

The background of the cover is a solid teal color. Overlaid on this are three white, feathered profiles of a person's head, facing left. The feathers are detailed and appear to be made of many fine, overlapping layers, giving them a soft, ethereal quality. The profiles are positioned in the upper half of the cover, with the central one slightly higher than the two flanking it.

The Weight of a Thousand Feathers

Costa Children's Book Award Winner

BRIAN CONAGHAN

BLOOMSBURY

The
Weight
of a
Thousand
Feathers

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LONDON OXFORD NEW YORK NEW DELHI SYDNEY

Seed's Salon

Mum is dead.

I find her propped up in her chair, hands resting gently against her lap. No rings, free from bling, just the way the little boy in me remembers. Her open eyes are like two sparkly saucers staring at the television; some chiselled-toothed guy is trying to punt an all-singing, all-dancing mop. £11.99 all in. Bargain.

I cuff her face four, maybe five, times, until my slaps morph into strokes. Long, soft ones. Her skin feels like December. I think about mouth-to-mouth, but there's no point. I stand tall and stare at her, my dead mother, as if she's an art exhibit.

Dead still.

Still beautiful.

I tighten my eyes, try to cry, then lean in, scroll her lids shut, kiss her wintery forehead and whisper, 'Goodbye, Mum.'

I've had that dream so many times, and it always ends the same way: me pecking her and whispering variations of *goodbye*. However, what made last night's dream different was *where* she died: it's rare she pops her clogs in the living room. Usually happens in her bedroom, in her own bed, surrounded by her own stuff. Because the bedroom is where Mum will go to live when she deteriorates. And she *will* deteriorate, because that's what happens with MS – it creeps up and bites sufferers on the arse when they're least expecting it.

So you're having zero symptoms?

Life chugging along as normal, is it?

What, you think you've defeated me? ME?

Well, let's just do something about that.

BOOM!

Here's another attack for you.

How's that for a relapse?

Now, get yourself back to Go.

MS is a slow burner. Waxes, wanes, skips along. Sometimes I wish she had the big C instead; at least the big C can be found, fought and defeated. Let's leave it at that.

It's Saturday. Last weekend of freedom before school restarts. Zero homework. But chores galore to do, as always.

I try as best I can to pamper Mum:

'Jesus, Bobby, I'm not a horse, be gentle.'

'I am being gentle.'

'Well, pretend I'm a baby then.'

'Way too creepy.'

'I pity the girl who gets you, Bobby Seed.'

'Oh, really, is that right?'

'Ouch! That's sore.'

'Sorry, brush slipped,' I say, smacking her dome with it.

Takes me generations to brush it. No joke. You could watch *The Sound of Music* during our session. I count the strokes, usually well over a hundred, until we're both satisfied. No way Mum could do a hundred strokes herself. Ten knackers her. She does try but then looks as if she's arrived somewhere on the back of a motorbike sans helmet.

'I'm telling you, Mum, you could definitely get a job in a farmer's field.'

'Oh, be quiet or I'll tell you where your real mother lives.'

'Just sit still.'

'I'm sure it's Her Majesty's Prison something or other.'

Mum's hair is like strands of silk. Still dark, still on the long side of short.

Wet.

Brush.

Stroke.

Sometimes she'll lob the odd grenade into the mix by requesting a plait. No bother, Mum, do I look like Vidal Sassoon? I keep telling her I'm more your pull-back-and-ponytail type of hairdresser though. In her youth she had hair like a black pearl. Her words not mine.

We find the action peaceful and therapeutic; allows for a physical contact that's full of quality. Space to relax and

reflect. Actually, balls to that. She needs me, she relies on me and, well ... she's my mother, isn't she? I know I'm *supposed* to love her, but it takes no effort. I love her from sole to summit. Life's not all darkness and thinking ill of the ill. We do laugh, honestly.

'Do your hairdresser, Bobby,' she asks.

