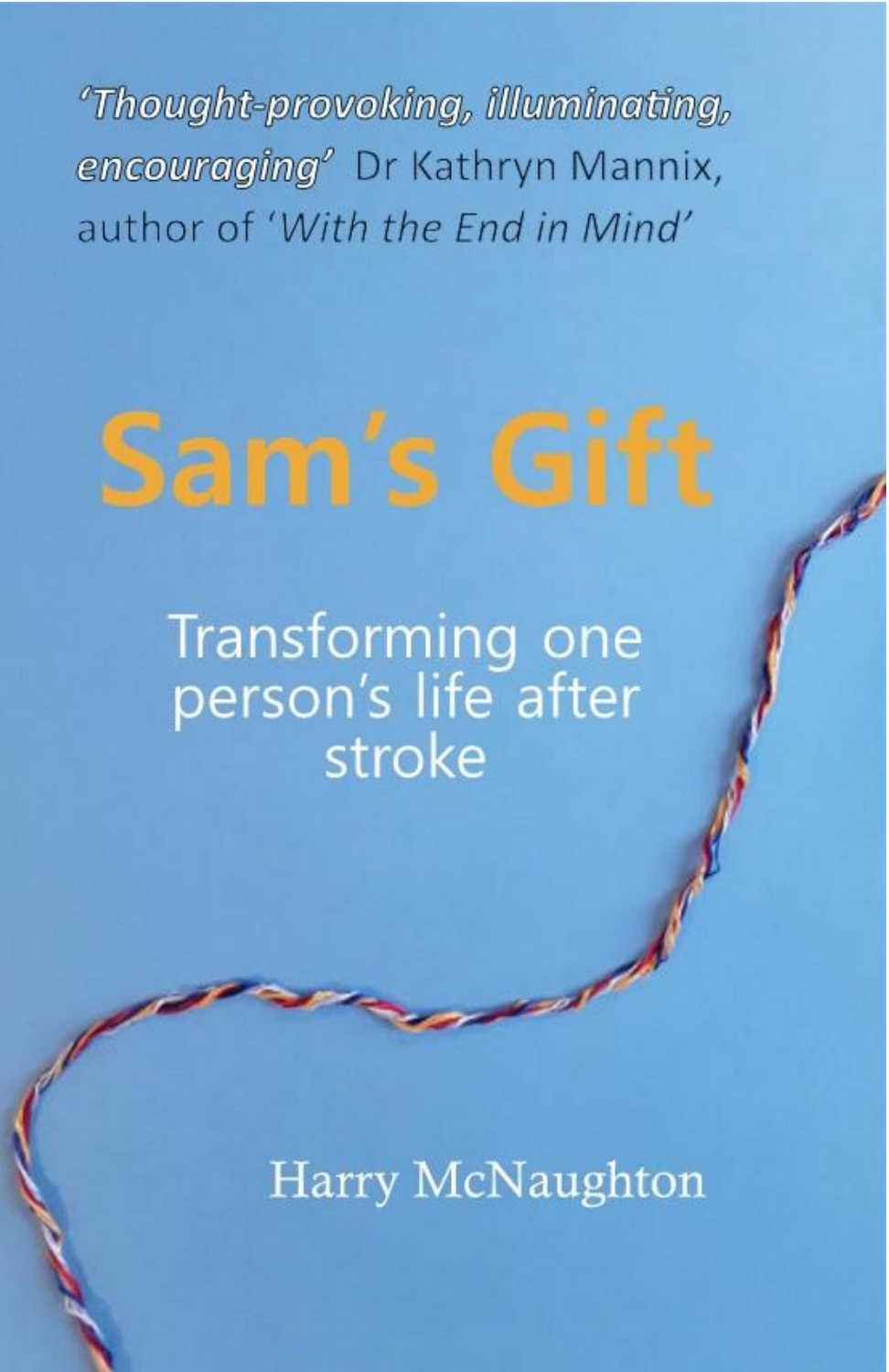
'Thought-provoking, illuminating, encouraging' Dr Kathryn Mannix, author of '*With the End in Mind*'

Sam's Gift

Transforming one person's life after stroke



Harry McNaughton

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For Amanda, Gillian, Andrew and John

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The playlist and links

You can choose to play an accompanying *Spotify* playlist called *'Sam's Gift'* while reading the book. It is about 4 hours long. It is an eclectic mix of contemporary, not-so-contemporary, classical and world music and features many of the songs and pieces of music mentioned in the book. Click here for the playlist, or otherwise go to https://open.spotify.com/playlist/7ISxgqUMrx50OTpNH8ilh5?si=7f1080e560af44c8

There are links like this throughout the book which take you to a track on the playlist, a poem, or article mentioned in the text. Click to open them. There are some useful links for more information in the 'Afterword'. Enjoy.

Home

1st May

He limped the short distance from his bedroom, along the passageway to the top of the stairs, and sat down. His short grey hair was all over the place after another restless night of non-sleep, matching the few-days-old stubble on his chin. The long navy flannelette dressing gown draped over his shoulders insulated him from the cold of the wooden stairs. Slowly, painfully, he bumped down each step to the bottom. It was easier this way, rather than trying to walk his way down; his stiff right leg kept on catching on the stairs, and he would end up having to grab the banister to stop himself from falling. At the bottom, he hauled himself up by his good arm, grabbed the stick that he left propped up next to the stairs and headed for the kitchen. Another small victory.

All this for a cup of coffee. Now he could almost say the word. "Ghorff", or something like it, was how it came out for the first couple of weeks in hospital. Not that it mattered today, as he was the only one at home and needed to make it for himself. Jayne had gone to work, and his first carer was not due for half an hour. He could work the capsule coffee machine one-handed so long as the reservoir was full. It offended his environmental sensibility to use the machine with all the waste from the used capsules. Jayne, however, loved the 'coolness' of it, and now he was grateful. He had always been something of a coffee snob and detested instant coffee. But he

needed two good hands to avoid spillage with the coffee plunger, and the cleaning up was currently too much for him. With two shots from the machine successfully dripped into a large-handled plain mug, he pulled himself up onto the kitchen stool, leant his stick against the bench and sipped. Not a bad effort, he thought to himself. But the micro-euphoria of a successfully made coffee was short-lived. As he drank, he looked up and caught his reflection in the kitchen window. His newly distorted self looked back.

Four weeks ago was a different world altogether. At that time, he was employed, healthy, happy. No worries. Well, not many. Another few years at the bank, and he could retire on a decent pension package. His idea of a perfect retirement was campervan holidays with bicycles, small hotels and backpacks full of books, but he knew that was never likely to win Jayne over. She had talked about cruises and travel to visit grandchildren. The last thing he wanted was to be cooped up on a ship for a week or more, but he supposed you could still do some exploring when the boat was in port. Jayne liked the glamour, the photos on Instagram, the endless socialising. If that's what she wanted, he would go along with it. But even that would be difficult now.

Hippocrates called it apoplexy - struck down by violence. Now it was simply 'stroke'. No warning. His GP had gone on about 'a touch of blood pressure' and offered pills for the last few years. He had taken them patchily.

The stroke happened at work. He was talking to a client in his office, and suddenly he wasn't - talking that is. He remembered the look of discomfort on the client's face as if they were watching someone throw up. And the sensation of wanting to say "Help". Tremendous pain in his head, then nothing. He was told it all went quickly after that. Ambulance, blue lights, a head scan, the stroke team. A bleed. A big bleed.

He didn't remember much about the first few days. He was uncomfortable much of the time with tubes in his arms, down his nose, in his bladder, air pumps around his legs that inflated and deflated like some invisible giantess squeezing his calves for her pleasure. And never stopped. So much noise day and night made his headache ten times worse, not that he could tell anyone. "Any pain, Daniel?" the nurses would ask. "Yes!", "You bet!" "Of course I've got a bloody headache!" and much, much worse but none of it came out. 'Aphasia', the speech therapist called it, literally 'no speech' from the Greek. But it was a bit more complicated than that. As far as he could work out, he had a combination of two problems: expressing language, the aphasia bit – he knew what he wanted to say but couldn't form the words, and a mechanical problem with his mouth and lips because the right side of his face was so weak, which also had a Greek name – dysarthria, trouble with articulation. Fortunately for him, the language problem started to improve pretty quickly so that proper words came out. Often, still, just fragments of sentences and words getting a bit mixed up. Largely understandable. It was the slurred speech that had persisted, making him sound a bit drunk each time

he tried to speak. And saliva escaping as he spoke. People will take me for an idiot, he thought.

It was quieter on the rehabilitation ward. He was quieter too. His humanity continued to drain away, day by day. It had started on the 'acute' stroke ward, like something from a Kafka novel. Disorientation, sensory overload, depersonalisation. There was a mesmerising cast of characters, changing daily: nurses, doctors, therapists, assistants of various sorts. Most of them didn't introduce themselves properly – just assumed he knew who they were and the writing on their name badges was too small to read. And why did they talk so loudly? Out of embarrassment? Just because he couldn't talk back? One or two had the bigger 'Hello, my name is' badges but even they were often hidden in a fold of clothing or on a lanyard turned back to front. There was some complicated colour accent for the therapists' uniforms which was supposed to differentiate the physio from the occupational therapist from the speech therapist. But they were basically all just white – couldn't they put 'Physio' or 'Speech' in big letters on the front somewhere? It was Anna, the health care assistant, who stopped him from going completely insane. She worked a series of mornings after he first woke up, was about his age and was a marvellous chatterer. She used the chatter to cover his embarrassment over all the intimate things that she did for him – the washing, the fiddling with the catheter, cleaning up when his bowels opened unexpectedly and explosively. She talked softly, told jokes and would wait patiently when he tried to say something. She always

involved him in the conversation when she could and asked questions about him that made him feel like a real person, however briefly.

The doctors were a mixed bag. The younger ones seemed to change every day and were always in a hurry. Checking things, putting in a new 'drip', hovering at the back when the older doctors hove into view. Most of them claimed not to know much about his stroke: "the consultant will see you tomorrow". He had seen three of these consultants already, and they all said slightly different things, which was very confusing. One of them genuinely seemed to have him mixed up with someone else. One was shocked that he still had a bladder catheter and made a big song and dance to the nurses about taking it out. Good riddance. On the rehabilitation ward, there was a lot less doctor-stuff altogether. Rather smile-and-wave and let the therapists do their thing.

He became a bed number. Not 'Daniel McIntyre' but 'Bed 3.3'. He would overhear the nurses, therapists and assistants talk about "the man in three-three" when discussing feeds and pills and drips and bed changes. Maybe it helps immunise them from feeling too much, he thought to himself, but it was a short step from there to feeling nothing at all.

And why were the nurses so obsessed with his bowels? It seemed to be a matter of national importance that he opened his bowels every day. What with bed pans, nasogastric-only feeds and virtually no movement out of his bed, it was no surprise to him that he couldn't have a decent crap. He was one of those easily embarrassed men who preferred at least two doors between the toilet seat

and any other human being. Expecting any action from him in a room of four people with flimsy curtains, able to be pulled back at any moment with "ooh, sorry, Daniel" was never going to happen. The nurses seemed much less concerned about the important stuff – when was he going to get better, go home, get his life back? "The OT should be here later on," they would say and be gone, a big black cross next to 'bowels' and mutterings about "getting the doctor to chart something." He eventually read the various leaflets about stroke and the 'stroke team'. There was a lot of emphasis on team working and patient-centred care, but he didn't see any evidence of that on the acute ward. No one seemed to know what the next person was doing or had done. Most of the important decisions were made by 'the team', whoever they were. Wasn't he a member of this team? How come he wasn't invited to these meetings that were deciding his future? That side of things was certainly better on the rehabilitation ward. The staff took more time to try and get to know him, and there was more continuity of doctors, nurses and therapists.

But so much of it was rules and rituals, clouded in uncertainty. There was much busyness from 7 am until 4 pm on weekdays: would the physio or occupational therapist come today, would the speech therapist fit him in now that his swallow was better and people could mostly understand what he was trying to say? He was just a ball on the roulette wheel, randomly falling who knows where, at someone else's whim. The choices were always someone else's, and the reasoning never completely clear or explained. Oh sure, there was a

cursory "shall we set some goals today, Daniel?" but you could tell by the body language and cues what you were supposed to say. Keep the therapists and assistants happy to make sure you got your fair share of their time. And after 5 pm? He'd never been to Siberia, but he imagined the silence and monotony of the ward at those times, and in the weekends, was something like it. Nothing to do, no easy way to get around, surrounded by much older men with hearing aids and troubles, if their night-time mutterings were anything to go by.

"Home next week?" Jayne had squealed nervously. It was the start of his fourth week in the hospital, and 'the team' had decreed that he could manage at home with some extra help for the first few weeks.

"But I'll be working," she said, no doubt worrying about both the grim reality of having him home and the possibility that her boss at the Big Four accountancy firm might not appreciate less billable hours. Once he was officially on the discharge list, he noticed an air of impatience from the staff, especially when the date was shifted back because of some problem with carers. "It's not my fault," he wanted to say. But no one was listening anyway, moving on to newcomers - time for you to move on too, Daniel.

So here he was, moved on, using one of those sticks with four little feet for support while swinging through his stiff, weak right leg. Still pretty slow but getting better. Horrible burning pains in his leg at night kept him awake. They tried some medicine in the rehab ward, but

it just zonked him and dried out his mouth. His right hand was working better. He could bend and straighten the fingers a little altogether but couldn't make them move one at a time. Plenty of pills for his blood pressure too, and he wasn't sure whether it was the pills or the bleed in his brain that made him so damned tired all the time. The young doctor had told him to see his GP if the tablets 'don't agree with you', but that was easier said than done. The same doctor also implied that his GP should have treated his blood pressure more aggressively before the stroke. Well, to give his entirely sensible GP her due, she had prescribed them; he could have been better at taking the tablets. At the time, he hadn't found the arguments for taking the medicine very compelling. It was a bit late to be worrying about that now.

A carer came each morning around 9 o'clock to help him shower and get dressed. He would get up before eight, bump his way down the stairs, and go into the kitchen in his dressing-gown for coffee, using a combination of a walking stick and furniture walking. That's where he would wait for the carer to arrive. Not always the same carer but always in a hurry. He didn't blame them - a pretty thankless job on the minimum wage. Yesterday the carer was Yulia, a young woman with sad eyes from Ukraine. She told him that her family had been forced out of the Crimean part of Ukraine when the Russians took over, and she finished her engineering degree in Odessa. But there was no work there, so she had come to England alone, hoping eventually to bring her family. He didn't ask about how she got here or her immigration status, or how it felt to be a qualified

engineer working for subsistence wages helping people take a shower or a thousand other questions that occurred to him. He was worried that he might seem too nosey or patronising or both. At least momentarily, it made him feel a little less sorry for himself. "There's always someone worse off than you," his mother used to say.

He wanted to look after himself; the sooner, the better. On weekdays, Jayne left early, before he woke up, to catch the train into work. She had been a bit too quick to suggest he sleep in the spare room because it was next to the toilet, and it would mean he could sleep in the mornings. Can't be any fun for her having me like this, he thought. They hadn't discussed sex at all since he got home. Not too surprising – he had never been much good at talking about sex. Right now, all he wanted was to be held and to feel that he wasn't too horrible to touch. The rest could wait.

A physio was coming tomorrow to improve his walking and an OT later in the week to work on his hand. Mumbled apologies about the speech therapist. 'Short-staffed', 'priority patients', 'could be a few weeks', and that sort of thing. He did his speaking exercises in front of the mirror, trying to make the right side of his face behave. Lots of spit. For some reason singing was easier. Having a rhythm helped start off the words. Finishing them was a proper bugger though.

