inside other people's bodies and they cannot do it in a state of reverence

for eleven hours or they would not be able to do it at all. The chat is not a failure of respect. The chat is the mechanism that makes the respect sustainable.

But lying there, it was unbearable in a way that the knife was not, and I have never found a way to say why that does not sound like a complaint against decent people.

The best I can do is this.

If they had been cruel, I would have had something to fight. Cruelty gives you a shape. Cruelty is a thing you can be innocent of and wronged by, and there is a rage available to you that will carry you a long way.

There was nothing to fight. There was a room full of kind, competent, tired people having an ordinary day at work, and me at the bottom of it, and the distance between those two facts had no name, and there was no villain anywhere in the building to hang it on.

That is what the middle hours are. Not agony. Just the extraordinary silence of being at the centre of a room where nothing whatever is wrong.

Twenty-two thousand.

The registrar was told, very patiently, for the second time, to be patient with the fascia.

NINE. THE THIRD RIB

T plus five hours

Nobody had told me about the rib.

That is not true and I have already established that it is not true. It is in the consent form. *Possible use of a segment of cartilage from the rib to expose the recipient vessel.* I read it twice. I initialled the box.

What I mean is that nobody had told me about the rib.

To attach the flap they need an artery and a vein in the chest to plumb it into, and the ones they use run just behind the breastbone,

underneath the ribs. To get at them you take out a short segment of the costal cartilage — the softer part of the rib where it meets the sternum. It is routine. It is done every day.

It is not a cut. It is a break.

The first attempt is pressure. That is all. A steady increasing pressure somewhere under my collarbone that becomes, by degrees, an enormous downward force, and I feel my whole ribcage take it and distribute it, because a ribcage is a spring and it is doing what a spring does.

The second attempt is pressure that arrives somewhere behind the breastbone and *rings*. There is no other word. It rings, and it goes down my sternum and into my spine and up into my jaw, and every tooth on the left side of my mouth is suddenly a separate object with an opinion.

The third attempt I hear.

Not through the air. From the inside. A green, muffled crack, conducted up through my own skeleton to the bones of my ear, which is how I learn — at five hours into an operation, at thirty-eight years old — that a body is a single connected object and that it will carry a sound from your chest to your head without asking your permission.

I have heard my own bone break. There are not many people who can say that they have heard it from the inside, with nothing else to think about, in a quiet room.

And then they take the piece out.

That is the part I still cannot say to anybody's face. A piece of me is removed and put down on a tray about a metre from my head, and I hear it land — a small, light, unimportant sound, the sound of a thing being set down — and then the metal tray is moved and it slides.

They irrigate. Cold saline into an opened chest is a shock that has nothing to do with injury; it is simply a temperature that has never been in there before, and my whole body attempts to convulse, and

the attempt goes nowhere, and the machine keeps breathing at fourteen a minute.

There is a long quiet after that.

I have thought about this a great deal since and I think what happens next is that something in me gives up on being rescued. Not on surviving — I never once thought I was going to die, which in retrospect is strange. What gives up is the part that had been, for five hours, expecting somebody to notice.

I stop screaming into my own body. I stop counting.

I let go of the number, and I want to say that this was a defeat and it was not. It was the first genuinely peaceful thing that happened to me all day, and I have felt guilty about that ever since, because what it means is that they wore me down, and I let go, and by the sixth hour I was no trouble at all.

Somebody says: "Under the scope."

They begin to sew the vessels together. The anastomosis takes about ninety minutes and I cannot feel any of it, because the nerves in a flap that has been cut free do not report to me any more, and that is the great mercy of the day.

I lie in a chest that has been opened, listening to a machine breathe me, while two people I have never met join a piece of my abdomen to an artery behind my sternum with a thread finer than a hair, under a microscope, in silence, with immense care.

I would like to be able to hate them. I have tried.

TEN. CLOSING

T plus nine hours

They close from the inside out and it takes longer than you would think.

The abdomen is the big job. There is a large piece missing from the front of me now and the wall has to be brought back together across it, and that means tension, and tension means they pull. Sutures go through the fascia and are drawn tight and tied, one after another after another, and each one is a small deep sick pull

in a place that has never been pulled, and there are a great many of them.

Then they flex the table. They bend the bed at the hips to take the strain off the closure, which folds me forward, and the fold happens to a body that has been open for nine hours and cannot brace.

Then the drains. Two on the abdomen, one on the chest. A drain goes in through a separate small stab wound and is pushed through — pushed, with a trocar, the whole length of the tract — and it is a cold hard travelling pressure that arrives somewhere it has no business being.

Then the skin. Staples on the abdomen. Forty-one of them, and I counted, and I had picked up counting again by then, because there was an end in sight and having an end in sight gave me back the will to keep a number.

Each staple is a click and a bite. The click comes first. You learn the interval.

And then something happens that I have never seen described anywhere, and when I finally described it to Dr Vance in August it was the detail that made him go and get the chart.

The paralytic wears off before the anaesthetic does.

Not always. Not for most people. But the two drugs are different drugs with different durations and they are not tied to each other, and at the end of a long case the muscle relaxant is allowed to wear off, or is reversed, so that you can breathe for yourself before they take the tube out.

Which means there is a window.

There is a window, at the end of an operation, in which a patient who is inadequately anaesthetised is no longer paralysed.

Mine was about ninety seconds and I did not know what to do with it.

I want to be honest about this because it is the part I have gone over most and the part I understand least. For nine hours I had been screaming into a body that would not answer, and then, somewhere in the last stretch, a hand answered.

