

ROYA
PUBLICATION
No. 35

THE WEIGHT OF HER

The Ghariban



C H E W Z
A Roya Publication

THE WEIGHT OF HER

Chew Z

Printed in the Reach

Roya Publication No. 35

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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.



FOR ROYA

1 April – 30 March

Ten years, eleven months, twenty-nine days.

Roya Publications is named for her.

It began because of her, and every book that carries the name is dedicated to her.

SYNOPSIS

We were offered a test at sixteen weeks and we did not have it.

That is the first thing anybody wants to know and it is the wrong thing, and I will explain why, and it will not help.

Roya was born in April. By nine months we knew something, and by fourteen months we had a word for it, and by three years we had a hoist in the ceiling and a wet room and a house chosen entirely for its doorways. She never sat unaided. She never spoke. She never held anything or reached for anything or turned her head when I came into a room.

She lived ten years and eleven months, and we moved four times for her, and she got heavier every single one of them.

This is an account of those ten years by her mother, written down because there is no other place to put it. It is about the therapy that saved her hips and hurt her every day. It is about a sister who was four when it started and asked for nothing for fifteen years. It is about a phrase that relatives use — silent angel — and what that phrase is actually for.

And it is about what happened afterwards, which nobody warns you about either, which is that life became more bearable and the grief was not one gram lighter for it, and that both of those were true at the same time, and only one of them could ever be said out loud.

A NOTE FROM THE AUTHOR

This is a short note and it is not about the book. It is about what to do, and it is the only part of this that is any use to anybody.

If somebody you love is caring for a child like Roya, you will want to help and you will not know how, and out of that not-knowing you will almost certainly do the three things that everyone does.

You will say *let me know if you need anything*. You will mean it entirely. And it will be useless, because it hands the whole job of being helped to the person with the least capacity left in the world — she now has to work out a need, find the words for it, ask a favour, and be grateful. Nobody with a decade of broken sleep can run that process. What works instead is a sentence with a time in it. *I'm coming Tuesday at two. I'll sit with her. Go to bed.*

You will ask how the child is. Ask how the mother is. Then ask again, because the first answer is always fine.

And after about a year you will stop coming, and you will not notice that you have stopped. The first year has visitors and casseroles. The sixth year has nothing at all, and the sixth year is worse than the first. Put it in your calendar if you have to. There is no shame in needing a reminder; there is a great deal of shame in the silence.

Two more, and they cost nothing.

Come into the house. Not coffee somewhere, not a walk — into the room where the child is, and sit in it. And touch her. Most people will not touch a child like Roya, and the parents notice every single time, and they never say anything about it, and they remember for years who did.

Say her name out loud. That one matters more than everything else on this list put together.

You will not know what to say. That is fine and it is expected and it is not a reason to stay away. Nobody knows what to say. There is nothing to say.

Say nothing and stay anyway.

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I. THE FLAT

ONE. SIXTEEN WEEKS

The first thing everybody wants to know

We were offered a test at sixteen weeks and we did not have it.

I am putting that on the first page because it is the first thing everybody wants to know, and because most of them are too polite to ask, and because I have watched perhaps forty people arrive at that question and go around it, and going around it takes longer and is worse.

Here is what happened. There was a screening result that was not alarming and was not perfect. A number. A midwife who was kind and unhurried explained that we could have an amniocentesis, that it would give us certainty about certain things, and that it carried a risk of miscarriage. The figure she gave us was small. It is always small. It was, at that time, somewhere under one in a hundred, and she said it in the way people say a small number when they want you to understand that small is not the same as none.

We were thirty-six and thirty-eight. We had Daena, who was three. We had waited fourteen months for Roya and there had been a loss before her that I have never written down anywhere and am not going to now.

We said no.

We said no in about four minutes, in a corridor, and it was not a difficult decision and neither of us has ever pretended it was. We said no because the risk was to the pregnancy and the pregnancy was the thing we wanted.

Now. Two things, and I need both of them held at once, because in ten years I have not met more than a handful of people who could manage it.

The first is that the decision was correct. It was correct on the information available, it is the decision the majority of people make, and I would make it again with a gun to my head. Nobody has ever told me otherwise to my face. Several people have told me otherwise with their eyebrows.

The second is that it does not matter at all, because the test would not have found this.

Roya does not have a chromosomal condition. There is nothing in an amniocentesis that would have shown me anything. What happened to my daughter happened at or around her birth, to a brain that was, as far as anybody has ever been able to tell me, entirely ordinary the day before.

So the question everybody wants to ask is not only intrusive, it is irrelevant, and I have spent ten years watching people work their way carefully towards a door that opens onto a wall.

But I want to say the rest of it, because this is the only place I am going to.

It did not stop me. For about four years I went back to that corridor most nights. Not because I believed the test would have found it — I knew within a fortnight of the diagnosis that it would not have — but because it was the last place where there had been a choice. Everything after that corridor is weather. Everything after that corridor happened to us. The corridor is the only room in the whole ten years with a door in it, and so I went and stood in it, over and over, for four years, in the dark, at three in the morning, doing something that was not thinking.

Mehran never did that. I asked him once, in year five, and he looked genuinely puzzled and said, “It wouldn’t have shown anything.”

I said I know.

He said, “So why would you go back to it?”

And I could not explain, and I have never been able to, and it is the single largest difference between us.

TWO. APRIL

The first fortnight

She was born on the first of April, on a Tuesday, at ten past six in the evening after eleven hours, and she was seven pounds and one ounce, and she was fine.

I want that sentence to sit on its own because for eleven days it was true.

There was a thing with the cord that I have read about six hundred times since, and a period during the labour where the trace was not what they wanted, and a doctor who came in walking quickly and then stopped walking quickly. It was not a disaster. Nobody said anything to us afterwards that suggested a disaster. She came out and she cried and her Apgar at five minutes was fine and they put her on my chest.

I have the photograph. Everybody has the photograph. In ours I look enormous and delighted and about nineteen, and Mehran is out of focus behind me with his hand over his mouth.

We took her home on the Thursday.

Daena was four and she had been told about the baby for six months and had lost interest in the concept twice, and when we came through the door she looked at Roya for a long moment and then said, "Is that it?"

That is still funny. That is the last uncomplicated funny thing in this book, so I am leaving it in.

For eleven days she fed and slept badly and cried and did all the things. She was, by every account including mine, a normal newborn. The midwife came and weighed her and was pleased. My mother came for a week and made too much food and cried when she left.

On day twelve she had what I described to a GP as a shudder.

It lasted a couple of seconds. Her arms went out and came back and her eyes did something. I mentioned it because you mention things, and the GP was thorough and unworried and said that newborns do a great many strange things and that if it happened again I should come back.

It happened again. It happened, I now know, a great many times, and I did not see most of them, because they were small and because I was asleep for four hours in every twenty-four and because you are not looking for it.

The word I did not have then is *seizure*. The words I did not have then, and would not have for another year, run to about a page.

She was five weeks old before anybody said anything, and what they said was that they would like to do some tests.

I want to be clear about something and then I will move on.

Nobody missed anything. I have gone over the notes with two consultants and a solicitor and there is no negligence in this story and I am not looking for one. That is not what this is. Sometimes a brain is injured in the last hours of getting into the world, and the injury is not visible, and the child comes home, and everything is normal for eleven days.

Eleven days is the length of time I got.

THREE. THE THING I KNEW

Weeks six to nine

I knew at six weeks.

I want to be very careful here, because this is the part that sounds like something invented afterwards, and because I have had it explained to me kindly by three separate professionals that hindsight reorganises everything, and they are right about that in general and they are wrong about this.

I knew at six weeks and I did not tell anybody for four months.

It was not the seizures. I did not connect the shudder to anything; I had no framework for it. It was not the stiffness, which came later. It was not any of the things on any list.

It was that she did not ask me for anything.

That is the closest I can get and I have had eleven years to find better words.

A baby is a demand. That is the whole design of them. They come out of you and they immediately, ferociously, incompetently *want*, and the wanting is aimed. It goes at you. A newborn of four weeks cannot see much and cannot do anything at all, and it can still find your face across a room and lock on to it like a thing arriving home,

and when it cries, the crying is *addressed*. It is a message with a recipient and the recipient is you.

Roya cried. She cried a great deal. And the crying was not addressed to anybody.

It went up into the room. It was weather. It came out of her the way rain comes out of a sky, and it stopped the way rain stops, and nothing I did altered its shape.

At six weeks I was sitting on the edge of the bath at two in the morning with her against my shoulder, and I had been in there twenty minutes, and I turned my head and looked at her and she was looking at the light fitting.

Not past me. That is what people assume and it is not what I mean. Babies look at light fittings, and lamps, and the edges of things, and that is entirely normal and I knew it then.

It was that I had been holding her for twenty minutes and there was no one at the other end of it.

And a thing arrived in me, complete, in about a second and a half, with no reasoning in front of it and no evidence behind it, and the thing was: *something is wrong with my daughter and it is not a small thing*.

Here is what I did with that.

Nothing. For four months.

I want to explain why, because I have been angry with myself about it for a decade and I have only recently stopped.

If I had said it at six weeks, I would have been saying: I have a feeling. There was nothing else. No missed milestone — she was too young to miss any. No abnormal finding. No incident anybody had recorded.

And there is a category of woman who says that at six weeks, and it is an enormous category, and it is almost entirely made up of exhausted first-time mothers whose babies are completely fine, and every professional in that building had met four hundred of them, and every single one of those women had been reassured and had turned out to be right to be reassured.

So the sentence available to me was: *I think something is wrong and I cannot tell you why.*

I knew exactly what that sentence would produce. It would produce kindness. It would produce a leaflet about postnatal anxiety, which is a real thing and a serious one and which I did in fact also have.

So I held it on my own from the middle of May to the middle of September and I told nobody, not Mehran, not my mother, not the health visitor, and I watched my daughter with an attention that I would not wish on anyone, and every week the evidence came in and I ticked it off against a thing I already knew.

That is the part nobody tells you about, and it is the reason I am writing this chapter.

The worst period was not after the diagnosis. After the diagnosis there was a word, and a team, and a plan.

The worst period was the four months in which I was the only person in the world who knew, and had nothing to show anybody, and had to go on saying *she's lovely, thank you, yes, she's feeding well* to a series of people who were doing their jobs properly.

FOUR. THE MILESTONES

Months three to nine

The way you find out is not the way you imagine. There is no scene. There is a slow accumulation of things that have not happened, and each one on its own is nothing, and every book and every website and every woman at the clinic tells you that they all do it in their own time.

Six weeks: smiling. Roya did not smile at six weeks. She smiled at about four months, and it was beautiful, and it turned out later that it was probably not a social smile and that I would never know.

Three months: head control. When you lift a baby of three months, the head comes with the body. Roya's did not. It went back. Every time, all the way through, for ten years. There is a specific way you learn to lift a child whose head does not come with

them, and your left hand does it forever afterwards, and I still do it now with other people's babies and they look at me strangely.

Four months: reaching. Nothing.

Five months: rolling. Nothing.

Six months: sitting with support. She could not be propped. She went sideways, always the same side, and something in the shape of her body was wrong in a way I could see and could not describe, and when I tried to describe it to a health visitor I said, "She doesn't fold in the right places," and the health visitor wrote something down and I could see that I had said something significant and had no idea what.

Seven months: transferring an object hand to hand. Her hands were closed. They had been closed since about eight weeks and I had thought it was sweet.

And under all of this, the thing nobody tells you about, which is the stiffness.

She was stiff. Not floppy — that is what people expect, and floppy would have been read faster. She was rigid. Changing her nappy involved a kind of negotiation with her legs. Getting her arm into a sleeve took forty seconds and both hands and there was a moment in the middle where I would feel her resist and I would think, quite clearly: *that is not a baby resisting*.

I raised it. I want the record to show that I raised it four times between four months and eight months, and that I was, every single time, treated kindly and taken seriously and given the correct reassurance, because at four months you cannot tell, and at six months you very often cannot tell, and the number of anxious mothers who present with a baby who is simply a bit late is enormous and the number who present with this is very small.

At nine months I stopped raising it and started using a different sentence.

I stopped saying *is she all right?* and started saying *I know something is wrong*.

That sentence works. I would recommend it to anybody. It changes the room in about a second and a half and I wish somebody had told me at four months.

We were referred that week.

FIVE. HOW MEHRAN FOUND OUT

September, and then a Saturday a fortnight later

Mehran did not know.

I need to say that carefully, because the obvious reading is that he was not paying attention, and it is wrong, and it took me years to see why.

He was in the room as much as I was. He did the eleven o'clock every night. He changed her and bathed her and walked her up and down the hall at three in the morning singing the same four bars of something.

He did all of it while operating on a completely different assumption, which was that this was what a baby was.

He had been at work for most of Daena's first year. He had very little to compare her to. He was not with her in the day, so he did not see the pattern of a whole week, only the ends of it. And — this is the real thing — he was working eleven-hour days and had constructed, entirely reasonably, a version of fatherhood in which his job was to hold the line while I did the assessing.

He trusted me to be the one who noticed. So when I said nothing for four months, he heard nothing.

I told him in September, in the kitchen, badly.

I had rehearsed it and what came out was: "I think there's something wrong with Roya."