Funnily enough, he wasn't too concerned about his speech, even the weakness down his right side. He could see for himself that they were improving, a bit too slow, it's true, but improving nevertheless. How much better

they would get was anyone's guess. What worried him more was the overwhelming fatigue, his inability to concentrate, and the headaches that were provoked by any reading, or even thinking hard. Physical disability he could probably manage, but if his thinking was permanently affected, where would that leave him? He had asked everyone he could find, and they all just brushed him off with, "it'll take some time, don't worry." He did worry.

There had been surprisingly little contact from work. A few cards, a visit from a colleague who no doubt reported back to the management team with a graphic description of current abilities, or lack of them. A non-committal letter from Human Resources making sympathetic noises, 'support of the whole team', and 'take as much time as you need'. How much time did he need? And then what?

He poured the rest of the coffee down the sink, switched on the radio and lowered himself down from the kitchen stool into an armchair, looking out into the garden, waiting for the carer to arrive. A dull day. Monochrome. Just like yesterday. Existing, languishing. Self-pity bubbled out of his pores into the room like fog. Why me? What now? What wouldn't he do for everything to be back as it was before? He would never be described as an 'emotional' type - very much steady-as-she-goes. So self-harm was never something that he had addressed before. But he could understand someone asking the question, "Is this better than dying?" Early days, he said to himself. Things can only get better.

Family Conference

10th April *[3 weeks earlier]*

"You won't recognise him," said Jayne as she poured a glass of wine for Max. "He can only get a few words out, and they're pretty garbled. His face is all pulled down on one side, and he can't move his right arm." They were at Jayne and Daniel's house together with Max's older sister Annie and Jayne's best friend Susannah, a colleague at work and keeper of all her secrets.

Jayne was expensively dressed as always, with professional-standard make-up, hair and nails, and was waving her hand in a Maggie Smith-in-Downtown over-dramatic way, acting the part.

"But Mum, he'll get better, won't he?" said Max hopefully. "He was in pretty good shape before this, and he's not that old?"

"Well, the doctor gave me the full doom and gloom thing that first day. 'Might not survive', 'significantly disabled if he makes it', you can imagine the rest. Lots of bleeding into the brain – intracerebral haemorrhage she called it - and she said the brain swells up because of the blood, which is why he was unconscious. I asked about surgery, but the stroke specialist said that surgery wouldn't help, and that the most important thing was that he was in a stroke unit and for me to stay positive. Easy for her to say! Daniel was out of it for the first few days, and he's only started to wake up the last couple of days. He knows who I am, which is a start, I suppose. It's

the dribbling that I really can't stand. I have to sit there with a paper towel, mopping up the saliva coming out the right side of his mouth. My God." She drained her glass and poured herself another one.

"So, when is he likely to come home?" asked Annie, three years older than Max and startlingly like her mother in both looks and outlook on life.

"God knows. Not too soon I hope," said Jayne. "I'm really not sure I'm up for it. The nurses can do all that washing, feeding, wiping his bum stuff but that's their job." Gone was the voice of the actress, and in its place something much less sure, a little frightened even.

"But it's only been a week," said Max. "Give him a chance."

"A chance?" she scoffed, regaining her poise. "He's had plenty of chances in the last 35 years. Your father could be a completely miserable bastard to live with before the stroke. I can't see that changing now." She topped up her glass.

"You need to look after yourself, Mum," chipped in Annie. "The hospital will have to provide all the carers and stuff. Don't let them get away with anything."

Max's natural inclination was to defend his father but he knew that Daniel's relationship with Jayne had been less than happy for some time. Daniel seemed to have retreated into his shell in recent years which just infuriated Jayne more. He was sure that Jayne still cared about Daniel, but the stroke was going to make their life together very difficult.

Not for the first time, Max reflected on his 'outsider' status in the family. He even looked different – taller than

Jayne and Daniel by some distance, beanpole-thin with wavy dark hair and sun-touched skin that gave him an exotic European look amongst all the Englishness of the others. He had flown in that day from Lisbon, where he and his Portuguese girlfriend, Maria, ran a small guest house for her parents, catering mainly to British tourists. Maria couldn't stand either Jayne or Annie, so he had come alone. His relationship with his mother had never been good, then completely imploded when he dropped out of university (Commerce and Accounting - what was he thinking?) and headed off to Spain with a backpack, some euros, a handshake from his father and overwhelming relief. He and Maria had come back once a couple of years ago for Daniel's 60th birthday, but it had been an unmitigated disaster. And now this.

"Well, I'd like to help if I can, but I've got to get back to Lisbon in a few days."

"Great," said Annie sarcastically. "Why don't you put him up in your guest house and let the saintly Maria look after him?"

"Maria's six months pregnant, and our flat in the guest house is pretty small, so that's not going to work," said Max, trying hard to keep the edge out of his voice. Annie had always been the sort of big sister that enjoyed winding him up. It was a family sport, and when they were all living together, Max, being the youngest, usually came out bloodied and beaten in the verbal battles. Daniel would stick up for him at the start, but after some time, his father would admit defeat, close his eyes and let Jayne and Annie have their fun.

"Presumably, you and Richard aren't volunteering to look after Dad?" he asked, knowing the answer but physically steeling himself for the inevitable retort.

"With a toddler?" she said, sneering, so you would have thought he had suggested that she provide shelter for a bunch of homeless people. Or immigrants.

Annie and her lawyer husband lived in some luxury about 50 miles away. The combination of anti-foreigner rhetoric and rub-your-noses-in-our-money comments had been prominent in the 60th birthday debacle which they had hosted. Maria had put up with it for the first day but in the end, had asked Max to bring forward their plane tickets, and they had left. He had felt sorry for his father, leaving him with those women.

"He's made his own choices," Maria had said. "We need to make ours."

Max looked around the room, thinking that his father's chances weren't great with a team like this one. He was going to visit his father at the hospital the next day, where he had been moved onto the rehabilitation ward. After that, he would talk to Maria about what support they could offer, but it wasn't a lot realistically. He would visit as much as he could and maybe spend some days with Daniel when he had left the hospital, whenever that might be. It was hard to avoid the conclusion that this stroke might crush whatever spirit his father had left after 35 years of marriage to Jayne. If only it were possible to dial up some 'spirit tonic' to get him through the worst of it.

There had been a time when his father was different. Max remembered wild times in the woods when he was

small - he and his father made dams and rope swings, climbed trees, floated down streams in rubber tyres and camped out in the bottom of the garden. That guy hadn't been frightened of anything. Of course, there had been plenty of accidents during their adventures, but they had always managed somehow. "What's the worst that can happen, Max?" was his father's favourite phrase. He hadn't heard him say that in decades. Well, Daniel was going to need to rediscover his adventurer self again to get out of this mess.

Sam

8th May

Sam was not tall but had undeniable presence. Naturally red hair, cut extremely short, and a faceful of freckles framed friendly eyes and a huge smile. Muscular arms and shoulders fit beneath an oversize white polo shirt with 'PHYSIO' across the right chest. Completing the outfit were navy track pants, white sneakers, and a canvas shoulder bag slung across the front.

"Hi," she said. "I'm Sam, your physio. Can I come in?"

"Sure," said Daniel as he closed the door behind her and gestured towards the living room. "Tea, coffee?" he asked.

"Glass of water would be perfect."

She followed him through to the kitchen and watched him place his stick against the countertop, swivel a little uncertainly to pick up a glass, use the water dispenser from the door of the fridge one-handed and then place the full glass on the counter in front of her.

"Thanks," she said. "Nice work."

"Was that some sort of a test?"

"Not really, but it puts me in the picture. You're better now than you were when you left the hospital, aren't you?"

"I suppose," he agreed, a little reluctantly.

"I'm here to see how you are and help where I can. Anything you particularly want to work on?"

"My walking," he said. "The physio in the hospital kept saying there was a problem with the quality of my movement and didn't want me to get too carried away. I feel I could do more, but now I'm a bit frightened about doing it wrong and falling."

"Oh God, that's all that Bobath bollocks," she exclaimed. "We learn that stuff like the Bible or something in Physio School. There isn't a shred of evidence to justify all the mumbo-jumbo they spout about 'quality movement'. If you want to move, move. You may fall a bit, but hey, there's carpet on the floor! I'd much prefer you to be taking a few risks and getting lots of walking practice than sitting on your chuff waiting for me to turn up and supervise. Now, show me what you can do."

They spent the next 30 minutes or so walking, first with his 4-pronged stick, then with a standard stick and then with nothing. Daniel was pretty ungainly, using furniture where he had to for support. By the end, he was exhausted but happy.

He sat down in an armchair with Sam perched on the arm of the settee across from him. She explained her philosophy around falling.

"I'm a climber," she said. "There was a time when I would be on a climbing wall or out on boulders every minute I wasn't working. And if you want to climb, you have to be prepared to fall—a lot. So you learn how to fall. You get a bit beaten up from time to time, but serious injuries aren't that common. That's how you improve as a climber, testing yourself against more and more difficult problems working out a way to do them — then

throwing yourself at it, over and over again until you crack it."

"Falling is also a pretty good metaphor for rehabilitation after a major stroke. Sometimes we have to let go of a lot of stuff – old baggage, old ideas, our egos - that we thought were important in our previous life before we really know where we want to go now. There's this amazing guy in New Mexico called Richard Rohr. He's a Catholic priest, but he's not a fan of organised religion, weird as that sounds, and he talks great sense. He wrote an awesome little book called 'Falling Upwards'. He says you can only start to climb and grow upwards as a person after falling to the bottom. That means letting go of plenty of things that you thought were important, accepting lots of knocks on the way down. Only you will know when you get there." She laughed gently.

"It feels pretty rock bottom right now, I can tell you," replied Daniel. "Everything is so hard. And sure, I can see improvements, but I'm not sure I'm really going anywhere. *Time held me green and dying…*"

"*Though I sang in my chains like the sea,"* Sam completed and laughed.

"How did you know that?"

"My Auntie Miriam is a big poetry fan and loves Dylan Thomas. We like to read his poems out loud for fun. I'll tell you about her one day. But I get what you mean."

Daniel went over to the bookcase and carefully pulled out his copy of the Dylan Thomas 'Collected Poems' that his English teacher, Hugh Proctor, had given him years ago in school and brought it to the table. Laboriously

pinning the back cover with his right hand and leafing through the pages with his left, he found 'Fern Hill'. "I was *happy as the grass was green* once," he said, "but it is a long time ago now. It's too difficult for me to read out loud. Would you read it for me?"

So she did, enjoying the wordplay, keeping the tone very light and optimistic, right towards the end, not letting the last few lines sound too gloomy. "You've got plenty of singing in you yet Daniel McIntyre," she said. "We're all dying, and for my money, Thomas was a bit of a gloom merchant when it came to death. Another way of looking at the poem is to say if you accept the inevitability of death - look Death right in the face, not run away from it, he says you're chained to it after all - it makes living so much more vital and real. Ha, there you have it - Sam's Psychology 101. No extra charge."

"Thanks for reading to me, Sam. I've always loved that poem. That's cheered me up no end. I don't feel like singing just yet, but who knows what the future might bring?" He closed the book and replaced it in the bookcase.

"Now, as we've completely sorted your walking," she said with a grin, "I want to do something different next time I come. There is a new technique that I've been using with a few people after stroke, and I think it could help you. It's called 'Take Charge', and it is just a couple of sessions of talking, writing, drawing and nothing else – no physical exercises. It puts you in the driving seat and helps with self-motivation. And it is 'scientifically proven' – not like those toothpaste ads claim - but in proper,

published trials with hundreds of people after stroke. Would you be up for that?"

"Why not? Do I have to pay?" Daniel asked.

"No, of course not. The developers have put all the materials on their website for free. Anyone can use it: no special training or anything. I just watched a webinar with one of the developers, read the manual and started using it. It is very simple, but I learn something new every time I use it. People are so different!"

One last big smile. "A colleague of mine, a physio assistant, will see you a couple of times a week for the next few weeks, doing the regular physio stuff. Eventually, we may move to sessions at the gym in the hospital. I'll see you here in a week or so."

"Take care - but not too much!" she called over her shoulder as she skipped down the path to the gate, her shoulder bag bouncing off her lower back as she went.

Daniel closed the door, walked down the hallway to the spare bedroom and fell onto the bed. What a day. Every ounce of energy was gone. But in its place was something much more precious. Hope.

He closed his eyes and slept.

Jayne

10th May

The sycamore leaves filtered the warm spring sun, bathing his face. He lay on his back staring up at the sky, stretched out on the lawn, thinking. Clouds were playing dodgems in the sky, blown about by some giant in the west. The overgrown lawn, measuring his days in the hospital, must have been wondering about its next haircut. He hated lawns. They were greedy for water and attention, giving back exactly nothing. He could admit that there was a certain 'niceness' when newly cut, but that was it. This lawn had borders in yellows and pinks, a few pots and statues, bought off a picture in *Country Life.* Jayne's lawn. A place for occasional barbecues for work colleagues and friends - bonhomie for the well-to-do.

So different from the place they had rented when they were hard up, and the kids were small, with its wild spaces among ancient fruit trees planted by some long-forgotten gardener. There had been a particularly fine damson plum and Bramleys for England in late summer – perfect for cooking up in crumbles and pies for the children. A wildflower meadow was their 'lawn' then, a sacred place for first camping adventures, bicycle races, summer picnics and cricket.

But that was the past, impenetrably distant. He pressed his left ear to the lawn and listened. Do lawns really hiss? *The Hissing of Summer Lawns* was one of the first albums he had ever owned - Joni Mitchell on cassette

castigating the privileged. It was the line from *Harry's House* that he used to hum, cycling through the posh suburbs in his teens, high on righteous indignation -

..Their paper wives and their paper kids,
Paper the walls, to keep their gut reactions hid.

Of course, now it was him living in the suburbs with his nice house and nice garden and nice cars in the driveway. Except none of this felt right anymore. Those four weeks in hospital, staring at the ceiling, thoughts churning, lots of it bad, were like a kick in the guts for his self-image. He'd cried a few times early on, causing the well-meaning nurse to scuttle off and report to higher beings. Not long after, a doctor, who looked 18, muttering *sotto voce* that "everyone finds it hard", began a series of questions about mood, clearly from a standard questionnaire. He wasn't sure whether he should tell her the truth or dissemble.

Was he feeling worthless? Of course.

Suicidal thoughts? You would have to be mad not to have thought of it in that place. Everyone said how happy he should be to be alive, given how 'touch and go' it was initially. But what if it would have been better not to survive?

More questions - *interest in sex?* He wished. Best just to play the game and agree that "I'm fine". Satisfied, she retreated. But now, having escaped the hospital, what was there really to look forward to?

Jayne came out onto the patio. "What are you doing?" she asked with the sharpness in her voice jolting him out of his thoughts.

"Thinking about the garden," he said, trying to prop himself up onto his good elbow.

"We'll have to get someone in to cut the lawn and do all the edges. It looks terrible."

"I was wondering about changing a few things," Daniel suggested, hoping for some positive feedback, receiving none.

"Suit yourself," Jayne said, "I've got work to do. There's a salad and your pills on the kitchen bench." She turned and marched back into the house.

