

T

here is a moment I wish my son dead. I wish for him to be killed instantly in a car crash. Can you imagine wishing your child dead? It's not something I would ever have thought possible, not until a stranger in a crisp Italian suit and polished leather shoes tells me that my 10-year-old son is going to die in a matter of months. That he'll die a torturous and undignified death that will rob him of his personality long before his heart finally stops beating.

Wouldn't you, too, find yourself wishing for a quick death for the child you love beyond reason, a child who has never had a day's illness in his life?

We stand in a small hospital playroom, my husband and I. Across the room from us perches a consultant.

He has ushered us from our son's hospital room and swept us across the corridor into this room. Over the next few months, we learn that good news is always delivered by our son's bedside, the consultant's relief palpable in the smile creasing his face, whereas bad news takes us into dark corridors or starkly lit rooms. We come to dread those words, 'Shall we find somewhere quiet to talk?'

The consultant asks us: 'Do either of you have a heart condition?'

We shake our heads. We are here to talk about our son's health, not our own.

'That's good,' he says, ignoring our confusion. He takes a deep breath and gazes out the window. A stream of words flows from his mouth.

'We've had the pathology results back. Your son has a high-grade glioma in his left parietal lobe. It's suggestive of a glioblastoma multiforme. It has been partially resected, but we couldn't fully remove it because of the risk of right-side hemiparesis.' He pauses. I try to decipher his words, but they slide away from me.

The bile rises in my throat and my fingers tingle as the blood drains from my limbs. I feel what is coming. I know it in my bones as only a mother can.

I want to scream at him to stop. I want to stick my fingers in my ears, but I can't move. 'He has an aggressive brain tumour. One of the worst. We couldn't take it all out as we didn't want to risk paralysing him on

one side of his body.' He pauses. 'There's no successful treatment for this type of tumour. I'm sorry, but your son is going die. He has 12-18 months with treatment and only a few without.'

Black spots crowd my vision and I dig my nails into the palm of my hand to stop the scream that is working its way up my throat. 'Some families choose not to undertake any treatment. We'll support you whatever you choose. There is no cure.'

'There has to be something,' Ben says, his voice cracking. 'Go back in. Take the rest of it out.'

The consultant shakes his head. 'It's not that simple. This type of tumour doesn't have clear edges. It infiltrates healthy brain tissue. No matter what we do, we won't be able to get it all out.'

Ben blanches. 'Doesn't anyone survive?'

'Very few ever survive,' the consultant says. 'Less than 10% of these children survive for two years.'

The colour bleeds out of the room. The walls close in, and the only thing I can hear is the frantic pounding of my heart. Ben veers off at a tangent to buy some breathing space. 'Can I ask why you wanted to know if either of us had a heart problem?'

The consultant nods. 'I've had parents keel over with a heart attack when I've had to give them this news. I like to be prepared.' He gives us a look full of pity. 'I'm sorry. I really am. I have children of my own.' That's it.

I picture the small boy in the nearby room, building his Lego model and laughing at YouTube videos, oblivious to the death sentence that has just been pronounced. The diagnosis is worse than we could have possibly imagined. We are falling, tumbling into an abyss. We've been left with nothing to hold on to — just a small boy lying alone in the next-door room, dreaming of his bright future.

It's August 2012. The sun is shining and Britain is in the grip of Olympic fever. Silas is under the weather and over a couple of days has a few headaches. We start to feel something is really amiss at Sunday lunchtime. We have guests. The house is

full of children and noise, but Silas sits on the stairs with his head buried in his hands.

'You don't understand,' he says, as one of his brothers accuses him of making a fuss. 'My headache's so bad.' He looks at us, his eyes big. 'I need to go to hospital. Please, please,' he begs. 'I feel like I'm dying.'

My eyes meet Ben's and I see my concern mirrored in his. Here's a 10-year-old boy telling us he's dying. We need to take him seriously. I am, though, a mother of four boys and I don't want to panic and spend several hours in our local A&E department on a Sunday afternoon.

We agree to give him some paracetamol and lie him down on the sofa. Outside the room, out of his hearing, we also agree that if things don't get better we will take him straight to hospital. Thoughts of meningitis fill my head. I make Silas bend his neck to his chest. I make him turn towards the sunlight and I relax when the light doesn't appear to hurt his eyes.

Within half an hour of the paracetamol, Silas feels better. He joins us for a big lunch full of ripe summer berries and sticky meringues. He chats and bickers with his brothers. He makes us and our guests laugh. We brush off the earlier episode, reassured that there is nothing seriously wrong with him. We play cricket in the garden and Silas hurls the ball down the makeshift crease. The shadows lengthen and we come inside. Silas walks into the kitchen.

'What do you want for supper, darling?' I ask.

I get no reply, so I repeat the question. He looks at me blankly. I turn away to empty the dishwasher and Silas mumbles a few unintelligible words — 'I, I, I...'

I look up. 'Are you OK?' I ask. My eyes search his face. He is frowning.

'I... I can't think,' he says. He sounds as though he's been at the whisky bottle. I hold his shoulders and lower myself to his level. 'Do you feel all right?'

He nods his head.

'What's the matter then?'

'I... I...' he stutters.

'Don't joke, Silas,' I say. 'It's not funny. Promise me you aren't joking.'

He shakes his head and the cold spreads deep within me.

'What's your name?' I ask

'Si... Si... Si...' His eyes widen in surprise and confusion.

'It's OK,' I whisper, although I know that it's far from OK. 'Let's go upstairs and lie down on Mummy's bed.' I want to get him somewhere quiet and away from the prying eyes of his brothers.

Silas collapses on my bed.