And he said, "What sort of something?"

And I could not answer, and it went badly, and it ended with him saying, gently and with real love, that I was exhausted and that Amina's boy had not walked until he was nearly two and was now a solicitor.

I let it go. I have thought about that a great deal. I let it go because I had no evidence and because I wanted him to be right, and there is a version of me that pushes that night and gets us to a paediatrician in October rather than the following January, and it would not have changed one single thing about my daughter's life, and I have had to say that to myself several thousand times.

He found out a fortnight later, at a barbecue, in about four seconds. There was a colleague of his there with a baby. A boy, four weeks younger than Roya. Four weeks.

And at some point in the afternoon that child, sitting on a rug, propped and wobbling but sitting, reached out and took a set of keys off the grass and put them in his mouth and looked up at his mother to see whether he had done something clever.

I watched Mehran watch him do it.

I saw the exact moment. It is the single clearest image I have from that entire year and I could draw it. He was holding a bottle of beer and he did not move and his face did not change at all, and then after about four seconds he put the bottle down on the wall, carefully, as though it mattered where it went.

Then he said he was going to get something from the car.

He was gone twenty-five minutes.

When he came back he was completely normal for the rest of the afternoon. He was charming. He carried plates. On the way home he drove and did not speak for eleven minutes and then he said:

"Right. Who do we ring."

That was it. That was the whole conversation and it is the only one we needed. He never once, in the ten years that followed, suggested that I had been imagining anything. He never said sorry about September either, and I never wanted him to.

But I want to record the difference, because it is the difference between us and it never closed.

Mine came at six weeks, from nothing, and arrived over four months as a slow confirmation of something I already carried.

His came in four seconds on a Saturday afternoon in somebody's garden, complete, with no warning at all, next to a barbecue.

I do not know which is worse. I have asked him and he says he does not know either.

What I do know is that he never went back to that garden. The colleague moved away two years later and they had been close and Mehran did not go to the leaving thing, and gave a reason, and the reason was not the reason.

SIX. THE ROOM WITH THE LIGHT BOX

Fourteen months

It took five more months and it ended in a room with a light box on the wall, which I understand is not how it is done any more, but that is what was in that room in that year.

There were two of them. A consultant paediatric neurologist and somebody else whose role I never established, and I have thought since that the somebody else was there because of what was about to be said.

He put the images up. He talked us through them and I did not understand a word and Mehran did, or pretended to, and asked two questions in the voice he uses at work.

Then he sat down, which was the signal, and he said the sentence.

I am not going to reproduce the sentence, because I have discovered that there is no way to write it down that carries any of it. It is four or five clauses long, it contains the words *significant* and *global* and *unlikely*, and it is constructed with enormous care by a person who has said it perhaps two hundred times and has never once got used to it.

What I remember is not the sentence. What I remember is that there was a radiator under the window and it was clicking, and that I looked at it for the whole of the middle part, and that afterwards, for about two years, the sound of a radiator clicking would take my legs.

I remember asking whether she would walk. He said it was very unlikely.

I remember asking whether she would talk. He said it was very unlikely.

And then I asked the question I did not know I was going to ask, which was: "Does she know me?"

And there was a pause.

That pause is the most important thing in this book. I want to give it its due, because I have had ten years to understand what was in it, and it was not evasion and it was not pity.

He said: "We can't answer that. Not now, and possibly not ever."

And then he said something that I did not appreciate until years later, and which I now think was the single most honest thing anybody said to me in a decade of appointments.

He said: "You will meet people who tell you there's nothing in there. You will meet people who tell you she understands everything. Both of them are guessing. I would be guessing too."

I said, "So what do I do?"

He said, "Assume she's in there. It costs you nothing and it might be true."

Mehran drove home. In the lift he said my name once, "Mona," and then did not finish the sentence, and we did not speak again until the ring road.

I sat in the back with her.

Here is the part I have never told anybody and am putting down because this is where things get put down.

In the car, somewhere on the ring road, with my daughter asleep in the seat beside me, I thought: *I want to go back.*

Not undo her. Not that. I want to be exact, because the difference matters and it has taken me ten years to be able to state it.

I wanted to go back to eleven days.

I wanted the flat, and the two of them asleep, and the version of my life in which I did not know yet, and I would have paid absolutely anything for it, and what I understood on the ring road was that the person I would have to pay was in the seat next to me.

Then I put my hand on her chest, because her chest was warm, and I did that all the way home.

INTERLUDE I

The first house

Warm, then less warm, then warm again.

That is all of it. That is the entire architecture and there is nothing underneath it and nothing on either side.

You are not anywhere. There is no room, because a room is a thing with edges and you have no edges. There is warm and there is the ending of warm and there is the enormous slow return.

Sometimes there is a brightness. It does not mean morning because there is no morning. It arrives and fills everything and then it is less and then it is not.

Something happens to you that is bigger than anything: you are turned over. The whole world tips and comes down on the other side and everything is different and there is nothing you did and nothing you could have done and it is not frightening, it is simply the largest event there is.

And then there is a thing that is not the same as the others.

Something moves on you. Along the arm, slow, the whole length. It goes at a speed. There are speeds that are wrong — too quick, and it is only a touching, it goes nowhere, it stops at the skin. This one is not that. This one goes at the speed that opens, and when it opens something in the middle of you goes quiet, and the going quiet is deeper down than the arm is.

It comes back. It goes down the arm and lifts and comes back to the beginning and goes down again.

There is no word for it and no need of one. There is only: this again, and the quiet underneath.

You do not know it is a hand. You do not know there is anyone.
There is no anyone anywhere in this, there is only the world doing
the slow thing, and the slow thing being right.

Warm. Less warm. The slow thing.

Warm again.

II. THE SEMI

SEVEN. SIX THINGS A DAY

Years one to two

Here is a day.

Stretches on waking, twenty minutes, both legs, both arms, and a specific thing with the hips that I will come to. Medication, three. Feed, forty minutes if it went well and ninety if it did not, because she could not co-ordinate a swallow properly and everything had to be thickened and everything had to be watched. Nappy. Positioning — she could not be left in one shape, so she was moved between a chair, a floor wedge and a standing frame on a rota I had written on the fridge.

Then again. Then again. Then the night, which had its own list.

Six things a day is what the physiotherapist said at the start, kindly, so as not to frighten us. Six things a day.

It was thirty-one. I counted, in year two, on a bad night, with a pen.

What nobody explains is that none of it is optional, and none of it works in the way you mean by *work*. The stretches do not make her better. The stretches slow the rate at which her body closes up. That is the whole of it. You do twenty minutes twice a day, seven days a week, for a decade, in order to lose more slowly.

I was extremely good at it. I want to say that plainly because there is no one else to say it. I did not miss a day in the first four years. I had a laminated sheet. I could do the whole hip protocol in the dark in a hotel room, and I did, twice.

And the other thing about a regime like that, which took me a long time to see, is that it is a kindness to the person doing it.

For twenty minutes twice a day I was not a woman whose daughter would never walk. I was a woman performing a technical procedure correctly. There is an enormous amount of relief in a task. Grief cannot get at you while you are counting to thirty with your hand on a femur.

I have wondered since how much of my competence was love and how much of it was hiding.

I think mostly love. I think about eighty per cent.

Mehran did the nights for the first two years. That was the arrangement and he never once broke it, and he was going into an office at eight in the morning on four hours of sleep for twenty-six months, and in the whole of that time he complained exactly once, in the kitchen, in March, and then apologised for it for a fortnight.

Daena was four, then five. She started school. Somebody had to take her and somebody had to collect her and there were two of us and three children's worth of things to do, and the arithmetic of that year has never fully left me. I can still feel the shape of it. Three o'clock was a cliff every single day.

She never once complained either.

At the time I was grateful for that. I want to write down what I think about it now, which is that a four-year-old who does not complain has already worked something out, and that what she worked out was that there was nowhere to put it.

EIGHT. WHAT WE LOOKED LIKE

The photographs of us

There is a photograph of the two of us at a wedding six weeks before Roya was born and another at a christening about two and a half years after, and for a long time I kept them in the same drawer and did not look at either.

I am going to describe them because it is the only way to say this without sounding like self-pity.

In the first one Mehran has a full head of dark hair with a bit of grey at the temple which he was vain about. He is laughing at something out of frame. He is thirty-eight.

In the second he is forty and a half. The grey has come up through the whole of it. He has lost about a stone he did not have to lose and there is a hollow under each cheekbone that was not there, and his eyes have gone back into his head, which is a thing I did not know was a real physical change and had assumed was a figure of speech.

He looks fifty. Not tired. Fifty.

In the first one I am eight months pregnant and enormous and happy in a way I can no longer entirely access.

In the second I have a different face. I want to be precise about it, because it is not that I look sad. I look *braced*. There is a set to the jaw and a thing around the eyes that I have since recognised on other women in clinic waiting rooms and never anywhere else. It is the face of somebody who is listening for a sound in another room. I have that face permanently now. It has softened. It has not gone.

I went grey at the front at thirty-eight. I have a photograph of me at thirty-eight with grey at the front.

Here is what actually did it, and it was not grief.

It was two years of four hours' sleep in pieces, and adrenaline running underneath all of it without a break, and a nervous system that never once stood down. There is a physiology to this and it has been studied in carers and the findings are not gentle. Your blood pressure goes up. Your immune function goes down. You are, measurably, doing damage to yourself, continuously, at a rate that would concern a doctor if a doctor ever measured it, and nobody ever measures it, because the person on the appointment letter is the child.

I was in that building perhaps two hundred times in ten years. Not once did anybody take my blood pressure.

That is not a complaint about them. There was no mechanism. I was not the patient.

Mehran had chest pain in year four and did not tell me for six weeks. It turned out to be nothing. He had it investigated on a Tuesday while I thought he was at work, and he told me afterwards, in the car, in the tone of a man confessing to an affair.

I said, "Why didn't you say?"

And he said, "Because there wasn't room."

That is the truest four-word description of those years that either of us has ever managed. There wasn't room. Not in the diary. In the house. In the marriage. In the two of us. Everything that was not

the immediate next thing that had to be done for Roya simply did not have anywhere to be put down.

We aged eleven years in three. Everybody who knew us then says some version of it, carefully, and only in the past tense, and only now.

NINE. THE FIRST YEAR OF CASSEROLES

Year one

The first year is loud with people.

My mother came for three weeks and then every fortnight. Mehran's sister came with food in foil trays, four times, and once cleaned the kitchen so thoroughly that I could not find anything for a week. There were cards. There was a woman from the antenatal group who turned up with shopping and did not come in, which at the time I found abrupt and which I now understand was the single most competent act of help I received that year.

People said the things. I want to record them without malice because there is no malice in any of this.

If anyone can do this, you can.

She's lucky to have you.

God only gives it to those who can handle it.

Everything happens for a reason.

She's teaching you all so much.

Every one of those was said to me by somebody who loved me. Every one of them was intended as a gift. And every one of them does the same thing, which is to convert an unbearable situation into a story with a moral, so that the person saying it can stop being frightened and go home.

I said thank you every time. What else is there.

And then it stops. Not suddenly. There is no day. The visits go from weekly to fortnightly to when-we-can, and the phone calls get shorter, and at some point in year two you realise that the last four times you spoke to somebody, you rang them.

I have thought about why for ten years and I have three answers and none of them is unkindness.

The first is that there is no arc. People can sustain enormous effort towards a crisis, because a crisis has a shape — it gets worse, and then it resolves, one way or the other. This does not resolve. It is the same in year six as in year one, except that everyone involved is older and more tired. There is nothing to rally for.

The second is that we became difficult to see. Not emotionally. Logistically. You cannot pop round to a house where a child is being suctioned. You cannot go for lunch with a woman who has a forty-minute window. Every act of contact required planning, and planning required somebody to do it, and I stopped having the capacity to do it at about eighteen months.

And the third is the one that took longest.

They did not know what to do, and there is no available instruction anywhere in our culture, and so rather than do the wrong thing they did nothing — and doing nothing felt, from inside their own lives, like respect.

I know that because I have since done it to somebody else. In year seven, a woman I know had a stroke, and I did not go, for four months, and when I finally went I understood every single thing that had happened to me.

TEN. WHEN EVERYBODY ELSE FOUND OUT

Months nine to thirty

Everybody else found out slowly, and separately, and mostly by working it out on their own, and almost nobody ever asked.

That is a strange sentence and it is accurate. There was no announcement. I have thought about why and the answer is that there was never a day on which there was something to announce — the diagnosis at fourteen months was a confirmation of a thing that had been true since before she came home, and by the time we had the word, half of them had already arrived somewhere near it without help.

So instead there was a period of about eighteen months in which our extended family and our friends worked it out, one at a time, at different speeds, and behaved accordingly, and nobody said anything to anybody.

Here is how it actually went.

The photographs. This was the first thing, and it happened before any of them consciously understood it.

I posted pictures. Everybody posts pictures. And at about seven months I noticed that the ones of Roya were getting a particular kind of response — warm, immediate, and slightly too fast. *Gorgeous. Beautiful girl.* Three or four words, and quickly, and then nothing.

Because the photographs were odd and they could all see it and none of them could have told you why.

