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So That's the Tale: A Sequence of Vignettes on Caring and Chronic Illness

ABSTRACT

'Disability isn't about being brave, it's about being organised' (Ian Dury).¹

This sequence of vignettes explores a family's experiences of living with multiple sclerosis. The stories are fictionalised, but drawn from my own family, and are part of a wider project exploring varying roles in caring and disability and the relational identities between carers, those cared for and others around them. In my writing, I use the short story to explore the smaller moments in characters' lives, eschewing longer narratives in order to avoid common disability tropes, such as heroism, bravery and stories that foreground characters overcoming their disability. Instead, my vignettes aim to reveal both the challenges and difficulties when living with chronic illness, but also moments of hope and humour.

KEY WORDS

Caring

Disability

Chronic illness

Vignettes

So That's the Tale

I'm hurrying to an OkCupid date when my mother calls on Facetime. After returning from teaching, I'd blow-dried my hair straight and only picked at my tea. *Do you look like your photo?* NorthernUproar2013 had texted. *Nope. I'm actually a middle-aged man.* My phone rings then another message pings as I cross the road outside Morrisons: *I'm in Electric. What do you want to drink?*

Rioja. I like to taste the barrels

☺Large?

Always

I could call Mum back later, but I never know if it's an emergency or not. And I want to dawdle; online dates kind of feel like job interviews. We make quick judgements of each other. Frizz-inducing rain starts to patter my face. I flick open my umbrella, smoothing my hair under my collar, then answer my phone. On the screen, my mother's blonde and grey hair is damp, and her cheeks are pink from the shower; she looks younger than sixty-eight. She starts to tell me about her new ceiling hoist.

'Didn't you already tell me this?' I say.

'No. I told you the story about it being fitted. This happened yesterday.'

'So, what happened?'

My father's hands dart in and out of the screen as he places another pillow behind her head. 'I've just put Mum through the car wash,' he says; he is not a man of jokes, but he has this joke, and he brandishes it every day. The image freezes with my mother's mouth hanging open and Dad's hand pointing towards her as if to say, *here, this*. A few moments later she says, 'Then he lost them. After all that.'

'What did he lose?'

‘The instructions the social worker told him. He wrote them down on an envelope, but we didn’t use the hoist for weeks, and now he can’t find it. We’ve searched everywhere and he can’t remember how to use the flipping thing. Have you got my cardigan?’ she says to Dad while he lifts her left hand to slot it into the sleeve, but her arm falls, and he grabs it and forces it through the hole. He leans over to draw the cardigan in front of her and insert her right hand into the other armhole. I remember that in bed it’s easier for her to wear her cardigan the wrong way round.

I arrive at the bar and peer inside. I recognise him from his photos. He’s sitting alone at a table in the corner, wearing a red and black checked shirt, and has that long, nineties indie hair still so popular in Manchester. On the table sits his pint and a large glass of red wine. He looks up and waves, his face bearing a friendly grin. I wave my phone, indicating I’m talking on it and his smile freezes and disappears. Then he shrugs and sips his drink. I perch on a chair in the smoking area outside the bar. The wind blows the rain through the wooden fence that separates the empty tables from the pavement. Rush hour traffic queues a few feet away, while on my phone, Dad’s hand appears again as he places something else on Mum’s tray—her earphones perhaps.

This isn’t unusual in our conversations; Mum calls and they carry on with whatever they are up to while I observe.

‘Andrew,’ she says. ‘Show her the hoist.’

I can see, suddenly, the ceiling where a hoist is attached to a rail going over Mum’s pneumatic bed. She has been a full-time bed user for a couple of years; she moved into the living room so she wasn’t stuck in her downstairs bedroom on her own. Now, she dislikes the fact people traipse through all the time, that she sleeps, eats and lives in the same room. The screen veers back to her while I tap my foot. I glance over. He knocks back the last of his

pint, then looks around at me, raising his eyebrows. I mouth. 'I'll be five minutes, it's my mother.' He turns away and stares at the space where I should be sitting, at the glass of Rioja.

So what do you do at the weekends?

I often help my family.... caring... you know...

Respect.

'Three times he tried to get me in the wheelchair with that thing,' Mum says. 'We were going to see the neurologist. The sling is supposed to go under you and lift you into a sitting position, but he couldn't remember which of the sling's loops to attach to the hoist so my legs were in the air. No wonder I was upset. No wonder I got suicidal. And he had the cheek to say *he* was suicidal. I was suicidal. Not him.'

'What do you mean, you were suicidal?'

'I was the one suicidal with the hoist,' Dad says, as he fits another pillow under an arm. 'I had to deal with the damn thing.'

Mum gives me a conspiratorial look. We know she has the right to feel suicidal. Not him.

'Not that pillow,' she says to Dad, 'The feather one,' and they start quarrelling over which pillow goes where.

'So,' she says, smiling, 'that's the tale!' She peers at me. 'You look tired. Have you not been sleeping? There's bags under your eyes. How's your hair? Is it still thinning?'