I pick up the phone and dial 999. The operator answers. I hang up. How can it be that serious? How can I need an ambulance? He was playing cricket not so long ago. I stand in the doorway and watch my son for a moment. He is lying on the bed with his hand covering his eyes. I take a

deep breath and dial the numbers again. 'I need an ambulance,' I say, my voice strong.

The noise of a siren drifts through the open windows. Two paramedics puff up the stairs carrying their equipment. The two girls assess the situation and quickly rule out meningitis. The only symptoms Silas displays are a headache and some confusion and slurred speech.

'Has he been outside in the sun?' one of them asks.

'Yes. We've been playing cricket, but it hasn't been that hot today.'

'Has he been drinking plenty of fluids?'

'Yes, lots.'

'It looks like sunstroke or heat exhaustion.'

'It's not sunstroke,' I say, my voice sharp.

The other girl puts her hand on my arm, patting me into submission. 'His Sats are fine and he doesn't have a temperature,' she says. 'We'll take him into the hospital, but it's just precautionary because of his confusion — nothing to worry about.'

I squeeze into the ambulance, while Ben follows in the car. Accident and emergency is quiet. There is no rush to treat Silas. I am left on my own with him. He becomes less responsive. He is drifting and absent; his eyes lose focus. I call over a junior doctor, but he appears nonplussed. Ben arrives just as Silas's heart rate plummets to 40bpm. He's clammy and barely conscious. We call the doctor back over and he inserts a cannula into a vein and takes some blood, then fits an oxygen mask to Silas's face.

'Has he hit his head in the last couple of days?' he asks.

'No,' we say in unison.

The doctor looks at Silas and his lips tighten. He spins round and disappears again. Silas suddenly writhes on the bed and vomits into the oxygen mask.

'Help,' I call, pulling off the mask. 'Help,' I scream as he is sick again over the bed. His eyes flutter, but they don't open. The doctor comes back with a big syringe and injects it into the cannula. 'We think your son has a swelling inside his head. This will help reduce pressure in his brain.'

'But he hasn't hit his head,' I murmur.

'Until we know otherwise,' says the doctor, 'we're going to assume he has some sort of head injury.'

They wheel Silas off to have a Cat scan. Afterwards, he is brought back into the resuscitation room. He's completely unresponsive. A grey-bearded man, with spectacles pushed high on the bridge of his nose, storms into the room. He turns to a monitor and switches on the screen. A few seconds later, the screen fills with an image of Silas's brain. There, on the left-hand side, are two large, circular anomalous masses, one in front of the other. The back one is three times the size of the front one, and appears to be the size of a tennis ball.

The man turns. 'Are you the parents of this boy?' he barks.



STILL SMILING Silas with his mother and little brother Inigo, eight weeks before he died

We nod. I don't trust myself to speak. This is worse, much worse, than meningitis. The doctor flings his next words at us, each word like a punch to the solar plexus.

'This boy is seriously ill. He has a significant mass on his brain, most likely a tumour. This is a life-threatening situation. We may lose him at any moment. You can remain if you stay calm, otherwise I will have you removed. Stay out of my way and let me work and I will do my best for your son.' He dismisses us and gets to work.

I dare not look at Ben. I look at the monitor again. How can something that size be in my son's head without us knowing? I learn later that the faster a brain tumour grows, the fewer symptoms there are. Slower-growing tumours tend to cause repeated visits to GPs before diagnosis.

Silas's tumour, though, is so aggressive that his brain has no time to react to the intrusion until it reaches crisis point and starts shutting down in shock.

I stumble out of the room, my mouth thick with saliva, and call my mother, who is with the other boys.

She struggles to comprehend what I'm telling her. I want to curl up in a ball and let her tell me everything is going to be all right, but I'm the mother now and I have to be strong. I can handle facts, but not emotion. Raw emotion will lead to panic and I cannot allow the panic in if I am to be of any help to my child. I push it deeper and cage it in my belly, where it festers and grumbles and makes a permanent home.

An ambulance moves Silas to King's College Hospital in London in the middle of the night. There's no room for Ben or me as they need to have a full medical team. We let Silas go with a bunch of strangers not knowing if we will ever see him alive again.

We arrive at King's in the small hours and spend frantic minutes trying to find out where they have taken Silas.

A nurse tries to brush us off, but then she sees the terror behind our eyes and her

demeanour softens. She makes a couple of phone calls and she sends us up to the paediatric high dependency unit. I want to hug her with relief: until that moment, we had no idea if we were going to be directed to a ward or the morgue.

Silas is in the far bed, lying so small and still, his face pale, his body connected to a battery of monitors. I lean down and kiss his smooth, warm cheek and bury my face in his neck to inhale his sweet scent.

In the morning, he wakes up and smiles at us. The massive dose of steroids they have administered has reduced the enormous swelling in his brain and his speech is nearly back to normal. He can recall very little about the night before, although he tells us that at one stage he knew he was in an ambulance — he could hear people talking and the sirens blaring.

After an assessment, the surgical team call us into a side room for a meeting.

'We need to operate immediately to remove as much tumour as possible,' says the surgical registrar.

Leaving our son in the operating theatre is one of the hardest things either of us has ever done. If he comes through the surgery all right we don't know what deficits he might have, whether he'll even be able to walk or talk. Ben and I walk to the nearest pub and have a stiff drink. We both have a cigarette, although neither of us has really smoked for years. We just need something to do with our shaking hands.

Hours later we get the call to head down to the recovery room.

'We did well. We managed to get about 70% of the mass out,' says the surgeon, a smile on his face. 'The rest of it was too close to his motor nerves. It was too risky to touch, but we got the big part out.'

'But what happens to the rest of it?'

'That depends on the pathology. If it's malignant you'll have to go down the route of radiation and chemotherapy.' He ➤➤➤

'This boy is seriously ill. You can remain if you stay calm, otherwise I will have you removed'