Jayne had always been a fine cook, and Daniel knew the salad would be delicious. Since the stroke, he had a problem with his sense of smell which affected his ability to taste anything. The doctors said the bleeding into his brain didn't explain it and wondered about some viral infection. Whatever the reason, his pleasure in eating was now largely gone, and he would just go through the motions knowing he should eat something, and that Jayne would get annoyed if he ignored her food. It was clear that Jayne was far from happy, with a noticeable chill in the air whenever they were in the house together. He asked for her help when he was desperate, and she usually did so without complaining, but there wasn't a lot of warmth involved. None of her usual easy laughter. It was easier to do almost everything for himself.

He put off trying to eat for now and headed for the piano. He had been a competent pianist in his youth but 'lacked application' according to his teacher and his mother. It was true, he didn't like practising scales and studies and much preferred fooling around, playing and harmonising tunes from the radio, working his way

through old songbooks, jazz standards, blues and folksongs. "For God's sake, play proper music," his mother would say. "We're paying a fortune for lessons. Do the bloody practice." He scraped through the necessary grade examinations largely on excellent sight-reading marks. In his teens and early twenties, his preference to listen to, and play for himself, was Bob Dylan, folk-singers of the '60s like Woodie Guthrie and Joan Baez and traditional folk songs from anywhere. Playing in front of people was a different manner. At university, his main party trick was to start to play straight Bach - something everyone knew like the D minor Toccata and Fugue, or Air on the G string, or a simple 2-part invention and then slowly jazz it up in the style of early Jacques Loussier. A discord here, blue note there, a little syncopation catching the audience by surprise, not sure if that was what Bach wrote or not. Then increasingly pulling out all the jazz stops for a while before putting it back together again as simple Bach. His other move was a medley starting with a couple of classical standards like *Eine Kleine* or the *Moonlight* sonata, then introducing fragments of tunes or styles people would know before finally ending up in an instantly recognisable pop song – *Hey Jude* worked well or *Roxanne*. Easy really. Have the necessary keys and chords and modulations in your head, aim for subtle or not-so-subtle transitions, add a bit of broken chord wallpaper music to smooth things out and hey presto. He was not normally very outgoing and rubbish with women, so the piano playing allowed him to indulge a different part of his personality - the dull commerce

student turned Billy Joel. People learned about his penchant for Bob Dylan and regularly taunted him with comments about what an awful singer Dylan was. So, for laughs, he would sometimes do a parody version of *Mr Tambourine Man* or *Idiot Wind*, overdoing the wailing on the high notes just to prove the taunters right. When, actually, he loved the songs - an early example of trading in some of his integrity to please the crowd.

Music was how he had got together with Jayne. She had an excellent voice, an untrained contralto with more than a hint of Marlene Dietrich. She had a repertoire that included Cole Porter, Gershwin, Irving Berlin, Nat King Cole, Edith Piaf and lots of songs from musicals. Daniel adored her from afar, one of the brightest lights in the university firmament, with her pick of the available men. They shared a Commerce class, but he had never actually spoken to her, and he doubted she would even know his name.

They finally met when they were both at a university party in their second year. There had been a general clamour for Jayne to 'sing something'.

"Where's a piano player when you need one?" she asked with palms upturned and a Dietrich swing of the hips.

Daniel was at the piano in no time. He had no trouble with *Cabaret* and *La Vie en Rose*, and when she turned her full smile and attention on him, softly clapping in his direction while the audience hooted, he was smitten. She stopped after a few songs, and the audience yelled, "Encore, encore".

"Do you know *Berkeley Square*?" he asked and began the intro. She laughed - such a laugh that took his breath away. And sang. Very sexy and quite soft, perhaps even singing in his direction for the last 'nightingales'.

"Hey, thanks Dan," she said at the end. "That was fab. I know who to ask next time I have to sing." No one ever called him 'Dan', but he wasn't complaining.

"Pleasure - any time."

And there was another time, a few months later, at a big society wedding - the bride was a good friend of Jayne's and Daniel knew the groom. A string quartet played for the dinner and a band after, but when the band packed up there was still a sizeable crowd. There was the usual clamour for Jayne to sing. She caught Daniel's eye and motioned with her head and a smile at the grand piano next to the stage. She looked gorgeous, and drunk. "We're on," she said.

She sang a set of six with Porter, Piaf, Oklahoma and a wondrously sultry version of *Summertime*. The audience wanted more. "I need a wee," she said, "and a drink. Can you play something while I take a break?"

So Daniel played Bach - very straight, not too loud - and the noise died down as they listened. As he started spicing it up a few people smiled, and by the time he was really cooking in full jazz improv mode, there were lots of people laughing, saluting him with their drinks and a few thumping the piano in more-or-less time. He calmed them down into a straight Bach finish to general applause.

Jayne was back with her arm round his shoulder. "I didn't know you could play like that," she gushed with more than a hint of a slur. "What a dark horse you are."

So he played some more, she sang some more, he ended up at her place for the night and out of nowhere they were 'a thing'.

He was flattered, of course, and completely captivated. She loved his parents - nice house, solidly wealthy, and they 'knew people'. In return, his parents were totally charmed by her.

That first year was the happiest of his life - excitement, notoriety and a frisson of unbelievability about the whole thing. Surely, one day, she would just walk away?

But she didn't. They were married, two kids in the first three years, a job at a good bank through a contact of his father's.

When exactly did Jayne stop loving him, he wondered? Probably pretty early on if he was honest. She took on much more of the parenting than he did, giving up opportunities for advancement with her job, and resenting him for it. They went through the motions of life together, gradually losing the sense of intimacy that he remembered from the early years. He blamed work.

He never stopped loving her. Life settled down into a predictable rhythm - work punctuated by parties and holidays. They still did their thing at parties – Jayne's voice was solid, and she'd added plenty of repertoire over the years - Les Miz, Phantom, big ballads from Bette Midler, Norah Jones, Eva Cassidy. He'd learnt all the parts, so they always came across as polished but spontaneous. They had worked at many of the songs at

home, sorting out the best keys for her range, experimenting, discarding those that didn't work so well. Jayne never sang with him at home now. No time.

He happily doodled away at the piano when she wasn't there, but he hadn't enjoyed it so much in the years before his stroke. He had tried to brush up his piano technique for a while, playing studies, even had a few lessons, but nothing came of it. Drifting.

The children had music lessons, of course - violin for Annie and piano for Max. Jayne did most of the taxiing around after school, monitoring their practice, handling the stress of exams. He went to their concerts and lavished praise on their efforts, but wasn't sure that either of the children really enjoyed what they were doing. Once they had their CV-burnishing Grade 8's in the bag, they both eventually packed it in. Pity really.

He provided. That was how he saw his role. Long hours at the bank were worth it for the eventual promotion and money but left little time for parenting. Annual holidays usually involved at least one other family, somewhere with a pool or beach, allowing parenting at a distance. Night-times were always raucous, too much booze, Daniel usually heading to bed earlier than the rest, having fulfilled his role as the piano player for at least a couple of Jayne's sets. She was always centre-stage, the men like moths around her flame.

He played a few notes on the piano with his left hand, felt discouraged and headed back to the kitchen to eat the salad, take his pills and ponder. What is going on? What to do?

He thought about Sam, the physio, and her philosophy of life. It might be interesting to find out a bit more. He texted her for a reading list - something to get his teeth into. At least the stroke hadn't affected his ability to read, so long as he took it in short bursts.

Sam's reply came almost straight back, three separate messages to fit it all in. *Anything by Richard Rohr, start w Falling Upwards. Navigating midlife by Robyn Vickers-?, Steph Dowrick esp Intimacy and Solitude and 1 about forgiveness. Thomas Moore Care of Soul. Gawande Being Mortal. Listen to Krista Tippett On Being podcasts. Poetry by Rilke, Rumi, Manley-Hopkins. Then follow your nose. Thomas Merton 7 storey mountain v cool but Catholic! Enough? Almost forgot - write a journal!*

What did he have to lose? He went inside, fired up his laptop and ordered some books.

Take Charge

24th May

Sam came back two weeks later, wide smile just like the first time.

"Is Jayne at work?" she asked.

"Gone. To her mother's place in the country. Apparently looking after an invalid wasn't in the job description. I'll spare you the gruesome details. It's just so weird that I had no idea, not until the hospital started talking about discharge. Finally, the penny dropped that she didn't want to be here, not with me."

Which wasn't entirely true. There had been a series of arguments over the last couple of years before his stroke. After a period of truce when he first came back from the hospital, hostilities had broken out again. "You've been squeezing the joy out of your own life for years, Daniel," Jayne said to him, icy-cold, and not for the first time. "I'm not going to let you squeeze the life out of mine." And the last time, "Stroke or no stroke, you need to get your shit together Daniel McIntyre. Life is for living – you need to try it some time." She had turned away from him, walked up the stairs and started to pack her bags.

"I'm so sorry, Daniel," Sam said.

"Don't be. I can manage, and who knows, it might be for the best. At least now I can do what I want with the garden."

"Are the carers still coming?" she asked.

"Also gone, but my call this time. It takes me a while, but I can do everything I need to do. I wear T-shirts, track pants and sneakers most of the time, I can't dry my back very well, and I eat pretty basic food, but I get by."

Sam explained that she had come to offer Daniel a new treatment, called 'Take Charge'. "First of all, I think this treatment could be absolutely brilliant for you. Second, it will only take a couple of hours, one now and another in about six weeks. And third, it has nothing to do with physical therapy. So today, I am here as a facilitator, not a physiotherapist."

"Sounds a bit mumbo-jumbo, touchy-feely to me," said Daniel.

"Fair enough. But as you will see, it is pretty straightforward. I'll try and explain what it's about, and if you are happy to carry on, we can try it."

They were sitting at the kitchen table, facing each other. Sam was wearing her big smile, elbows on the table and fingers clasped together in front of her. In front of her was a small A4 booklet with *Taking Charge after Stroke* on the cover and an amateurishly drawn stick figure brandishing a walking stick over his/her head. She had also put out some extra paper sheets and a selection of coloured pencils and fat crayons.

"So, here's my philosophy of rehabilitation after stroke, Daniel. I don't want people to 'do OK' or 'improve a bit'. I want people to really flourish. Enjoy their lives. So, what makes the difference whether people flourish after a stroke or not? Well, obviously how big the stroke is, is important," she said, answering her own question. "The more brain that is affected, in general, the worse the

stroke and the more difficult the recovery. Getting good quality rehabilitation in hospital makes a difference. But once the person with stroke leaves the hospital, what makes the biggest difference then? Some people seem to do much better than others, even starting from about the same position when they leave the hospital. So here's the thing: the people that flourish once they have left hospital are the ones who are properly motivated in some way. Nothing much to do with their stroke. I've seen this so many times. In both directions. Some people with fairly minor strokes, but no real drive to get back into life end up much more disabled than I expected. And then others with severe strokes who do stunningly well. The people who make the stunning recoveries almost always have three things going for them."

Sam held up her hand and started ticking them off on her fingers. "First one, they have a big dream. There is something that they really want to do with their life, and they are motivated to make it happen. Sometimes it is specific, like being able to walk their daughter down the aisle on their wedding day or being able to sail again or get back to work. Sometimes it is more about the sort of life they want to have in the future. The key seems to be that the dream isn't about their stroke, but about their whole life."

"The second one is an attitude. These are the sort of people who when you try and be a bit cautious about how much they may be able to do in the future, they say "I don't care what you think, I'm going to show you". I like it when people swear at me - if they can tell me to "bugger off" I know they've got the right attitude. They

are often stubborn but driven. The opposite is also true. If they go along with everything I tell them, or say something like "whatever you say, dear", my heart sinks."

She waggled a third finger. "The third thing is having someone who is fighting in your corner. They may be a spouse or daughter, sometimes just a good friend. Someone who is going to be there for you through thick and thin. Prepared to get tough with the doctor or social worker. Someone who won't let you down. If you've got all three of those things, almost anything is possible".

"Ha," said Daniel, "that's JJ."

"Who?"

"JJ. A big Jamaican guy in the rehab ward with me. He had a problem with his speech after his stroke, so it was difficult for him to string words together. But he still had this lilting way of saying "JJ" and thumping his chest that used to crack me up. And man, did he have attitude! His right leg was weak, and the physios told him that he could only walk with two people helping him. Not JJ. As soon as it got to 5.30, dinner over, all the therapists gone home and the nurses gossiping in the staff room, JJ would get out of bed and try to walk. And fall! God, he had some falls. He was tall, so when he hit the floor there was always an almighty bang. He ended up with plenty of bruises. The nurses and physios would tell him off, but as soon as he had a chance, off he would go again. He had this totally loving family who would come in and help him and hassle the staff to let him practise car transfers so that he could go home for the weekend. All JJ wanted was to be at home with his family and play in some reggae band, so he wouldn't let himself be pushed

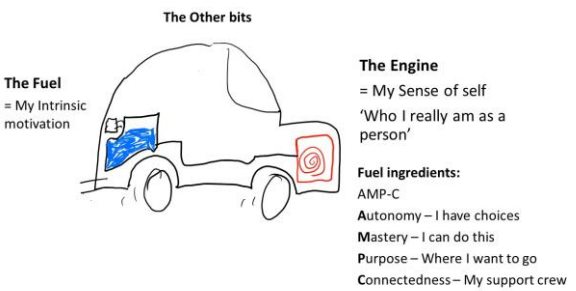
around by the staff and do what they told him. He made much faster progress than I did and got out sooner than me. I wonder what's happened to him now?"

Sam looked at him. And smiled.

"JJ was Taking Charge," she said. "If I'm right, I expect his stroke outcome will be better than someone else with exactly the same stroke but not the same attitude. Take Charge tries to help everybody after stroke to be a bit more like JJ."

"But surely you either have got it, or you haven't?" he asked.

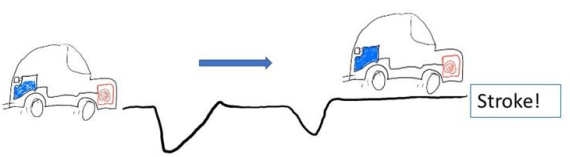
"Well, there probably is a range. I saw a podcast where one of the team who tested Take Charge in research trials explained it. He said we could imagine the person with stroke as a car. Like this."



Sam sketched out a car on a piece of paper. There was a red engine in the front and a fuel tank with blue fuel in the back.

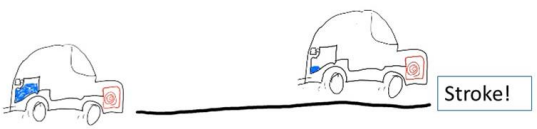
"The Engine is what defines the car: for the person this is what psychologists call the 'sense of self' – who I really am. The Fuel is what keeps the engine running: for the person - this is their internal motivation. The ingredients of the fuel are critical: most important is Purpose, then Autonomy, Mastery and Connectedness. And you're right, some of us probably have more or less of those things than other people do, because of our nature, but we've all got some. I'll try and explain in a minute how you can boost your fuel, whoever you are. Anyway, for the purposes of this discussion, the rest of the car isn't important – they are just 'the other bits', useful but not essential."

"Now imagine two different people on a journey towards the day that they have a stroke."



Sam sketched a line with a couple of deep valleys, and the car/person headed towards a stroke.

"This first person has faced lots of challenges in his life: jobs, relationships, health. He has had to overcome the knocks in life - those are the valleys - and develop resilience, which you get from climbing up the other side. People who have overcome adversity in the past like this are better prepared for the new challenge of a stroke when it comes – we say they have a stronger sense of mastery and autonomy – more fuel for their car. So when he arrives at the time of stroke he has a full tank of fuel, rich with purpose, autonomy and mastery. Hey, sorry about all the 'he's. Of course, this applies to men and women too."



She sketched another almost flat line below the first one.