'I have to go now,' I say, moving the phone away from my face. 'I'm meeting someone.'

'Who?'

'Oh, just a friend.'

‘Go meet your friend, Michelle,’ she says, but neither of us hangs up. She has to get Dad to end the call for her. Dad’s hand appears again, then there’s a deep bark from somewhere. ‘That must be Toby,’ Mum says. ‘He’s at the backdoor. Let him in, Andrew.’

Dad disappears to open the door for the neighbour’s Great Dane, who often visits with his owners, Mike and Trisha. Toby sits on the couch like a human, his paws reaching the carpet.

‘Toby’s started visiting on his own,’ Mum says. ‘We leave the gate open between the gardens, and he trots over every day for Andrew to rub arnica gel onto his hips. He’s having trouble with them again. Let me tell you about the chocolates. There were none left in the white cupboard,’ she says as if the idea of the hall cupboard not containing Thornton’s chocolates is inconceivable. ‘Two boxes of Continental we bought, and you know what, he’s lost them. No idea where he put them. No idea.’ She looks to see if Dad’s come back, then lowers her voice. ‘I was so annoyed, what with him losing both the hoist instructions and the chocolate, I could have got a gun and shot him.’ She pauses. ‘But I couldn’t because my hands don’t work.’

I glance around the bar. There’s just the empty pint glass and the full glass of wine on the table. He’s not at the bar ordering another. Maybe he’s in the loo or the beer garden at the back, having a smoke. After I hang up, I go and sit down in front of the wine and run my hands through my damp hair. I suppose it’s a bit rude being late then standing in the doorway on the phone for—I check the time—twenty minutes. My last boyfriend got fed up and dumped me after I stood him up on his birthday when Mum had an accident.

I look at my phone. No messages. I start to type, *I’m here where are you?* But then tap to look at a photo Dad sent of the hoist. The sling dangles over the empty bed, which reminds me of a shot in Jurassic Park, of a crane lowering a cow into the pen of the Tyrannosaurus Rex, and then lifting out an empty and ripped harness.

I sip my wine. ‘You won’t believe it,’ Mum had said when I called a couple of days ago. Dad had inserted her fingers into the handle of her coffee cup, which if placed correctly, could hold the cup and she could sip it unassisted through a straw. She took a sip and told me that Liz the social worker had shown Dad how to use the hoist and he had written down her instructions on the back of an envelope. ‘You see. We’d spent our savings on the hoist—there wasn’t enough funding, but Liz had insisted that your Dad couldn’t keep lifting me.’ She paused. ‘The straw...’

Dad put the straw back again. She took another sip and said, ‘So your Dad had me back in my old bed while they installed the hoist. Liz said he should practice using it on her. She lay on the bed, showing him how to lean her forward to get the sling behind her back and under her legs.’ Mum chuckled. ‘He felt so awkward, didn’t you?’ Dad’s head swung into the screen, and he shook it, also laughing. ‘I didn’t know what part of the social worker I was permitted to roll!’

‘And while he was doing this, Mike and Toby came in!’

‘They just walked in?’

‘They always pop round. Mike found your Dad not rolling me, but another woman around on the bed! He was very confused. An odd form of infidelity.’ We both laughed, Mum losing her straw again. ‘Oh, you’ll never meet a man like your father,’ she said, but her tone didn’t reveal whether this was a good or bad thing.

I look around. He’s not come back. The bar is mostly empty. Just one young man with a laptop in the corner. I get up again and check the door to the back beer garden. There’s just vacant tables and chairs. I watch the rain, how it drips off the parasols like great fat tears.

Maybe I was so engrossed I didn’t notice him leave. No messages. Nothing. That’s my strike gone. Or is it his? I go back to the table and finish my Rioja to smooth it over. I order another at the bar, this time for the guilt that hums in the background, that feeling of

never really doing enough. The barman fills my glass to the top to finish off the bottle. I give him a smile, feeling a sweeping gratitude for this extra bit of wine, and carry it carefully back to my table. I'll go home when it stops raining, when everything has been smoothed over.

'So that's the tale,' Mum says to end her stories about Dad's mishaps. She never complains about her illness. Her stories are buffers; tales of things other than what she feels.

The Pillbox

Andrew is rifling through the scarves hanging on the back of the bedroom door. His wife had asked for a blue scarf and blue earrings, but the pieces of floaty material all look the same. The cat—he or she, can never remember which, and anyway, aren't all cats a 'she', really?—has followed him through and sits in the doorway, watching, judging. Not the same as having a dog; their old dog was a trooper, always there, giving him support, his wing-poodle. Next door's Great Dane preferred women to men, and Andrew was just the doorman, the butler for all the pets.

The old downstairs bedroom is his room and she sleeps in the living room. He hauls the scarves onto the single bed. The cat, cheeky blighter, jumps up and finding a comfy dip, snuggles into the silk.