Shirt tucked tight. Hair back and parted. Mannerisms exaggerated. Voice effeminate. I assume my position behind her.

'OMG! Your hair is total gorge, Anne.'

'Think so?'

'Know how many of my customers would kill for locks like that?'

'Many?'

'Too bloody many.'

Wet.

Brush.

Stroke.

'Going out tonight?' I ask.

'Few drinks with the girls just.'

'Up to Memory Lane?'

'Where else?'

'I snogged the barman up there once. Like a washing machine on full spin so he was. Thought I was going to pass out with dizziness.'

'Is he not married?'

'Erm ... he said nothing to me.'

Wet.

Brush.

Stroke.

'Going on any holidays, Anne?'

'Magaluf with the girls just.'

'Oh, it's a pure riot over there.'

'You been?'

'Two summers in my early twenties.'

'Nice?'

'Can't tell you about it, they'll lock me up.'

'Sounds a hoot.'

'Pure MEN-tal. Oh, don't get me started.'

Mum's pretty good right now, but there've been loads of days when she's too shattered to laugh, too sore to speak. Then my brushing feels tired and tragic. But even then I know I'll miss these moments in Seed's Salon. Give me misery over nothing any day.

Danny Distant

While looking after Mum is physically draining, it's that little brother of mine who takes up tons of my emotional energy. Affectionately known as Danny or Dan by those close to him, i.e. Mum and me. To the cruel, he is Danny Distant; I'll spare any vile anecdotes. There's no official diagnosis for what Dan has – Mum didn't want one. She didn't want him branded like some swine awaiting slaughter. Danny is just different ... idiosyncratic ... distant. Not a crime. No need to pin a hefty life label on him, is there?

Danny compressed:

Three-year-old: no issues. Typical toddler.

Six-year-old: hadn't progressed beyond the world of the three-year-old. Eyebrows raised. Loads of furtive whispers.

Ten-year-old: hovered in six land ... Oh, Christ, that poor boy!

And so on.

You get the idea.

Now fourteen, three years my junior, Danny teeters around the nine or ten mark. Sometimes older, sometimes younger. Depends on the day. But our Danny is made of greatness. I know it. Mum knows it. Think Bel knows it too.

I'm not the only nominee for the Social Bravery Award. Bel sometimes helps out, especially with Danny; she's my girl friend. Not *girlfriend*. She's a friend who happens to inhabit a female body. We're pals. Probably best pals. Although I think she'd like to move the goalposts on the whole pals act thingy.

Evidence? OK, here's the evidence: once upon a Friday (last week) we bought some nasty cider from the no ID required shop and bolted back to mine. We were thinking of starting a ritual called Drowning Our Sorrows Friday. This was to be our opening night; getting a bit tipsy and giddy would help take our minds off stuff. Bel has her own shit to contend with: cliché boozed-up father. He's got her date of birth tattooed on his knuckles. I know, enough said.

Anyway, cutting a dead long story short, we got cider-rattled and Bel tried to plank the lips on me. Then she threw out the L-bomb. I pretended to be drunker than I was, slapping her on the thigh and squealing: 'Shut your trap, Bel. You're totally pissed out your knickers.'

Conveniently that little episode has been forgotten, not a word spoken about it since.

Oh, what happened yesterday? I can't remember a thing.

Me neither.

I'm never drinking again.

Me neither.

To be honest, I'm still spitting a bit as all that lips and love shit could've put a massive dent in our palship. And Bel's the only real friend I have. Real gem.

It helps that Danny trusts her and has no problems allowing Bel to enter his world. It's a beautiful thing seeing both of them in action.

'If anyone at school calls me Danny Distant again, I'm going to dynamite their balls,' he says.

'Do those people love you, Dan?' Bel says.

'No. Stupid.'

'Do they even know what you're good at?'

'They don't know shit from shampoo.'

'But Bobby and me and your mum love you and we know you're amazing at most things.'