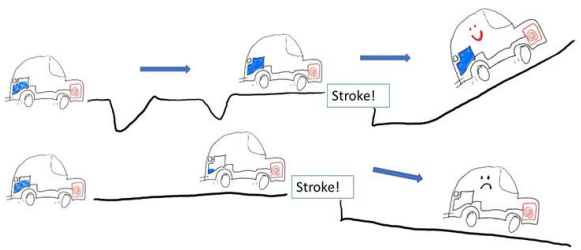
"On the other hand, this second person has gone through life fairly smoothy, never tested much by adversity. Maybe not quite sure where they are headed, hasn't learnt resilience, and arrives at the time of stroke low on fuel, lacking purpose, autonomy and any feeling of mastery, and not well prepared for the challenge of having a stroke."

"That feels like me," said Daniel.

Sam said nothing but just let the comment hang in the air.

"So what happens when they have their stroke?" she asked.

More sketching. She continued the two lines beyond the stroke with the top one dipping down then climbing, while the second one headed downwards.



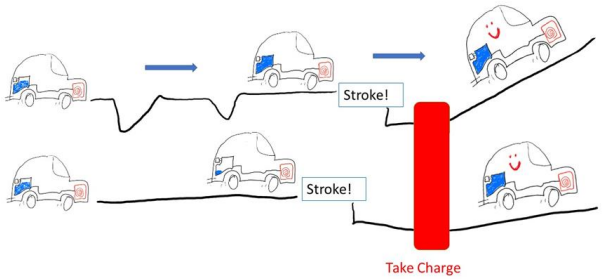
"Although the stroke is likely to temporarily slow down most people, the outcome for the upper person, with a tank full of motivation is likely to be much better than for the lower one, now completely out of fuel, going nowhere."

"Oops," said Daniel. "That doesn't look good."

"Exactly. That's where Take Charge comes in. If we can use Take Charge to fill up a person's tank, the outcome should be better. Like this."

She added a bold red bar just after the stroke, and labelled it 'Take Charge'. Take Charge is the best tool we've got to encourage lives to flourish after stroke." She

changed the trajectory of the lower car to a more positive one and added a smiley face.



"Take Charge helps fill up your tank even if it was pretty empty to start with."

"OK, I think I get it. I'm still not sure how I'm going to fill up my tank. I feel pretty empty right now."

"Alright. Let's start and see how you get on."

"First are a few questions that help you see where you are right now. A sort of stock-take."

Sam ran Daniel through a short questionnaire - 17 questions in total covering different activities ('How often do you do light housework?', 'How many times a month do you go out of the house to socialise?'), and a few 'psychological' statements at the end to agree/disagree with ('I feel in control of my life', 'My life has a clear sense of purpose'). It made Daniel feel uncomfortable, annoyed, even angry. He knew he was a lot better than when he was first admitted to hospital, and even since he was transferred to the rehabilitation ward. He could look after himself now, but he wasn't doing many 'normal' things.

And no, he didn't feel in control of his life or that he had much sense of purpose. That was pretty bloody obvious.

"OK?" asked Sam.

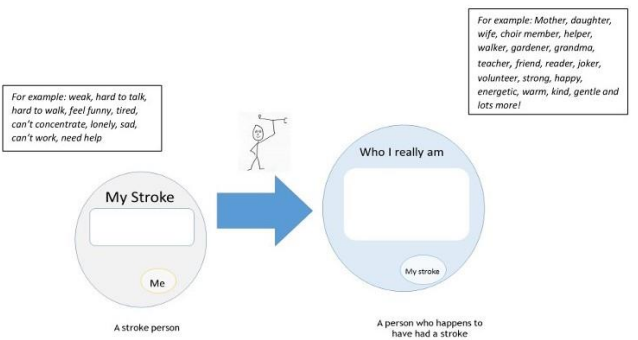
"Not OK actually," retorted Daniel. "I feel like my whole life has been tipped down the toilet. I want my life back."

Sam could see Daniel was struggling not to cry. She waited a while.

"I think the first page of the booklet will help you let out some of that frustration."

She showed him a page with two large circles; the one on the left was labelled 'My Stroke', and the one on the right was higher up the page and labelled 'Who I really am'.

"Let's start over here," said Sam pointing to the left-hand circle. "You get to write down everything you want about the stroke. Can you write with your left hand?"



"No," said Daniel, with a hint of petulance. "Can't you write for me?"

"We try and make sure that everything that is written down comes from you and not me. It is always better if you do the writing. I can do it this time, but I am only going to write down your actual words. OK?"

"OK."

Sam held the pen over the left-hand circle and looked over at Daniel. She raised her eyebrows in invitation. Silence.

"Well, what do you want me to say?" Daniel demanded.

"*I* don't want you to say anything. This is a chance for *you* to write down how *you* feel about *your stroke.* This isn't about me."

More silence.

"Weak," he finally offered. "Tired all the time. Knackered. Actually knacker's yard about sums it up," he mumbled with an attempt at a wry smile.

Sam smiled back. Otherwise, she didn't respond directly and just copied the words into and around the circle.

"Can't speak properly"…."Lonely"…"cut off"…"anxious, can't concentrate" came out over the next couple of minutes.

"You can add to these any time you want," said Sam. "This whole booklet is for you to keep. Some people separate the pages and stick them up around the house."

"Shall we try the second circle? This time, ignore the stroke completely and write down who you really are as a person."

"Who I really am?" he said with a puzzled look. "I'm not sure I get what you mean."

"What makes you 'you'?" Sam said. "Your personality, your hobbies, your relationships, the things you care about." Silence.

"Family person. Provider. Successful. Not-very-good musician. Likes cycling and Bob Dylan. Not necessarily in that order. Frustrated gardener."

Sam transcribed each word without saying anything. Then, after some time, she said that Take Charge was a process that aimed for transformation from 'A Stroke Person', where the stroke was the defining thing, to 'A person who happened to have had a stroke', where it was all about the person that they wanted to be.

"Easy for you to say," said Daniel.

"Next page?" offered Sam.

She turned the page. There were just two typed lists, one headed 'My hopes' and the other one 'My fears'. A couple of roughly drawn stick figures emphasised the starkness of it.



Overall hopes, aims, aspirations for next 12 months

1.
2.
3.
4.



Main fears

1.
2.
3.

Daniel looked at the page for a long time without saying anything.

"Does this mean some sort of bucket list?" he asked.

Sam smiled. "That's up to you. This is just inviting you to think about what you want to do with the rest of your life – where you want to be in 12 months for starters. And sure, there may be some specific things that you want to get done in that time. If there are, write them down, now or later. My job is just to write down what you say you want, no more, no less. If you say, "I want to win an Olympic 100 metres gold medal", that's what I will write down."

While Daniel digested this, Sam thought back to the webinar where she had first heard about Take Charge. The speaker had been talking about wanting people to 'dream big'. Someone asked if this would lead to the person with stroke having unrealistic expectations that

would inevitably be disappointed and that this would be a 'bad thing'. Sam had been taught at Physio School to set 'SMART' goals: Specific, Measurable, Achievable, Realistic/relevant and Timed. Her lecturers said that you shouldn't let the person set a goal that you knew was not achievable. The Take Charge guy on the webinar thought this was totally the wrong approach and could actually harm people after stroke. He called Take Charge 'anti-SMART' saying SMART goals were fine in factories making widgets, but not good for real people. Something along the lines of who were we to say what was and wasn't achievable or realistic for that person? Tens of thousands of people dream of winning an Olympic gold medal, but only a very few can achieve it. With odds that bad, should we stop all those people dreaming? What amazing things might they achieve because they were dreaming of, and working towards, Olympic gold? Why shouldn't the same apply to the person with stroke?

Sam knew it was tempting to reason with the person with stroke, when your experience told you that what they were aiming for was probably out of reach. "Do you think that is a good idea? Do you think that might be too ambitious?" Before discovering Take Charge, this had been Sam's approach when setting goals with patients. Especially if you knew that one of the performance indicators for the whole rehab service was 'successful goal achievement'. The Take Charge guy said that the facilitator's most important job was to shut up and let the person talk. To let them say in their own words what they wanted and what was important to them. He said, "as soon as you open your mouth and say, 'I think…' or 'Do

you think…?' (which amounts to the same thing) you start taking power and control away from the person with stroke. Try to say nothing." It had been tough to start with to follow this path, but it was astonishing what could happen when you stayed silent and listened hard. Not every time. But often enough for her to realise how much she had tried to control the process before.

"I want to get back to normal," Daniel said finally. "Is that too much to ask?"

Sam wrote "I want to get back to normal" in the first space under 'Hopes' but didn't say anything. More silence.

Finally, Sam asked gently, "You say you want to get back to normal. So what does that mean?"

"Well, everything," Daniel spluttered. "Job, family, do things again. Able to play the piano."

Sam completed the list:

1. I want to get back to normal
2. Job
3. Family
4. Play the piano

"Same job, different job, any particular 'things'?" she asked.

"Of course, the same job," Daniel said rather testily. "That's what I do. Cycling," he said after a while. "I would like to get back on my bike and just ride."

Sam added the extra words.

"And what are your fears for the future?" she asked after some time.

"Well, that none of this is going to happen, I suppose. I'd be no good with clients with my speech like this - work will probably try and get rid of me. No wife, no kids anywhere close. I can't see myself on a pushbike anytime soon, can you? What if this is as good as I'm going to get? What if I have another stroke?" he asked, pleading with Sam for reassurance.

Sam wrote down under 'Fears':

1. No improvement
2. Can't get my job back
3. Family not around
4. Unable to ride a bike
5. Have another stroke

"Is that what you mean?"

"Yes, I guess so," said Daniel, sullenly.

"Daniel, I'm only a facilitator, trying to get you to say what are the important things for you. Just saying them out loud is good. To go back to your question, just about everyone who survives the first few weeks improves after a stroke—especially a young, healthy guy like you. But no one can say for sure how much improvement will happen and how long it will take. That's just the way it is. What I'm trying to help you to do is to look beyond the stroke to the rest of your life."

"Thanks. I'm sorry for being grumpy. I feel as if I have lost everything, and I want it back. Badly."

"Do you think Jayne is coming back?" asked Sam quietly.

"I suppose not."

"OK, here is a nice cheerful page," said Sam, turning the page to reveal a drawing labelled 'My Best Day' with

scattered stick figures and various props, including boats and sunshine.

"Some people like to draw, and others write words to fill in the space. You can use these coloured pencils and crayons if you want. What would *your* Best Day look like? Where would you be, who would be there, what would you be doing?"



"Car," began Daniel after some time, "Lots of room. I'm driving, Jayne beside me and kids in the back. 2 bicycles on the roof. Lake. Sunshine. Hills in the background. French flag."

Sam sketched as Daniel talked, struggling with the colours of the flag ("Is it blue, white, red or red, white and blue?").

"Happy with that?" she asked as she indicated her sketch to Daniel. He nodded.

"Is that somewhere that you've been?" she asked.

"No, but we always talked about a family holiday in France, and I've always wanted to go cycling with Max - Jayne and Annie aren't keen on strenuous activity of any sort."

Sam was silent, thinking to herself that Daniel's 'Best Day' seemed to be in a mythical past life, but resisting the strong temptation to say something about it.

"So now we need to look forward," she began, turning another page. We have a range of topics here, and we won't cover them all today. She showed him pages labelled 'Physical things', 'Communication', 'Emotional issues', 'Information needs', 'Financial issues', 'My support network', and 'Preventing a new stroke'.

"These pages can help you plan for the future. What needs to happen to make any one of your hopes for the future to come about? For instance, to get you back to your old job, what would we need to do? Brainstorm it. Anything that you can think of."

"Drive, I suppose. Or bus. Talk to my boss. Use a keyboard. Get a lot more energy. Maybe work fewer hours at the start?"

"It's good that you can think of so many things now. Your job is to write a few of them down and start working on how they could happen. You will likely need some help along the way. Who could do that for you? A friend? Work colleague? One of your children?"

"I don't know. The list isn't very long, I'm afraid. My parents are both dead, my brother Robbie died from a heart attack a couple of years ago, and I don't see Jamie at all these days. I can't see Max or Annie being able to help. Most of our friends know Jayne better than me. It could

be a bit awkward. Is it so important to have someone around?"

"Well, for some people, it can be. You are probably getting tired, but I'll tell you one more story. I belong to a Facebook group of people who use Take Charge, and someone shared this story which might help. The story is about Jim, who retired in his 60s. His wife died some years ago from cancer. He was a glass half empty kind of guy – never one to look too far on the brighter side of life. Luckily for him, he had two devoted daughters who lived in the same town. Jim had a major stroke and struggled to get around, even after several weeks in hospital. He had been housebound since the stroke. My colleague said that the first Take Charge session with Jim was going badly. During the assessment part, Jim was really negative. He said he was 'stuffed' and that the physio 'knew it was hopeless'. He got to the 3rd page of the booklet - the 'Best day' bit and just said, "What can I do – I'm stuffed". The facilitator asked, "What did you enjoy doing before?" and he still wasn't able to answer. After some time, one of his daughters reminded him that the thing he liked doing the most since his wife died was to go every week to the local shopping mall and sit outside a café drinking coffee, watching the world go by, and passing the time of day with some of the shopkeepers. Jim said, "Well, I can't do that now, can I? How would I get there? I'd be too embarrassed." His daughters took on the challenge and organised a wheelchair taxi to take him to the mall the next week. Jim felt very self-conscious and uncomfortable about the whole thing but went along with it. He was touched by

the number of people who came up to him and said, "we've missed you", and how good it was to see him there after the stroke that they all seemed to know about. He went every week after that. By the time of the 2nd Take Charge session six weeks later, there was no change in his overall mobility, but he was a different man. One daughter said, "He has got his zest for life back." He filled in a lot more of the booklet and started making concrete plans for the future – "I'm not going to live like this for the rest of my life." Jim was starting to look beyond his stroke and not give up. The point of the story is that the transformation in his attitude probably wouldn't have happened without his daughters getting involved."

"OK, but I can do it on my own if I have to?"

"Of course you can. But if someone offers to help, it is OK to say 'yes'. I don't think you are going to recognise yourself in six months' time, Daniel. Life might be feeling pretty crap right now, but sometimes it takes something like a stroke or cancer to really wake people up."

"Can't you be my support person?"

"Oh, Daniel. It can't be me. You see, I'm like a will-o'-the-wisp. I never stay very long in any one place. You need someone who can be there for the long haul. Think about it. I'll be back in about six weeks to do the second Take Charge session, and we can go over some of these things again then."

"You'll be getting tired now, and I don't want to wear you out. In the back of the booklet, there are copies of the first three pages to have another go if you want to. Have a look at the other pages and see if you want to write

anything down there. I'll bring a new booklet in six weeks. In the meantime, you could put some of your sheets up on the fridge door – that might help you to add a few more things, change others, you know?"

"I couldn't do that," said Daniel. "Too personal."

"That's fine. You're the boss. Take care."

"See you, Sam."

And like the last time, she left, bag swinging, red hair catching the spring sun, disappearing from view.

Max

27th May

Later that week, Max came. He hadn't seen Daniel for over two weeks, and the initial conversation was stilted and clumsy. Neither mentioned Jayne's absence. After some updates from Portugal and Daniel's description of the first Take Charge session, Max showed him a photo of a very pregnant Maria on his phone. Daniel liked Maria and still felt guilty about what had happened at his 60th birthday party.

"I'm sorry we treated her so badly," said Daniel.

"She doesn't blame you," said Max. "Shall we call her?"