Her head is not doing what a seven-month-old's head does. She is being held in a way that is not how you hold a seven-month-old. She is not looking at the camera and she is not looking at me and she is not looking at anything. In the ones with Daena in, my four-year-old is doing all the work of the picture and my baby is being carried by the frame.

Nobody said a word. Every single one of them replied *gorgeous*.

The questions, which stopped. For the first six months I got the ordinary interrogation that every mother gets — is she sleeping, is she feeding, is she smiling yet, is she rolling.

Around month eight they stopped. All at once, from everybody, without co-ordination.

That is what people do when they suspect the answer will be bad. They stop asking, out of kindness, and the effect of the kindness is that you are now in a family where nobody asks about your baby.

The two who asked. My cousin Sam, on the phone, in month nine: "Mo. Is Roya all right?" Just that. And I said, "No, I don't think she is," and it was the first time I had said it to anybody except Mehran, and I sat down on the bottom stair.

And Mehran's father, who was eighty and did not have time for any of it, at a lunch, in front of eleven people: "What is wrong with the child?"

There was a silence of about four seconds that I can still hear. Mehran's mother said his name. He said, "Well. Somebody has to."

He was right. He was the only one who was right about anything for two years.

The gatherings. This is the part I would most want people to understand.

We kept going for the first eighteen months. Eids, birthdays, a christening, two weddings. We took her, with the equipment, which by then was substantial, and we sat in somebody's front room.

And what happened, at every single one, was that the room organised itself around not looking.

Nobody was unkind. Not once, in ten years, was anybody unkind to my daughter in my presence. What happened was subtler and worse: people would come and say hello to me, and to Daena, and their eyes would go to Roya and then move off her at speed, like a hand off a hot thing, and then they would ask me a question about parking.

The children were the exception. Children came right up and looked at her properly and asked direct questions — why doesn't she sit up, why are her hands like that, can she hear me — and every time, every single time, an adult would arrive at speed and take them away and apologise to me.

I never once wanted the apology. The child asking was the best thing that happened to me at any of those gatherings, and I would have answered every question, and I was never allowed to.

And then we stopped going. Not by decision. It got harder — the transfers, the equipment, the fact that she needed suctioning and there is nowhere in somebody's semi to do that — and each individual absence had a completely legitimate reason, and after about two years of legitimate reasons we simply were not at things any more.

They noticed. I know they noticed because I have since been told, by two different people, that there were conversations about us.

Nobody rang.

ELEVEN. LET ME KNOW IF YOU NEED ANYTHING

Years two to ten

I heard that sentence, at a conservative estimate, four hundred times.

I have never once acted on it. Not once, in ten years, from anybody.

For a long time I thought that was a failing in me — some pride thing, some inability to accept help. I have since worked out that it is not, and I want to set out what that sentence actually asks of you, because everybody says it and nobody has examined it.

To act on *let me know if you need anything*, you must:

Identify a specific need, which requires standing outside your own situation far enough to see it, which is precisely the capacity that this life removes first.

Judge whether the need is proportionate to the relationship. Is this a cousin-sized favour? Is it too much to ask? You will run this calculation for a long time and you will usually conclude that it is too much.

Then find the words, and make the approach, and expose yourself to the possibility of a no, or worse, a yes that is grudging.

Then be grateful, visibly, in a way that costs energy, and then afterwards manage the small ongoing debt that now exists between you.

That is six pieces of work, and every one of them falls on the person who has none left. It is an offer of help that is, structurally, a request for labour. It sounds like a door being opened. It is a door being pointed at.

Here is what worked. There were four of these in ten years and I remember all four.

Nasrin — Mehran's colleague's wife, whom I had met twice — sent a message in year three that said: *I'm outside on Thursday at 2. I'll take Daena to the park for two hours. Don't come out, don't make me a coffee, just open the door.*

Our neighbour Pat, who was seventy-one, knocked one afternoon and said, "I've done too much shepherd's pie again," which was a lie she told for four years.

My cousin Sam, who came in year five, sat on the floor next to Roya, put his hand on her leg, and stayed for two hours mostly not talking. He is the only person in my extended family who ever touched her without a reason.

And a woman at the clinic, whose name I never learned, who once said to me in a corridor: "It's shit, isn't it."

That is it. That is the complete list. Four people in ten years, and what all four have in common is that none of them asked me a question.

If you take one thing from this book, take that. Do not ask what they need. **They do not know.** Turn up with a time and a task, and be prepared to be refused, and come back anyway.

TWELVE. DAENA, SIX

Year two

There is a word for what Daena became and I did not learn it until she was fifteen. **Glass child.** The sibling that people look through.

I hate the term. It is also exactly right.

At six she could do the following: put a wash on, make toast for herself, get her own reading book out of her bag and do it without being asked, and tell an adult at the door in a clear voice that her mum was busy with her sister and could they come back.

At six.

At the time I thought I had an exceptional child. I told people so. My mother said she was an old soul. And she is exceptional, and she is not an old soul, she was a small girl who had correctly

identified that the household had a fixed quantity of adult attention and that the way to get any of it was to require none.

The things I did not see, and which she told me about at nineteen:

That she stopped bringing schoolwork home in year three because I was always in the middle of something and she had learned to read the exact expression on my face that meant *not now*.

That she used to sit outside the bathroom door when I was in there because it was the only place in the house where I was reliably still.

That for about two years she believed Roya's condition was contagious and that she might get it, and told nobody, because she understood that this was a shameful thing to think.

And that she never once, in her whole childhood, had a friend to the house.

I asked her why not. She said, "You had enough on."

She was seven when she decided that.

The thing I want to put down here, though, is the other side of it, because it would be dishonest to leave you with only the damage.

Daena was the best thing in Roya's life.

She was the only person who was not on a schedule. Everybody else who came near my daughter came to do something to her — feed, stretch, suction, change, medicate. Daena came to lie on the floor next to her and read out loud, badly, for hours, from books far too old for either of them, with her face about six inches from Roya's face.

She sang to her. Terribly. She did voices.

She started doing Roya's voice at about eight and I will give that its own chapter later, because it deserves one and because it is the thing she would most want kept. The first one I ever heard was in the semi, in the front room, aimed at me. I had put a cardigan on Roya that my mother had knitted and that was, objectively, hideous.

Daena looked at her sister for a moment and then said, in a voice not her own: "Roya says absolutely not."

I said, "Daena."

She said, "I'm only telling you what she said."

I have thought many times that if there was anything in there at all, then the best hours of my daughter's life were spent with a small girl who had no idea she was doing anything remarkable.

INTERLUDE II

The second house

There are two speeds.

The first is the slow one and it comes most. It goes along the arm, down and back and down, at the speed that opens the quiet underneath. When the slow one is happening, the thing in the middle of you that pulls tight goes loose, and the loose is better than anything.

The second one is quick. It is not bad. It is only that it stays at the top of the skin and does not go down. It comes with a warmth close to the face and a lot of sound, and the sound is not made of anything, it is a shape that goes up and comes down and goes up.

The quick one puts its face very near. There is a smell that is not the inside smell. It is the smell of outside — cold on cloth, and something green.

The quick one goes on for a long time. It does not stop when it has finished, it starts again. The sound goes up and down and up and down and there is no reason in it.

And the thing that happens then, which has no name and no shape and comes from nowhere in particular: everything in you goes towards it.

Not moving. There is no moving. But something goes.

It is the same going as the slow one, and it is not the same, because the slow one arrives on you and this one comes out.

Then the quick one is not there. The going does not stop when the quick one stops. It stays out, reaching, with nothing at the end of it, for a long time.

That is the first bad thing. It is the first thing that is not warm or cold or bright or turned over. It is a going with nothing at the end.

Later — there is no later, but there is a further-on — the quick one comes back.

The going finds it.

That is the whole of it. That is everything that ever happens.

III. THE BUNGALOW

THIRTEEN. THE HOIST

Year three

We moved because I dropped her.

Not far. She was three and about thirteen kilos and I was carrying her up the stairs, which I had done perhaps four thousand times, and my back went at the fourth step from the top, and I got her down onto the landing without hurting her and could not then get up myself.

I lay on that landing for eleven minutes with my daughter beside me making a sound I had not heard before, and Daena, who was seven, came up, and I told her not to try to lift her and to go and ring her father, and she did both of those things perfectly.

The bungalow had a wet room and a bedroom that would take a hoist and no stairs anywhere in it. It cost more than the semi and was in a worse place and we were there within four months.

The hoist goes in the ceiling. There is a track, and a spreader bar, and a sling that goes under her, and a hand control with an up and a down.

It arrived on a Tuesday and two men fitted it in six hours and one of them was very good with her and talked to her the entire time.

I need to say what a hoist actually is, because it is presented as equipment and it is not equipment.

It is a machine for lifting your child, because your child now weighs more than a person can safely lift, and it will lift her every day for the rest of her life, and she will get heavier and the hoist will not change, and that is the arrangement.

The first time we used it I cried afterwards, in the wet room, with the door shut and the extractor on.

Not because it was undignified. It was not undignified — she went up smoothly and she did not mind it and by the end she may even have liked the movement. I cried because of a thing that took me another two years to say out loud, which is:

I could no longer pick up my daughter.

That was the day. Not the diagnosis. There is a common assumption that the diagnosis is the worst day and it is not. The diagnosis is a fact arriving. The day the hoist went in was the day a specific ordinary thing that mothers do stopped being available to me forever, and there was no ceremony, and two men had a cup of tea afterwards and left.

I still lifted her. For years. When there was no one watching, when it was just her and me and the sofa four feet away, I lifted her, because I wanted to, and because it was mine.

I was told by three separate physiotherapists not to.

I did it anyway, less and less often, and then only from the chair to the sofa, and then not at all.

The last time I picked up my own daughter I did not know that it was the last time. Nobody does. That is the standard arrangement for all mothers everywhere, and it is the one part of this that is completely ordinary, and it is somehow not any easier for being so.

FOURTEEN. THE STRETCHES

Years three to nine

This is the hardest chapter and it is four pages and then it is over.

The hips of a child who cannot bear weight will, if left alone, migrate. The head of the femur drifts out of the socket. It is measured as a percentage on an X-ray and it goes up, and past a certain figure it becomes a dislocation, and a dislocated hip in a child like Roya is a catastrophe — pain, an inability to sit, the loss of the chair, the loss of everything the chair makes possible.

It is preventable. That is the crucial fact. Surveillance and physiotherapy and, if needed, surgery, and hip dislocation in this population has been driven down to almost nothing in the countries that do it properly.

So you stretch. Twice a day. The adductors, held at end of range, for a count that seems short on paper and is not short.

And it hurts her.

I knew that within a week. She could not tell me and she told me constantly — a change in the breathing, a particular note in the sound she made, a hardening under my hands that was not spasticity. I have never in my life been more certain of anything than I was that this hurt my daughter.

And the research, when I finally went and read it years later, says exactly that. Pain is common in children like Roya. The hips and the feet are the main sites. And **joint mobilisation** — this, the thing I was doing with my hands, twice a day, for six years — is the most frequently identified source of it.

So here is what I did, every morning and every evening, for most of a decade.

I laid my daughter on a mat. I positioned her. I put my hands on her and I hurt her for twenty minutes while she made a sound I could not answer. And then I picked her up and held her, and she went quiet against me, and the person comforting her was the person who had done it.

That is not a metaphor for anything. That is a description.

There is a version of this book in which I stop. I have imagined it. In that version I put the laminated sheet in a drawer and I let her be comfortable, and her hips go, and by nine she cannot sit, and the last year of her life is spent in pain that cannot be fixed and in a body that cannot be positioned, and I have taken from her the only thing she had, which was being upright in a room with people in it.

I did the right thing. I know I did the right thing. I have had it confirmed by four professionals, including one I begged for absolution from in a corridor in year five.

And the correct decision, executed correctly, twice a day, for six years, is: I hurt her about four thousand three hundred times.

There is no arithmetic that makes that lighter. I have tried all of them. The one I use, on the bad nights, is that it bought her the chair, and the chair meant she was in the room, and being in the room is where the slow thing happened.

Some nights that works.

FIFTEEN. TRYING

Years two to six

I want to be careful here, because there is a version of this story where a desperate family is fleeced, and that is not what happened to us, and I do not want to be lumped in with it.

Nobody defrauded us. We were not sold a miracle. What happened was smaller and more ordinary and I think more common.

We tried things.

We tried the intensive programme in year two, which was three weeks residential and cost about as much as a car, and which was staffed by people who were qualified and kind and who never once promised us anything. She was better afterwards, for about five weeks, in the way that any child is better after three weeks of eight-hour-a-day attention.

We tried a diet in year three that had no evidence behind it and no harm in it either. We tried a suit. We tried an approach involving a great deal of floor work that a woman in Bristol taught me over two weekends and that I did faithfully for eleven months.

We looked at a clinic abroad and did not go. We looked at it for a long time. What stopped us was not scepticism; it was that the flight was fourteen hours and she could not sit for fourteen hours.

None of it did anything. I want to be exact: none of it did anything to the underlying thing, and some of it did something to us, and one of the things it did to us was give us somewhere to put the year.

Mehran stopped in year four.

He stopped in a Travelodge outside Birmingham at eleven at night after the second day of an assessment. He was sitting on the end of the bed with his shoes still on and he said, "Mona. She isn't going to get better."