'I'm amazing at eating pizza.'

'Exactly. I bet none of those guys at school are.'

'They're idiots.'

'Agreed.'

'Dicks.'

'Probably.'

'Arsehole punchers ...'

'Right,' Bel says. 'Get yourself off that couch and go get groomed online, or whatever boys your age do.'

She has that ability to drag him back into life. I take comfort in seeing her play both mother and big sister. We're both lucky to have her.

Anyway, Drowning Our Sorrows Friday is a non-starter for a glut of reasons, but mainly because boozing is like gargling on your own vomit: Bel's battling against becoming a chip off the old block, while I need to be my best Bobby Seed, you know, just in case.

I guess you could say we're just your archetypal damaged nuclear family. Although my brain tells me we're about to become more nuclear.

Pins and Needles

It kicked off with the occasional pangs of pins and needles in her feet, before moving steadily to her legs. I was twelve. Tingles frequently began creeping up the right side of her body. This went on for months. Mum told no one. She only visited the doctor when those black spots started to skew her vision. That's when she felt everything collapsing, she said.

My memory is different though. I'm fourteen. We're doing the big shop in Asda. For some reason Danny isn't with us, can't remember why. Maybe a school thing.

Trolley's bulging at the seams. Mum's pushing. I'm looking for things to have, eat, want. I usually persuaded Mum to let me drink a Coke while walking around, putting the empty can through the checkout at the end. (Shhh, didn't do this ever. I shelved it before we got there.

Not exactly aggravated robbery, but still. Mum never found out.)

‘Can we have Pot Noodles for dinner, Mum?’

‘No chance. Broccoli and kale tonight.’

‘Don’t even know what that is,’ I said.

‘It’s brain food.’

‘Aw, really?’

‘Yup, and stacks of it is required since yours is so weak.’

‘Why can’t we have what other families have?’

‘Oh, stop being a teenager, Bobby, or I’ll abandon you in aisle six. Do something useful – reach up and get that cranberry juice for me.’

I’m on tiptoes, hand in the sky, pure Superman pose, when I hear a deflating puff of air from behind. Mum’s slouched over the trolley.

‘Mum! What happened? ... Mum, you OK?’ Didn’t know whether to drag her off the fruit and veg mountain or leave her be.

‘Help me up, Bobby.’

She’s upright.

‘Just felt really dizzy there for a second.’

‘Here, drink this.’ I handed her the Coke I was saving.
‘Drink loads of it. Might help.’

She sipped. I could tell it wasn’t going down well.

‘Better?’

‘Better,’ she said.

The colour returned to her cheeks, but her expression screamed defeat.

'Mum?'

'I'm good, Bobby. I'm better.'

'Honest?'

'Honest,' she said. I didn't believe her. 'Did you get that cranberry juice?'

I launched my frame up again and scooped a carton off the shelf. Jammed it into the trolley.

'Mum, can I get a Starbar?' I imagined munching it, feeling the chocolate paint my mouth, knowing full well she'd say, 'No chance.' Mum thought apples were treats while chocolate bars were the devil's diet. But I always asked. She always refused. Our recurring joke.

'You can have what you want, son,' she said.

'Mum, seriously, are you OK?'

'Just tired, Bobby.'

'Anything I can do?'

'Maybe push the trolley. I don't have the energy.'

But the wheels made it easy to push, even with weight in it. I didn't say that. It was clear she couldn't shove it another yard. That trolley could've been overflowing with steam and she'd have been too weak for it.

'Course I'll push,' I said.

'Let's get you a Starbar.'

I no longer wanted one.

I wanted my mum.

I wanted her to take the piss out of me, embarrass me, put me in my place with the slice of a sentence. But that day I understood, a good two years after those pins and needles started nipping away, that I'd be getting a new mum, a totally different one. And my heart was broken. Torn to shreds in fucking Asda.