"Perhaps later. Have you got any more photos?"

Max flicked through a few more. One was a selfie of Maria with Max holding a guitar.

"I didn't know you played the guitar."

"Not well. I taught myself some chords. Maria has been teaching me Portuguese and Spanish songs, and the guitar chords go well with them. I used to love listening to you fooling around on the piano when we were kids."

"Really?" said Daniel. "Well, I can't do it now."

"But your left hand works fine. Got any piano music we can play? I'll play the right hand, although I'm a bit out of practice."

They opened a couple of box files of piano music - Mozart, Schubert, Satie. They played. Not well, but it felt good for both of them. Without saying anything, Max started playing *La Mer*, one of the songs Daniel used to do

with Jayne. Daniel watched him play and noticed that he was handling the piano very competently, adding a few flourishes of his own. He had a good singing voice too - a lovely tenor range with no trouble hitting the higher notes as he modulated upwards the second time through. He also started hamming up the melody and accompaniment, turning his perfectly good French accent into something out of "Hello, Hello", encouraging Daniel to join in. They sang together, falling about with laughter by the end.

"Where did you learn to play like that?" Daniel asked.

"From you, you numpty. I reckoned if you could do it, so could I."

"So you play by ear?"

"Sure, but I learn the parts as well!" He started the intro for *Autumn Leaves* and did a passable imitation of Yves Montand for the first verse. After that, the two of them engaged in some mutual schmaltz with the melody seeing who could hold the high note longest, again with much laughter.

Max carried on playing and started singing Peter Skellern's *Where do we go from here?* with lots of sensitivity and colour. Daniel wiped away a tear or two as Max sung the lines:

What if it's over
Where do we go from here?

Daniel had taught himself the song off the record a long time ago and had played it forever. He had tried to interest Jayne in singing it years ago. "Too northern, too common," was her response. She hated the brass band

accompaniment on their recording, and that had been that.

"Do you want to talk about Mum?" asked Max as he finished the song with a few bars of instrumental. Daniel smiled to himself at Max's clever set up with the song.

"Oh, it's been coming for a long time," started Daniel. "We've decided to see how things go, apart for a while, but it feels to me like it really is over. I think Jayne wants a different life to this one." The hint of self-pity was hard to disguise.

"Perhaps," said Max, "but you could look on the bright side. You're still young, have lots of skills, a good brain. Maria and I would certainly like to see more of you than we have done up to now."

"Enough, enough," protested Daniel. "Let's talk about it another time. Can you sing me any of the songs that Maria has taught you?"

Without replying, Max started playing, talking over the top of the music. "Do you know Mercedes Sosa?" Daniel shook his head. "From Argentina. This is one of her most famous covers – 'Thanks to life, which has given me so much'". He started singing *Gracias a la vida* in Spanish, adding an English summary of the words for Daniel between verses. "One more?" he asked. Daniel nodded enthusiastically. "She sings a lot about the poor and the oppressed. This is *Sólo le pido a Dios* – 'I ask only of God that I am not unmoved by suffering.'" This was a much more rhythmic accompaniment and Max's singing was powerful now, clearly with feeling and Daniel was moved.

"That's great, Max. The song means a lot to you?"

"And Maria. We try and do as much as we can for the poor people in Lisbon, and there are lots of them. Soup kitchens, homeless shelters, you know the drill. It's a really big problem, and this song is like our anthem."

He gave his father's shoulder a squeeze.

"Thanks," said Daniel.

"Ditto. Didn't Ravel write a piano concerto for left hand only?"

"Yeah, yeah. A bit out of my league at the minute don't you think?" but with a smile nonetheless.

"You won't know 'til you try. What's the worst that can happen?" said Max. "Anyway, who's to say you won't get plenty of use back in those stroke fingers? You don't need much to pick out a melody?"

"You're right. I need to pull my finger out and practise, no matter how awful it sounds to start with. Sam would have me writing it down as something to work towards."

"Have you got a list or something?"

Daniel showed him the first three pages from the Take Charge booklet. Max looked at the hopes and fears first then studied the picture of the family group on holiday.

"If you don't mind me saying, this isn't exactly looking forwards, is it?" he said gently.

"I guess not."

"Well, what are you going to write about playing the piano?"

"To be able to play the piano like I used to, I suppose."

"What we did just now wasn't playing like you used to, but it was a load of fun just the same?" offered Max.

"Fair enough." Daniel thought for a while. "How about just 'Enjoy playing the piano again'?"

"Sounds good to me," said Max and wrote it down.

After Max had gone, Daniel sat at the piano, playing the left hand of *La Mer* and singing along. He tried to work out the emotions that were overwhelming him - mainly happiness at the chance to spend time with his son, and some pride at the way Max had embraced music-making despite Daniel's pitiful attempts to support him when he was younger. But there was also regret at the times they could have spent together over the last 10 years and hadn't. Could he make up for that now? Would Max (and Maria) want him to? And even if they said "yes" how much of it would be out of pity for his current predicament and how much because they really wanted to?

Journal

30th May

The pen moved laboriously across the page. Daniel had found that a two-finger grip around the pen shaft, made fatter with sticking plaster, gave the best compromise between stability and agility. Even so, he needed plenty of movement of his right forearm to form the letters, and it was tiring, both physically and mentally. He wrote in the journal every day, half the time with his left hand for speed, and half the time with his right hand, gradually improving legibility, stamina and speed. He had once kept a journal when he was 13 years old - a birthday present from an aunt: secret thoughts, descriptions of people, fragments of poems. But after a few months, his older brother Jamie had found it and walked round the house reading out passages, despite Daniel's frantic efforts and pleas to his parents to stop him. Everyone laughed. The humiliation was total. He had thrown the journal in the fire and cried.

This time was different. There was the element of challenge to the writing itself, and he was determined to aim for a clear, legible script - something he had always struggled with before. More important were the words themselves. He had been surprised at how many of the books that Sam had suggested advocated journal writing to work through important issues. 'Write every day' was a common theme. And so he did. At first, he had written in short bursts, sometimes just single words, as the act of

writing itself was so difficult. But gradually, fluency was returning, and today he had written more than a page of passable legibility. He was reflecting on Max's comments about his 'Best Day' picture. 'Not exactly looking forward' or something like that. And Max was right. Why would I want things to be like they were before? He had been shaken up by reading Robyn Vickers-Willis' *Navigating midlife* and recognising himself as someone whose feet were planted firmly in the first half of life, focussed on achievement with no real idea of a life beyond that. Well, like it or not, this stroke was going to change that. Some part of him could see a better, more healthy life ahead of him if he dared to grasp the opportunity. Lots of fear and uncertainty remained, but at the same time, he kept telling himself, what was there to lose?

Over the last week he had written about his marriage and his relationship with his children, much of which had been painful to put down. Plenty of self-pity initially, becoming clearer. Thomas Moore's *Soul mates* had helped him to come to terms with the end of his marriage, something that should probably have happened some time ago. Paraphrasing, 'Relationships end. We just need to recognise when the relationship has run its course'.

To balance the pain, he also wrote about happy moments. Hugh Proctor, his English teacher for one. Hugh, who had fired up his love of words and language. English and French were his favourite subjects in his first few years at secondary school, but in the end, he had done what his parents suggested and dropped French for Economics. "Think of your future," his father had said.

In the back of the journal he had been sketching out plans for the garden. He had lots of ideas - mainly getting rid of the lawn, growing vegetables, herbs and fruit trees and flowers maybe. His father had been passionate about dahlias, religiously lifting them for over-wintering and replanting them in the spring. He used to enter them in the local show - even won the odd prize. Daniel realised that his plans were ambitious and that it would take him ages, just doing the digging. He had thought of employing a gardener, but he wanted to do as much as he could himself. 'Just do it' seemed as good a motto as any. Tomorrow maybe – the weather had taken a turn for the better, and he could feel his fingertips itching to play with the soil.

Ravi

2nd June

"Hi, Mr McIntyre."

Daniel looked round and saw a young South Asian man calling to him from over his neighbour's wall.

"Can I give you a hand?"

Daniel was kneeling on a mat in the middle of the lawn, and he looked at the mess he was making. There were scattered lumps of turf, garden tools, compost, bamboo canes and seed packets. "Sure, that would be great."

The young man came into the garden through the connecting gate in the wall separating the properties. "I'm Ravi," he said. He looked about 16, tall and slim, dressed in jeans, a sky-blue short-sleeved shirt with a cricketing motif and sneakers. Neat, dark hair and very white teeth.

Daniel stood up, using a garden fork as a simple prop. "Nice to meet you, Ravi. Are you a gardener?"

"Well, not exactly. Mum saw you working and wondered if you needed some help digging or whatever."

Daniel laughed. "Fair enough. Good call from your Mum. I'll explain what I am trying to do, and you can tell me whether I am mad or not." Ravi smiled, saying nothing.

"OK, so I want to get rid of the lawn and this agapanthus and grow vegetables and put in some fruit trees. What I was trying to do here was dig up enough

lawn to plant some French beans and put up some bamboo canes for support."

"Cool," said Ravi. "Got a spade?"

Ravi made light work of creating the first small bed and quickly erected a wigwam of bamboo canes. Daniel set about opening one of the seed packets, using scissors in his left hand. With due ceremony, the two of them planted two seeds at the base of each of the bamboo canes and watered them in.

Over the next couple of hours, Ravi dug up two large rectangles of lawn, and after mixing in copious amounts of compost to form mounds, they planted beetroot, chard, cabbage and broccoli. They agreed that raised beds made the most sense in the long term, but Daniel was impatient to get seeds in the ground. He promised to order some timber for the beds, and Ravi said he would come back to construct them. They heaped up the clods of lawn near the fence for compost. Daniel's plan for the compost bins was to use wooden pallets that businesses at the local industrial estate left out on the pavement for anyone to collect. He didn't think that it would take much to join them together. Ravi was keen and offered to convince his Dad to pick some up that weekend using his estate car.

Later, they sat down with cold drinks and snacks that Daniel rustled up from the kitchen.

"What are you planning to do when you leave school?" Daniel asked.

"Ha!" Ravi laughed. "I call that the "C" question. All my relatives ask, "what will your Career be Ravi? What is your Aim in Life, Ravindra? It's OK," he said, waving away Daniel's apology. "Well, my parents want me to do

Engineering," said Ravi. "I'm good at Maths and Physics, and there are lots of opportunities for graduates."

"And what does Ravi want to do?" asked Daniel.

"I don't know. I wish I could play cricket like Virat Kohli, and then I wouldn't have to worry about university." He smiled. "Me and about a billion others."

"Do you play cricket then?" asked Daniel.

"Of course. My mum says that I play too much cricket and don't do enough study! I play for the school 2nd XI but I hope to get into the firsts next year."

"And this Virat guy is a good player?" asked Daniel. He had never paid much attention to cricket as a sport and only knew a handful of the celebrity cricketers by name.

"A good player?" exclaimed Ravi, incredulous. "You haven't heard of Virat Kohli? Ohmygod. He is the most beautiful batsman in the world. Such technique. Such incredible power. Dad took me to Trent Bridge a couple of years ago for the England-India test match, and Kohli scored 97 in the first innings and 103 in the 2nd. That was one of the happiest days of my life watching him get that century. And he signed my bat!"

Ravi kept talking, but it may as well have been a foreign language for Daniel - backswing, timing, reverse this and that, some stuff about other batsmen and why they weren't a patch on Virat. But Ravi's enthusiasm for his subject was totally infectious. He seemed to know everything there was to know about Kohli and the Indian team, details of matches, famous Kohli innings, on and on it went until he finally ran out of steam.

"So, you practise a lot?"

"Oh, yes," said Ravi. "I hit balls against the garage door and practise hitting a ball with just a single stump - like Bradman! It drives Mum crazy, but Dad understands. He says as long as I do my schoolwork, he is happy. He says everyone should have a passion."

"And what is your Dad's passion?" asked Daniel.

Ravi laughed. "The works of Rabindranath Tagore and Indian modern history. He is forever quoting Tagore about this and that. He even taught himself Bengali so he could read him in the original language. Do you know Tagore was the first non-European to win a Nobel Prize for Literature? In 1913! Dad asks everyone that. His favourite Tagore saying is that 'proper teaching doesn't explain things, proper teaching stokes curiosity'. My Dad isn't a big fan of modern education you might say. My name is a version of Tagore's first name, Rabindranath."

"He must love you very much. He sounds like a fascinating man to me. Were you born here?"

"No, in India. A city called Jamnagar, in Gujarat. Ravindra Jadeja was born there – he's another brilliant cricketer even if he does play for Chennai Super Kings," said Ravi with undisguised contempt for that particular team. "He's best at the one-day game. Same name as me though, so that's cool. We came here when I was seven years old, and my sister Ragini was 5. Mum got a job as a psychiatrist, and Dad came and did an MBA. He runs a big company making laboratory equipment."

"That's great. What language do you speak with them?"

"Oh, English mainly. But my grandmother also lives with us, and we speak Gujarati with her. And when we go back to India, most of the time we speak Gujarati. I can

read the script, but I can't write it well. One of these days I should learn it properly I suppose."

"Ravindra!" A woman's voice calling from the other side of the wall.

"Yes Mum! I'm coming. Thanks for the drink Mr McIntyre. I'll come again on Saturday. I'll bring one of Mum's curries and some roti. She is the best cook in the world. It'll blow you away compared to that chicken tikka masala rubbish that you get in the restaurants here. See you!" he called and was off.

"Thanks for all your help," called Daniel to Ravi's disappearing back.

He sat for a while thinking about the afternoon. It had been good to make a start on the garden, and he was pleased about that. But it was Ravi's energy and drive that had made the biggest impression. He couldn't think back to a time when he had had that sort of energy and passion for something, but at the same time there was something about Ravi that reminded him of his younger self. What might have been. There had been an undercurrent of fear throughout his life - of getting it wrong, or looking bad, or being embarrassed. Wanting to please his parents, and Jayne. Well, now there was no one to please but himself. He was only 62. He thought back to Sam's questions from the Take Charge session. All that 'Big Picture' stuff and hopes for the future. He looked at the newly dug earth and bean poles in the middle of the lawn and smiled. As good a start as any, he thought.

Jayne returns

2nd July

Jayne came down the hallway, having let herself in.

"Anybody home?" she called.

"In the kitchen."

She came through and stopped just inside the doorway, eyeing him up, no suggestion of a hug or kiss.

Mercedes Sosa was singing loudly on the stereo, and Daniel picked up the remote control and turned it off.

"How ya doing?" he asked, not quite achieving the lightness of tone he was looking for.

"Oh fine, just fine," she said affecting boredom. "I've just come for a few more things."

"Help yourself. Can I make you tea, coffee?"

"Isn't that …?"

"Too difficult for me? No. Not a competition of course, but here goes." He quickly organised coffee using the capsule that she preferred and offered it to her on a tray.

"Not bad," she said trying hard not to sound too impressed. "Thank you." It was as much his forthright manner as the actual physical performance that had surprised her.

There had been a few phone calls since Jayne left. Daniel had whined terribly on the first call. "Why now? You can't leave me like this. Are you completely heartless?" and so on. Jayne had matter-of-factly said that she had been planning to leave even before the stroke, they both needed to move on, it was better he got himself

sorted out, rather than relying on her. Subsequent calls had hammered out the details around joint bank accounts, trust funds, and organising for Suzannah to come round and pick up more clothes. Today's visit hadn't been on the schedule.

Daniel smiled. "So, how's life in the country? You've always been so much a city girl."

