

puts a hand on my arm. “Don’t think about it now. We’ll know more in a few days.”

A few days later we are standing in the hospital playroom, being told that there is no hope and that with treatment our son has 12-18 months. After the consultant leaves, we plaster smiles on our faces and scoop Silas up out of the ward and take him home. He chats away in the back of the car, excited to be going home, oblivious to the tears that drip down my cheeks and make a damp patch on my shirt.

We get home and can’t talk to anyone about the diagnosis. Not even my mother, who’s been looking after the other boys. “It’s not good news,” I say, watching Silas run into the house. “Don’t ask me any questions. I can’t talk about it.”

That first night, my mind is far away in a deep, dark place. Ben and I can barely communicate. We are like two pinballs crashing around in random directions. At one point, I say that I am glad I have him by my side, that I don’t have the strength for this journey without him. Ben’s reply cuts me deep, even though I know he doesn’t mean to hurt me; he just cannot contemplate the pain to come. “I wish we had never met,” he states simply, as if erasing our history together and mapping out a different life for both of us could remove his agony.

After Silas is diagnosed, I look at people with what I perceive are gilded, perfect lives and I can taste the bitterness. It is difficult not to feel hard done by when you are hit with odds of 250,000 to 1.

Those first few days after Silas’s diagnosis, Ben and I function on autopilot. We take the children to their cousins’ house in Wales, and while they run about on the beach kayaking, skimming stones and eating ice creams, we hold war councils. I need to know what I am dealing with before I meet with the oncology team. Information on the internet is sobering and terrifying. Glioblastoma multiforme, or GBM as it is more commonly known, is a frightening disease. It’s one of the most aggressive cancers in humans and the average survival is one year. Many of those diagnosed only live a few short months. Children and adults who have their tumours fully removed prior to radiotherapy have a greater chance of surviving longer. This is difficult for us to read as Silas has a large portion of tumour left inside his head.

We decide to take charge of his future and the first step is to name Silas’s tumour, to take away the fear it engenders in us. The children are watching TV with their cousins. “Hey, guys,” I say. “We need to think of a name for Silas’s tumour. Something silly. What shall we call it?”

At that moment, Rowan Atkinson walks on screen in a rerun of *Blackadder II*. His voice echoes out from the TV. “Well, Bob, welcome on board.” Almost instantly, Silas pipes up, “What about Bob?” It’s perfect.



**BATTING ON** After his operation, Silas (left) resumed his boisterous life with his brothers

Harmless and silly, especially if you picture Rowan Atkinson saying it in that pursed-lip, tight-arsed sort of way. From that moment on we are in a battle with Bob.

We watch Silas from a distance. Every laugh, giggle and proclamation of love is a turn of the screw. We are overprotective and alert. We ply him with medicine. At the same time we don’t want to stop him living and we bite our tongues as he cycles down steep hills and climbs rocky headlands. He looks just like any other 10-year-old boy on the beach in swimming trunks, running through the surf, except for a striped beanie hat protecting his stitches and the enormous S-shaped scar that cuts a swathe through the hair above his left ear. His brothers show him no allowances and grapple with him on the sofa – their pent-up resentment at being stuck with Granny for a week while he enjoyed both of us in hospital coming to the fore.

Silas is a child first and foremost, and for him thoughts of cancer are fleeting and ephemeral. Something he doesn’t want to think about and, bar the constant rounds of medication, could easily forget in that wonderful, innocent way that children possess. The way a scraped knee

can be instantly erased by a sticky lollipop.

At the hospital we walk into a room lined with strange faces — paediatric oncologists, clinical oncologists, clinical fellows and neuro-oncology nurses. Silas is unfazed by all the attention and allows the doctors to prod and poke him.

The consultant is pleased with his progress and the plan is to proceed with radical radiotherapy in combination with a chemotherapy drug called temozolomide, which is well tolerated in children. There is talk of immunotherapy trials. We learn there is another surgeon willing to go back in and remove the rest of the tumour. We have to sign consent forms that you would baulk at for yourself, let alone your child. Forms that state we are putting him at risk of hearing loss, strokes, growth problems, hormone problems, cognitive problems and, believe it or not, future brain tumours. Radiation to the brain can wipe nearly 10 points off an individual’s IQ level, but we have no choice and put pen to paper. But, for the first time since Silas’s diagnosis, Ben and I feel buoyed with optimism. Maybe, just maybe, we can beat Bob. Silas goes back to school and life returns to some semblance of normality.

**Less than a month later:** the bubble of hope we have encased ourselves in pops with a bang. Two days before Silas’s radiation is due to start, he complains of a sudden headache on the way to school and vomits into a bag in the car. We sit in the hospital room in horror. The consultant says those dreaded words, “Let’s go somewhere more private to have a chat.”

The tumour has regrown. “He’ll have to go back on steroids and the radiotherapy will probably just be palliative now.” Tears fill my eyes. All of a sudden we are back at death’s door. The consultant puts his hand on my arm. “I’m sorry,” he says. “I really am.” I shrug him off. I’m fed up with people saying they are sorry.

We tell very few people about the true diagnosis. Our priority is always Silas. We don’t want him to find out that he’s going to die. Not until he has to.

There’s only one time that Silas asks outright if he’s going to die. We are sitting in the waiting room at the Royal Marsden a few months into his chemotherapy treatment and I have picked up a book with lots of drawings in it by children with cancer. As we turn the pages, Silas becomes quieter. At the back of the book is an epilogue. It reads: “These pictures were all drawn by children receiving treatment for cancer. At the time of going to print 17 of these children were still alive.”

Silas draws in a sharp breath next to me. “What happened to the other children?” he asks. “They didn’t die, did they?”

“I guess they must have,” I say. His mouth drops open and his face pales.

“That’s not going to happen to me, is —>

**“What happened to the other children? They didn’t die, did they? I don’t want to die!”**