Must be months since they last went out. Just to the Trafford Centre. The days when they had a season ticket at the Royal Exchange Theatre are long gone, with his free carer ticket, though he still paid, mind. They are finally used to the hoist, and though they are nearly ready, they will never leave the house if she insists on these blue earrings.

When she gets an idea in her head, when she wants to wear a particular thing, the one thing she's not seen in two years, then nothing else will do. Nothing he can find at least. And

today it's the blue sapphire earrings, well, not real sapphire, some other blue stone they had on QVC, and the flipping matching scarf.

He searches through the jewellery box, but he can't see any blue ones.

Then the Alexa thing rings; his wife's weak, tinny voice announces through the speaker, 'Hey, Andrew. Can you come through.'

He shoos the cat off the scarves, then carries the whole lot through to the living room. She is sitting on her wheelchair, with the new headrest to support her neck. These days she has to be tipped slightly backwards, so her feet stick out, and pushing the wheelchair is like driving a lorry; he has to turn corners at a wide-angle. At least she's dressed, shoes on, some makeup, though she'd spent the whole time complaining, 'Don't just rub the foundation in one spot, Andrew. It goes all over my face.'

'Which one?' he says, letting the words out in a sigh.

'Never mind...'

'No, no. I'll find it.' He dumps the scarves on the couch and holds up the jewellery box. 'Which ones?'

'Bring it closer.'

He holds the box in front of her, his arms heavy with fatigue; he wakes two or three times a night, blundering through, always fearful something's happened.

She's frowning. He looks in the box too. Rows of small earrings, dangly ones, rings in all sorts of colours.

'Lift the tray out.'

Underneath, silver bracelets, necklaces of pink pearls.

'What's wrong with these?' he says.

'They're the wrong ones!'

‘Well I don’t know. I really don’t know!’ he says. Yes, wearing earrings makes her feel good, but surely any earrings will do? ‘What about these?’ he says, holding up a perfectly fine diamante pair.

‘No, they’re not the right ones.’

‘Well, what do you want then? What *do you want?*’ His voice has risen. Her face crumples. She breathes heavily and starts to cry, and he can see things turning, their day being ruined, them never leaving the house.

His wife sobs in front of him, her hand slipping from her knee to dangle down the side of the wheelchair.

‘Lovey, I’m sorry. It’s OK...’

‘Let’s not bother,’ she says. ‘Let’s not bother going out. Just put me back, put me back in bed.’

He flops onto the couch, landing on the piles of scarves, and puts his head in his hands, pressing his palms into his face. ‘It’s always like this,’ she says. ‘You can never find anything. Every day like this.’

He turns to the jewellery box beside him, and breathes deeply, saying, ‘What about these, lovey?’ But she just shakes her head. As he stares into the box, he has a sense that they will never be the right earrings; there are no right earrings. He will never find them. That whatever he does will never be enough. He can’t make up for her illness, he can’t make her better. Not until the paradise at least. But in moments like these, even years of Bible study and his hope for the future recedes, and he’s just a man fumbling with earrings. It feels sometimes that all his attempts fail; she was always so sharp, and he can never do things for her the way she wants them done. He can’t really be her arms.

Before, he never had to think about finding things, about cooking, about where things went or how to run a house, but now, these tasks are like learning a new language; he can never work out how to do them.

She was his first love, his first girlfriend. When they met at the Kingdom Hall in Oban while he was pioneering with his friend and listening to tapes of Bob Dylan, she'd just got off the boat from Australia. She stuffed her hands in the pockets of her duffle coat, frowning at him over her glasses. It took a while to fall in love. But they had. And now, he leans over to place her hand on her knee, and he looks around the room, hoping for an answer, some kind of inspiration, a flash of divine light; something to keep them going. He sees it. He spots her pillbox.

All her tablets are ready to take morning and night: Baclofen, Gabapentin, Tegretol, Sertraline. He jumps up and rummages in the drawers beside her bed. There, a spare pillbox is still in its plastic, the days of the week clearly marked on each slot. He holds it up.

‘What are you doing with that?’

‘Look,’ he says. ‘Choose which earrings you want to wear, plan them for each day, and then they are ready for me to find.’

She nods. ‘OK,’ she says. ‘We can organise the earrings.’

He pulls out the drawer of the jewellery box, letting her choose a pair for every day of the week, then he carefully places them in each section of the pillbox, ready to wear for each day. He holds it in front of her and she smiles. He can do this at least. This one small thing.