Teacher Tries Her Best

I can't get back to sleep after another dead mother dream. I wait for the sun to smile. Thinking a thousand tiny thoughts:

Should I have a fiddle?

When reciting the alphabet, why do I say L-M-N-O-P really quickly?

What's another word for 'thesaurus'?

If I had a sealed envelope with my death date written inside, would I open it?

Why us?

First week back at school after summer and all I want is to rest my head on the desk. Turn my bag into a pillow. This double life of domestic god and diligent schoolboy sure rips strips off your strength.

The teacher's up front rabbiting on about something: white noise. Bel's doodling and shaking her knee under the

desk as if desperate for a pee. My head's heavy, a swaying tree.

I feel a dunt in the ribs. Sore. I guess I'd rather take a rib punch than a lip plant though.

'Hey,' I whisper. 'That was painful.'

'You were practically sleeping on me,' Bel says.

'Right, OK, but no need to –'

'Do I look like the Premier fucking Inn?'

'I'm a bit tired,' I say.

'No wonder, listening to this shit.' Bel nods towards the teacher.

'What's happening?'

'Some guff about poetry.'

I perk up because poetry is a kind of secret pleasure of mine. No one knows that I inhale it in the dead of night, that it answers many questions I have swirling in my head. I've even, you know, tried to, like, dabble myself.

'Pure nerd fest,' she says.

We snigger.

Teacher clocks it and marches up to us.

'Something to add, Bel?' teacher says.

'No, miss. Just chatting about what you were saying.'

'Really?'

'Really, miss.'

'So what was the last thing I said then?'

'Poetry stuff,' Bel replies.

Giggles from the class fill the awkwardness.

'This is an important year, Bel. I suggest you take it seriously.'

'Will do, miss. Thanks for the heads-up.'

Teacher dismisses Bel as a no-hoper, then focuses on me. Her expression relaxes. Soft focus. The face of pity.

'You OK, Bobby?'

'Just a bit tired, miss,' I say.

'It's to be expected,' she says.

Bel's eyes whack the ceiling.

'I think the poetry element of the course will be a strong point for you this year, Bobby.'

'Hope so, miss.'

Teacher gives Bel the sneer-face before turning on her high-rise heels. *Clickety-click*.

'Right, everyone turn to page sixty-six. "Poppies in October."'

After the long summer hanging out with Bel, making sure Danny didn't get the shit kicked out of himself for whatever reason – staring sternly at someone in his *you fuckin' want some?* manner or letting his tongue run before engaging his brain ('Look at that woman's giant arse!') – I thought that going back to school would be a breeze compared with the daily demands of being me:

Can you change these sheets, son?

Bobby, is my bath ready?

Where's all the Rice Krispies gone?

Have you taken the washing out?

There's clothes still on the line.

Is Danny eating properly?

This is cold!

This year is a biggie: exam year. Making-informed-decisions-about-the-future year. Getting-the-finger-out-the-arse year. Total stress. Naturally, being seventeen, I have no clue what to do when school's over, and I can't stop the constant motherly jabs on the issue.

'What do you want to be when you grow up, son?' Mum asks.

'As in *grown up* like a man?'

'Well, the jury's still out on that one, but let's imagine you're all grown up, and, yes, we can pretend you're a man too.'

'I'm honoured.'

'So, what are you thinking then?'

'Apart from being a priest?'

'Apart from that, Father.'

'Think I'd be suited to the astronaut life.'

'Well, I've always said you're a bit of a rocket.'

The chats never really develop beyond nonsense. Mum knows I'll be OK; she knows I'll make the right choices. She understands the gulf between teen life and adulthood is vast, so why waste those years trying to leap forward?

'Seriously, Bobby, what *are* you going to do when you leave school?'

'I'm thinking boxing trainer or lion tamer.'

‘Good practice with our Danny. Go for it.’

That’s generally how we play it.