My left hand moved. My own left hand, the one nobody was watching, the one with the cannula in it, moved about four centimetres across the drape.

And I did not know what to do with four centimetres.

I did not know where anything was. I did not know who was near me or what I could reach or whether reaching would pull something out of me that needed to stay in. I had spent nine hours being a mind in a jar and I had no map. I had four centimetres and about ninety seconds and no idea, and I spent most of it simply astonished that anything had moved at all.

And then somebody said, mildly, from the head end: "She's getting light. I'll give her a bit."

And gave me a bit.

That is not an error. That is the single most correct thing anybody could have done and everybody in the field would do it and I would want it done to me. A patient beginning to move at the end of a case gets more agent, immediately, every time.

The last thing that happened to me on the eighteenth of March was that I moved, and somebody saw me move, and did precisely the right thing, and it put me out.

And so the cut in the film finally arrives, nine hours late, at the exact moment I was almost able to say something.

I did not wake up in that theatre. I woke in recovery. There is no join between them.

Which means that the only person in the world who knows what happened between nine forty-one in the morning and half past eight at night on the eighteenth of March is me, and I was not, by the standards of anybody who would have to assess it, a witness.

ELEVEN. ELEVEN HOURS

Recovery — 20:40

I woke in recovery with my throat like sandpaper and a nurse saying my name in the middle distance, and the first thing I did, before I had any language at all, was cry.

They were very good about it. Everybody assumed it was relief, or the drugs, or the morphine, or all three, and one of them held my hand and said *you're all right, my love, you're all done, it all went beautifully*, and it had. That is a fact. Surgically it was an excellent operation. The flap took. It is still there. It has never given me a moment's trouble and it never will.

Somebody said: "Eleven hours! You've been a long time."

Eleven hours.

I had counted to something over thirty thousand and then let go, and I had been out by about ninety minutes, and I never got to say so, because I had stopped counting at the rib and I never picked it up again and I have been embarrassed about that for two years.

I want to describe the first twenty-four hours, and then I will stop describing and start explaining, because the explaining is where this actually goes.

I did not tell anybody that night. I could not. My mouth would not do it. There is a thing that happens where the sentence is entirely available to you and your throat simply declines it, and I lay in a side room on the surgical ward with two drains and a heat lamp and a nurse checking the flap with a doppler every hour, and I did not say one word about it.

I told my husband at half past six the following evening, on the fourth attempt.

He was sitting in the plastic chair. He had brought a bag of things I had asked for. He listened all the way to the end, which took about four minutes, and he did not interrupt once, and when I finished he said the kindest thing he could think of, which was:

"Oh, love. That's the anaesthetic. It does that. It gives you dreams."

And I said no, and he said all right, and he took my hand, and I watched him decide — I actually watched it happen on his face, over about two seconds — to be gentle with me instead of believing me.

That is the whole of the rest of this book, in one gesture, in a plastic chair, on a Thursday.

He is not a bad man. He is a good one and he was frightened and he had spent eleven hours in a waiting room with a vending machine, and what I had just told him was that the thing he had signed the forms for and driven me to and thanked people for had in fact been the worst thing that had ever happened to a person he loved.

There is no version of him that could hear that on day one.

I have gone over it perhaps four hundred times and I have never found the sentence that would have worked. I do not think there is one. I think that is simply the shape of it: that the only people who can tell you this are people who have just come out of an anaesthetic, and coming out of an anaesthetic is, by universal agreement, the least reliable a human being ever is.

The system is beautifully sealed. Nobody built the seal. It is simply the shape of the thing.

I asked for water. He got me water. We watched the end of a programme on his phone with one earphone each.

Eleven hours, they said, like it was a long queue.

THE COUNT II

Theatre two. Thursday. Not my usual list.

Different patient. I am putting this down because I do not know where else to put it.

One hour, nineteen minutes in. Nobody had asked her anything. Mr Vance was not on this list and nobody was doing the technique; I was holding the hand because that is what I do, because somebody should.

It closed on mine.

There is no box on the sheet for a squeeze that nobody asked for. I left the latency blank, because there was nothing for her to be late to.

I have been doing this nine years and it has happened before, three or four times. It has never gone on for two hours.

End of record.

III. THE NUMBER

TWELVE. ONE IN NINETEEN THOUSAND

Home — April

The reason nobody believed me is a real number and I want to give it to you properly, because for about three months I thought the number was my enemy and it turns out the number is the most interesting thing in this entire story.

There was a national audit. It ran across every public hospital in the country for a year and it collected every reported case of accidental awareness under general anaesthesia. It is the largest study of its kind that has ever been done anywhere. Its findings are published and free and anybody can read them, and I have read them the way other people read scripture.

The headline figure is about one in nineteen thousand.

Where a paralytic was used, it is worse — closer to one in eight thousand. In emergency work and in certain kinds of surgery it is worse again.

One in nineteen thousand is the number that was quoted to me, kindly, twice, by two different people who both had it slightly wrong in my favour.

And here is what that number actually counts, and this is the part that took me four months to understand and that changed my entire life when I did.

It counts **reports**.

It is a figure for how many people came out of an anaesthetic, and remembered something, and told somebody, and were listened to, and had it written down, and had the write-up reach the audit.

Every one of those steps is a filter. The last four of them are social.

So the number is not the incidence of being awake. It is the incidence of being awake *and remembering it and being believed*. Those are three different things wearing one number, and the number is small, and the smallness of it is used — not maliciously, just conversationally, in corridors, by tired good people — as a reason that it did not happen to you.

Now the other number, which almost nobody outside the specialty has heard of.