I said I know that.

He said, "No, you don't. Because if you knew it we wouldn't be here."

And I said something unforgivable, which I am putting in because leaving it out would make this a nicer book than it deserves to be. I said: "It must be nice to be able to stop."

He did not answer that. He went and had a shower for a very long time.

We did not speak about it again for three years.

Here is what I understand now. He had not stopped loving her and he had not given up on her. He had given up on a *future* for her, which is a different thing, and he had done it four years before I could, and the four-year gap is the whole of the difficulty between us.

He was in the present with our daughter from year four onwards. He fed her and changed her and lay on the floor with her and sang to her — badly, the same as Daena, they had the same terrible voice — and he did not once ask anybody whether anything could be done, because he had accepted that nothing could.

I was still in the future, sending applications, reading papers at two in the morning.

Only one of us was actually with her during those years. It was not me.

SIXTEEN. SILENT ANGEL

Year four

It was Mehran's aunt, at a family thing, in a kitchen, holding a plate.

She had not seen Roya since she was about eighteen months. She had asked after her, warmly, every time we met, for years, and she had not been to the house since the first winter.

She said: "She's an angel, isn't she. A silent angel. God has sent you an angel."

And she put her hand on my arm, and her eyes were wet, and she meant every single word of it.

I said thank you.

I have taken that phrase apart perhaps a thousand times since and here is what it does.

An angel is not a person with needs. An angel does not require you to learn how to hold a head that does not come with the body. An angel does not need suctioning. An angel is a visitation — something that arrives, that is beautiful, that is *for* you in some way, and that does not have a hip migration percentage.

The word *silent* does the second half of the job. It converts the thing that is hardest about my daughter — that she could not tell me anything, that ten years went by without her ever once saying my name — into a quality. A grace. A stillness.

And once she is a silent angel, you do not have to come to the house.

You cannot help an angel. You can only be moved by one. So the phrase relocates my daughter from the category of *child in a room who could be sat with* to the category of *mystery to be honoured from a distance*, and the person who says it walks away lighter, and they are not lying and they are not being cruel and they will cry about her sincerely at the ceremony six years later.

I never corrected anybody. Not once. What would I have said?

I said thank you, and I went and stood in the garden.

And here is the part that I cannot get around, and which is why the phrase is still in my head ten years later rather than simply discarded.

I use it too.

Not to relatives. To myself, at four in the morning, in the years when I needed a way to think about what she was for. My silent angel. I have caught myself doing it, and I know exactly what it does when I do it, and I do it anyway, because sometimes you cannot carry the real one and you need the light version for an hour.

Everybody in this book is doing their best with an unbearable thing. That is not a consolation. It is just true.

INTERLUDE III

The third house

There is a new thing and it is not like anything.

It arrives in the same place every time, which is the front of the leg where it joins, and it comes from the outside and goes all the way in, past everything, into the part that has no outside.

It is not cold and it is not bright. It is its own. There is no other one of it.

While it is happening there is nothing else. Warm is not there. The slow thing is not there. There is only this, filling everything, in the leg and then not only the leg, and something goes out of you that is not a sound because there is no sound, but it is the closest there is.

And then it stops.

Then it comes again in the other one.

Then it stops, and everything comes back — warm, the room-that-is-not-a-room, the going of it.

Here is the part that has no shape and cannot be held.

The one who does it is the slow one.

There is no knowing that. There is no putting-together in you, no line from one thing to another, no this-then-that. Everything is only now. So the hurting is now and the slow one is now and there is nothing that could join them into a thing that means something.

But afterwards, always, without fail, there is the being-picked-up. The whole weight of you gathered and brought in against the warm, and the smell that is the inside smell, and the slow going of a hand on the back of the head.

And the quiet underneath comes back.

So the shape of it — if there were shapes — would be: the worst thing, and then the best thing, and the best thing has the same hands.

There is nothing in you that could ever object to that. There is nothing in you that could ever ask for it to be different, or wonder, or hold it against anyone.

You go towards the warm. Every time. That is all there is and it never once fails.

IV. THE HOUSE NEAR THE SCHOOL

SEVENTEEN. TWELVE MILES

Year six

The school was twelve miles away and it was the right school and there was no other one.

We had been doing the twelve miles for eighteen months — twenty-five minutes each way if the traffic held, fifty if it did not, twice a day, in a van with a ramp, with a child who could not be left in it for a second at either end.

Two hours a day, minimum, in a vehicle. Ten hours a week. Four hundred hours a year.

So we moved again. Fourth house. A 1970s box with a downstairs room and a drive we could get the ramp onto, in a place neither of us had chosen and neither of us liked, eleven minutes from the gates.

Daena was ten. She changed school.

I asked her. I want that on the record — I sat her down and I asked her, and she said, “It’s fine, I’ll be fine,” and she was ten years old and she gave the correct answer, which was the answer that made the move possible.

She cried in the car on the last day. Once, briefly, and then stopped herself, and I saw her stop herself in the mirror, and I did not pull over.

I have thought about not pulling over more than almost anything else in this book. It would have cost four minutes. Roya had a feed at four and the whole day was built around the feed at four, and I did the arithmetic in about a second and a half and I drove on.

That is what it does. It is not that you love one child less. It is that one of them has a hard deadline and the other one does not, and a decade of small arithmetic goes only one way, and the child without the deadline learns the result of every single sum.

The school was good. It was genuinely good — a specialist place with hydrotherapy and a proper physio and staff who knew her within a fortnight and called her by her name in a way that made me have to leave the room the first time.

She went four days a week from six to ten and it saved us. There is no version of the last four years that we survive without those hours.

And I want to record what those hours were actually like for me, because I had imagined them for two years as freedom.

The first month I slept. The second month I cleaned things. Then I ran out of things and there were four hours in the middle of the day with no child in the house and I found that I did not know what to do with myself, and that I was frightened of the quiet, and that I would get in the van at half one and go and sit in the car park at the school forty minutes early.

I did that most days for about a year.

Not to check on her. She was fine. I did it because the quiet had a thing in it that I could not be alone with, and the car park did not.

EIGHTEEN. GLASS

Years six to nine

Daena's adolescence happened at the edge of my vision and I have had to reconstruct most of it from what she has told me since.

Here is what I saw at the time. A capable, quiet, extremely self-sufficient girl who did her homework, got on with things, never asked for money, and had two close friends whom I met perhaps four times.

Here is what was actually happening.

She was doing about two hours of caring a day by the age of twelve. Not because we asked. Because it was there and she could see it. Feeds, positioning, the fetching of things, sitting with Roya so I could shower. She was, in the language of the forms I did not fill in for another three years, a **young carer**, and she was one for six years before anybody used the word in our house.

She had panic attacks from thirteen. I did not know until she was seventeen.

She was, in her own account, permanently and quietly furious, and permanently and quietly ashamed of being furious, and the shame

was much larger than the fury, and she managed both of them entirely alone in a bedroom eleven feet from her sister.

And she never once said anything, because — and this is her sentence, at twenty, in a kitchen — “There wasn’t a version where I complained that didn’t make me the worst person in the house.”

At thirteen she said the thing.

It was an ordinary evening. There had been a bad afternoon; Roya had been sick and everything had run late and Daena had asked me something twice and I had said *in a minute* twice, and the third time she said, quite calmly, without any drama at all:

“It’s fine. I’m used to it. You’ve got about ten minutes a day and I know exactly which ones they are.”

And she went upstairs and did her homework.

I stood in the kitchen with a bowl in my hand for a long time.

There is no answer to that. I have looked for one for four years. The obvious answers are all lies — *that’s not true*, which it was; *I’m sorry*, which does not address it; *she needs more than you do*, which is true and is the cruellest sentence available to a mother and which I very nearly said.

What I did was go up ten minutes later and sit on the end of her bed and say, “You’re right.”

She said, “I know.”

And then, after a while, “It’s not your fault.”

And I said, “It’s not yours either,” and that is the only genuinely good thing I did as a parent to my elder daughter in the whole of that decade, and it took four seconds, and I should have done it eleven years earlier.

NINETEEN. DAENA’S RULE

Years four to eleven

I have left something out and it is the thing Daena would most want in here, so I am putting it where she can find it.

She was funny about Roya. Very funny. Relentlessly, specifically, filthily funny, from about the age of eight until the day her sister died, and nobody outside this house ever heard a word of it.

The hoist was **the claw**. She did the noise. She would come into the room while I had Roya halfway to the bed and say, in the voice of a documentary narrator, “The claw selects its prey,” and I would tell her to stop and she would not stop, and Roya’s whole face would do the thing it did.

The wheelchair was **the Bentley**, because it cost eleven thousand pounds and had a suspension system and, in Daena’s words, “she still can’t drive it.”

The suction unit was **Hoover**. The standing frame was **the naughty step**. The feed pump, which had an alarm that went off at three in the morning approximately once a fortnight, was **Kevin**, and Kevin was, according to Daena, “having a personal crisis again.”

She did Roya’s voice. That was the main thing. From about eight years old she gave her sister a running interior monologue in an extremely posh, extremely bored register, and it went on for six years.

Roya says she’d like the good sofa and she’d like you off it.

Roya says that if she has to listen to this album one more time she will simply leave.

Roya says your boyfriend was here again and she has thoughts.

At Christmas, when my mother had been fussing over the tree for an hour: *Roya says she can’t see the tree from here and that this is, and I quote, a design failure.*

Once, in the car, after a very long clinic appointment where a registrar had talked over both of us for forty minutes: *Roya says he was patronising and she noted his name.*

I laughed until I had to pull over. That is a true thing that happened in a car park in year seven and it is one of the four or five best moments of my adult life.

Here is what I want to be understood about all of it.

There was not one particle of cruelty in it. Not one. It was not a child coping by making her sister a joke. It was the opposite — it was the only place in the entire world where Roya was treated as a person with opinions, and preferences, and a low tolerance for idiots, rather than as a set of needs on a laminated sheet.

Everybody else in Roya's life was gentle with her. Everybody. The gentleness was constant and it was well meant and it was, I have come to think, a kind of absence — because you are only gentle with something you have decided cannot take anything else.

Daena was not gentle with her. Daena was rude to her, on her behalf, for six years.

And there was a rule, and it was absolute, and nobody ever had to be told it.

The rule was: **only Daena.**

I saw it enforced twice.

The first time, a cousin of Mehran's, meaning entirely well, having heard Daena do the voice at a family thing, tried it himself. He said something perfectly harmless — a joke about Roya being the one in charge of the remote.

Daena was fourteen. She did not say anything. She looked at him for about three seconds and then turned and left the room, and she did not speak to him again that day or, as far as I know, ever, and he is a nice man and he still does not know what he did.

The second time was a boy at school in year nine who did an impression. She hit him. Properly — she was excluded for a day and a half and I was called in, and I sat in an office and listened to a deputy head explain restorative approaches, and I said all the right things, and in the car afterwards I said, "Don't do that again," and she said, "Okay," and neither of us meant it and both of us knew.

Mehran never joined in. Not once in ten years, and he could have, and I have asked him since why not, and he said, "Because it wasn't mine."

Which is exactly right, and he understood it years before I did.

I did join in. Twice. Both times Daena let it go by and did not laugh, and I understood, and stopped.

That was correct too. It was not mine either.

It belonged to a girl who had been given a sister who could not speak, and who had spent her entire childhood in a house where everybody spoke about that sister in a soft voice, and who had responded — at eight years old, entirely on her own, without being taught — by giving her one.

A rude one. A magnificently rude one, with excellent taste and no patience.

I do not know whether Roya understood a single word of it. Nobody knows and nobody ever will. But she went still when Daena talked, and she went still in a particular way that was not the way she went still for anybody else, and I watched that happen four thousand times, and I will believe what I believe.

At the ceremony, Daena did not speak. She had said no immediately and I did not push her.

Afterwards, at the tea, one of the carers said something kind about how peaceful Roya had looked at the end.

And Daena said, not unkindly, to nobody in particular, “She’d have hated that dress.”

And Bev, who had washed my daughter’s hair every Tuesday for six years, laughed so hard she had to put her cup down.

TWENTY. HEAVIER

Years seven to nine

She got heavier. That is the plot of those years. There is nothing else in them.

Thirteen kilos at three. Nineteen at six. Twenty-six at nine.

It sounds like nothing written down. It is the entire architecture of a life. Everything we owned was rated for a weight and had to be replaced when she passed it — the chair, the sling, the car seat, the bath support, the standing frame. Every eighteen months, a new

assessment, a new form, a wait, a delivery, and a period in the middle where the old thing was too small and the new thing had not come and you managed.

And the people. The people got older and she got heavier and those two lines crossed somewhere around year eight.

Her carers were called Bev and Ify and Marta. Bev had been with us from year four. She was fifty-nine by year nine and she had a bad shoulder and she never mentioned it once in my presence, and I only found out because Ify told me.

Two-person transfers became mandatory in year seven. That meant that nothing could happen unless there were two adults in the room, which meant that spontaneity of any kind ended entirely.

There is a specific arithmetic that runs in a house like ours from about year seven and nobody says it out loud and every single person in it is doing it.

She is twenty-six kilos and she is nine.

At sixteen she will be forty. At twenty she may be fifty. I am forty-five and my back has gone twice. Mehran is forty-seven. Bev is fifty-nine and will not be doing this in five years.