"Oh, well, you're right. I miss the city, and at some stage, I'll have to move. The commuting is a bit of a drag, but I stay over in town a fair bit."

"With Geoffrey?"

Again, she was surprised by the directness of the question. "Yes, Geoff and I are spending plenty of time together. He's got a lovely flat in town."

"And is he still married to that woman with the unfortunate laugh – Belinda or something?"

"Separated. Bronwyn. It's nothing very serious for us Daniel, just a bit of fun."

"I hope you enjoy yourself and don't end up getting hurt. He always enjoyed pretty women and ostentatious displays of wealth."

"Don't worry, I can look after myself." She looked around and out into the garden, noticing for the first time some of the changes.

"Wow, Daniel, Max said I would notice a few differences, but I wasn't quite expecting this. You seem so different. It's as if you've got some of your old spine back at last. You had turned into such a bloody doormat, Daniel. Anybody who wanted to, could wipe their shoes. Mainly me, I guess. Sorry. I was expecting you to be, well …"

"Dribbling into my porridge?" offered Daniel.

"No. Not that. More sorry for yourself, I suppose. But whatever has happened, it suits you. You look happy for a change."

"Yes, I am happy. Happier for sure, anyway. I was the one that allowed myself to be the doormat. I was too frightened of losing you. Somehow, I thought we could get back to the way we were in the beginning, but now I realise I was just kidding myself."

"Oh, but we had some fun while it lasted, didn't we Dan?" and she came over to him, placed her hands on his arms and kissed him gently on the cheek.

"Joan Armatrading, *Tall in the saddle,*" he said.

For as long as they had known each other, they had played a game of song lines, trying to keep a conversation going with only lines from songs. The other person had to say which song the line was from. It was their private joke that they would start at boring dinner parties or family get-togethers. At home it would always finish with one or the other using the song-title *Je t'aime* as a final card; a signal for at least a kiss. They both loved Jane Birkin and Serge Gainsbourg and had a few of the well-known ones in their repertoire.

"But *it's all over now, Baby Blue*", Daniel said with a small smile.

"Mr Dylan as always for you, Daniel," Jayne said. "In the end, according to me, *love is all you need.*" A wry smile.

"I don't disagree with you or John Lennon."

Jayne applauded softly. "It's true. I'll always hold a place for you in my heart," she offered.

Daniel thought for a few moments and shook his head, not sure whether she was still playing or being profound. "Don't know," he said.

"Tracy Chapman *The Promise*," Jayne said, "and I mean it. *Je ne regrette* absolutely rien."

"Me neither, I guess. I fell for you when you were singing Piaf; heart on your sleeve and giving it everything you had."

"That's me. What you see is what you get. Hopefully, I won't end up quite so sad as her. Will you show me the garden?" she asked. She took his hand, and they walked out through the French doors to the garden.

Jayne listened to his plans for the garden and about Ravi's role in the transformation. She made supportive noises as they went around. Sitting on deck chairs looking out to the garden, she asked, "So you want to stay in the house then? *Where do we go from here*?" And having sung the last few words, she laughed, in a way he hadn't heard her do for years. She was 25 again, beautiful, dazzling, soul of the party; Circe the enchantress, irresistible.

Funnily enough, he didn't feel remotely tempted. "Oh my - Peter Skellern! I thought that you hated that song? And yes, I think I do want to stay here. The house is too big for me on my own, but I'm feeling happier than I have for a long time, so I don't want to move just yet."

"That's fine, Daniel. Shall we just let the lawyers sort it out?"

"Sure. One thing I'd like you to take away is the damned coffee machine. I can make coffee for myself without those hideous capsules. Actually, take whatever

you want. I can't believe that we are talking about this without any yelling and screaming."

"That's because you've got a *heart of gold* Dan. Thanks for sharing it with me."

He resisted the temptation to say, 'Neil Young' and just squeezed her hand instead.

Jayne got up and said, "I'll let myself out." She whispered, "*Je t'aime*, always," as she bent and kissed him on the cheek.

"And you, my *Brown-eyed Girl,*" he replied.

She laughed out loud. "Van the Man! Oh Dan, do you remember that night in Dorset when we went swimming in the sea to *Moondance*? Oh my, *what a night*."

"*Un-for-gett-able*," he said, half singing it, and smiling. He blew her a kiss. "Thanks for coming, Jayne. See you sometime."

Walk in the park

5th July

The bench was on a bank above the golf course, looking out to wooded hills, an endless variety of greens and golds. The roofline of a grand country house was just visible amongst the trees - no other houses, roads, cars. He had walked up here from his home - almost a mile using his stick, and now he was feeling exhausted from the effort. An older man in a beaten-up parka and boots carrying a dog lead and following an excited red setter, paused briefly. "It's a fair view," he remarked in a broad local accent, characteristically understated. "A fair view," agreed Daniel. And the man moved on.

Daniel had brought his journal along with a thermos of tea and sandwiches. He sipped his tea out of the small cup that formed the thermos lid. Not bad, he thought, out of the house, beautiful spot, hot tea. He drank some more and ate part of a sandwich – homemade bread even. He had become a bit evangelical about salt in his diet. Much Googling of 'how to manage high blood pressure without pills' had made him realise that salt was important, and he had been eating lots of it in commercial bread – even their 'organic' one – and muesli. So, he had sharpened up his breadmaker skills, kept the salt to a minimum, switched to porridge oats and (homemade) yoghurt for breakfast and – hey, presto – his blood pressure was better. He didn't know if it was the salt or the tablets or both, but it didn't matter which - one more thing that he

was able to do for himself. He had borrowed a book from the local library about making sourdough bread – something he had always hankered after doing - and he thought he could manage it if he made the dough in the breadmaker before shaping the loaves. What was the worst that could happen?

He was aware of the sidelong glances and stares he received on the walk - the stick, his stiff right leg and arm. He had felt like shouting, "It's only a stroke. You should have seen me two months ago!" but didn't. Actually, it had been three months and two days since his stroke. Sam was coming back in a few days for the second Take Charge session, and he was looking forward to it. So much seemed to have changed in the six weeks since he had last seen her - not so much in his body, although he could see the improvements in what he could do, every week, but in his head. So many new ideas, different ideas. A few nights before, he had watched the Spielberg film *Bridge of Spies*. He was most taken by the 'Rudolf Abel' character played by Mark Rylance. When Tom Hanks asked him, "Aren't you worried?" and it was clear he had plenty to be worried about, all he said was, "Would it help?" Daniel had laughed out loud. It seemed so obvious. Of course, it wouldn't help. So why do we do so much worrying then? As it turns out (more Google), Abel's real name was William Fisher, and he was born in Newcastle in the UK! Since then, he had 'channelled the Russian' whenever he could feel his emotions going out of control. Don't worry, be happy. It helped.

He had looked up his well-thumbed copy of Stephen Covey's *7 Habits of highly effective people* - bought when

trying to climb the banking ladder, years before. Habit #2 was 'Begin with the end in mind'. Which was another way of asking, "what is your purpose in life?" And from a book on the Stoics, he found, "A person who doesn't know their purpose in life, doesn't know who they are." Guilty as charged. Doormat Dan. If he didn't take responsibility for his own life now, who would?

He could see now that the first three pages of the Take Charge booklet were all about Purpose; describe who you really are as a person, describe your hopes for the future (where you want to go), describe what getting there might look like (your best day). It seemed so obvious. What had his purpose in life been before the stroke? He hadn't particularly thought about it.

He started to draw: a doormat with *WELCOME* emblazoned across it. Jayne's doormat. Had that been him all these years? At the time, he had seen it as keeping the peace, but, with hindsight, he could see the spinelessness of it all. And the fear that was behind it. Fear of losing Jayne. He had been overwhelmed by her glamour from the start. It had taken him a while to realise that Jayne only had one setting - full volume centre of attention. For that she required people around her to uncritically reflect her brilliance. He remembered a male friend telling him once, "Jayne looks like an angel, cooks like an angel, sings like an angel. You are the luckiest man in the world." His mother was equally besotted. "Don't let her go," was one of her constant refrains. So, he had done everything he could to hang on to her. Playing his part - a bit part to her main act. Jayne's agenda, no confrontation, turn a blind eye. But at what cost? As long

as just a little of her attention came his way. What would have happened if he had stood up to her? She may have left earlier. Would that have been a bad thing? Not as if he had ever entertained leaving or been in other relationships. So why was it so easy now?

Would his whole life have been different if he had stood up for what he wanted? What if he'd done an Arts rather than Commerce degree? Who knows? The past was out of his control. But the thoughts about the past were something he could control. Not much point in dwelling on it, he reasoned. The future, that was different.

The walk home beckoned. Journal, thermos and sandwich bag stowed away in his backpack, stick at the ready, a life to live, one step at a time.

Take Charge 2

8th July

The bell rang. He walked down the hallway, no stick, to open the door. Sam's big smile lit up the space between them.

"Hi, Daniel. Good to see you again. How has it been going?"

"Fine," he said. "Come in".

She was thinner than he remembered. Not gaunt, but not completely healthy either. The white polo shirt looked too white against her skin and hung off her shoulders.

"Are you OK?" he asked, not wanting to appear nosey and trying to articulate the words precisely, so she wouldn't have to ask him to repeat himself.

"Oh, it's nothing. A bit run down. I need to eat some better food. Stay away from the take-out pizzas. God forbid, eat some meat again." Another big smile.

They discussed tea, decided to wait until the end of the session and sat down at the kitchen table.

"So, tell me what has been happening since we last met," Sam began, folding her hands on the table.

"Well, it's easier to talk, and I'm walking faster."

"OK, I get that the stroke things are better. Excellent. But what about you?" she went on, emphasising the final word and smiling again.

He told her about the books he had read and the garden, about how much he loved seeing seeds

germinate and plants grow and how he had never had the time to notice before. He stopped himself after a while, realising that he was getting carried away. "Sorry," he said, sheepishly.

"No problem at all," Sam replied. "It's the first time I've heard you properly enthusiastic about something. Is anyone helping you in the garden?"

He told her about Ravi and the family next door. He explained the ins and outs of the family dynamics, Ravi's conflicts about what his family wanted for him and what he wanted for himself.

"Sounds like someone needs to explain 'Taking Charge' to him," said Sam with a grin.

"Nice segue," countered Daniel.

"Let's do it."

"Do you want me to bring out the sheets from last time?" Daniel asked.

"Only if you want to. I've got plenty of blank sheets here. We can start again if you like."

She took him through the assessments again, and they could both see how things had become a little easier, which was translating into more activity in and out of the house. Nevertheless, Daniel could feel a chill bass note sounding somewhere inside him. Was this it? A bit of gardening, a few trips a week to the shop, the odd cup of tea with a friend? It was 12 weeks since his stroke. He'd read somewhere that all stroke recovery was over by three months. He asked Sam.

"Bollocks," she said with that note of disgust in her voice that she seemed to reserve for academics and textbook writers. "That information comes from studies

from the Dark Ages. And it is plain wrong. People after stroke are so different from each other. Part of it is that all those researchers measured physical things like walking speed and strength and not what people actually do, or want to do, or get a kick out of doing. Three months is early days, pal. Now is the time to dream really big."

Sam opened a new booklet at the 'Two circles' page, offered Daniel a pen and said, "What do you want to write here today?"

This time he started with the circle on the right: 'Who I really am'. He wrote the words 'Not a Doormat', awkwardly, his stiff right hand gripping the pen, making a mess of the curved lines. She looked at him with that quizzical eyebrow-raised thing that she did.

"It's a long story, but I think I have spent my whole life being the person my family wanted me to be: university, my job, my wife, everything. Jayne called me a doormat the other day, and I think she was right. That's not the real me."

Sam didn't say anything for a couple of minutes.

"Anything you want to write in the left-hand circle – about the stroke?"

"Well, there is all the usual stuff – weak arm and leg, slurred speech, too tired – but, funnily enough, none of that seems all that important right now. I'm kind of used to it. I would much rather concentrate over here," pointing to the right-hand circle.

He wrote down a few words: Dad, Granddad, gardener, outdoors enthusiast, musician, Stoic, reader, interested in people, explorer, which took him some minutes to complete.

"Wow," said Sam. "That is quite the list. Different from the first time round, isn't it? Shall we turn the page?"

But Daniel was already there, flipping the page nonchalantly with his left hand and starting to write down his 'Hopes and Fears'.

This time his list of Hopes was:

1. Build a relationship with my children and grandchildren
2. Help other people
3. Do more reading and writing
4. Explore – bicycle tour?

The list of Fears was:

1. Family see me as damaged goods
2. Family embarrassed by me
3. Can't keep up with other people/grandkids
4. Too tired/unable to cycle

"You look like you've been thinking about some of these things for a while," remarked Sam, part statement, part question.

"Oh, yes. All those books you suggested, podcasts, writing a journal – gets the grey cells going."

He had already picked up one of the coloured crayons that Sam had brought with her in his left hand and started sketching shapes.

"Nice work," Sam remarked. "You must have been practising with your left hand?"

"Oh, yeah, I have. Sketching is quite fun with my left as long as I keep the movements fairly small. It should get

better with practice. With any luck, I'll end up ambidextrous!"

Bicycles appeared and a van with an oversize *VW* badge on the front, although the Combi van shape was readily recognisable from the drawing. A small tent. A billy over an open fire. Two people as stick figures.

Sam left him to draw and headed out the back to the garden. A transformation was in progress with raised beds full of seedlings, sunflowers, dahlias and a bean wigwam creating height leading to a mini-orchard with a climbing rose spread along the brick wall at the back. Bees buzzed round the sunflower heads. She took some deep breaths and closed her eyes, letting the sun warm her eyelids.

"Do you like it?" Daniel asked, suddenly appearing at her side.

"Oh, Daniel, it's wonderful. It's happened so quickly!"

"Yes, well, I bought a lot of seedlings, and it's the wrong time to plant fruit trees, but who cares?"

"Everything is just flourishing! What's that beautiful tree over there?", she asked pointing towards the far wall.

"Rivers' Early Plum," he pronounced proudly. "Gorgeous, isn't it? It was bred in the early 1800s by Thomas Rivers in Hertfordshire, one of England's real heroes. His nursery is gone now, couldn't compete with the big garden centres. But his trees live on."

"Ravi's done all the digging and knocking together the raised beds and paths. I help with the planting and watering and trying to fight off the slugs. Glad you like it."

They went back in. Sam looked at Daniel's 'Best Day' and noted to herself the use of brighter colours, smiles on the figures' faces, and smiled herself. Daniel, too, seemed pleased.

"Quite different this time round, don't you think? Why is that?" he asked.

Sam paused. "First thing, it is pretty common to see a difference at the second session like this. Second thing, nobody knows for sure why. I think the best explanation is what people call the 'Normality Narrative'. Most people in the first few days and weeks after stroke tell themselves something along the lines of, "I'm going to get back to normal – just like I was before." They see themselves in a battle to 'beat the stroke'. And for some people, this does happen – they recover completely from their stroke and can do everything they did before. The trouble is, most people don't fully recover after stroke – perhaps only one person in 10, and that is usually after a mild stroke in the first place. So what happens to the other 90%? Some die, of course. Of the rest, some keep on trying to 'beat their stroke', even when it is clear that they are never going to 'fully recover'. They are often aided and abetted by rehab professionals like me. They continue to have this idea of 'normal like before', which just isn't going to happen. And it sort of traps them – they can't get on with the rest of their life until the stroke is beaten."