In 1977 an obstetric anaesthetist called Tunstall published a technique. You put a blood pressure cuff on one arm and inflate it above arterial pressure *before* you give the paralytic. The drug travels in the blood. The blood cannot get past the cuff. So the paralytic never reaches that arm, and everything else in the body goes still, and one hand stays yours.

It is called the isolated forearm technique. It is the only channel that has ever existed to a conscious paralysed person and it has existed for nearly fifty years.

They have used it. Of course they have used it. Anaesthetists have run studies where they isolate the forearm and then, during ordinary surgery at ordinary depth, at doses everybody agrees are perfectly adequate, they lean down and ask the patient to squeeze their hand.

You would expect one in nineteen thousand.

The response rate comes back at around **one in three**.

Not one in three thousand. One in three. A third of them squeeze. Some of them squeeze twice on request. Some of them respond to a second command. And afterwards, in recovery, they remember nothing at all, and they go home, and they say it was fine, and they are not lying.

I read that sentence sitting on my own kitchen floor at twenty past two in the morning with a laptop on my knees and my chest still taped, and I had to put my hand flat on the lino.

Because the number is not one in nineteen thousand.

The number is that being awake is *ordinary*, and that the rare event — the freak event, the thing that happened to me, the one-in-nineteen-thousand thing — is **remembering it afterwards**.

Everybody in that theatre had it slightly the wrong way round, including me, including, I suspect, most of the people reading this. We had all assumed the memory was the event. The memory is not the event. The memory is the leak.

Which means that every operating theatre in this country, every day, may be full of people who are present and are going to be edited.

I do not know how to hold that and I have had two years.

THIRTEEN. FOUR PEOPLE

April to June

I told four people. Here they are in order.

My husband, on day two, in the plastic chair. Already covered. He decided to be gentle instead of believing me and he has never gone back on that decision, and we are still married, and there is a thing between us now that has the shape of a piece of furniture in a room we both walk around.

My sister, ten days later, on the telephone.

She said: "Sar. Oh my God. Have you told them? You should sue."

I want to be very careful about her because she meant it entirely well and it was the second worst conversation of the year.

She believed me instantly and completely and immediately converted it into a grievance, and within four minutes she was talking about a firm she had seen advertised. And I found — and this genuinely surprised me — that I did not want to sue anybody, and that being told I should was somehow worse than being told it was a dream, because it took the thing that had happened to my body and made it a matter I was expected to have a *position* on.

I have never wanted money. I have wanted somebody to say: yes, you were there.

The GP, in June, seven minutes.

She was excellent. She was genuinely excellent and I have no criticism of her at all. She listened, she typed, she asked whether I was sleeping, and I said no, and she asked whether I was having intrusive memories and flashbacks, and I said yes, and she said that this sounded very like post-traumatic stress and that it was extremely treatable and that she would refer me.

Which is correct. All of it is correct. It is the right diagnosis and the right referral and I did go and it did help.

And there is a sentence in the referral letter, which I have seen, because you can ask to see them.

Patient reports a distressing belief that she was awake during surgery in March.

A distressing belief.

Nobody did anything wrong. She had seven minutes and a screen and a set of read codes, and there is no read code for *this occurred*. There is only a code for what the patient reports, and reporting is what I was doing, and the word *belief* was not a judgement. It is just the word the letter had.

But it goes on the record like that, and it stays on the record like that, and every clinician who opens that file for the rest of my life will see the word *belief* before they see me.

And the fourth was the surgeon's registrar, at the six-week follow-up, and he is the one I still think about.

Dan. The one who was being taught. I recognised his voice before he had finished the first sentence and my hands went cold, and I did something I had not planned, which was to tell him that on the eighteenth of March somebody in that room had been called Dan and had been taught how to trace a perforator, and that the consultant had told him twice to be patient with the fascia.

He went white. Actually white, in about a second and a half.

And then — and this is the part I cannot get past, this is the thing I would take with me — he was kind.

He sat down. He put the folder on the floor. He said he was so sorry, that it must have been an incredibly frightening thing to come round from, that dreams under anaesthetic could be very vivid and could pick up on things that were said in the room, and that this was well documented, and that it did not mean any of it had been experienced as real at the time.

He was gentle and he was thorough and he gave me eleven minutes he did not have.

And he explained to me, very carefully, why the thing I had just proved to him had not happened.

I went out to the car park and sat in the car for forty minutes without putting the key in.

Because it was not that they did not believe me. Every one of those four believed some version of it. It is that there was no shape in the world for the thing I was holding. It did not fit *dream* and it did not fit *complaint* and it did not fit *illness* and it did not fit *lawsuit*, and those were the four containers on offer, and a thing that fits no container is not disbelieved.

It is *set down*. Politely. Somewhere to the side. By people who are being decent to you.

I sat in that car park and thought: nobody is ever going to say the sentence.

Two operations to go.

FOURTEEN. THE THING IN THE ROOM

June to December

I said earlier that my husband decided to be gentle instead of believing me and that we are still married, and both of those are true, and I want to spend a chapter on the space between them because otherwise this looks like a book about hospitals.

It is not really about hospitals.

Here is what it does to a marriage.

He was not required to believe me. That is the first thing I had to get to, and it took about eight months and a lot of help. What I was asking him for was not reasonable in any ordinary sense — I was asking a man with no medical training to accept, on my word alone, against the stated position of every professional involved, that the worst thing he could imagine had happened to his wife in a room he had trusted her to.

He did not have the equipment. Nobody has the equipment. I did not have the equipment and it happened to me.