You do not finish that thought. You get about that far and you stop, every time, because the end of it is a question about the rest of your daughter's life and where she will be living it and who will be lifting her when you cannot.

I never once said that out loud to anybody. Not to Mehran, not to my mother, not to a professional.

And every parent in that school car park was running the same sum, and we all knew it, and we talked about the traffic.

INTERLUDE IV

The fourth house

The slow thing has changed.

It still comes. It goes down the arm at the speed that opens. But there is something in it now that was not there, which is that after a while it stops working.

It goes down and back and down and back, and the first ones open the quiet, and then the openings get smaller, and then it is only a thing moving on the arm and the underneath does not answer.

It is not gone. It is used up.

There is no way to make it stop and there is no way to make it start again and there is nothing at all that could be done about it in any direction. It simply arrives, and works, and then works less, and then the hand goes away and later it comes back and it works again.

That is the first thing that is not enough.

There is also a new place. It is bright and loud and there is water in it, and being in the water is the other best thing — the whole weight of you gone, everything loose, no place where anything presses. In the water there is no leg and no back and no head that has to be held. There is only warm on all sides at once.

And there is a sound in the new place that is not the shape-that-goes-up-and-down. It is the sound of many, and it has edges, and something in you goes towards it the way the going goes.

Then it ends, and there is cold, and the weight comes back all at once.

The weight is the thing.

You do not know it is weight. There is no word and no comparing. But there is a difference between the water and the after-water, and the difference has a name in everybody else's mouth and none in yours, and it is the largest fact about you, and you carry it and cannot know that you are carrying it.

The going still goes. When the quick one comes with the outside smell, the going still goes out, every time, with nothing at the end of it, and finds her.

That has never once been used up.

V. THE ONE THEY CAN'T SELL

TWENTY-ONE. THE LAST HOUSE

Year nine

The fifth house was bought for a wet room, a through-floor lift we never installed, a ceiling track in two rooms, a widened door, a ramp, a hardstanding, and a room downstairs with a window at bed height so that a child who could not turn her head could see a garden.

It is worth about eleven per cent less than we paid for it and we have never tried to sell it, and after a certain point I understood that we never would, and that this was not a financial problem, it was a description of our life.

You cannot un-adapt a house. You can, technically. Nobody does. It costs money you do not have to remove things you may still need, in order to make a building look like a building where nothing happened.

Ours still has the track in the ceiling of the back room. It is there now. It is above my head as I write this.

The other thing about the fifth house is that it was where we stopped pretending we would go anywhere.

We had not had a holiday since Daena was four. Not one. There had been two attempts — a cottage in year three, which was a disaster involving a bath she could not be got into and a floor that could not take the chair, and a Travelodge outside Birmingham which was not a holiday.

By the fifth house I no longer looked at the pictures when other people came back from places. Not out of bitterness. It had simply stopped being a category that applied to us, in the same way that I did not look at pictures of people's skiing.

There is a word for what our life had become by then and the word is *small*. I do not mean it as a complaint and I am not sure I mean it as a criticism. Our world was four rooms, a van, a school eleven minutes away, and a hospital forty minutes away, and within that there was a very great deal of love and an enormous amount of competence and almost nothing else at all.

I was forty-five. I had not had a conversation about anything other than my children in about six years.

That is the shape of it and it does not change. It would have gone on exactly like that until one of us could not lift her, and then it would have changed into something worse.

I am aware of what that sentence implies about what happened next.

I am going to write the next part carefully and I am only going to write it once.

TWENTY-TWO. THE THING AT THE WINDOW

Years nine and ten

The fifth house was bought for a window.

Everything else on the list was a doorway or a floor or a socket. The window was the only thing on it that was for her rather than for the equipment, and I want to put down how it was chosen, because it is the last decision I made about my daughter's life that had any pleasure in it.

Her bed went along the back wall. She could not turn her head. She could not lift it and she could not roll and she could not, past year eight, be got into a chair. So whatever was in front of her face was the whole of the visual world, permanently, for the last eighteen months of her life, and I had one chance to choose it.

The estate agent thought I was mad. I stood in that back room with a tape measure and worked out the height of a mattress plus a pressure mattress plus the depth of her chest, and then measured the sill, and it was forty-one centimetres too high, and we had the whole thing taken out and a lower one put in before we moved the furniture.

It cost about what a fortnight's respite would have cost and I would do it again.

Then I planted the border.

I did it in the March. I dug the whole thing out along that wall and I put in the things that bring insects — valerian, buddleia, verbenas, a

jasmine that has since taken the fence and everything on the other side of it — and I did it badly, because I am not a gardener, and most of it came up anyway because those plants do not need you to be good.

I did it for one reason. There was nothing else I could give her. She could not be read to in any way I could verify, and she could not be taken anywhere without four people and a van, and every other thing I did to her that year was clinical.

So I gave her a rectangle of moving things.

They started coming in the June.

Bees first, obviously, in enormous numbers, and then the hoverflies, and then in the last week of July, at about four in the afternoon, the first one.

I was in the room. I had my hands on her at the time; I remember precisely, I was doing the afternoon reposition.

It came to the valerian at the left edge of the window and hung there. And I said something out loud, on my own, in a back room in a house in July.

I looked it up that evening and I have known what it is for eleven years and I am going to say it once here and then not again: it is a hummingbird hawk-moth. It is a moth. It is common in warm summers, it migrates up from the south, and it is mistaken for a hummingbird by thousands of people every year because it hovers, and because it has a long tongue, and because it moves like nothing else in this country.

It does not matter. It has never mattered, and I want to be honest that it stopped mattering within about four days.

It came back. That is the thing. Most days that summer, and again the following one, between about three and six in the afternoon, on the warm days, and I did not have to look for it because I was always in that room.

And I started arranging things around it.

I moved the afternoon reposition to four o'clock. I did the second lot of stretches at half two so they were done. On a good afternoon

I would have her turned towards the glass and everything finished and both of us just there.

Mehran knew. He never said a word about it for two years and then said one thing, in the September of her last year, which was: "Was it out today?"

Now the part I actually want to write down.

I do not know whether she saw it. I have to say that plainly because I have said everything else plainly.

She could not track. Her gaze did not follow moving objects and had not since she was a baby, and I had had that confirmed twice by people who had no reason to soften it. There is a version of those two summers in which a moth hovered eleven inches from my daughter's face and nothing whatever happened in her.

But she went still.

Not every time. Perhaps a third of the times. There is a particular quality of stillness that I could recognise in her at forty paces after ten years, and it was not sleep and it was not the flattening that came with the bad chests, and it happened in that room on those afternoons more often than chance.

Ellen would say — did say, when I asked her, carefully, in a corridor — that it was probably the light. A fast-moving object at that distance throws a shifting shadow across a face, and a change in light is a thing Roya could definitely register, and that would be enough to explain all of it.

Which is probably right.

And I sat in that room on perhaps ninety afternoons across two summers and watched my daughter go still while a thing hovered at the glass, and I know what I think, and I have never once said it to Ellen.

Here is the analogy and then I will stop.

I worked it out in the second summer and I have never got past it.

That creature has no yesterday. It cannot be holding a grudge or expecting anything; there is nothing in it that can construct a

Thursday. It is entirely, completely, without remainder inside the four seconds it is in front of you, and then it is gone, and it does not know it has gone anywhere.

And that is my daughter. That is exactly and precisely my daughter, and it is the only true description of her I have ever found.

Roya had no before and no after. She could not want a thing that had not arrived yet and she could not miss one that had gone. There was no line running through her from one moment to the next on which any of it could be strung. Everything she ever had was now, at full volume, with nothing on either side of it — the warm, the hurting, the hand that stayed, all of it arriving complete and unattached.

We treat that as an absence. It is written down everywhere in her notes as an absence. Profound global impairment. No functional communication. No demonstrable object permanence.

And there was a thing outside her window every summer afternoon that is built exactly the same way, and nobody calls that a tragedy. People stand in gardens and are delighted by it. There are books about learning to live like that.

The other half of it is the half I did not let myself look at until afterwards.

You cannot keep one. That is the whole of what everybody says about them — they are beautiful and they will not be held, and they are gone before you have finished pointing at them, and the entire feeling they produce in a person is *look now, because this will not last*.

I had that in front of me for two summers, hovering eleven inches from my dying daughter, and I did not once make the connection until she had been in the ocean for eleven months.

TWENTY-THREE. HIPS

Year eight, February

The hips went in the end anyway.

Not dislocated. The migration percentage had been creeping for two years despite everything, and in the February of her eighth year the orthopaedic team put the films up and used the word *reconstruction*, and talked us through a procedure involving the femur and the pelvis and a recovery of some months in a particular kind of cast.

I want to record what I felt, because it was not what I expected.

I felt relief. There was a plan. There was something to be done. After six years of holding a line I was being offered an operation, and an operation has a date and a ward and an afterwards, and I had not had an afterwards in a very long time.

Mehran said, in the corridor: "She's eight."

I said, "I know how old she is."

He said, "I mean, what is it for."

And I turned round in a corridor in a hospital and I said something to my husband that I have not repeated to anybody until now.

I said: "It's so she can sit. It's so she can be in a room with people in it. What do you think it's for?"

And he said, "All right."

And he put his hand up, the way you do, and he went and got two coffees from the machine and we drank them and we booked the surgery for June.

She never had it.

In the April she started coughing at the end of feeds, and by the summer she had been in twice with her chest, and by the October there was a tube in her stomach and the hip surgery had been postponed for review and was never rebooked, because by then she was a child who could not be got into a chair and there was no longer very much for the hip to be for.

So the pain stayed. That is the plain fact of it and there is no way to write it that is not what it is.

The place in her hip that had been there since she was seven was there for the rest of her life, and we managed it, and managing it is not the same as stopping it, and everybody involved knew the difference and nobody ever said so out loud.

I did the stretches until the March she died. Twice a day. To the end.

Not because they were going to achieve anything by then. Because stopping would have been a decision, and I was not able to make it, and because — this is the true reason and it took me four years to be able to write it — those forty minutes a day were the only time in the last two years of my daughter's life when I was doing something rather than watching.

TWENTY-FOUR. THE TUBE

Year eight

She stopped being able to eat.

It did not happen in a day. It came the way everything in this book came, which is slowly, in a series of small events that were nothing on their own, and then all at once with a date on it.

She had always been slow. Forty minutes for a feed if it went well, ninety if it did not, everything thickened, everything watched. That had been true since she was four months old and I had got so good at it that I could do it while reading.

In the spring of her ninth year she started coughing at the end of feeds. Then during them. Then she had a chest infection in May and another in July, and the second one put her in for five days, and a consultant said the word I had been not-hearing for about two years.

Aspiration. It means that some of what goes in is going the wrong way. It means that the act of feeding my daughter — the thing I had done four times a day for eight years, the one wholly ordinary maternal thing I still had — was putting food into her lungs.

They were very good about it. They did a study where she swallowed something with contrast in it under an X-ray, and I stood in the room in a lead apron and watched it happen on a screen. I saw it. There is a moment on that film where you can see it go where it should not go, and my daughter's face on the pillow did not change at all, because she had no way of knowing, and I have never been able to unsee it.

The recommendation was a gastrostomy. A tube through the abdominal wall directly into the stomach. Surgery under general anaesthetic, one night in, home the next day if it went well.

We said yes in about four minutes. There was nothing else. The alternative was pneumonia, repeatedly, until one of them was the one.

I want to describe what a gastrostomy actually is in a house, because it is presented as a solution and it is a transaction.

What it gives you. She stopped coughing. She stopped getting chest infections for eleven months. She gained two kilos in a year, having not gained anything in three. Her medications, which had been a forty-minute battle four times a day, took ninety seconds. She was, by every clinical measure, better.

What it takes. The feeding stops being feeding.

There is no more holding her. There is a pump, and a giving set, and a bag on a stand, and a rate in millilitres per hour, and a button on her stomach that has to be cleaned and checked and turned. It runs overnight, mostly, so she is attached to a machine from nine in the evening until six in the morning, and the machine alarms — the machine alarms constantly, for occlusion, for air, for a bag that has finished, for reasons that never become clear.

Daena named the pump **Kevin** the week it arrived and Kevin is in this book already, and Kevin is why.

There is no more mouth. That is the thing. From that October she never took anything by mouth again except a sponge swab for comfort, and the last meal my daughter ever ate was a yoghurt on a Tuesday afternoon in September and I did not know it was the last one, and I have no memory of it whatsoever.

I fed her four times a day for eight years. I did it badly for the first month and superbly for the rest. It was the only thing in the entire architecture of her care that was not clinical, that had no protocol, that was just a mother and a child and a spoon.

And it was taken away in order to save her life, and it did save her life, and it was the correct decision, and I would make it again this afternoon.

That is the fourth or fifth time in this book that I have written that sentence and it is the last.

INTERLUDE V

The last two years

There is a place in the hip now and it is always.

Not the arriving-and-going of the hands. That still comes, twice, and it still fills everything and then stops. This is underneath and it does not stop. It is there in the dark and in the light and when the slow thing is happening and when it is not, and there is no before it.

You do not know it is a hip. There is no hip. There is a place, low on one side, that is always saying something, and it has become the floor that everything else stands on.