I’ve always thought something creative is a possibility. Now, when I say *creative*, what I mean is writing. Hey, I can rattle off a short story or poem like the best seventeen-year-olds: angsty and lamentable. Any loot to be made in that game? Probably not.

Food. I like to eat. I enjoy watching *MasterChef*. Being chief cook for Mum and Dan, *MasterChef* is essential viewing. Mum finds it hard to swallow at times so soup is a staple on the Seed menu.

I read books. Librarian/editor?

I like clothes. Fashion designer/blogger?

I like money. Banker/accountant?

I like brushing hair. Hairdresser/up-stylist?

I like school. Teacher/student?

I like staring into space. Philosopher/dole sponger?

I like not having an illness. Doctor/nurse?

Not sure my talents stretch to any occupation.

Lunchtime, and Mrs Sneddon, the school counsellor, practically drags me into her office for ‘a little chat’. Don’t get me wrong, I like Mrs Sneddon – she genuinely cares about the students, no bullshit there – but sometimes she plays the role of God’s true disciple, plonked into our school with a single remit: heal the infirm and needy. Ladies and gentlemen, and those unsure, I give you Bobby Seed!

‘How was your summer, Bobby, love?’ Mrs Sneddon calls

us 'love' and 'darling' and gets away with it, but imagine Mr Conroy, Mr McClair or Mr Melrose saying that. I see frogmarching, cameras flashing, blankets draped over heads. Careers and marriages shattered. Can't beat a double standard.

'Summer was fine, miss.'

'And your mum, how's she doing?'

'Same, no change really.'

'Well, that's good, at least she isn't deteriorating.'

Mrs Sneddon doesn't have to listen to the painful howls when Mum's muscles spasm uncontrollably. Mrs Sneddon doesn't have to witness the look of mortification on Mum's face when I'm fumbling around her listless body during 'bath time'. Mrs Sneddon doesn't have to hear the humiliation in Mum's voice when I'm reminded that the baby wipes are running low. No, Mrs Sneddon, Mum isn't deteriorating, but maybe I am.

'And what about your brother? Is he OK, love? Is he coping?'

'Danny's doing fine, he just plods on with life. Being back at school is good for him.'

'The school he's at is perfect, I know it well.'

'Yeah, he likes it.'

'He feels safe there?'

'Yeah.'

'And you, darling. What about you? How are you doing?'

'I'm doing OK,' I say, which is sort of a grand lie.

'It's all a huge pressure on you, Bobby.' I stare at my feet.
'Don't think we don't recognise this, love.'

'It is what it is, miss.'

'It's not easy being a young carer, Bobby.'

Tell me something I don't know.

'Yeah, well,' I say.

'It's OK, I understand.' Her hand rests on my forearm. I nod a type of fake thanks for her *understanding*.

See, child experts will tell you that I'm way too young to carry such a burden of responsibility on my tender shoulders. Their job is to make assumptions and evaluations. Really, what do they know other than what I'm prepared to tell them? I'll tell you what they know, shall I? Assumptions and evaluations. Teachers *feel my pain*. I can tell by the way they look at me, giving me a wide berth that no one else seems to get. Thinking they know the score. They don't. Thinking I can't handle it. They're wrong. Thinking I'm psychologically damaged by it. I wouldn't use the word 'damaged' to describe it. Funny how no one ever uses the word 'love' when discussing my case. I do what I do because she's my mum; she's the only one I have, so wouldn't mind holding on to her for a bit longer. That pure and that simple. Now, tell me this: do you need a PhD and a sack of certificates to work that out? I reckon some common sense and good judgement. Makes me laugh that they all think they know me. I could fill a book about what they *don't* know.

Thing is, I'm just your average seventeen-year-old: same

fears, same desires, same hang-ups, same, same, same. Dull, dull, dull. OK, hands up, there's the seventeen-year-old in me who's poles apart from everyone else as well. Unique. The seventeen-year-old who has to brush his mother's locks every day, sort out her medicine, sponge her clean three times a week, ooze positivity when all I want to do is punch the shit out of a wall or wail in the shower.