Goals

You were on holiday when you realised something was wrong, really wrong; as you walked to the beach in Bordeaux, you were struggling behind us, when you clutched your long skirt around your legs, saying you were going back to the gîte as you felt a hot rush down your legs; later that year, after granddad (your father) died, and I was studying in Paris, the illness came on suddenly, dizziness when you tried to walk; after tests you hoped the MS could be controlled or at least slowed by steroids and a strict diet; then years later, there was an afternoon when you forgot—just for a few minutes—your limits, your incapacities: after returning from a trip to Asda and the MS Centre where you’d sat in a pressurised tank and breathed oxygen through a mask, which seemed to boost your energy, and I pushed you up the ramp into the front door and helped you to stand, then went to unpack the car, (thinking as I carried the bags of shopping how much I hated my PhD, how I couldn’t even bear to sit at my desk) while you stretched your legs by walking down the hall, holding onto the rail; you still had enough strength to take a few steps, buoyed by the dose of oxygen, though you had to check where to place your feet, swollen in Velcro-closed shoes (easy on, easy off); you paused at the door of your bedroom, glimpsing the commode, the new QVC box of card-making supplies; then you took a few more steps, but the phone started to ring as you reached the two steps that led down to the backdoor and the living room, (the whole back part of the house being lower than the front); all you had to do was get down those steps then you’d be in the living room and you could grab hold of the couch and it was only another step or two to the phone and perhaps it was my brother calling from Tokyo (his move to Japan as a post-doc in physics still a wound, worsened by the infrequency of his phone calls) or Brother Brown from the Kingdom Hall with a message for Dad, so you held onto the rail with your left hand and lifted your left foot down the step, then the right foot, though you had to keep

an eye on that one, the right side of your body taking a worse hit from MS than the left, while the phone continued to ring; you had always prided yourself on your independence, saved for a car at seventeen, in the 1970s you special-pioneered around Queensland; later, you cared for the family in Salford, baked my brother special egg-free apple cakes when ‘free-from’ wasn’t a thing, when allergies weren’t believed by doctors—those long, lonely years of my brother’s asthma, Dad never having to consider practical things like where to store potatoes and carrots (these days stashed in a pan on the windowsill) or how long to boil broccoli (an hour until it was mush); you kept the house tidy, though forever plagued by the pile of ironing and by thoughts of your mother who had ironed every single thing; you always worked, always had your own money, took evening shifts at Norweb’s call centre, listening to mothers unable to heat their baby bottles due to power cuts; Dad’s wage barely covered the mortgage during the Thatcher years with interest rates at 15%, and it was years before you’d saved enough for that holiday in France, and now you were so close, of course you could answer the phone, so you stepped down with your right foot, but then slipped off the step and fell heavily, your hip slamming onto the mat, your head banging against the wooden door; pain shot out from your hip, your right leg poking out at a strange angle, and as the phone stopped ringing and I charged down the hall, you knew that your hip was fractured and you wouldn’t be coming back from it.

The Burns

‘Pain’s a funny thing,’ my mother is saying. ‘Sometimes, if your Dad touches my legs when he’s turning me in bed, it hurts more than the scalding.’

My mother has been put through her daily car wash, and after her shower, lies half-naked on the bed. She is on her side, and her face is pressed into the sheet when I come in the room in search of my purse. Dad is peering at her as if she is the engine of an old, beloved car; she requires tinkering and his particular brand of maintenance.

My father has always loved cars, particularly old cars in need of upkeep. Hidden at the bottom of wardrobes are stacks of *Classic Car* magazines. His car engines have been held together with coat hangers and string. For years, I drove a 1980's Nissan without a working speedometer, petrol gauge or locking doors, which he had 'fixed up' for me. Nowadays, they have a Motability car, and I use their old Renault since it enables me to get to them in case of an emergency.

I rummage through the cushions on the chair next to her bed. 'Won't be a second.' I turn to see him pulling her nightie up over the scarring on her thigh to check the wounds. 'Do you need any help?'

'Yes, of course!' Dad says like I shouldn't have to ask. He shakes his head while he puts the ointments and bandages back into a plastic bag.

'How do the scars look?' Mum says. 'He keeps saying the burns look better.'

'Not great.'

'They're nearly healed,' Dad says, pointing to the scars. 'There's white around the edges. See.' He huffs as if annoyed at our doubts, at our negativity, and turns to plump up the pillows that will be used to prop her up in bed.

Mum can't turn to see the scarring on right side, hip and thigh. 'They're not "nearly healed",' she says. 'I know they're not.'

'I'll take a photo, so you can see?'

Though Dad is an honest person about big things, he is also an optimist and through his optimism, a purveyor of small lies. Her scars have healed. He hasn't lost Thornton's

chocolates. They haven't run out of toilet rolls, of course he bought some. There are definitely not piles of *Classic Car* magazine at the bottom of the wardrobe. Oh no, he threw them out.

Since Mum is a bearer of harsh truths to me (your hair's looking thin again!) she expects no less in return. I find her iPhone and take a close up of her thigh and hip. I try to show the photos to her. She squints because she's not wearing her glasses and half her face is buried in the mattress.

'I'll show you properly when you're dressed.'