The other thing is that the wanting has gone.

There used to be a wanting. It came up from underneath, and it was enormous, and it made everything else stop, and then something arrived — a warmth at the mouth, a fullness that came slowly and spread — and the wanting went, and the going-away of it was one of the four or five things there were.

That has stopped happening.

Now the fullness simply arrives. It comes on its own, from nowhere, without any wanting in front of it, at a rate, for a long time. It does not spread. It is just there, in the middle, a steady low pressure that begins and does not stop for a very long while and then stops.

Nothing came before it and nothing was asked and nothing was answered.

So there is no going-away any more, because there is no wanting, and the going-away was the thing that was good.

There is a sound near you now that was not there before. It is small and even and it goes on all night, and every so often it changes and makes an edge, and when it makes the edge somebody comes. The somebody is the slow one. She comes in the dark and touches the thing that makes the sound and then, always, always, before she goes, she puts her hand flat on the middle of you and leaves it there for a while.

That is the best thing there is now.

Not the slow going down the arm. That still comes and it is still right, but the best thing now is the flat hand that does not move at all, in the dark, after the sound has made its edge.

It has no speed. It just stays.

And everything that is tight — the place in the hip that is always, the pressure in the middle, all of it — does not go away, and does not get smaller, and something happens anyway that is like the quiet underneath but is not the same, because it does not need the tight to stop.

It only needs the hand to stay.

It stays a long time. Longer than it used to.

—

And there is a thing at the bright.

The bright is a shape that is always there in one direction, and it changes, and it has never once done anything.

Now something crosses it.

It is small and it is fast and it does not go the way things go. It stops in the middle of nothing and stays stopped, which nothing does, and then it is somewhere else without having gone between.

While it is there the bright goes wrong in a way that has no name — flickering, edged, a fast small dark that is not the slow dark of the turning-over.

Everything in you stops.

Not the going. The going does not go out to it, because the going only goes to the warm and to the quick one, and this is neither.

Something else happens, and it is nearer to the flat hand than to anything, and it lasts as long as the thing lasts and no longer.

Then the bright is only the bright again.

There is no waiting for it. There is no such thing as waiting. It is not gone, because gone requires a before, and there is no before.

It happens, and it is the whole of everything while it happens, and then there is warm, and the sound with the edge, and the hand.

TWENTY-FIVE. THREE TIMES IN A WEEK

Years eight to eleven

The last two years were the worst and I am going to be brief about them because there is not much to say about hell except how long it went on.

She was bedridden from the surgery onwards. Not by anybody's decision — the chair became harder, then uncomfortable, then impossible, and the hips were part of it and the chest was part of it, and at some point in her ninth year we stopped getting her up and the standing frame stood empty and nobody ever said out loud that she was now a child who lived in a bed.

The infections came in a pattern. Chest, mostly. Urine sometimes. She would be fine on a Thursday and by Saturday afternoon there would be a note in her breathing that only three people on earth could hear — me, Mehran, and Bev.

And then it would be the middle of the night. It was always the middle of the night. I have thought about that a great deal and I think it is simply that the chest gets worse lying down and that a body is at its lowest at four in the morning, and I know that is the true answer and it still felt personal.

There was a week in the January of her eleventh year when we went in three times.

Sunday night, home Monday. Wednesday night, home Thursday. Friday night, kept until Tuesday.

I do not remember most of that week. I remember individual frames. I remember the specific reflective strip on the sleeve of a paramedic's jacket. I remember standing in the drive in a coat over pyjamas at ten past three watching them work in the back of the ambulance and doing arithmetic about who would take Daena to school. I remember a nurse in resus who was about twenty-four and who was so gentle with my daughter that I had to go and stand in a corridor.

Mehran did not sleep at all that week. He went to work on the Thursday. I asked him why and he said, "Because if I stop I won't start again."

Here is the part that I did not expect and that nobody warns you about.

We got good at it. By the end there was a bag by the door. It had the notes, the medications list, the feeding regime, the DNACPR, spare tubing, a phone charger with a long lead, and a jumper. It stayed packed. I checked it on Sundays.

You become extremely competent at the worst thing in your life. You get faster at it. You learn which of them to ask for and how to say the sentence that gets you seen, and you develop a reputation, and there were three consultants who knew our name before we said it.

And you cannot go back from that. I am fifty-seven and I still hear an ambulance and my body does a thing.

The last one was the twelfth of March.

We went in at two in the morning with a chest that was not responding, and this time nobody talked about home. On the fourth day a consultant I liked very much came and sat down, which is the signal, and it was the same signal as the room with the light box nearly ten years earlier, and I knew what he was going to say before he had arranged his hands.

He said that we were now managing her comfort.

I said, "Say it properly."

And he said, "I don't think Roya is going to get better, and I think we should be thinking about where she would be most comfortable for the time she has."

I said, "How long."

And he said the honest thing, which was: "I don't know. Days. Possibly not weeks."

She was ten years and eleven months old.

TWENTY-SIX. HOSPICE

The last three days

They moved her on the Thursday and she died on the Sunday at dusk.

I am going to write this once, plainly, and then I am not going to write about it again.

The hospice was a children's one and I had been frightened of the idea of it for eight years and it was, from the first four minutes, the kindest building I have ever been inside. There was a garden. There was a bed for us, in the same room, not down a corridor. There was a woman called Trina who took the whole of the medication regime off me on the first afternoon — took it, physically took the folder out of my hands — and said, "You're her mum now. That's the only job."

I had not been only her mother in ten years and eleven months. I did not know what to do with my hands.

The first day she was uncomfortable and they fixed it, quickly, with something in a syringe driver, and after about two hours she went soft in a way I had not seen since she was a baby. Everything that had been tight for a decade let go. The hands opened. I want that recorded because it is the only time in her life I saw her hands open.

The second day was long. Mehran read to her. I did the stretches, out of habit, and got about four minutes in before Trina put a hand on my shoulder and said, "You don't have to do those any more,"

and I sat down on the floor of a hospice with my back against a bed and made a noise.

Six years. Twice a day. Four thousand three hundred times.

The third day she stopped opening her eyes and her breathing changed into the pattern that everybody who has sat with a dying person knows and nobody can describe. Long gaps. You count them without deciding to.

And in the afternoon a doctor came in — a young woman, very quiet — and she said the thing that I have turned over more than anything else anybody said to me in ten years.

She said: “Sometimes it helps to give them a bit of space. Some of them wait. If there’s someone in the room they’re holding on for, they’ll hold on.”

I said, “Are you telling me to leave?”

And she said, “I’m telling you that if you want to go and have a cup of tea, that’s allowed. That’s all.”

I have gone round and round about whether that is a real thing. I have read about it since. There is a body of nursing observation and there is no mechanism and the evidence is anecdote and there are perfectly good reasons why it might look true when it is not.

It does not matter what is true. What matters is that I was told it, and having been told it, I could not un-be-told it, because if I stayed and she went on for another day in that breathing then I had done it to her.

So at about six o’clock Mehran and I went and stood in the garden.

We were gone eleven minutes.

Trina came out and did not have to say anything.

The light was going. It was the thirtieth of March and the sun had gone behind the roof of the building and everything was that colour it goes, and my daughter died at dusk on the thirtieth of March, two days before her eleventh birthday.

The cards had come. Two of them were on the shelf at home.
Daena did not come to the hospice.

She was fifteen. We asked her twice and she said no both times, calmly, and she gave no reason, and I did not push and Mehran did not push, and I have never in ten years asked her about it.

She told me herself, last year, in a kitchen.

She said she had said goodbye to her sister on the afternoon the doctor told us we could go and stand in the garden — she had rung, and I had told her what had been said, and she had understood in about four seconds what it meant and had made a decision.

She said: “You needed to be allowed to leave the room. If I’d been there you’d have had to look after me, and then you’d never have gone, and she’d still have been doing that breathing on the Tuesday.”

I said, “That’s not why you didn’t come.”

And she said, “No. But it’s one of the reasons, and it’s the one I’d like on the record.”

The other reason she gave me is hers and I am not putting it in a book.

INTERLUDE VI

The last house

Warm.

The slow thing is happening and it is not being used up. It goes and goes and does not stop and the quiet underneath opens and keeps opening and there is no end to it this time.

The tight in the middle is going loose. All of it, everywhere, the places that have been tight so long they were not a thing any more, only the shape of you. They are going.

It is like the water. It is more than the water. Nothing presses anywhere.

There is the inside smell.

There is a sound close to the ear, low, the kind that goes down and not up, and something in you goes towards it.

The going goes out.

It goes out further than it has gone. There is no reaching in it because there is nothing to reach for and no distance to cross, there is only the going, out and out, and the warm is all the way around it.

And this is the thing, and it has never happened before, and there is no one to tell and no telling in you and no need of either:

The going does not come back with nothing at the end of it.

The going finds the warm and the warm is not a thing at the end of it. The warm is what the going is made of.

There is no difference any more between the going out and the being held.

Warm.

Less warm.

Warm.

TWENTY-SEVEN. THE CEREMONY

April

There was no funeral. I want to explain that, because it upset people.

Mehran's family expected one and my mother expected one and there was a difficult fortnight in the middle of everything else. What I said, and I said it once and then did not discuss it, was that I could not stand in a room while people who had not been in my house since she was two spoke about my daughter.

She was cremated in the first week of April, privately, with the four of us there and nobody else.

Then we had a ceremony, eleven days later, in the hall at her school, on a Thursday afternoon, with tea afterwards.

I want to write down who came, because I have thought about that room more than any other room in my life.

Bev came, who had been her carer for six years, who had a shoulder that had never been right since year seven, and who had washed my daughter's hair every Tuesday for a very long time. **Ify** and **Marta** came. Marta drove three hours.

Ellen, her physiotherapist, came. Ellen had been the one who taught me the stretches in the second house, and who had reassessed her twice a year for eight years, and who had, in year five, in a corridor, when I asked her outright whether I was hurting my daughter, told me the truth, which was yes, and then sat down on a plastic chair with me for forty minutes when she had a clinic waiting.

Mr Dattani, who was to have done her hips two years earlier. He came in his work clothes on his way to somewhere and stayed eleven minutes and shook Mehran's hand and did not say very much.

Six people from the school. Her teacher. Two learning support assistants. The hydrotherapy woman. The man who drove the bus, who had been driving my daughter to school four days a week for four years and who had a photograph of her in his wallet, which I found out that afternoon.

Her respite nurses. Her dietitian. The woman from the wheelchair service.

And my cousin **Sam**, who had sat on the floor with her in year five.

And then everybody else. The aunts. The cousins. Mehran's aunt, who had called her a silent angel in a kitchen six years earlier and who cried harder than anybody in that hall and who was not performing, and I want to be fair to her here at the end: she loved my daughter. She loved her at a distance, in the only way she knew, and she came, and she cried, and I held her afterwards by the tea urn.

Here is what I understood standing at the front of that room.

The people who had actually known my daughter — who had touched her, who knew which side she preferred, who knew that she went quiet for a low voice and not a high one, who knew the sound she made when the sun came round onto the left side of her face at about three in the afternoon — were nearly all of them being paid to be there.

That is not a criticism of them. They are the best people I have ever met and I would go to war for every one of them.

It is a fact about how we do this.

The family who loved her had almost no information about her. The people who had the information were her care team. And every one of them had a caseload, and other families, and would go home that night and be somewhere else on Monday.

Ellen spoke. I asked her to and she said yes immediately and then rang me twice in a week to check what I wanted, and what she said was four minutes long and had no God in it and no angels in it.

She said that Roya had a preference for the left. She said that she had, over eight years, come to be certain that Roya knew the difference between people, and that she could not prove it, and that she was saying it anyway because she had been asked to say something true.

And then she said: "She was very hard work. She was. And she was worth it, and I don't say that about everybody, and I'm not going to pretend otherwise today."

Bev did the reading. The bus driver cried through the whole thing and apologised afterwards to me, to me, for crying.

We had tea in the same hall with the tables pushed back.

It went on for two hours and nobody wanted to leave, and that is the only good memory I have from that entire year.

TWENTY-EIGHT. THE OCEAN

April

We had her cremated. There was no discussion about it; both of us knew, separately, before either said anything.

The ceremony in the school hall was eleven days later and is already in this account.

The ashes were in a container that I had not been prepared for. Nobody prepares you. It is a plastic screw-top thing inside a bag inside a box and there is a label on it with a reference number and my daughter's name spelled correctly, and it sat on the shelf in the back room for four weeks because neither of us could decide.

What decided it was Mehran, at breakfast, in May.

He said: "She was never anywhere."

I said what.

He said, "Ten years. Five houses. She was never anywhere she chose. Every room she was ever in was a room we put her in because of a doorway."

And that was it. That was the whole conversation and we went the following Saturday.

It was a beach on the west coast that we had been to twice before Daena was born and never since, and it took four hours, and it was cold and grey and the wind was off the sea, and there were about nine other people on two miles of sand.

Daena came. She travelled separately and arrived twenty minutes after us and left about an hour after it was done, and that was also a decision and I did not ask about that either.

There is no ritual for this. There is nothing to say and no order to do it in, and both of us had assumed the other had thought about it and neither had.