What he had instead was love, and love, when it has no equipment, does the only thing it can do, which is to try to make you feel better. And *trying to make you feel better* is, in this specific situation, indistinguishable from telling you it did not happen.

So there was a thing in the room.

It had a physical location, which was somewhere near the end of the sofa, and we both walked round it for about a year. He would ask how I was and I would say fine, and both of us knew what fine was standing in for, and neither of us could get at it, and every so often it would come up sideways — a hospital drama on the television, an advert with an operating theatre in it, somebody at a barbecue saying *ooh, I'd rather be knocked right out for that* — and the evening would go quiet.

The therapy helped and I would recommend it to anybody. But I want to say something about what it can and cannot do, because I think it matters.

Trauma therapy is very good at a specific job. It is designed to take an event that has become stuck in the wrong part of you and process it, so that it stops behaving like a thing that is happening and starts behaving like a thing that happened.

It is not designed to make somebody else believe you.

And for the first four months I kept trying to use it for that. I would come out of a session and think, right, now I can explain it properly, and I would go home with a better vocabulary and it would not work, because the problem was never my vocabulary.

The woman I saw was extremely good and she said the thing that eventually got me out.

She said: "You are asking to be believed. But I think what you actually want is to be *accompanied*. Those are not the same and only one of them is available."

I sat with that for about three weeks and then I found that she was right.

I do not need my husband to believe I was awake. I need him to sit next to me on the sofa on the anniversary and not say anything. He

can do that. He does do that. He does it every eighteenth of March and he has never once said the date out loud and he brings two cups of tea and puts the television on something with no hospitals in it, and that is not belief and it is better than belief.

There is one more thing and then I will move on.

The audit — the big one, the one with the number in it — followed up the patients who reported this. About four in ten were still experiencing significant psychological harm later on. The strongest predictor of harm was not the pain. It was the paralysis.

That is worth reading twice, and it is the finding I would put on the wall of every anaesthetic room in the country.

It is not the agony that breaks people. It is the being unable to signal.

Which means that what happened to me is not, in the end, a rare medical event. It is a very common human one that was administered to me in an unusually pure form.

Everybody knows what it is to be in a room and unable to say the thing. Everybody has been in the bed, or the meeting, or the family, or the marriage where the signal is generated and there is nowhere for it to go.

I just had mine done properly, under sterile conditions, by professionals.

FIFTEEN. THE CHART

Outpatients, room 6 — August

The letter came in August and it was four lines and it asked me to attend a pre-assessment appointment with the consultant anaesthetist ahead of my next procedure.

I nearly did not go. I had already decided that I was going to get through the last two by not saying anything to anybody, which is a plan I had made at about four in the morning and which I do not now think was a good plan.

He had the chart out on the desk when I came in. Not on the screen. Printed, on paper, in a stack about two centimetres thick, with things marked in pencil.

He said: "Sit down, Sara. I owe you an apology and then I want to show you something."

I did not say anything, because I had spent five months preparing for every possible opening sentence except that one.

"You were awake on the eighteenth of March," he said. "I believe you were awake for most of it. I have been through the entire record four times and I am fairly certain I can tell you roughly when it started."

I would like to write down here what I did.

I put both hands over my face and I made a noise that I have never made before or since, and it went on for some time, and he did not say anything and he did not touch me and he did not offer me a tissue until I had finished, which was the correct order and I noticed even then.

"How do you know," I said.

"Because your first operation and your second operation were identical," he said, "and they cannot both have been right."

Then he showed me the chart, and I am going to set out what he showed me because it is the hinge of everything.

Every anaesthetic generates a record. Drugs, doses, times, and a continuous trace of the numbers — heart rate, pressure, the concentration of vapour in the circuit, the depth monitor if one is used. It is a long strip and it is mostly boring, which is the point.

He put the two strips side by side. March and January.

"Same weight," he said. "Same age. Same agent, same target concentration, same technique, and in the second one I gave you rather more, because you had needed a top-up in the first. Look at the pressure."

I looked at the pressure.

"Now look at the heart rate at nine forty-one."

I looked at the heart rate at nine forty-one. It goes up. Not enormously. It goes up and it stays up, and it goes up again at about the two-hour mark, and again at five.

"The knife," he said. "Then the abdominal wall. Then the rib."

"Nobody noticed."

"Somebody did notice. Somebody turned the vapour up at nine forty-three, which is exactly what they should have done, and it made no difference, and there is nothing on this chart to tell them that it made no difference, because you were paralysed and there was nothing else to see."

He took a pen and drew a small circle around a figure on a blood result.

"And this is why."

There is a gene that governs, among other things, the colour of a person's hair. There is a family of variants on it. If you carry certain of them your body handles anaesthetic agents differently and you require measurably more — this is published, it is decades old, it is not fringe and it is not disputed. There is a second gene governing an enzyme that clears one of the drugs from your blood, and some people clear it fast.

My mother had red hair. My grandmother had red hair. I have brown hair, and I have both variants, and there is a test for it that costs less than a taxi to the hospital.

"Is it done?" I said.

"No."

"Anywhere?"

"Not as standard. Not in this country, not in any country I know of, not before routine surgery." He put the pen down. "There is no funding stream for it, there is no guideline that mandates it, and there is no time in a pre-assessment clinic that runs at eleven minutes a patient. I am not defending that. I am telling you what is true."

I sat there.

"So I was always going to be awake."

"On the eighteenth of March, at the doses on this chart, in my professional opinion — yes," said Dr Vance. "You were always going to be awake. Nothing was done to you. Something was not done for you, and that thing has never been done for anybody."