Dad huffs and tuts while he finishes covering her scars with bandages. 'They are getting better,' he says, almost to himself. I catch Mum's eye, and despite her face being buried in the pillow, she manages to raise an eyebrow. I pull down her nightie, and then we turn her onto her back; she doesn't cry out or indicate if any of this hurts. Dad's quiet while he positions pillows under her wounded hip and behind her head, while I push the bed-tray with her laptop into the room. Usually he chats non-stop while helping Mum in bed, and she has to say, 'Andrew, stop talking and get on with it.' But he's still not himself. He's greyer, tired, and as I show the photo to Mum, he turns away, not wanting to look at it; not wanting to remember what happened. He carries the used bandages out of the room. I can hear him in the hall, muttering to himself. The front door opens and clangs shut. He must be putting things in the bins.

We examine the photo of mottled purple scar tissue, the edges starting to heal to white (Dad is partly right) but there are still areas of raw flesh. My skin starts to prick and I shudder. The scars from when scalding hot liquid had spilt on her right arm, side and hip, and dripped into the bed, and she'd sat in boiling peppermint tea because she couldn't move out of the way.

The night of ‘the burns’, I had been on my second glass of wine after commuting home from my new lecturing job. It was after ten. I had turned into one of those respectable home drinkers, who works her way through a few bottles a week.

My parents’ home number beeped on my phone. I sipped some more wine. Not now. I didn’t feel like talking now. I drank some more. The phone rang again, so I sighed and picked up.

‘He won’t stop touching my arm,’ Mum cried. ‘He keeps touching it!’

‘I was just trying to give her a cup of tea...’ Dad said.

‘What?’ I said.

‘He spilt it all over me. And he won’t stop touching my arm. Tell him, tell him to stop touching my arm. It’s burning!’

‘I was just,’ Dad said. ‘Just trying to plug her laptop in.’

‘He knocked my hot tea all over me! Stop touching it!’

‘Don’t you think you should call an ambulance?’

‘I told him to get some water, but he took ages and then pats it on my arm! It’s burning!’

‘Just phone an ambulance! Then call me back immediately.’

In a couple of minutes, my phone rang again. During that time, I had considered my steadiness and whether it was legal to drive or not.

‘The boiling tea went down into the bed,’ Mum said when I answered again. ‘That’s where it hurts. I’m sitting in it.’

‘Tell him to pour cool water on you. Pour it on you.’

‘It hurts,’ she kept saying as if I didn’t believe her. ‘Can you come?’

I got off the phone and looked at my empty wine glass. Adrenaline pumped through me. My head felt suddenly clear; I would drive over. I could do it.

As I drove, time slowed as if I was driving a tractor through Manchester to get to my mother, every headlight, every streetlight stinging my retina. I had never felt so alive, so awake to every car, every pedestrian on the road.

By the time I got there, the ambulance had arrived, and two young Scouse paramedics were crammed into the small living room. They chatted with Mum, flirting, while they lifted her onto a stretcher, ‘Oh, Joan, what are we going to do with you, hey?’ Dad stood behind them, for once not telling them how to move her; his face was white and strained, arms by his sides, unable to believe what he’d just done.

Over the next few months, they waited every day for the district nurses to come and change her bandages. The scalding was third-degree in places and took months to heal. Dad developed strong opinions on how the bandages needed to be changed and how the various nurses were either not covering all of the burns or the tape they were using irritated Mum’s skin. Each day a different nurse, who either didn’t do a good job or didn’t turn up until midday.

When I visited a few weeks later, Mum’s right arm was bandaged, and her left hand held a plastic mug propped on her stomach (she could prop up a cup if you inserted her fingers carefully into the handle). In the mug was a straw and with the straw, she was sipping red wine. Her cheeks were flushed.

My family might be religious, but it doesn’t mean they are stingy with alcohol. In fact, the more they drink, the more they like to share their drinking.

Dad, on hearing me come in the front door, hurried through bearing a grubby tumbler of wine (having broken all the wine glasses, he now barely rinsed the remaining glasses in case of breakage). I’d promised to come at lunchtime, give him a break by helping out and making tea while he rested. Instead, I turned up at five pm since I’d been trying to finish my overdue marking. If Mum looked a little flushed with wine, then Dad seemed quite drunk. In

the kitchen, Radio 4 was on. There was an empty bottle, and it appeared he'd emptied all the cupboards onto the table while he roasted chicken. This was the one thing he could make, and he liked to listen to the cricket or Radio 4 in the new downstairs kitchen, which had finally been cleared of junk and built by my cousin, with patio doors onto the garden.

Since Mum could no longer feed herself, Dad liked to help her eat first, and then relax afterwards with his own dinner. I said I'd feed her, but he insisted he would do it. I came into the kitchen to see he had served two bowls of food with spoons. One for Mum and one for me, whether he thought we should all eat with spoons since Mum did, or he couldn't differentiate between us, I wasn't sure.

I was trying to be a vegetarian, but not 100% successful, so I quietly got myself a knife and fork, then went to sit on the couch while Dad sat next to her bed on the hard wooden chair he sat on for this purpose.