In the end Mehran waded out to about his knees in his trousers with his shoes in his hand and I stood at the edge and Daena stood further back, and he opened it, and the wind took most of it immediately in one direction and the rest went down into the water where it went white for a second and then was nothing.

It took about four seconds. That is what nobody tells you. Ten years, five houses, a hoist in a ceiling, four thousand three hundred stretches, three ambulances in a week — and the last physical act of it takes four seconds and then you are three people standing on a beach in the cold with an empty container.

Nobody cried. I want that recorded because it surprised all of us. We had all done our crying in a hospice in March. What we felt on that beach, and we have since established that all three of us felt it, was something much closer to relief on her behalf — an enormous, uncomplicated gladness that she was in the biggest place there is and that nobody was going to move her again.

We had chips in the car on the way back. Daena said something about the seagulls that I am not going to write down and that made Mehran laugh so hard he had to pull into a lay-by.

I go back about once a year. Mehran comes sometimes. I do not do anything when I am there. I stand and look at it for a while and then I go and have a cup of tea somewhere, and that is the whole of my daughter's grave and it is four hundred miles long and it moves.

VI. AFTERMATH

TWENTY-NINE. THE FIRST YEAR

Year one after

Nobody prepares you for the first Tuesday.

The house had run on a timetable for ten years. Feeds, meds, stretches, positioning, the bus at eight-ten and the bus at three-forty, Bev on Tuesdays and Thursdays, physio on alternate Wednesdays, clinic every eleven weeks, the whole of it written on a whiteboard in the kitchen in four colours.

On the first Tuesday I got up at ten past six because that is when I got up, and I stood in the kitchen, and there was nothing.

I want to describe the next bit accurately because it is the thing I most need somebody else to read and recognise.

It was not grief. Grief came later and came properly. The first thing was **withdrawal**. My body had been running on adrenaline and a schedule for a decade and both were switched off in a single afternoon, and what was left was a woman of forty-seven standing in a kitchen at quarter past six in the morning with her hands shaking, physically unable to work out what to do with an hour.

I cleaned the whiteboard on the ninth day. It took four minutes and then I sat down on the floor.

The equipment went back over about five weeks. This is a thing nobody tells you and it is brutal and it is nobody's fault, because the chair costs eleven thousand pounds and another child needs it.

The chair went first. Two men and a van, perfectly nice, one of them said sorry for your loss and meant it. Then the hoist sling, then the standing frame, then the bath support, then the nebuliser, then the suction unit, then a box of unopened feed that a nurse took away because it could not be donated.

The ceiling track stayed. Nobody came for the track.

By the sixth week the back room had a bed in it and nothing else, and I could not go in, and Mehran went in and sat in there quite often, and we did not discuss that either.

And underneath all of it, from about the second week, the thing I could not say.

The house was easier.

I could leave it. I could stand in a shop and not be counting. I could sleep the whole way through and did, for the first time in ten years, in the fourth week, and I woke at seven in a panic and then remembered, and the remembering had relief in it, and the relief lasted about a second and a half and I have been paying for that second and a half ever since.

I said none of this to anybody for four years.

There is no one you can say it to. You cannot say it to your husband, because he is doing his own version and yours might be worse than his. You cannot say it to your surviving child, obviously, ever. You cannot say it to your mother, or to a friend, or to the woman at the bereavement group, who lost a son of nineteen in a car and whose grief has no relief anywhere in it and who would be entitled to hit me.

The person you have most need to confess it to is the only person in the world it cannot hurt.

And she was gone. That is the arrangement. That is the actual shape of it.

THIRTY. THE CRYING

Still

We still hear her.

I have put off writing this because it is the thing that makes people's faces change, and I have decided that it belongs here precisely because of that.

Perhaps four or five times a year, both of us, sometimes on the same night — we wake at two or three in the morning, absolutely certain, and we are out of bed before we are awake.

It is not a dream. I want to be exact. A dream is a thing you were inside and are now outside of. This is different: you surface into a completely ordinary bedroom in an ordinary house at three in the

morning having heard, in the room downstairs, the specific sound your daughter made when her chest was not right.

Mehran got to the bottom of the stairs once. That was in the first year. He stood in the doorway of the back room in the dark for a while and then came back up and got into bed and said nothing and neither did I.

It is not madness and I have looked into it. It has a name and it is extremely common in the recently bereaved and even commoner in people who spent years listening for a sound. Auditory hypervigilance does not switch off because the thing it was listening for has stopped. You trained a nervous system for a decade to detect one specific noise at four in the morning through two walls, and you cannot untrain it, and every so often it fires on nothing.

That is the explanation and it is correct and it does not touch the experience at all.

Here is what I would want another mother to know.

It gets less. It went from most weeks in the first year to a handful of times a year now. It has never gone and I no longer expect it to.

And — this is the part I would not have believed at the time — it stopped being frightening at around year three and became something else.

Now, when it happens, I lie there for a moment and then I get up anyway. Not to check. There is nothing to check; there is a bed in that room and a chest of drawers and nothing else. I go down and I stand in the doorway for perhaps a minute and then I go back up.

Mehran knows. He does not come with me and he does not ask.

It is the only regular appointment I still have with my daughter, and it is at three in the morning, and it is in the room where she lived, and I would not give it up for anything.

THIRTY-ONE. FIVE YEARS

Year five after

We went to Portugal.

That was Daena's doing. She was twenty and she booked it and told us afterwards, which is the only way it was ever going to happen, and she came with us for the first four days and then went off with a friend and left us to it, which was also deliberate and which I did not spot at the time.

I could not enjoy the first three days.

I want to be honest about the mechanism because it surprised me. It was not sadness. It was **arithmetic**, running constantly, unstoppably, underneath everything.

I would be sitting on a balcony in the sun with a coffee and the sum would run: *we could not have done this*. The flight. The transfer. The bathroom. The heat, which she could not regulate. The chair on that pavement. The feed times. There is no version of this holiday with Roya in it.

And the second half of the sum, which arrived every time about four seconds later and which I did not permit myself to finish for three days:

So this is what it cost.

On the fourth evening Mehran said something at dinner about a place we could go the next day, and he laughed at something, and I realised — sitting there with a glass in my hand — that I had not heard him laugh like that in eleven years. Not once. Not a polite laugh; the other one, the one from lower down.

Eleven years.

I went to the bathroom of a restaurant in Lagos and cried for about six minutes and came back and said the fish was good.

We have travelled every year since. Spain, Italy, Georgia, and last year the place my mother was born, which I had not seen since I was nine.

I am not going to apologise for that in this book. It has taken me a long time to be able to write a sentence about a holiday without hedging it, and I am fifty-two. We go away, and I like it, and Mehran has become someone who reads about places, which he was before Daena was born and had not been since.

The photographs are in the hall.

All of them, on a shelf, in the same frames, and there are perhaps twenty of her, and here is the thing about them that I did not notice for years and cannot now unsee.

In every single one, she is smiling.

Ten years of photographs, thousands of them on phones and cards, and the twenty in frames are twenty in which my daughter's face happened to do the thing that reads as joy. She could not control her face. It moved for its own reasons. And out of ten years of that, the shots we kept and framed and put up in the hall are the fraction of a second, over and over, in which she looked like a happy child.

Visitors see them and say, "She looks so happy."

And I say yes.

I know exactly what those photographs are. They are the fraction that let us bear it, and they are curated, and they are a fiction we assembled by accident over ten years.

They are also true. She did smile. Not always for a reason, and possibly not at anything, but the face in that frame is my daughter's actual face and it did that.

Both. Always both.

THIRTY-TWO. HOW DAENA MOTHERS

Nava, months one to eleven

I have watched my elder daughter become a mother and I have kept most of my observations to myself, and this is where they go.

She cannot let Nava cry. I do not mean she does not like it. I mean she cannot — it is not a preference, it is a physical event that

happens in her, and it happens fast, and I have watched it from across a room.

Every book will tell you that a certain amount is normal and necessary and that a baby who is fed and dry and safe can be permitted three minutes. Daena has never once permitted three minutes. She is out of the chair before the second sound.

I know exactly why and I have never said it to her.

She spent her entire childhood eleven feet from a sister whose crying could not be answered. Not *would* not — could not. There was no fixing it, most of the time; there was no cause to find, and you could do everything on the list and it would go on, and Daena grew up in a house where a child cried and nothing anybody did made any difference.

So she has a daughter now whose crying **can** be answered, and she answers it, every time, within about a second and a half, and she will go on doing that for as long as it is physically possible, and I would not dream of correcting her.

She checks the breathing. Nava is eleven months old and Daena still goes in. Not once. She puts her hand flat on her daughter's back, in the dark, and leaves it there, and waits.

She learned that hand from me and I learned it from a doctor in year one, and I did it four times a night for a decade.

And she talks to her constantly.

This is the thing I noticed first and did not understand for about eight months.

Daena narrates. Every minute of the day, out loud, to a baby with no language — what she is doing, what she is about to do, what she thinks of it, what she assumes Nava thinks of it. In the kitchen. In the car. Changing her. It is relentless and it is very funny and it is, by a distance, the most striking thing about her as a mother.

Tom said something about it once, affectionately — *she never stops* — and Daena laughed and did not explain.

I understood in the summer, standing in her kitchen, listening to her tell an eight-month-old exactly what she thought of a jar of something.

She learned to mother on a child who could never answer.

Six years of doing Roya's voice. Six years of talking to a sister who gave nothing back, of building the whole of a relationship out of one side of it, of assuming a person in there and addressing that person continuously without one single piece of evidence.

She is doing to Nava what she did to Roya. It is the only way she knows.

And Nava, who is eleven months old and can hear and will speak, is getting the full force of a way of loving somebody that was designed for a child who could not.

I have never seen a baby laugh so much in my life.

There is one more thing and it is not funny.

She was frightened through the whole pregnancy, which I will come to, and the fear has not gone. It has changed shape. She watches Nava for milestones with an intensity that Tom does not have and cannot follow — not anxiously, exactly, but she knows every single one and the week it is due and she does not tell anybody she is counting.

Nava walked at eleven months, which is unremarkable.

Daena rang me from the kitchen floor.

THIRTY-THREE. THE WAY YOU HOLD THEM

The first time

I want to write down the two seconds in the hall.

Nava was nine days old. They had come to us because Daena's flat had no room and because she wanted her mother, which she had not wanted since she was about fourteen, and I had been ready for a fortnight.

Daena came through the door with her in a car seat and I did the ordinary things — the coat, the kettle, the fuss — and then she lifted her out and turned round and held her out to me.

And my hands went where my hands go.

The left one went up and back and low, cupped, to the exact place it had gone for ten years and eleven months, which is behind and below where a head is going to be — because a head that does not come with the body goes back, and it goes fast, and if your hand is not already there when you lift then the whole weight of it arrives on the neck.

That is not a technique I was taught. I worked it out in about week fourteen and then I did it four hundred thousand times.

I did it in a hall in front of my daughter without one particle of thought.

And Nava's head came with her.

It just followed. The way a head does. The way every head I had ever picked up before Roya was born had done, and the way I had entirely, physically, in the meat of my arms, forgotten that heads do.

So I was standing in my own hall holding a nine-day-old baby in a shape built for a child who could not hold her own head — my left hand out in space behind a neck that did not need it, my whole body braced for a weight that did not arrive — and something went through me that I have no name for and that lasted about two seconds.

I said, "Sorry — my arm," and gave her back.

And I went into the kitchen and stood with both hands flat on the worktop.

Daena did not follow me. I want to record that, because at fifteen she would have, and at twenty-four she did not. She gave me four minutes. Then she came in with the baby and stood next to me and said nothing at all about it, and then she said:

"Do you want to try again? I'll show you."

And my daughter — who was four years old when it started and who has spent her entire life in the wake of it — taught her mother how to hold a baby, in a kitchen, at fifty-six, patiently, without one word of commentary.

She said, “You don’t need that hand. Just here. She’ll do it.”

And she did. Nava held her own head up and looked at the light fitting over my shoulder the way babies do, and I stood there with my arms in a completely unfamiliar shape and thought: *this is what it was supposed to be like.*

That was not grief. I have been very careful in this book to distinguish between things and I am going to be careful about this one.

It was **information**. It was ten years of a fact I had known and never once felt, arriving all at once in my forearms in a hall. Every mother knows that a baby’s head comes with the body. I knew it. I had done it with Daena. And I had gone ten years and eleven months without the physical experience of it and I had rebuilt myself around its absence.

I have held Nava perhaps six hundred times since and I do it correctly now.

But the first movement my left hand makes, every single time, before it corrects — every time, at fifty-seven, ten years on — is up and back and low.

It goes to where my other daughter’s head would have been.

I have stopped trying to train it out. I looked into it, briefly, in the way I look into everything, and there is nothing to be done and no reason to do it.

It is the last thing my body still does for her. I am not giving it up.

THIRTY-FOUR. TEN YEARS

Year ten after

Grief stops being an event and becomes a climate. Nobody tells you that either, and it is not a bad thing, and I want to describe it because the descriptions available are all wrong.

It is not that it fades. It is that it stops arriving. For the first three or four years it came at you — you would be somewhere ordinary and it would land, and you would have to go and sit in a car. That stops. What replaces it is a permanent, low, background condition, like the weather of a country you have moved to. You are simply a person who lives in this now. It has a season — for me, late April into May — and the rest of the year it is the air.