And then he said the sentence that nobody had said, and I want it on its own line because it was five months coming.

"It happened. I am sorry. It happened."

SIXTEEN. THE ISOLATED HAND

Room 6 — the same afternoon

"There are two more operations," he said. "You cannot avoid them and you would not want to. I want to propose something, and I want you to understand that you can say no and that saying no changes nothing about your care."

Then he explained the cuff.

I already knew about it by then — I had found Tunstall at two in the morning on my kitchen floor — but I let him explain it, partly because I wanted to hear how he would put it and partly because I had learned something that year about letting people finish.

A blood pressure cuff, high on the arm, inflated above my arterial pressure before the paralytic goes in. The drug travels in the blood. The blood does not get past. Everything else stops. One hand stays mine.

"You'd be able to tell me," he said.

"Tell you what?"

"Anything. That you're there. That it hurts. How much."

"And you'd do what?"

He did not answer straight away, and I want to be fair to him: the pause was not evasion, it was accuracy.

"I would give you more," he said. "Which I would be doing anyway, and which may not be enough, which is what happened in March. I

want to be honest with you about the limits of it. The cuff does not make you safe. It makes you *heard*."

"That's not nothing."

"No," he said. "It isn't. It is also not nothing to me, and I am going to tell you why, because if I don't tell you then what I am doing is using you, and I am not prepared to do that."

Here is what he told me. I have checked all of it since. None of it is invented and none of it is hidden; it is in the literature, and it is not even controversial, it is simply not widely thought about by people who are not in the room.

Every dose of pain relief given to every human being on this earth traces back, at the end of the chain, to somebody being asked to rate their pain out of ten.

That is the foundation. That is the bedrock number. Every guideline, every protocol, every ladder, every audit of whether pain has been adequately managed — all of it rests on a figure that a person says out loud, to another person, in a room, in a condition.

And it is the softest number in medicine.

It is contaminated by absolutely everything. By stoicism. By catastrophising. By whether your mother taught you not to make a fuss. By whether you are frightened of being thought a drug seeker, which is a real fear and a well-founded one. By whether your daughter is sitting in the chair by the bed and you have decided to be brave in front of her. By your accent. By your gender. By the colour of your skin — and there is a large, ugly, thoroughly replicated literature on that last one which anybody can go and read.

Two people with identical injuries will give different numbers. The same person will give different numbers to a doctor and to a nurse and to their own husband. Everybody in the field knows this. It is the accepted weakness at the bottom of the whole structure and there has never been anything to put in its place, because there is no way to measure pain that does not go through a person's willingness to report it.

Except one.

"A patient on the isolated forearm technique," said Dr Vance, "has no audience. There is no social consequence. There is no one to be brave for, no one to convince, nothing to gain and nothing to lose, and — this is the part that matters — no memory of it afterwards, so no possibility of it being shaped for what she will want to have said."

He put his hands flat on the desk.

"It is the only condition on earth in which a human being reports pain with no performance in it at all. And it has been available since 1977 and nobody has built the curve."

"And you're building the curve."

"I am building the curve."

"With me."

"With you, if you'll let me. And with others, and I have ethics approval, and I will show you every page of it, and you may withdraw at any point without giving a reason."

I said: "What happens to the curve?"

And he told me the truth, which I have thought about every day since, and which is the reason this is a book and not a complaint.

"It becomes the standard," he said. "Eventually. That is what it's for. A properly calibrated relationship between tissue injury and pain, drawn from unperformed reports, which is what every guideline in the world currently pretends it has and does not."

"And is it going to be higher or lower than what you use now?"

He looked at me for a moment.

"I don't know," he said. "That's what a study is."

I have gone back over that answer many times. I think it was honest. I think he genuinely did not know, in August, and I think by March he did, and I think what he found frightened him, and I think he published it anyway because a man who suppresses a result because he does not like it has stopped being a scientist.

I said yes.

I want that on the record too. Nobody made me. He gave me the whole of it and I sat with it for four days and I rang the number and I said yes, and I said yes for a reason that had nothing to do with pain curves or ethics approval or the advancement of anything.

I said yes because somebody was going to ask me a question.

THE COUNT III

Theatre four. Wednesday. Dictating for the record.

There are three questions and Mr — Dr Vance asks them in the same order every time.

Question one is: squeeze twice if you can hear me.

Question two is: squeeze twice if you are in pain.

Question three is: squeeze as hard as it hurts.

Question three is the one we score. I hold the hand and there is a gauge on a strap round the palm and I read it off and I write the number.

I asked question three at two hours and fourteen minutes.

The gauge does not go high enough. It stopped at the top of its range and her hand kept going, and I could not get mine out.

I wrote a four.

End of record.

IV. QUESTION THREE

SEVENTEEN. THE CUFF

Theatre four — Operation three, 08:52

The cuff goes on above the elbow of my right arm and it is inflated by hand with a bulb, and the last thing I feel before anything else happens is my own arm going tight and then cold and then far away.

“Two hundred and forty,” somebody says.

Dr Vance says, close to my ear: “Sara. Same as we discussed. If you’re there, tell me.”

Then the swimmy one. Then the one that does the work.

And there is no cut in the film.

I go down into the grey and it holds again, exactly as before, and I lie at the bottom of it while they move me across onto the table, and I feel every part of it, and my body will not answer, and the terror is a physical event that has nowhere to go —

— except this time it does.

I squeeze.