'Dear Jehovah,' he said, as he and Mum closed their eyes. 'Thank you for the food and what you have provided for us today. Thank you for the strength you have given us...' Then he stopped, swallowed, his voice wavering, and then said, 'Amen.'

We were all quiet for a moment, me because I had not been religious for a long time, but that was another story, and Dad because he was swallowing, holding still as if trying not to cry. Mum said nothing, her eyes closed, possibly in her own prayer. A few moments later, Dad cleared his throat and launched into what he had been listening to on Radio 4. QVC was muted on the TV on the wall. Mum nodded her head to turn up the volume via the remote control 'spot' on her glasses, which transmitted a command through her laptop to the TV on the wall. Today's Special Value was her favourite SBC Arnica Gel, while Dad held a spoonful of chicken in the air, saying something about Eddy Mair and a programme on Syria while I closed my eyes, which were sore from worrying about things every night, between two and five am. Dad continued talking, his spoonful failing to go near Mum's mouth.

‘He does this,’ Mum said. ‘Won’t stop talking when he’s been on the wine.’

Dad turned to me, resting the bowl on his knee. ‘We’ve not been out,’ he said quietly. ‘We can’t go out. Every day we have to wait for the nurses. Every day.’

I didn’t know what to say to this. He picked up more chicken and overcooked broccoli and gave Mum a spoonful, then he surreptitiously whisked a roast potato into his own mouth.

‘Did you see that?’ Mum said. ‘He’s stealing my dinner. He always does this. Steals the crispy bits!’

‘I do not,’ Dad said, through his mouthful. ‘Of course, I don’t.’

Now, as we look at the photo of the scalding, I say, ‘It’s whiter around the edges where it’s healing, but the centre is still raw.’ My skin pricks as I think about having to sit in a bed of boiling tea.

She is sitting up in bed, dressed in her nightie again, hands propped on cushions and her cardigan on the wrong way round. In the hall, I can still hear Dad. The door of the cellar bangs; he must be bringing up washing. He never stops. Just does one thing after another.

‘OK,’ she says, satisfied now she’s seen the damage. ‘Will you trim my fringe?’

I take the scissors and comb and snip her hair until it’s just above her eyebrows.

‘Would you like some layers around your face?’

‘Nope.’

‘Just one or two?’

‘I’ve seen the layers you give your cat.’

This is disappointing. I comb through her blonde fringe, checking it’s level. Then I find a lipstick, a vibrant berry, and apply it carefully. There. Lovely. I hold up a hand mirror for her to see. She looks fresh-faced and young.

‘He’s not the same,’ Mum says.

Dad walks back through with the wash basket. ‘You OK, Dad?’ I say, but he just shakes his head as he walks out again.

‘Check on him,’ Mum says to me.

‘Sure.’ I follow him to the small bedroom on the ground floor, where he sleeps. He’s sorting through the piles of duvet covers. ‘This is a single, isn’t it?’ he says, holding it up.

‘Yeah. Are you OK?’

He opens his mouth as if to say something, but then shakes his head as if what he was going to say was silly.

I look around the room. What could I do to make him better? His single bed is ruffled, not made. It seems a shame for him since he’s six foot. ‘Why don’t you have the double bed in here. It would fit.’

‘No, no, I couldn’t. Not on my own.’ He places the duvet and sheets on the bed and darts out the room again. On the floor are piles of *Watchtower* and *Awake* magazines, his *New World Translation*, then his papers of notes and scriptures scribbled down. He can quote any part of the Bible, loves talking to people on the ministry. Beneath the papers, a copy of *Classic Car*, even though he loves his Motability car. Next to the bed, a drawer is open, vests and socks spilling from it. This room, now that neither Mum nor visitors see it, rarely gets tidied. I flop onto the bed and sit there for a moment, all my energy gone. *Not on my own*. I’d never thought of that, of how Dad might feel now he no longer shares a bed with Mum, and a sharp stab of sadness hits my stomach; I want to protect him from it, somehow. But, you can’t protect others from the pain they feel.

The Clear Out

‘We’re here!’

Mum stops nodding her head as I bring my partner into the living room. She’s squinting at the laptop on her tray.

‘I’ve brought reinforcements. This is Simon.’

‘Hello Simon,’ she says, and gives him that focused stare when she’s really taking in someone, noting his hair (lots of it), his red *Anti-Fascist* t-shirt. I’ve told her about my new boyfriend and that he is keen to help out.

‘Simon’s good at organising things,’ I say. ‘That’s his job.’

‘We only need you to put stuff in the hall. Your Dad will sort through...’

‘He won’t get round to it. We’re going to sort it all *today*.’

Mum’s about to argue, so I say, ‘Show Simon your ‘dot’. She bobs her head. We step closer to her bed and peer at her screen. ‘Mum can type by nodding and the dot on her glasses is a remote control.’

‘What are you doing now?’

‘I’m just sorting my torrents,’ Mum says, bobbing her head again.

