it? I’m not going to die.” He shakes his head vigorously. “I don’t want to die!” I look at my 10-year-old son and see the panic building behind his eyes. I decide the time isn’t right. Nowhere near right. “That’s why we are doing all this treatment.”

The weeks stretch into months. Silas’s next scan is good. Bob has shrunk, against all the odds. We celebrate. We pack our bags and spend Silas’s 11th birthday by climbing a rocky promontory in Ibiza and carving our initials in a tree trunk. As we sing Happy Birthday and Silas blows out the candles on his chocolate cake, my heart clenches.

In September, just over a year after he had first been diagnosed, our bubble bursts for the final time. Silas’s scan is due on Friday 13th — not a good omen — and the day before he has his first headache for months. He sits in the bathroom as I give him some paracetamol. “I don’t think I’m going to have a good scan tomorrow,” he says, hanging his head. “Maybe not,” I agree, keeping my tone light. “But it won’t be the end of the world.” Just the end of our little world, I think to myself.

A few days later, the phone rings. Ben comes into the kitchen and I put the man on speakerphone. “We have the scan results...” He pauses. “It’s not good news, I’m afraid. It looks as though there is a widespread increase in abnormality.”

“So that’s it, isn’t it?” I ask. “It’s 100% fatal on relapse, isn’t it?” There is silence on the other end of the phone. “Isn’t it?” I repeat. A beat. “I’m afraid so.”

The tumour is like an octopus that’s spread its tentacles into every corner of our son’s brain.

A new chemo regime requires Silas to have an operation to insert a port-a-cath under the skin of his chest to infuse the new chemo drug vincristine. It will be easier than constantly battling to insert cannulas into his arms — or so we hope.

“Maybe you should think about not putting the port in,” says the doctor. “We can continue the chemo without the vincristine. There is some evidence that it doesn’t add much to the treatment and he will tolerate the other two drugs better.”

Neither Ben nor I want to put Silas through an unnecessary operation, but we still want to fight tooth and nail for him. We know now that we are working with months, maybe even weeks, and we cannot stave off the inevitable, but suddenly every extra day seems vital.

“No, we want to continue with the plan. Let’s give him the best chance,” says Ben.

The outcome is a traumatic operation for both Silas and ourselves, which ends up with Silas screaming at us and telling us that he hates us and that we are torturers.

How does a parent choose when to stop trying to save their child from a monstrous death? How do you choose when is the right time to let go? When that child is laughing and joking with you and telling you how much he loves you? When his body is failing so gradually that even he is not aware? Where do you draw the line?

That day we chose the operation haunts me; the doctor tried to tell us it was time to stop, but I was unable to listen. All I can think about is not being able to hold my boy in my arms ever again; never dancing around the kitchen with him; never having him bound into my bedroom with a smile on his lips first thing in the morning; never getting to hear him say one more time, “I really, really love you, Mummy.” How can I live without those things? How can I even begin to? Am I just trying to keep him alive for my own selfish reasons?

One afternoon, Silas and I sit on the bench in our kitchen. He plays with my hair and somehow he gets onto the topic of dying. “Mummy, I would hate it if you died.”

“I’m not going to die, darling, not for a long time yet.”

“I know, but I couldn’t bear it if you did. I love you too much. I couldn’t be happy without you.”

“I’d be an old lady by then and you would have your own family.” I look away knowing this will never happen, and turn back with a smile plastered on my face. I find myself telling him in great detail that in my imagination dying is like going to Narnia — that time will flow differently in heaven for the person that dies, so that a few decades on earth will pass in the blink of an eye in heaven. I tell him the parting will be brief and magical. I tell him all this, hiding the silent scream that is tearing my heart in two. I wonder all the time whether this talk of death is a way of preparing himself. He must know at some level what is happening to him, even if it is only in his subconscious.

Silas’s balance deteriorates, a slight list to the left increasingly visible, like a ship gradually taking on water. He takes a few tumbles down the stairs. Both Ben and I want Silas to die at home. It may be impossible to keep him out of hospital, but the nursing team have assured us they will help us if they can.

Silas no longer has control over what comes out of his mouth. He says what he thinks, even if that thought is unkind or inappropriate. Silas showers us with kisses. Love oozes out of his every pore. At bedtimes, he constantly calls us back for kiss after kiss, just one more, then another one, then a last one. I whisper in his ear as he sleeps about how much his mummy and daddy love him. He rolls over without waking and says clearly: “Same — I love them so, so much.”

> **“Love oozes out of his every pore. At bedtimes, he constantly calls us back for kiss after kiss, just one more”**

At the end of November, scans show that Bob is in a rush to finish his mission.

Silas no longer walks. He lurches, bouncing off the walls, bumping into doorways, tripping over his own feet. I find him standing in the downstairs loo, swaying gently from side to side, a look of confusion on his face.

“What is it, darling?” I ask. He wrinkles his brow. “I… I can’t remember what I was doing.” A few days into the Christmas holidays, we put the tree up and start to decorate it. Silas sits on the sofa. He doesn’t engage. He keeps looking towards the door of the room as though he can hear some distant noise that we cannot, as though there’s an exclusive party happening elsewhere that he’s keen to join. Standing on the top of a ladder putting the star on the tree, it hits me in the solar plexus. I double over in agony as the realisation explodes inside me. He’s leaving us. That’s exactly what is happening. His journey somewhere else has begun. My heart pounds. I’m not ready. I’m not ready.

The day after we put the Christmas tree up, I ring the oncologist and say we have decided to stop the chemo. He’s not surprised and agrees that it sounds like the right decision. I hang up the phone and am left wondering for how long exactly he’s felt this way. Why has it been left to us, Ben and me, who have no experience of the course this disease takes, to make the call?

Silas lies in our bed before breakfast only a few days after we stop the chemo.

“I love you, Splodge,” says Ben, kissing his cheeks. “I really love you, Daddy,” says Silas, his eyes wandering towards the window.

“What about Mummy?” says Ben. Silas pulls his gaze back and looks at him blankly. “Aren’t you going to tell Mummy how much you love her?” says Ben, nodding his head in my direction. Silas’s eyes focus on my face lying on the pillow next to his. “I really, really love you, Mummy.”

“Ditto,” I say, rubbing his nose with mine. I hold my thumb and forefinger a small distance apart. “But just a smidgen more.”

He smiles. Those are the last words he ever speaks to us. Simple and perfect ■

A Mighty Boy: A Mother’s Journey Through Grief by Sarah Pullen, is published on August 24 (Unbound £15). All Sarah’s proceeds will be donated to the Brain Tumour Charity. To donate, visit thebraintumourcharity.org