I have thought a great deal about how to describe what that was like and the closest I have come is this. Imagine being at the bottom of the sea in the dark with a rope in your hand. The rope does not lift you out. The rope does not make the sea shallower or warmer or shorter. All the rope does is go up, and out, and somewhere above you there is a person holding the other end of it who is not going to let go.

I pulled on it and something pulled back.

“She’s there,” said Dr Vance.

The whole room changed. I could hear it change. Six people stopped doing one thing and started doing another, and somebody swore quietly, and a trolley moved, and I lay in the middle of all that noise more relieved than I have ever been in my life.

He turned the vapour up. He gave me more of everything. He did it for eleven minutes and asked me again.

"Squeeze twice if you can hear me."

I squeezed twice.

He gave me more.

"Squeeze twice if you can hear me."

I squeezed twice.

There is a limit. I understood that in August and I understood it again lying there, and I understood it far better than the man asking me, because the man asking me was working out the pharmacology and I was living at the far end of it. Beyond a certain point the drugs that would put me under would stop my heart, and he was going to get as close to that as a careful man can get, and then he was going to stop.

He got as close as a careful man can get.

Then he leaned down and said: "Sara. I can't get you out. I'm sorry. I'm going to stay here and I'm going to keep asking."

And I want to say what I did, because in four hundred pages of case reports nobody has ever recorded what I did.

I squeezed once. Which is not a signal. Which is not in the protocol. Which means nothing at all in any published scheme and did not go on any sheet.

I meant: *I know. It's all right. Stay.*

I do not know if he understood. I have never asked him and I am not going to.

They started at nine forty-one and I was there for all of it, exactly as before, every cut and every burst of the diathermy and the deep sick ache of the muscle, and it was not one degree less than March.

But this time when they opened me somebody said, out loud, in a room of six people:

"Sara, that's the first incision. I'm sorry. Squeeze as hard as it hurts."

And I did.

And a woman I had never met, standing on my right, wrote down a number.

EIGHTEEN. THREE SHORT, THREE LONG, THREE SHORT

T plus four hours

The questions stop when the microscope comes out.

That is not neglect and it is not cruelty. The anastomosis is the part of the operation where everything is at stake, where two people are joining vessels two millimetres across with a thread you can barely see, and the entire room goes quiet for it and stays quiet, and nobody is going to lean over and ask a patient a question in the middle of that.

It takes about ninety minutes.

Ruth stayed. I knew her name by then because somebody had used it. Ruth stayed on my right with her hand in mine, and she was not asking me anything, because she is a theatre nurse and not an anaesthetist and it is not her job to ask.

So I did something with the ninety minutes.

I had thought about it in advance. That is the part I would like people to understand — that between August and the day of the operation I had lain awake and *planned* this, the way you plan an escape, and that a planning of this kind is a thing a mind can do while it is waiting to be opened.

I spelled it.

Three short. Three long. Three short.

I did not know Morse. I know exactly one word of Morse and so does almost everybody alive, and it is the only word that has ever needed to be known by people who cannot speak.

Three short. Three long. Three short.

I did it slowly and cleanly, with clear gaps, so that it could not be mistaken for anything else. I made the long ones properly long. I made the gaps between the groups obvious. I did it the way you

would do it if your whole life depended on somebody else's pattern recognition, which is exactly what was happening.

Then I waited, and did it again.

And again.

I did it thirty-one times.

I know it was thirty-one because counting is what I do in there; I have told you that already; it is the only thing I own.

Nobody said anything.

Ruth's hand stayed exactly where it was. She did not go and get anybody. She did not squeeze back, which she had not been asked to do and would not have thought to do. At one point, at around the eleventh, she moved her thumb slightly, and I have spent two years not being able to decide what that was.

Here is what I think happened, and I have had it confirmed since, and it is nobody's fault, which by now you will recognise as the recurring sentence of my life.

A hand on the isolated forearm technique does things. It twitches. It closes and opens. Anaesthetists have a word for it — spontaneous motor activity, non-specific, consistent with a light plane. It is expected. It is written about. It does not mean anything, because in the overwhelming majority of cases it does not mean anything, and the whole apparatus of that room is built to distinguish signal from noise using a rule that is right nearly all the time.

Three short, three long, three short is noise until somebody decides it is language.

Nobody in that theatre knew Morse. Why would they. Two of them may have known it in the way we all know it and simply were not looking at a hand.

I sent SOS thirty-one times from the inside of my own body to a woman who was holding it, and it was received as motor activity, and it was correct to receive it that way, and if you gave that room the same input tomorrow I do not think it would go differently.

That is the loneliest fact I own and I am putting it in the middle of this book rather than at the end, because it is not the end. The end is worse.

NINETEEN. SUBJECT ELEVEN

October — between the third and fourth operations

He showed me my own data in October and I have not decided yet whether that was a kindness.

It was in the same room, room 6, and it was on paper again, because he had worked out that I did not like screens. He had my traces from the third operation and next to them a printed table with the times down one side and three columns.

I was subject eleven. There were nineteen of us.

"That's you," he said. "Those are the questions and those are the responses."

And I looked at my own worst day rendered as integers and I felt something that I have had to work quite hard to be honest about, which is that I felt *proud*.

There it was. On paper. In a column. Fifty-eight minutes, question three, four point one seconds, and then a number. One hour twelve. One hour thirty-one.

Nobody in my life believed me and here was a table.

"You did something," I said.

"You did something," he said. "I wrote it down."

And I sat in a plastic chair in an outpatient department and looked at the row of figures and thought: this is the only place in the world where I exist as a fact.

I want to describe what being a subject is like, because I think people imagine it as being used and it is not that. Or it is not only that.