‘I’m sure the council will be pleased you’ve put it to good use,’ I say, then usher Simon through to the backroom, where we stare at the room full of piles of boxes, the two wardrobes with bags of clothes stuffed in them. A table and chairs. Boxes of books and black bags of old curtains and duvets.

‘How long has this been here?’

‘Maybe fifteen years...’

‘That’s a lot of stuff.’

I tell him some of the duvets and furniture were here when they moved in. It had been a small old people's home when my family bought it, thinking it would be more accessible with its wet room and stairlift, but the kitchen is upstairs and not actually accessible by the stairlift. Mum has to listen to Dad stomping above her head, dropping plates, then denying anything is broken. So, we've been meaning to turn this downstairs back room into the kitchen.

Simon is already peering inside a bag. 'It can all go!' he says extending the 'all' with relish.

'We'll have to get is past Mum. And then Dad will be lurking in the hall ready to rugby tackle you.'

'Don't worry. We can do this.'

Dad comes in with a bottle of cider for each of us, asking what Simon does. He says he's a community organiser for Hope Not Hate, the antifascist organisation, while they take out old chairs, and he's in the North West to oust Nick Griffin as regional MEP. While they're talking, I untie a black plastic bag full of material from when Mum used to sew and make her own clothes. In a nearby box, there are piles of patterns from the eighties. I carry the bag of material through hoping my mother doesn't see it. I know throwing this out will be a struggle for her so maybe it's better if she doesn't even realise that's what I'm doing.

'What's that? My sewing?' she asks like she has x-ray glasses, which is always how it feels when she looks at me.

'Just some old material,' I say, trying to get through the room.

'Can I see?'

'OK.' I sigh as I pull out a folded piece of maroon corduroy, and bring it over to the bed.

‘I bought that from Eccles Market, I was going to make it into a suit. ‘There’s a Simplicity pattern there somewhere.’

‘Well, why didn’t you make it then?’ I snap. I don’t want to be pulled down nostalgia lane.

‘Well, I was just so tired. For years I was so tired and didn’t know why. You remember me going to bed after work.’

‘Yeah.’ I do. I remember standing in the doorway of the bedroom, my mother hidden under the sheets, then tip-toeing away. ‘There’s no point keeping it now,’ I say.

‘I know there isn’t! Of course I know that...’

‘I’ll make a pile for the charity shop.’

She nods. ‘OK.’

Simon and Dad carry through boxes of books, Mum’s murder mysteries and thrillers. Simon says he could give them to a library, and Dad says that’s a good idea. He could take them to Height Library. As I carry through a bag of old duvets, Mum doesn’t ask to look at them. She turns her face away so she can’t see.

Later, when the back room is mostly cleared, I pause and look in the last couple of boxes, the voices of Simon and Dad echoing in the hall. The sun flickers in the window. It will make a lovely kitchen. So much bigger than the poky one upstairs. It’s a shame we didn’t manage to do this when Mum was more mobile. In our old house they didn’t hoard like this, didn’t let things accumulate. All that stuff feels like some kind of geological strata, built up in our lives. After Mum’s diagnosis, they moved here, but no one was able to sort or clear things. I find a box of Dad’s *Classic Car* magazines. Dad comes in and sees them. ‘I’ll take those out,’ he says, but then after he’s gone, I hear the stairs creak. He’s squirrelling them away upstairs. I look in the next box. Folders of university work from my MA. I kneel down and rifle

through. I pull out a dusty copy of the rambling essay I wrote about Becketts' *Trilogy*. Beneath it, I find my creative work, all the stories and bits of writing from when I first started to write about the messiness of illness, of caring. The marker said my writing had no structure. And she was right. They had no shape, no beginning and end; I hadn't been able to turn these experiences into a story, at least not then. I feel hot and cold all over, then a sudden heat in my stomach. I get why they have shored up all these things, kept them against the vicissitudes of illness—the need to hold onto bits of yourself, to not let them go. But my life too has stalled and stuttered; it's also part of this strata. I carry the box outside, but then hide it in my car so I can go through it properly later, alone.

When we've finished, Simon and I admire the piles of belongings, labelled with their destinations: charity shop, recycling, local library, the tip.

'Good work,' I say.

'Doesn't it feel good to throw things out?'

'Yes and no.'

I go to say goodbye to my parents, but pause in the doorway of the living room; they don't seem to notice I'm there. My father is sitting on the chair next to Mum's bed, and out of a black plastic bag, he pulls out pieces of material, and my mother looks at each and nods, like she's saying goodbye: the maroon corduroy, a thick grey tweed, then a piece of blue satin, its price tag still stapled to the fraying edge. 'Don't worry, Joan,' he whispers. 'When they've gone, we can put these in the loft.' At the bottom of the bag, he finds a *Vogue American Designer* pattern, the packet yellowing and unopened, still waiting to be made.