Same yet not.

'I understand,' Mrs Sneddon says again.

Worst thing anyone can say is that they understand what you're going through when, clearly, they haven't a scrap of understanding. Ever want to rile someone? Tell them you understand their pain: that'll work a treat. Unless somebody has walked an inch in my shoes they couldn't possibly understand what I'm experiencing. Yes, they might get the sadness or loss part, but it's the whole gamut of other emotions they're clueless about. Emotions that consume my every waking hour. Occasionally I flick out of them, reflect on other things, normal things, but it's too fleeting; I'm quickly yanked back into its clutches. Fear, obviously, is the worst. Fear of losing Mum, of me and Danny having to fend for ourselves. I fear a life of hovering above all the action because I've had to care for everyone else.

Then there's the head-numbing isolation. I don't get to experience what my peers are doing; I don't get time to hang about the streets or go to the cinema or attend some crap nightclub or sit in a mate's bedroom listening to tunes all

night. No, I have stuff to do, stuff I can't share with anyone. Sharing isn't part of my grind. OK, Bel knows that Mum is ill and Danny is, well, Danny, but she doesn't know the inner workings of my mind, what I want, what I need. Bel doesn't know how tearful and resentful I often get, or how certain thoughts scare me to death.

Then there's the fact that I'm seventeen. Seventeen, for God's sake. My parents should be chastising me about my internet use. I should be teetering on the margins of criminality, having furtive meetings with online strangers; I should be full of angst and nervous energy and spending insurmountable periods in the bathroom. But I'm too buggered for that. Life equals exhaustion. So what's the point in blurting out all this to Mrs Sneddon? She *understands*, right?

'I want you to have a look at this, Bobby,' she says, handing me a folded A4 leaflet.

'What is it?'

'You don't have to read it now. Take it away with you, look at it in your own time.'

I open the flaps. It's from the Department of Education, but has the logo of a group calling themselves Poztive. How cool, hip and down-with-it are they?

'Now, you don't have to make any quick decisions this minute,' she says. 'Mull it over first, OK?'

I scan. Read bits. Look at some smiling teens. Lots of teeth.

'Erm ...'

'Now, I know what you're thinking ...'

'I'm not sure about this, miss.'

'Just thought I'd let you see. No one is forcing you, love.'

'I'm not really into the whole self-help thing.'

'It's not self-help, Bobby. It's a type of peer-group meeting.'

'It all seems a bit circle time to me.'

'That's not a bad analogy.'

'That's what I was afraid of.'

'It's about shared experiences with people your own age.

You might get something from it.'

'Yeah, apathy or eczema,' I say.

'Some people can be energised by these groups,' she says, pointing at the leaflet. I wince.

'Not for me.'

'Well, I'll just leave it with you for now, love. You make up your own mind about it.'

'Thanks.' I stand. 'Why are you offering this to me now?' I ask.

'Because it's a new initiative,' she says. 'Solely targeted at young people your age, people who might be facing issues outside the realms of being a carer – you know what I mean, Bobby?'

Couldn't possibly have a clue who she's talking about.

'Right,' I say, tucking the leaflet inside my school blazer pocket.

'I applied on your behalf. I hope you don't mind, sweetie?'

'No, I don't mind, miss.'

The bell rings.

'OK, you best be getting off.'

'See you later, miss.' I pull the door towards me.

'Bobby?'

'Yeah?'

'Any thoughts on what you're thinking of doing?'

'I've got double biology, miss.'

'No, I mean when you're done with this place.'

'Not completely, but it'll definitely be something in the sewage industry.'

Mrs Sneddon giggles.

'Go on. Get out of here. Sewage! Would you ever listen to yourself.'

On the way to biology I feel the leaflet rubbing against my nipple. I'm late. I smarten the pace. The leaflet attacks my nipple with vigour. I hate being late for class, having to stand there while some jumped-up power-hound teacher gives you a bollocking. I enter.