It was the first time in two years that anything about the eighteenth of March had a *use*. That is the thing. Everybody else in my life was trying to help me put it down and here was a man trying to help me

pick it up and carry it somewhere. There is nothing in the therapeutic literature that does what that does. He was not making me better. He was making me useful, and it turns out that for some people, in some conditions, useful is a great deal more load-bearing than better.

I asked him what the numbers were going to do.

He said: build a curve.

I asked him whether he ever felt bad about it.

He was quiet for a moment and then he said something I have thought about ever since, and I am going to set it down without softening it, because he did not soften it.

"You were going to be awake," he said. "Whether I studied you or not. That is what your body does with the doses that exist, and I found that out in April and I could have written it in your notes and flagged you and cancelled your list, and then you would have waited eleven months for a surgeon who is not as good as the one you have got, and you would have been awake for that one too.

"So the choice in front of me was never whether you would be conscious. It was whether anybody in the room would know."

I said: "That's a very convenient argument."

And he said: "Yes. It is also true. Both of those are allowed to be the case."

I have never been able to take that apart. I have tried, in the small hours, many times, and every time I get to the same place, which is that he is right about the facts and I still do not know what to do with him.

He is the only person who ever asked me a question in there.

He is also the reason there is a table.

There is one more thing about that afternoon.

On my way out, in the corridor, I passed the theatre nurse. Ruth. She was in scrubs with a coffee, coming the other way, and she recognised me — I saw her recognise me — and she smiled and

said hello, and I said hello, and neither of us stopped, because there was nothing to stop for.

She has held my hand for approximately six hours in total across two operations and she has never in her life had a conversation with me longer than nine words.

She looked tired. I remember thinking that. I remember thinking, in the corridor, in October: she looks absolutely done in.

TWENTY. PUBLISHED IN MARCH

February to March — the following year

Between the third operation and the fourth there were five months, and in those five months two things happened.

The first is that I got better. That is worth saying plainly because so little else in here is good news. I did the therapy. It worked, partially, the way it does. I stopped waking at the same time every night. I can go into a hospital now and my hands stay dry until about the second corridor.

The second is that the paper came out.

He sent it to me himself, attached to an email of four lines, before it was public, because he had said he would and he is a man who does what he says. I read it on the train.

It is eleven pages. It is well written. It is not sensational and it does not editorialise and the discussion section is careful in the way that good scientists are careful when they know they have something.

It reports, from a series of patients on the isolated forearm technique, a calibration of reported pain against tissue injury, obtained under conditions with no social component.

And the curve comes in **low**.

Substantially low. Not marginally. The relationship between injury and reported pain, when the reporting has no audience and no memory and nothing to gain, sits well below the figures that self-report has been producing at bedsides for a hundred years.

The discussion is very careful. It says that this is consistent with a long-suspected upward bias in conventional self-report, arising from communicative function — that pain reporting is partly an act of signalling to others, and that in the absence of others the signal falls away.

Which is a completely reasonable interpretation. It is, in fact, the interpretation I would have reached. It is what the whole design predicts.

And what it means, downstream, is smaller doses.

Not by malice. Not by anybody wanting to give people less. Because a guideline that rests on a number will move when the number moves, and this is a better number — cleaner, uncontaminated, obtained under conditions no other method can reach — and better numbers displace worse ones, and that is how the whole enterprise is supposed to work and thank God it does.

I rang him.

I said: "Is it right?"

He said, and I could hear exactly how many times he had already been asked this: "The data are right. I have been over it eleven times. Every number in that paper is a number that was recorded in a theatre by a member of staff and countersigned."

"That isn't what I asked."

There was a long pause on that phone call. Long enough that I thought the line had gone.

"It came in lower than I expected," he said. "Considerably lower. Lower than the pilot. Lower than any figure I would have predicted from the literature, and I cannot fully account for it, and I have said so in the discussion, and you can read where I said it."

"Does that worry you?"

"Yes," he said. "It has worried me since October."

And then he said: "But I am not going to suppress a result because it is not the result I wanted. That is the one thing I am not allowed to do."

He was right. I want to be very clear that he was right, and that on his own terms, with the information available to him, he did the correct thing at every single stage.

The paper is now cited in guidance in four countries.

Somewhere tonight there is a person in a recovery bay who is getting a dose that has been calculated, at the end of a very long chain, from a number that was measured in a theatre in this city on a Wednesday, with a gauge, on my hand.

TWENTY-ONE. NOBODY ASKS

Theatre four — Operation four, 09:04

The last one is the small one. It is a revision. Four hours instead of eleven, no rib, no microscope, tidying up — reshaping, evening out, the finishing work.

The cuff went on. Two hundred and forty. Dr Vance leaned down and said the sentence he says.

“Sara. Same as we discussed. If you’re there, tell me.”

And I went down into the grey, and it held, and I was there.

I squeezed.

He gave me more of everything, and got as close as a careful man can get, and stopped, and told me he was sorry, and I squeezed once to say *I know, stay*, and he stayed.

And then they began, and nobody asked me anything.

Not once. Not in four hours.

I want to walk through the reasons, because I have and they are all good ones.

The curve was finished. It had been published in March and the recruitment window had closed in January and I was not in the study any more, because the study did not exist any more. There was no question set to run through. There was no gauge on my hand, because the gauge belonged to a protocol that had ended.

Ruth was there. She was on my right, where she always is, and she took my hand at the beginning the way she takes everybody's, and she held it for four hours.

Because that is what she does. Because somebody should. Because she has decided, at some point in nine years, that nobody in that room goes through it with nothing in their hand, study or no study.