"For many other people after stroke, however, sometime from a few days to months later, they throw away the idea of returning to 'before-normality' and aim for a 'new normal', accepting that life will be different,

but that it is still a life worth living. 'Take Charge' can help by kick-starting the conversation about a 'new normal'. So sometimes, at the first session, the person is still focussed on the 'Normality Narrative', but the first Take Charge session allows the person to see that it is not sustainable. By the second session, the person is prepared to look forward more to life after stroke. Does that sound like you?"

"For sure," said Daniel. "But actually, it feels like I should have done this Take Charge process even if I hadn't had a stroke – sorting out priorities, what matters to me, who matters to me."

Sam just looked at him and smiled.

Daniel looked straight at her. "So you would say that Take Charge isn't really about the stroke at all, am I right?"

"Exactly. The stroke is just one event that provokes someone to look at their life. Take Charge can be helpful for people with any kind of medical condition or just helping healthy people focus on what is important for them."

"Everyone should use it?"

"Ha! I wish," said Sam.

"But if it is so good, why haven't I heard about it before? Why isn't it offered to everyone with stroke?"

"Who knows?" said Sam. "There is precious little that we do in rehab that is proven to work, and here is something that is. It's cheap, available wherever you live, effective. It is probably just too counter-cultural at the moment. The Rehab world is controlled by influencers who write the guidelines and speak at all the big

meetings. They generally believe that people get better because of therapy. Their problem is they haven't been able to get results from a big trial to prove it. Eventually, they will have to include Take Charge in the guidelines, but that is years away. And then the great rehab industrial complex will claim ownership of Take Charge, incorporate some elements into their usual goal-setting, tick the Take Charge box on the form and keep behaving like they always have – 'us' the clinicians and 'them' the patients.

"No cynicism, then?" asked Daniel with a smile.

"Ha!" snorted Sam. "Take Charge isn't magic, Daniel. It is only the start—a way in. There is so much work to do to become the person you really are, deep down. And it's hard. But it's work we all have to do. Most people never start, no matter how often they are pushed in the right direction. But that is what we are on this planet for. This life. Only one. No dress rehearsal. Help others. Be compassionate. Give back. Nothing else matters."

Daniel thought guiltily back to Jayne telling him much the same thing before she walked out on him.

"But I've talked too much already," said Sam. "Do you want to look at the next few pages?"

"If it is alright with you, perhaps we could leave it there for now. I would rather stay focused on the big picture. I can see how some people might want to break the big picture down into gettable bits, but that's not me right now. I've found the risk factor page quite useful though."

"Yes, that is absolutely OK. You're the boss. I'm sure that the main money for you is in the first three pages of

the booklet, so it is good that you've thought about those. You're right that some people do like to have very specific goals to work towards – walking distance, or how much they can carry, or what they can do without help, and setting a timeframe can be an incentive to work harder for some people. That is how we have always done it in Rehab, so it is there for you to use if you want to."

While Sam was talking, Daniel got himself up and headed to the kitchen to turn on the kettle. "Tea?" he asked.

"Sure," replied Sam.

"You don't need to be somewhere else?"

"Cancellation. My time."

She joined him in the kitchen and accepted the proffered tea mug.

"Tell me, Sam," Daniel asked, "how did you get to be so wise?"

"Me? Wise?" She laughed. "The mistakes I have made. Oh, Daniel, so many mistakes. But you learn from them."

Her story was laced with plenty of sadness. Her father had died in a car accident when she was 10. She had loved him to bits. His energy and humour had kept the family together despite hard times with frequent periods of unemployment, too often medicated with alcohol. Her mother had struggled with depression and alcohol even before her husband's death. Sam's much older sister Toni left home the year before their father died, after one too many fights with her mother. Sam didn't see Toni now, last heard of living in northern Germany, Hamburg possibly. Sam and her mother had carried on, far from

entirely happy together. Home was too toxic for her to flourish academically at school, and despite good GCSE results, she had left school, and home, as soon as she could. She had always been good at sports, getting into county teams at hockey and netball, but she preferred solo sports. Climbing had been something of a miracle discovery for Sam, and before long, she found herself down at the local climbing gym most mornings by 6.30, helping out to get a discount on membership and shoes. She loved the combination of physical strength and agility mixed with the intellectual challenge of working out each problem and the easy camaraderie of the other climbers. She had quickly improved and performed OK at a few regional competitions earning her a level of respect among the climbers at the gym. Injuries were part of the territory, and she had one prolonged layoff following an ankle strain after a fall. She was keen to get back onto a climbing wall as soon as possible, and a couple of sessions with an inspiring older physio whose motto seemed to be 'don't be too cautious' had first brought up the idea of physiotherapy as a career.

But she didn't have sufficient school qualifications, so instead, she had done the Jack Kerouac thing and hit the road. Travelling, bar work, WWOOFing, fruit picking, relationships, lots of stuff. However, she couldn't shake the idea of physiotherapy and had enrolled at night school to get the A levels that she needed.

Physio school had been a load of laughs. She had thought that her climbing and sports background would make her want to follow a musculoskeletal path, but it was the neurological stuff that lit her fire. So many ways

that the brain and spinal cord could interfere with how your muscles behaved. And the psychology of illness also fascinated her - how people with the same physical problems could recover (or not) in such different ways.

About a year after qualifying, she reluctantly saw a doctor because she was tired and had horrible pelvic pain like periods the whole time. It didn't take them long to work out she had cervical cancer, and it was pretty bad, spreading out into her pelvis.

A couple of operations, some radiotherapy and chemotherapy and things were largely under control. No chance of children though.

"So, cured then?" said Daniel.

"Cured? Ha! Those cancer doctors talk with pretty forked tongues. They can't bear to tell you bad news and spin everything as positive. The real numbers are bad. Stage 4 cervical cancer has about a 15% 5-year survival rate. But I'm doing OK."

"Cancer makes you look hard at yourself, Daniel. I read lots. I saw lots of my Auntie Miriam - my Dad's sister. She always had a tricky relationship with my mother, and she wasn't allowed in the house after my Dad died. But I met up with her again after I left home - she has been amazing. She was married for a while and now lives alone in a little cottage on the edge of town. She has this beautiful garden and a conservatory where she can paint and sew. She works in charity shops and the library and helps out with babysitting for her neighbour - a Polish solo mum nurse who has to work night shifts every few weeks—all for nothing. I've never been clear what she lives on, but it can't be much. She walks everywhere - no

car, and grows lots of her food. She does sell her paintings from time to time, but I'm not sure that brings in much money. But you wouldn't know she was poor. She is always very calm and happy, and she listens. And when she listens, she really looks at you. Like inside you. You can just feel this love oozing out of her. So wise. She has this brilliant collection of books which she lends me. Those books by Richard Rohr, Stephanie Dowrick and all those I first read from her stash.

"Do you see her now?" Daniel asked.

"Oh yes. All the time. We talk a lot. She's my Wise Woman. It would be good for you to meet her one day. I think you would get along."

Daniel laughed. "My social circle is pretty restricted at the minute, that's for sure. Send me an invite; you know where I live."

They talked for a long time, about poetry, banking, the Stoics, the joys of writing in a journal. Daniel couldn't remember the last time he had talked like this, and with a woman who was not only virtually a stranger but over 30 years his junior. Something to thank his stroke for, he thought.

As she was leaving, Sam explained that with the two Take Charge sessions over, there were no further scheduled visits. "Hope everything goes well for you, Daniel. I had a lovely time today, and I am so happy that you got to try Take Charge. Be courageous." And she was gone.

Although he was sad to see her go, Daniel had the feeling that the day was something of a line in the sand –

from here, anything was possible, and it was up to him to make it happen.

Making connections

12th July

His heart thumped away in his chest as his left knee pumped down, down, down, dragging the right one with it, his right foot strapped into the pedal of the stationary bike. He had only been cycling for about 5 minutes and was already breathing heavily.

"Keep going," encouraged Ravi, who had done all the heavy work, setting the bike up in the spare room. At first, Daniel was embarrassed by the trouble he had with his right leg just getting onto the bike. But Ravi took everything in his stride, happy to support him onto the saddle and experiment with seat height and foot straps until Daniel could comfortably pedal without his right foot becoming dislodged. "You might need some music or a podcast or something to stop getting too bored," Ravi offered.

"Yeah, yeah," puffed Daniel. "Once I build up enough stamina to last long enough to get bored!"

Actually, Daniel was pretty pleased with himself. The exercycle was an obvious first step towards cycling on the road, and without the worries of balancing, the cycling motion itself was straightforward. He was already thinking about what it would take to manage a real bike. The main issues were getting on and off, reduced power from his right leg and less dexterity of his right thumb for

working the shifter. One of those e-bikes with a step-through design might work, he thought. Move the shifter to the left side, maybe. Worth exploring, anyway.

"What are you smiling about?" interrupted Ravi.

"Oh, just how lovely it is to be back on a bicycle again," said Daniel, still having to catch his breath between words. "That'll do for starters." With Ravi's help, he got off the bike, and they went through into the kitchen.

"Before you know it, you'll be cycling to work," said Ravi.

"Cycling maybe, but not to work. I've resigned."

"Why? Did they make you?"

"No, it was my decision. Banking is not what I want to be doing right now. I'm certainly not passionate about it. They offered me a nice severance package for long service so I won't starve."

"What are you going to do now?" asked Ravi.

"I don't know yet, but I'm going to do lots of reading and thinking about it and spend time in the garden."

"The garden's starting to look really good. My Dad said it reminded him of a Tagore poem - everything reminds him of a Tagore poem or song! Anyway, he wrote this out for you." Ravi smoothed out a folded piece of heavy notepaper. "That's Bengali script at the top and the English translation below. Dad says it isn't quite the same in translation, even though Tagore did it himself, but he hopes you like it. This poem is from a book called *The Gardener*. He hopes you will get much joy from your garden."

Who are you, reader, reading my poems an hundred years hence?

I cannot send you one single flower from this wealth of the spring, one single streak of gold from yonder clouds.

Open your doors and look abroad.

From your blossoming garden gather fragrant memories of the vanished flowers of an hundred years before.

In the joy of your heart may you feel the living joy that sang one spring morning, sending its glad voice across an hundred years.

"I love that line, 'Open your doors and look abroad'. Sort of have another look at what is around you and how you live your life."

Daniel looked at Ravi and marvelled again. It was so shockingly wonderful to be getting a psychology lesson from a 16-year-old!

"Thank your father very much from me. Do you like poetry then?"

"I play around a bit. I think that one day I will write lyrics for a song that will make me famous. Or not."

"Well, if you do write a poem or song, I would love to see it. I've got plenty of poetry and songbooks here if you want to borrow any of them any time. Help yourself."

"Thanks very much, Mr McIntyre. I'd better go and get my homework done. See you again."

The following day it was Ravi's mother who came by. He opened the door, and there she was, dressed casually in jeans and sweatshirt, hair streaked grey and tied back,

and a smile just like Ravi's. She was holding a three-tier stainless steel tiffin set in her right hand.

"Hi, I'm Meera, Ravi's mum. I come bearing curries, chapati and rice," she said in a mock-ceremonial tone gesturing towards the tiffin, followed by a laugh. "I hope you like hot food."

"Love it," replied Daniel, "though for some reason, my sense of smell has died since the stroke. Please come in."

They went through to the kitchen, and Meera lifted the tiffin set onto the table. She unstacked the containers and removed their lids to show Daniel the contents. A yoghurty curry with whole red chillies and curry leaves, a mixed vegetable curry, fragrant yellow rice dotted with cashews and a stack of chapatis. It looked magnificent, and he thanked Meera again.

"I want to thank *you* for all the time you've spent with Ravi," she said. "He enjoys the work in the garden and talking to you."

"Ravi's been great. You must be proud of him. He is such a lovely young man."

"Oh, we are proud of him. It's a tricky time just now. He isn't sure what he wants to do apart from play cricket a lot!"

"He tells me that you and your husband are keen for him to be an engineer?"

"Did he say that? Mainly, we just want him to be happy. He is good with Maths and Physics, and Deepak thinks Engineering would suit him, but it was only a suggestion. He doesn't seem to have many ideas of his own. My mum wants him to do Medicine like me. It wouldn't be my choice for him, although I have had a

wonderful time as a doctor. Things have changed so much. But I am pretty sure he could get the marks to go to Medical School if he wanted to."

"He told me it was your idea for him to come and help, so thanks for that. He also said that you are a psychiatrist?"

"Yes. I work part-time at the hospital. Plenty of time for cooking - my number one weakness!"

"Was it difficult getting work here when you first came?"

"Not really. There are always plenty of vacancies for psychiatrists, especially outside the big teaching centres. We all know there is plenty of racism in the NHS, but in psychiatry there have always been lots of South Asian doctors and women. I've been lucky. I don't want to sound patronising, but you seem to be getting on well since your stroke? We haven't seen your wife for a while?"

Daniel explained about Jayne and also about resigning from his job at the bank.

"Yes, Ravi told me that you had resigned from the bank. Actually, I'd like to ask you a small favour if that's all right?"

"Go ahead."

"I work with a couple of local charities that help people with mental health issues and homelessness. They both run on the smell of an oily rag and every year they struggle with the accounts that need to be submitted to the Charities Commission. We need to get the accounts checked by an independent examiner, and I wondered if you could do that for us? There is lots of information on

the Charity Commission website and sample reports and all that stuff. We can't pay you, but I am happy to bribe you with curries!"

"I would be honoured," said Daniel. "I know a bit about the regulations already, but as long as the turnover isn't huge, I should be able to do that for you. Send me over the accounts as they are and the contacts of any people I should speak to. Or better still, maybe I could visit them directly with you and pick up the files?"

"Perfect," said Meera, "I'm going there later in the week. I'll give you a ride."

"Excellent. I'm sorry, I should have offered you tea."

"Not for me, thank you. I almost forgot," she said diving into her handbag. She produced a small thermos flask.

"Masala chai," she said. "My mother's secret recipe, said to have powerful healing properties." A little raise of the eyebrows and twinkle of the eyes. "Hope you enjoy the food and tea. I've got to go. Lovely to meet you, and thanks for offering to help. That is going to be so good."

After Meera had gone, Daniel took a dinner plate from the drying rack and served himself some of the food. Despite his impaired smell, it was delicious and streets ahead of anything he had eaten in the last few weeks. The spiced tea, heavy with ginger and cardamom, was also just what he needed. He struggled to reconcile the generosity of Ravi and Meera with his own behaviour over the several years that they had lived side by side. He hadn't spoken more than a few words to them over that time, cursory hellos on meeting on the way out or back to the house, and the odd parcel delivered to the wrong

address. He could hear his mother saying something like "not our kind of people". How much richer their lives could have been if they had got to know their neighbours sooner. Well, better late than never.

On stroke

4th August

Another day, another journal session. He looked forward to it, the end of the day suiting him better than the start.

He tended to write in short non-grammatical sentences when he was in his 'thinking about things' mood but at other times he would write short prose or poetry sketches. Today was definitely a 'thinking about things' day.