Worse Than Death

I tell my dentist that my mother has to have her teeth brushed by someone else, my father mostly. I do it when I'm there, though I try to avoid this task, preferring to be her beautician or manicurist. It's hard not to bang the toothbrush against her teeth and gums. On top of this, Mum has neuralgia in her face and brushing can cause electric shocks. When these happen, nothing seems to ease them apart from whisky, because being of Scottish heritage, her pain levels are particularly receptive to the prescription of single malt, so she holds Glenmorangie in her mouth until it calms the nerve. I tell my dentist about this while we wait for my mouth to grow numb. He leans over me, saying, 'There are things worse than death,' and begins to drill.

My dentist is from South Africa. He's white, but his family were defiantly left-wing and had been involved in the anti-apartheid struggle. He said he'd been a member of a group more militant than the ANC. But the year apartheid ended, his marriage fell apart. 'A divorce is a divorce, he said at another appointment. 'You are sundered, riven apart.' After his divorce, he moved to the UK.

The smell of ground-up metal fills my nose—he's replacing an old, broken filling, which has decay beneath it. I flinch as a sharp pain reverberates down my jaw. I hold up my hand politely. 'Excuse me, can I have some more?'

I assume he's going to tell me that having an incurable degenerative illness like multiple sclerosis is worse than death. However, after he's injected my gum for a second time, he says, 'There's nothing worse than seeing someone you love become ill. And to watch them deteriorate. Nothing.'

He starts to drill again. I feel disconcerted by this statement, but because my mouth is packed with tissue and the assistant is holding a tube to suck out my saliva, I can't give a full and adequate reply. One of my hands squeezes the other as if to provide it with reassurance.

Mum was looking at me when she said, 'I didn't eat for two days. I had decided to starve myself. I wanted to end it.' That was the last time I knew things were really hard. Now they have direct payments to pay two Sisters in their congregation to help with showers and night-time changes. Other friends in their congregation make them meals, which they deliver in neatly labelled takeaway boxes. The last time things were really unbearable was when they had care workers from an agency, outsourced by the local council. For a few weeks, two care assistants came in the mornings. Mum was very unhappy about it, and when I visited, she started to list what they did wrong.

'But you need help every day,' I said. 'Dad really struggles. He's exhausted.'

'You don't know what it's like having strangers in the house. I didn't mind the nurses. They're professionals. And I've had carers in the past, remember, when Dad worked. But these women...' She knew they weren't paid enough, and they had to walk to each service user, spending twelve to fourteen hours a day on their feet because they weren't paid for travel time. But they didn't listen to what she wanted. They talked over her as if she wasn't there. They treated her like she was stupid. Then they'd had a row because blood had appeared in her stools and they'd insisted she immediately go to A&E, which was their protocol. 'I didn't need to go. This sometimes happens.' They hadn't listened, standing over Dad until he phoned 999.

Mum ended up telling them to leave.

'I got him to call the agency and tell them not to come again. I was so upset I didn't eat for two days.'

'What?' I said. 'You didn't eat at all?'

‘No. I decided to end it all, just starve myself to death. I’d had it. I’d had enough.’

‘Oh, Mum, why didn’t you call?’

She ignored that, saying, ‘I just told him I didn’t want any food, and for two days I didn’t eat. But,’ she said, and then there was a gleam in her eye as she paused to give me the end of her story. ‘The next day, he came in with a roast dinner and sat next to me on the chair and started eating it right in front of me! I was so hungry I said, Andrew, give me some of that roast potato.’

When she told me this I’d laughed, in awe of her mischievous irony, of how she was deadpan about her story of suicide. Dad had blustered through it all, pretending it wasn’t happening, not able to countenance such a thing. Roast potatoes had saved her.

Now, my dentist presses the new filling into my tooth. ‘When you see someone you love get ill...’ he repeats, but he doesn’t finish the sentence. He’s not talking about my mother. Her fate is not worse than death. Ours is, the ones who watch. I remember a sharp pang, a sudden moment of loss, when, years ago, I saw her try to sign a check, but her signature, which had been so neat and italic, had become a scrawl, unrecognisable. Watching a slow tide of creeping adjustments amidst moments of irrevocable change. But mostly it’s just how things are; we get used to it. It’s not unbearable all the time. But that’s my perspective; that’s what I tell myself. Maybe it’s different for Dad. He keeps his feelings tightly hidden, only occasionally after a couple of wines while cooking the dinner will he turn to me and say, ‘It’s just...’ but then he shakes his head as if he can’t explain how he feels, and the moment passes.

As I swill my mouth in the tiny sink, my dentist looks at the scan of my teeth on the screen. He sighs as if he has made himself sad talking about this thing worse than death. I wait, and for a moment, the room is silent. But then he glances around and sees my face. ‘I had to burn your gum away. It was overlapping the broken tooth. I didn’t charge you for it,

though.’ I dab my cheeks with a tissue, but my skin is springy with numbness. ‘Here,’ he says, and, leaning in with a clean tissue, he wipes the blood and then the tears off my face.

¹ Cited in Reach disability awareness leaflet, Chorley, 2013.

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