'Sorry I'm late, miss,' I say.

Mrs Lennox is a teacher to be feared in the school. She's on the total-nuts spectrum. Bel says she's a people hater and would rather live on an island, fawning over plants and frogs.

I spy Bel behind Mrs Lennox's shoulder. She's wearing an *oh-you-are-so-dead* face, revelling in my tardy transgression.

'Bobby!' Mrs Lennox blurts.

I'm like, what? Seventy-eight seconds late. What's the stress?

'I was with Mrs Sneddon, miss. In her office,' I explain.

'That's no problem, Bobby.' In a nanosecond, Mrs Lennox's face changes from reinforced steel to squidgy putty. 'We've barely started.'

Honestly?

No belittling in front of the class?

No insulting my intellectual capacity?

Nothing?

Suddenly I feel myself wanting to be scolded. I don't need special treatment. I want to be on par with every other dick-head and downbeat.

'Right,' I say, and make my way to a clearly exasperated Bel, who mouths, '*You fucker.*' I raise a victory eyebrow.

'Perk of the job,' I whisper. I might enjoy fleeting moments of special treatment, but I don't crave the full-time sympathy vote.

'Section six, Bobby. We're starting the Krebs cycle.'

I open my book and scratch my chest.

Bel slowly leans into me.

'I hate you, Bobby Seed.'

'My nipple is killing me, so a little kindness, please.'

'I hope it falls off.'

Positive Thinking

Before you attend your first Poztive meeting we'd love to hear a little about YOU.

- 1. Tell us about your daily routine as a young carer*
- 2. Tell us what your plans and/or ambitions are*
- 3. Tell us about your hobbies and pastimes*
- 4. Tell us about anything else we might find interesting*

1.

I get up around 6.30–7, have a quick shower, get dressed then wake my little brother. I make sure he gets washed and dressed properly and has everything he needs for school.

Around 7.30 we have breakfast. I fix my brother cereal, followed by toast and apple juice. When he's comfortable in

front of the TV, I go back upstairs to check on Mum.

I'll rouse her, prop the pillows and switch the radio on. BBC 5 Live or 6 Music.

Usually she needs the toilet so I help with that.

I return downstairs, look in on my brother, and get Mum her pills. Some days she's feeling strong and wants to get dressed and come downstairs, other days she's weak and prefers to remain in bed. I take her some jasmine tea. She enjoys a boiled egg and toast. Most days she wants nothing.

I might have to change the sheets, but not every day. Mum still tries to do this herself, but it's best if I take charge as this usually exhausts her.

I keep an eye on Mum's mood, making sure she is relaxed and happy.

I inhale a bowl of cereal and a glass of water.

I try cleaning as I go.

I sniff through my brother's school bag, make sure he hasn't forgotten anything.

I walk him to his school, point him in the direction of his first class.

I like school, but it's hard being away from Mum; I tend to worry the whole time I'm there, thinking of her safety.

The worry of death never leaves you.

I try blocking these thoughts out and concentrate on schoolwork. By midday I'm shattered.

After school we generally head to Lidl or Aldi to buy dinner or essentials.

Once home I make my brother change his clothes and do whatever homework he has. Always a struggle.

I ask Mum about her day, give her any medicine she needs, then I dive into my civvies.

I come downstairs and do general cleaning chores, just to make sure the house isn't a kip.

I'll scan the fridge and find a meal to cobble together, making sure it's nutritious and that Mum can physically eat it.

My brother is very fussy – he likes pizza, pasta and McDonald's. Veg is tough.

I get my brother to lay the table.

Another struggle.

And, if Mum's legs are in good nick, we all sit down together. These days she has hers in bed.

Once dinner is over, me and Danny do the clean-up.

I can't even tell you the struggle this is.