I am fifty-seven. Mehran is fifty-nine and retires in the spring and talks about it constantly and I do not mind.

Daena is twenty-five. She is a paediatric occupational therapist, which she came to entirely on her own and which she is extremely good at, and which she would tell you is not about Roya and which is completely about Roya, and I have never said so and I never will.

She married a man called Tom who is kind and unremarkable in the best sense and who, the first time he came to this house, went and stood in the hall and looked at the photographs for a long time and then asked me what she was like. Not what happened to her. What she was like.

I have loved him since that afternoon.

There is one more thing about my elder daughter and it belongs here.

She still does the voice.

Not often. Perhaps three times a year, always without warning, always when a room has gone slightly too solemn about something. Last Christmas my mother was thirty minutes into an account of a hospital appointment and Daena said, to nobody, in the register she has had since she was eight:

“Roya says she’s heard this one.”

Nobody else in that room knew what to do with it. Mehran put his hand over his eyes. I laughed until it turned into the other thing, and Daena put her hand flat on my back and left it there and did not apologise for any of it, and she was right not to.

She had a baby last year. A girl.

I want to write about the pregnancy carefully because it is the last hard thing in this book.

She was frightened for all of it. Not normally frightened — she was frightened in a way that Tom could not follow, and did not know the shape of, and could not be told, because the shape of it was a childhood.

At the twenty-week scan she made me come. Not Tom. Me. And we sat in a room with a screen and I watched my daughter's face and not the screen, and when the sonographer said the ordinary sentence — everything looks as we'd expect — Daena did not react at all.

She got up, and thanked her, and walked out, and got to the car park, and then she went. Forty minutes, in a car park, at twenty-four years old, with her mother holding her.

And in the middle of it she said the thing I had been waiting eleven years to hear and had never once asked for.

She said: "I loved her. Everyone thinks I didn't and I did."

I said, "I know. I was there. You were the best thing in her life."

They called the baby Nava. Not Roya. I was glad about that and I have never said so, and I think Daena chose it for exactly that reason and has never said so either.

She is eleven months old now and she is at the stage of putting her hand on your face, and she does it with a flat palm, hard, the way babies do.

The first time she did it to me I had to put her down and go into the kitchen.

THIRTY-FIVE. THE FEEDER

From year two after

I bought the feeder in the second summer, about a fortnight after the first one came.

It hangs on a bracket outside the back window — the window of the room she lived in — and it holds sugar water, and I change it every

four days in warm weather because it ferments, and there is a small shallow dish next to it that I keep filled and that they use to drink from and, twice that I have seen, to sit in.

I know that hummingbird hawk-moths do not use feeders. I have known that for eleven years. They take nectar from flowers on the wing and they will investigate a feeder and they will not, on the whole, feed from one, and I have planted the things they actually want in the border under that window — valerian, and buddleia, and a great deal of jasmine that has now taken over the fence.

So I have a feeder that is mostly for me, and a border that is for them, and I know exactly which is which, and I fill the feeder anyway.

Something else does use it. There is a robin who has worked it out and a great many bees.

The practice has changed since I last wrote about it and I want to record what it is now, because it is the last thing in this book that is still going on.

I open the window.

The same window. That is the entire point of it and it took me until about year four to understand that it was the point.

It is forty-one centimetres lower than it should be. It was cut down and reset by two men in a week in March eleven years ago so that a child who could not turn her head would have something in front of her face, and it is the only alteration in this house that was made for her rather than for a hoist or a chair or a wheelchair turning circle.

Everything else went back. The chair went in five weeks. The sling, the frame, the pump, the suction unit, the box of unopened feed. The track is in the ceiling because nobody came for it, not because we kept it.

The window is the one thing in this house that we chose.

They do come in. Not often; three times, over eleven years, that I am certain of. Once for perhaps nine seconds, once for less, and once in the August of year six for what I would swear was nearly a

minute, in the back room, at the height of the sill — her height, the height it was cut to — and then out.

The rest of the time I stand at an open window in a cold house and nothing happens.

Mehran knows and has never once made a face about it. He fixed the bracket when it came loose. That is the entirety of what he has ever said on the subject and it is exactly enough and I married the right person.

He asked me once, in the second summer after, whether it was out. Not *has one been* — *was it out*, which is the question he asked me exactly once while she was alive, in the same words, in the same room.

I said yes. He said good, and went and put the kettle on.

Daena knows. Daena brings Nava and does not comment.

And in September of year eight, with the window open and nothing outside it at all, I said the thing I have already written down in this account — that it is easier without her and that I am sorry and that I would give all of it back — and nothing happened, and I closed the window and went and put the kettle on.

I have said a great many things at that window since. I tell her about Nava. I told her when Daena got married, standing at that window in a suit at half past six in the morning before anybody was up.

I have never once had an answer and I have never once expected one.

It is not that I think she is in there. I want to be very precise, because I have been precise about everything else and this is the last thing I have to be precise about.

I do not believe my daughter is a moth.

I believe that a thing which has no yesterday and no tomorrow, which cannot be held for longer than it chooses to stay, and which was at my daughter's window on ninety afternoons in the last two summers of her life, is the only accurate picture of her that exists — and that I did not choose it, and that it arrived on its own in the

July of her ninth year and hung there for four seconds while I had my hands on her.

And I believe that a person who has spent ten years unable to say the true thing to anybody needs a room to say it in, and that I have one, and that the window of it is forty-one centimetres too low, and that the whole arrangement costs me about four pounds a year in sugar.

I have started calling it hers. Out loud, to Nava, who is eleven months old and does not care.

That's your auntie's bird.

I am aware of what that is. I know precisely what I am doing when I say it and I know it is not true in any sense that would survive being written down in a notebook, and I have written down a great many true things in this account and I am going to end on that one.

THIRTY-SIX. THE THREE QUESTIONS

Now

There are three questions and I am going to set them all down, because I have carried them for ten years and I have never said any of them out loud to another human being, and because if I do not put them here then this whole account is a polite version of itself.

The first question is: was her death good for us?

The honest answer is yes.

I have to write it like that, on its own, without softening, because every instinct I have is to bury it in a paragraph and I have spent this entire book refusing to do that.

Yes. Measurably. We sleep. We have been to seven countries. Mehran laughs from lower down. I went back to work and got good at it again and my manager said something kind that I had to go to the toilets about. Daena has a husband and a daughter and a career, and she built all three in the ten years after, and I do not think she could have built any of them in the five years before.

Our lives, in every way that can be written down, are better.

The second question is: would it have been better if she had gone sooner?

This is the one that arrives at four in the morning and it is the ugliest thing I own.

If she had died at four, we would have had six of those years back. Daena would have had her adolescence. I would not have gone grey at thirty-eight. There would have been no gastrostomy, no bedridden years, no January with three ambulances in it, and — and this is the part that makes it an actual question rather than a piece of self-harm — **she would have had six fewer years of pain.**

Because she was in pain. I have written a chapter about it. There was a place in her hip that never stopped, and it did not stop for the last three years of her life, and there was nothing that fixed it, and I know that as well as I know anything.

So the second question is not only a selfish one. That is what makes it unanswerable. Half of it is about us and half of it is about her, and the half that is about her is the half I cannot argue with. **And the third question is: would I have wanted her for as long as she breathed?**

Yes. Instantly. Without any thought at all.

If somebody had come to me in that hospice on the Saturday and said, *she can have five more years exactly like the last two*, I would have said yes before they finished the sentence. I would have said yes to five more years of Kevin alarming at four in the morning and three ambulances in a January and a body that got heavier every year and a hip that never stopped hurting.

I would have said yes and I would have meant it and I would have been, on any reasonable analysis, wrong.

—

Now. Here is what I have worked out in ten years, and it is not much, and it is the only thing I have to offer anybody else standing where I stood.

All three answers are true.

Not one of them is a mistake. Not one of them is what I really think underneath the others. They are three true things about the same ten years, and they do not resolve, and they will not resolve, and I have stopped expecting them to.

The mistake I made for four years was assuming that one of them had to be the real one, and that my job was to find out which, and that until I found out I was in some sense lying to myself.

I was not lying. A person can hold three contradictory true things about their own child. It turns out to be one of the ordinary capacities of a human being and nobody ever mentions it, in the same way that nobody mentions the arithmetic, or the four in the morning, or the head that does not come with the body.

What I would say to the woman I was at forty-seven, standing in a kitchen with a whiteboard she had just cleaned:

The questions are not a moral test. You are not being asked to choose. The choosing is not available and was never available, and the part of you that keeps running the sum at three in the morning is not conscience — it is a nervous system that spent ten years solving problems and has not been given anything else to solve.

It will find something else eventually. Mine found a granddaughter.

And there is a fourth question, which I did not know was there until I had written the first three down, and it is the only one with an answer.

Would I have had her at all?

I have never once asked that. Not at four in the morning, not in the corridor at sixteen weeks, not on the ring road, not in the hospice, not on the beach, not in ten years since.

It has never appeared. There is no version of me that generates it.

That is not virtue and I want to be clear about it. It is simply that the question requires a world with no Roya in it, and I cannot construct one, and I have tried, on purpose, twice, out of a kind of scientific curiosity at two in the morning, and there is nothing there. The mind will not do it. It is like being asked to imagine a colour.

So there are three questions with no answers and one question that never gets asked, and that is what ten years leaves you with, and I have decided it is enough.

THIRTY-SEVEN. THE WEIGHT OF HER

Now

Thirteen kilos at three. Nineteen at six. Twenty-six at nine. Twenty-eight at the end.

I can tell you exactly what my daughter weighed at every stage of her life, in a way that no other mother I know can, because for ten years her weight was the number that determined everything — the sling, the chair, the van, the two-person transfers, the shape of a house, the state of Bev's shoulder, the whole architecture of four moves and eleven years.

It was the central fact of her and it was the thing that made her impossible.

And it is also, now, the only part of her I can still feel.

Not her face. I have the photographs and the photographs have replaced it; I know that has happened and I cannot undo it. Not her voice, because there was not one. Not her hand in mine, because her hands were closed until the last three days of her life.

But if I sit still, with my eyes shut, I can have the exact weight of my daughter across my forearms, and the way her head went back so that the left hand had to go there, and the particular heaviness of a body that does not help you hold it — which is a different weight entirely from a sleeping child, and which anybody who has carried one will know at once and nobody else will ever understand.

That is what is left. Not a silent angel. Twenty-eight kilos of my own child, and the way you have to stand to take it.

—

Mehran retires in the spring and talks about it constantly and I do not mind.

Daena is twenty-five and Nava is walking and there is another one coming in July, which we found out three weeks ago and which I have not written down anywhere until this sentence.

The house still has the track in the ceiling of the back room. We had a quote once, in year three after, and never rang them back.

There are twenty photographs in the hall and she is smiling in all of them, and I have already explained what those photographs are and I have not taken a single one down.

Here is what I want to say at the end, and then I am finished.

The three of us went through a thing that has no name and that I have never been able to explain to anybody who was not in that house. Not to my mother, who loved us. Not to a therapist who was extremely good. Not in this book, which is the best I can do and is not it.

There is a particular look that passes between Mehran and Daena and me, perhaps twice a year, usually at something completely trivial — a phrase on the television, somebody in a shop being slow about something — and in that look is the entire ten years, all of it, in about a fifth of a second, and none of us ever says anything, and we do not need to.

That is what we have instead of being understood. Two other people who were there.

It is not enough and it is a very great deal, and I have watched families come apart over less, and I do not know why we did not, and I have stopped investigating it in case it turns out to be luck.

She was here for ten years and eleven months and twenty-nine days.

She never spoke and never sat and never held anything and never once turned her head when I came into a room, and she was extremely hard work, and Ellen said so in a school hall in front of ninety people and it was the truest thing said that day.

And she is in all of us permanently, in ways that have nothing to do with memory. In Daena's hands, which cannot let a baby cry. In Mehran, who will not go back to a certain garden. In my left arm,

which still goes up and back and low, ten years on, every single time.

We did not get her for very long and we did not get very much of her and what we got has not gone anywhere.

The window is open. It is November and there is nothing outside it.

Daena is in the front room with Nava and she has not asked, because she never asks.

She has just come through and put a cup of tea down beside me on the sill, and gone back, and opened the other one.

We were offered a test at sixteen weeks and we did not have it. That is the first thing anybody wants to know and it is the wrong thing, and I will explain why, and it will not help.

Roya was born in April. By nine months we knew something, and by fourteen months we had a word for it, and by three years we had a hoist in the ceiling and a wet room and a house chosen entirely for its doorways. She never sat unaided. She never spoke. She never held anything or reached for anything or turned her head when I came into a room.

She lived ten years and eleven months, and we moved four times for her, and she got heavier every single one of them.

This is an account of those ten years by her mother, written down because there is no other place to put it. It is about the therapy that saved her hips and hurt her every day. It is about a sister who was four when it started and asked for nothing for fifteen years. It is about a phrase that relatives use — silent angel — and what that phrase is actually for.

And it is about what happened afterwards, which nobody warns you about either, which is that life became more bearable and the grief was not one gram lighter for it, and that both of those were true at the same time, and only one of them could ever be said out loud.

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