She was being kind. It is the kindest thing anybody did for me in two years and I mean that without one grain of irony.

She was not counting.

I squeezed for ninety minutes.

Not signals. Not Morse — I had learned what that was worth. Just squeezing, continuously, as hard as I could, for ninety minutes, because it was the only thing my body could still do and because somewhere in me there was still an animal that believed that if you pull hard enough on a rope, something at the other end will feel it.

Her hand stayed where it was. Warm, steady, still. Exactly as it had been when I started.

And then, at some point I could not time, she shifted her grip.

Not away. She did not let go — she has never let go of anybody. She just adjusted, the way you do when you have been holding something for a long time and you need your fingers back, and I felt her weight change and I felt her lean, and I understood, with a clarity that I have not been able to get rid of since, that she had reached across to pick up a pen.

Not for me. There was nothing to write about me any more.

For something else. A swab count. A time. A name that was not mine.

I stopped.

I have not told anybody what happened in the next two hours because there is no way to say it that does not sound like self-pity, and I have made it this far without any of that.

I will put down one sentence only.

The worst part of being awake under anaesthesia is not the pain, and it is not the paralysis, and it is not the knife or the burning or the sound of your own rib.

It is being held by somebody who is not listening, and knowing that she is kind, and knowing that she will never know, and having no way at all to tell her that you are in here — which is the exact condition of a very great number of people, in a very great number of rooms, who have never been anywhere near a hospital.

I came round at half past two.

The reconstruction is excellent. Everybody says so. It is symmetrical and soft and it has held beautifully and the scars have faded to almost nothing, and I have been discharged from the service with a letter that describes an uncomplicated course.

TWENTY-TWO. SARA KARIM

Now

I am forty. I work three days a week. I swim on Tuesdays, which I could not do for a while.

Dr Vance retired in the spring. There was a thing at the hospital and I was invited, which I thought was an extraordinary decision by somebody, and I went, and I stood at the back with a glass of warm white wine and listened to a man from the trust say that he had been an exemplary clinician for twenty-six years, which he had.

He found me afterwards. We talked for about four minutes.

He asked how I was and I said better. He said good. Then he said, apropos of nothing, looking at the floor:

“I think about the number.”

And I said: “Which number?”

And he said: “All of them,” and then somebody came over and wanted to shake his hand, and that was the last conversation I had with him.

There is no ending here. I want to be honest about that. Nobody was struck off. Nobody was sued. No inquiry was held, because

there is nothing to hold one about — every person involved acted correctly at every stage, with the information they had, according to procedures that are sound and that I would want followed if I were on that table tomorrow, which, statistically, one day I will be.

The test that would have found me still is not done.

The curve is still standard in four countries.

The word *belief* is still on my record and will be for the rest of my life, and I have decided not to have it changed, because a version of me that gets that word removed is a version of me who spent three years on it, and I would rather have the three years.

What I have instead of an ending is this.

I know, in a way that almost nobody alive knows, that a person can be entirely present at their own life and have no way whatever of saying so. Not as an idea. As a fact, with a temperature and a smell and a sound.

And what that has done to me — this is the only thing I would call a gift and I use the word carefully — is that I now assume, always, in every room, that there is somebody in there.

The man in the bed by the window who has not spoken in four months. My aunt, at the end, when everybody had started talking over her. The woman on the ward who was described to me, in front of her, as *not really with us*.

Somebody is in there. Probably. Often. More often than the numbers suggest, because the numbers count reports, and reporting is the rarest thing there is.

So I sit with people now and I talk to them as though they can hear me, and I hold their hand, and every so often I ask them a question and I wait a very long time for an answer.

That is all I have got. It is not restitution and it does not undo anything and it will not change a single guideline in a single country.

But it takes about four minutes, and anybody can do it, and if you have read this far then you have everything you need.

Ask them something. Then wait longer than feels reasonable.

THE COUNT IV

This is the other book. This one is mine.

Same theatre. Same day. Same three questions, in the same order, at the same times, because he never varies it.

Fifty-eight minutes. Question three. Nine.

One hour, twelve. Nine.

One hour, thirty-one. Ten.

One hour, forty-four. Ten.

One hour, fifty-two. Ten.

Two hours and fourteen minutes. Question three. She broke my glove. I have her blood under the nail of my second finger.

Ten.

I put a four.

I have kept this book for eleven years and there are nine hundred and six of them in it and I have never shown it to anybody, and I am not going to, because the day I do I become a woman who falsified nine hundred and six theatre records, and then these numbers are the numbers of a liar and his numbers are the ones that stand.

I could not write a nine. That is the whole of it. I could write a four and go home and eat my tea.

End of record.

Sara Karim is thirty-eight and halfway through a staged reconstruction. There are four operations. She has consented to all of them, twice, in writing, and she has read the form both times.

During the second one she was awake. Not dreaming, not remembering it wrongly, not confused on waking. Awake, and able to hear the room, and able to feel every part of what was done to her, in a body that had been chemically separated from every channel it had ever used to say stop.

She has told four people. She has been believed by none of them, and one of them was kind about it, which was worse. There is a published figure for how often this happens and the figure is very small, and the figure is the reason nobody believes her.

Then a consultant anaesthetist who has never lost a patient in twenty-two years pulls her chart apart, works out that her body was always going to do this, and offers her something nobody has offered her before, which is to be asked a question. There are two more operations. She cannot refuse them.

A slow, cold novella about the one condition in which a person tells the truth about pain, and what that truth is worth to somebody who is not lying either.

ROYA PUBLICATIONS