I go see if Mum needs anything and we chat for a while. She likes to wag on about my future or tell me how great music and stuff was when she was my age. She asks about my day, we talk general rubbish and laugh loads. This is our time in the day to forget about the obvious.

If I can catch some downtime (hate that phrase), I might read or write something.

Very relaxing.

Then all I want to do is sleep.

I get my brother ready for bed: teeth brushed, face washed, computer off.

My Lord, the struggle with that!

I help Mum to the toilet so she can get cleaned and prepared for the night ahead.

When I'm sure there is silence, I might need to put a wash on or do homework or something else.

After that I'm beyond being wiped out.

I go to bed.

Then the day starts again: worry, tiredness ... and so on.

I put the pen down, shake my arm into life again, look at questions 2, 3 and 4 and think: *Someone give me a gun!*

In Arms

Mum's care while I'm at school is far from perfect. Some white coat comes to give her a laughable sponge-down, a bit of food (mush) and administer afternoon medicine. Then they bolt. No circulating the muscles. No fresh air. Zero craic. A twenty-minute in and out job. Gets right on my goat, so it does. But it's the NHS and it's free, so step away from the goat.

No sooner out the door when Danny's nipping at my ankles. See, I haven't told him her MS is worsening, that she's not going to miraculously leap out of bed one morning and treat us to a swift shopping spree in town. I didn't tell him because, well, because I prayed for this miracle too. Pure denial. But now he wants to know the score.

'What's happening, Bobby?'

'Nothing to worry about, mate.'

'Not telling makes me worry more.'

I wet my lips, straighten my shoulders.

'Thing is ...' My voice wavers. 'Mum's developed a type of cold now, Dan,' I spout.

'A cold?'

'Yeah.'

'Like a runny nose and coughs?'

'Well, yes, but a bit worse than that.'

'Worse how?'

'Like a really bad cold that's hard to shake off.'

'So when is she going to get better?'

'Soon I hope, but I've got a feeling it'll be a while.'

'Next week? Next month?'

'Who knows. She's going to have good days and bad,' I tell him.

'Like me.'

'We need to be very patient with her, Dan. Don't demand too much, OK?'

'Roger that.'

A cold? How can I shrink Mum's declining state of MS into being a fucking cold? Maybe I'm trying to convince myself: head wedged up my arse with denial, ill-prepared for what's glaring. As big brother, I should have all the answers for Danny. Still, I need to protect him. But, as Mum taught us, truth lessens the weight and opens the doors; lying shackles you and darkens everything. I guess even truth has to be tempered with compassion; I mean, who benefits

from Danny knowing what to expect until it's facing us square?

'When will it be gone, Bobby? When will she not have it?'

'She's going to have it forever, Danny.'

'That's stupid, all colds go away.'

'Not this one.'

'Will you get it?'

'Don't think so.'

'Will I?'

'No, and stop thinking like that, Danny.'

'I hate it.'

'Me too.'

'I really hate it, Bobby.'

'I know.'

'And I fucking hate those walking sticks she uses.'

'She needs them, Dan.'

'She's like an old granny.'

'Don't say that. Don't ever say that. She needs those sticks, OK?'

'I just want her to be like all the other mums. That's all I want.'

'Hey, come on, buddy.' I wrap my arms around him, squeeze his head into my chest. Try to control his convulsions.

'Why can't she be like all the other mums?'

'Don't cry, mate.'

'I just miss my mum, Bobby.'

And he says it over and over again.

'She's still here. She'll always be with us.'

'I want her every day. To go for walks or run around the garden or shout at me.'

'Me too, Dan.' I find it hard to say anything else after that. We hold each other until the well runs dry.

#1 ... *incomplete*

*there's a rousing future
in us all
except, of course, those who don't
crave its coming*

*there's a rib-tickle
in us all
except, of course, those who don't
care for the howl*

*there's a vast reservoir
in us all
except, of course, those who don't
covet its rise*

I wonder what riches await me ...

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