On stroke. He had read a lot about stroke in the last couple of weeks, deciding that he wanted to understand the condition, as a way of helping to put it behind him. Number, causes, treatments, recovery, personal stories, newspaper articles, he had devoured them all. Well, not all. It infuriated him that some of the best science - the journal articles of new treatments - were behind paywalls. Did he want to pay $US 35 to read a single 3,000-word article? Research mainly paid for through public grants - surely it should be accessible for everyone? Fortunately, the main Take Charge article was 'open access', free to everyone, so he could confirm everything Sam had said. Two trials, both positive. He had even been able to watch a recording of a feisty young New Zealand doctor present the results at a big international stroke meeting in Milan. She was quite something. Take Charge was cheap and straightforward, even cost-saving, but largely missing from any other

reports and reviews. Why wasn't it being used for everybody after stroke? He had ransacked the Take Charge website for information and materials, and understood better a lot of what Sam had told him. He even found the original car drawings. Following another link, he found the four short films that were used in the first Take Charge study. Beautifully made videos - he was inspired and moved by Richie, the jazz musician, and especially by Rose. What a fighter she was. She was much more limited than Daniel due to her stroke but determined to get back to her ancestral family place. She somehow got on a tiny plane and made it there. Daniel wept for her and marvelled at the strength (or power?) that she seemed to be giving to the huge extended family just by being there. It is all about connection, as Richard Rohr would say. He wished everyone after stroke could watch the films.

On getting back to normal. Like Sam had said, we're not talking about 'normal' anymore. He had looked up the numbers. About 10% of people 'recover fully' after a stroke. Which means 90% are no longer 'normal-as-before'. About 15% die in the first month, so that leaves 75% who survived the stroke but were not back to 'normal'. Take away another 15% or so who are discharged from hospital to nursing home or the equivalent. That's 60% who survive, are not discharged to a care home but are not 'fully recovered'. In the UK that is 60,000 people a year. So why do the 'dealing with your stroke' advice pages and leaflets talk about 'helping you get back to normal'? Poppycock. He looked back and realised that was exactly what he had wanted the first

time Sam talked to him about Take Charge—going back to normal. And maybe it takes some time for that to sink in. But if you don't let go of the 'getting back to normal' story at some stage, you're always going to be fighting the stroke - the numbers just aren't on your side.

On guilt. He had thought a lot about risk. Mainly feeling guilty about whether he could/should have prevented his stroke from happening in the first place. Risk was an important part of banking, and he thought he was in a reasonable position to understand the numbers around risk of stroke. A few online calculators were available so he had used these as if he was the person before his stroke. For him, prior to his stroke happening, he came up with 15% risk of having a stroke or heart attack in the next 10 years. Most of his increased risk was due to his blood pressure, but even a 'healthy' person of his age would have about a 10% 10-year risk. But what did that really mean? Put more positively, he had 98.5 chances in 100 of not having a stroke each year for 10 years. And if he had controlled his blood pressure to normal with pills, his odds would improve to 99 chances out of 100. That didn't seem like enough to change his behaviour prior to the stroke. Message: don't feel guilty.

On blood pressure. But now that he had had a stroke his future risk was much higher: perhaps a 15% chance of a further bleed in the next 5 years on top of the risk of a 'blockage' kind of stroke or heart attack. Yikes. Still 95 or 96 chances out of 100 of not having another bleed, stroke or heart attack each year, so no reason to stay awake at night. But there was pretty sound evidence that he could

reduce his risk by about a third just by reducing the systolic (top number) blood pressure by about 10 units. There was a blood pressure recording sheet in the Take Charge booklet which had started him off, but he had decided it was something he was going to do long term. He kept his systolic blood pressure recordings on a computer spreadsheet (years of being a banker) and worked out the average every week. His systolic blood pressure at home was now consistently between 125 and 135, and the average was steadily dropping; last week was 129. He had checked with his GP, and before the stroke his systolics were mainly in the high 140s, occasionally over 150. He sent the current numbers by email to his GP every fortnight or so, and she was happy with the way things were going. He had asked her whether he should reduce the medication now his blood pressure was lower. She had emailed straight back: "You are doing great! The lower your blood pressure the better. Keep taking the pills!" Which made plenty of sense to him.

On labels. He kept reading about 'stroke victims' and 'stroke sufferers', which upset him. He hated this sort of language, particularly prevalent in newspaper articles of 'wonder treatments' but still finding its way onto some stroke support websites, including that of the UK Stroke Association. The terms implied the stroke itself had agency and inflicted damage and suffering in some consciously malign fashion like a criminal might. Surely stroke just happened? He'd had a stroke, not 'suffered' one, and he certainly didn't see himself as the 'victim' of one. He liked better the language in the Take Charge

booklet: he was a person that happened to have had a stroke. He worried that the victim/sufferer language could affect recovery for some people. In his reading, he had stumbled across Nortin Hadler, a rheumatologist, who used the term 'predicament', which Daniel liked. The predicament of back pain. The predicament of stroke. Hadler had shown that as soon as people with the predicament of back pain saw a doctor (and became a back pain 'patient') or sought compensation (became both a 'litigant' and 'injured'), their outcome was worse than if they dealt with the problem themselves. Daniel could see this applying to people after stroke also. A stroke 'victim' wants someone to 'put it right' - a medical court, perhaps? A stroke 'sufferer' wants the sympathy of others. But as the Stoics would have it - these options are both beyond your control, dependent on others. What is within your control? How you think about it. Daniel wrote down:

I've had a stroke.

I am a person who has had a stroke.

I am a person.

Below, he wrote out one of his favourite Stoic quotes from Epictetus:

Let go of the past. We must only begin.

On disability. Daniel had also read a lot about rehabilitation. He was surprised at how recently the concerns of people with different abilities - from stroke, other disease, injuries, genetics - had started to be taken seriously by the medical and political establishment. The WHO had dumped the terms 'disability' and 'handicap'

20 years ago, but they were still commonly used today. The replacement terms – 'activity limitation' for disability and 'participation restriction' for handicap were better but didn't exactly roll off the tongue. He didn't feel disabled or handicapped. There were things that he was less good at than before - mainly to do with using his right hand like typing fast, playing the piano, breaking an egg. But there was nothing critical to his existence, and usually there was a work-around, possibly taking a bit longer. He couldn't run, but he could walk pretty well after a fashion. Stairs were a problem, especially coming down. People stared. He ignored them.

On purpose. Having purpose was a key element of Take Charge. The second Take Charge session had hammered that home to him. The Stoics placed Purpose as the most important element in life itself. Daniel had just finished Hilary Cottam's superb *Radical Help*, with her team using a Take Charge-like approach full of purpose to help all sorts of people on the fringes of society (poor, old, homeless, out of work). But before his stroke, how would he have answered the question, "What is your life's purpose?" Providing for his family? Preparing for retirement? Both of which could translate into 'making money'. Well, yes, but hardly the sort of thing you would want read out at your funeral was it? Being a generally 'nice guy'? So what? Richard Rohr might say that as a society we have lost our sense of purpose and replaced it with materialism; mistaken money and goods for real purpose. Once upon a time, JS Bach or Michelangelo or any number of priests, monks and nuns, said their purpose was 'to serve God'. Take God out of it, and it

remains 'to serve', and only needs the word 'others'. He had come across the word 'generative' to describe this act of leaving society/ the world a better place than when he arrived. He sat for a long time thinking this through and what it meant for him. Finally, he wrote the Stoic quote down again:

Let go of the past. We must only begin.

His right hand was cramping up, and his left was still too slow to keep up with his thoughts. It was already dark and getting cold. He got himself up, stretched his stiff limbs and walked towards the kitchen. As he passed the piano, he played a few chords with his left hand, plonking down a few melody notes with his right and smiled. Begin again.

Wales

2nd September

He looked out the window at the sea - the Bristol Channel and, with the eye of faith, the north Devon coast beyond. Max was driving the two of them to Three Cliffs Bay on the Gower peninsula in a simple white van with the logo of a well-known rental company shouting from the sides.

"Beautiful, isn't it?" remarked Max watching the September sun shine through scattered clouds out of a blue sky.

"Stunning," confirmed Daniel. "Why have I never been here before?" he murmured, not expecting an answer.

"We are going to have such a good time," chirped Max, threading a course along narrow lanes to the camp site.

Max had organised everything: a precious few days away from Maria and their new baby Inês, with Maria's full blessing; the glamping tent at the campsite with a double bed plus camp stretcher, sofa, fire pit and well-stocked shop; the van with mysterious cargo that Max had kept under wraps since his arrival, and some sensational early September weather.

They had promised each other a walk to the beach, and with their gear unloaded, Max carrying a small backpack and Daniel with two blue walking poles fresh from the outdoor shop, off they headed. The first piece was straightforward, but when they turned right at the sign for Three Cliffs Bay, the path suddenly became steep and

uneven, with large stone steps offering a choice of descent.

"Are you sure about this, Dad?"

"I haven't been surer about anything in my whole life. Lead on MacDuff."

They picked their way slowly down the path, Max helping to stabilise his father's trunk on some of the bigger steps; a few mini-stumbles but no falls. A yell of triumph from Daniel at the bottom. Ahead of them were just a couple of sand dunes to negotiate before the beach itself. Daniel kicked off his sneakers and stood barefoot in the sand. Max leaned down, picked up their shoes and stuffed them into his backpack before heading up the first dune. Both of them slid a few times in the deep sand, and there was a memorable face plant from Daniel when he lost his footing in the loose sand just over the rise.

"Bastard," he muttered, spitting out sand from his mouth. But his smile was broad.

They hit the firm sand of the beach, and Daniel started laughing. Max joined in. They stood together and laughed away the years until they cried.

Closer to the water, Daniel noticed a man in his early 30s perhaps, teaching his daughter to ride a bodyboard. She could only have been 4 or 5 - each time her father would set her on the board waiting for the wave and release her at precisely the right time for a gentle surf up onto the beach. Each time she squealed with pleasure. Each time he applauded extravagantly. Each time she grabbed the cord attached to the board and pulled it back towards her father. "Again," she pleaded. Each time he smiled and did exactly that until finally she tired, and

they walked hand-in-hand, victorious, up the beach to their towels.

Daniel stopped watching them and turned to Max. "I am so sorry."

"Whatever for?" asked Max.

"For all those years when I wasn't there for you. When I didn't stand up for you. When I let Annie and Jayne tease you. For everything."

Max looked at him, placed a hand on each cheek and kissed him on the forehead. "You're forgiven. Today you've made me the happiest son in the entire world."

"Ha!" said Daniel. "And I am the happiest, luckiest, proudest father."

Max looked at the water and then at his father. "Are we doing this?"

"Nothing surer. What's the worst that could happen?"

They stripped down to swimming trunks, Daniel manipulating his clothes expertly, lying on the sand. He leapt up with a big smile and strode purposefully towards the water, *sans* sticks, Max at his side.

The first touch of the water wasn't as cold as he had imagined. "Warm for Wales," he laughed. Max grinned.

Further in they went, water up to their waists, small waves breaking into their midriffs. Without warning, Daniel dived through the next wave. Total joy - flipping onto his back, looking towards the beach, floating gloriously, his right leg weightless. It was so easy to use both his arms to paddle underneath him and perform little circles in the water. Brilliantly easy. Max too was fooling around, floating, kicking, swimming, laughing - always laughing.

Finally, Daniel and Max stood up together, knee-deep in the water. Daniel grabbed his son in a bear-hug. "This is the best day of my life. Thank you."

They were both thinking the same thing: this would never have happened except for the stroke.

After a long time, Max released himself and said, "We should thank Sam. When will you see her next?"

"Well, I'm not due to see her again. It was just two sessions, and now I go to physio sessions at the hospital once a week."

"Well, if you do see her, thank her for me," said Max.

They started to walk back up the beach where their gear was lying. "You know, it is one of the things Sam said to me about Take Charge that I've finally understood I think. She said that the studies of Take Charge showed people improved in a physical kind of way even though Take Charge is a psychological type of treatment. People were able to do more, but it wasn't because of an effect on mood or anxiety. The people that developed it thought this was strange. They knew it worked, but they weren't sure how it worked. Well, it is pretty obvious to me how it works - if you set your mind on something and really work hard to make it happen, of course you will improve faster physically. Without Take Charge, there is no way I would have managed the walk down here today. It just about killed me, but I did it. And now that I've done it, nothing is going to hold me back."

Max draped his arm around his father's shoulder and squeezed. "Exactly."

Going back up the hill was much more tiring but less scary. By the time they got back to the tent they were

both exhausted. Daniel flopped down on the double bed, and Max sat on the sofa. "This is really comfortable and all that, but next time we'll bring our own tents," said Max. "We can camp at the top of the hill and look out over the beach and the sea. Wouldn't that be amazing?" It was a quirk of the campsite that the very best pitches were at the top of a steep hill on the beach side of the site, looking out to sea, whereas the glamping tents were on a flat area with no view of the sea at all.

"Next time?" thought Daniel. Future tense. Virtually every day since his stroke had been in the present tense. Or going over the past. "One day at a time, Daniel," they all had said. But Max was talking about the future, something they could plan together, look forward to with an expectation that it might actually happen. Now that was a gift indeed.

The next day, Daniel woke to the sound and smell of a barbecue. Sausages, bacon, mushrooms and Max humming to himself as he manipulated the food on the grill, just outside the tent.

"I can smell it!" shouted Daniel. "Really smell it!"

"That's great," said Max, not understanding how significant the switch was for his father. "You're going to need a big breakfast today, so sit down and pour the coffee."

This, too, smelt real and wonderful for Daniel. Had the swim yesterday done something? Salt water up his nose? Cleared out his sinuses? Who knows? Who cared? The food was delicious. He was hungry and looking forward to whatever Max had planned.

"Come with me," said Max after they'd washed up the breakfast dishes. They headed over to the back of the van, which Max opened with a flourish. Daniel peered in at the contraption inside. Wheels, pedals, chain, handlebars but not enough for two bikes.

"Watch," said Max as he expertly assembled the bits on the ground beside the van.

"A tandem!" said Daniel admiringly.

"Not just any tandem, but a recumbent tandem", added Max. "Climb in. We're going for a ride."

He handed Daniel a helmet from the van. The rear of the tandem was fairly orthodox, but the front rider lay down, pedals ahead, hand grips down by the hips. With Daniel in the tandem, Max was close behind with his hand grips right above Daniel's shoulders. There were special straps for the front pedals so that Daniel's right leg could sit on the pedal without risk of it falling off. Max stashed drinks, snacks and his phone in the small bag mounted on the rear rack.

"Amazing," was all Daniel could say as he grinned stupidly.

"Pedal when you feel like it," said Max, "but when we get to a hill, pedal like a bastard."

"You're on."

Daniel felt like he was in an impossible, magical dream. They zoomed off down the hill heading for the next bay, fields, flowers, trees, and birds keeping them company. A few small inclines were no bother as he got used to the pedals and the feel of the bike. Max chatted away, telling him how he and Maria had bought the bike after seeing a video of a couple of keen cyclists using one.

The wife had had a stroke, but they still cycled hundreds of miles on the tandem. Max and Maria thought it would also be a great thing for the two of them and their new baby, and they had already been out a few times together in Portugal. The airline had been fairly relaxed about shipping it, and here they were.

"Thank you so much," said Daniel as they cruised down to the first beach. "A million thank yous to you and Maria."

"Well, you will get to thank her tomorrow morning – we've arranged a video call, and she can't wait to talk to you about the tandem."

From the beach, there was only one direction, and that was up. "Are you ready?" Max called. Daniel nodded. "Pedal like a bastard," Max shouted and up they went, lots of low gears to keep things possible, lots of horsepower from the legs of the two riders. Once up, the lanes were fairly flat beside fields, passing small hamlets, heading west to Rhossili. They got used to the banter of passing cyclists. Coming towards them, enough time only for one or two syllables. "Morning" sometimes with an exclamation mark, "Nice day", "Tandem!" always with an exclamation, "Brilliant!". And going their way, the simple "on your right" from the serious crowd and a little more time for a chat from the rest. "Have a great day", "always wanted a tandem", "Go granddad!" and many more.

After some time, a group of three older women in matching bright pink T-shirts and black cycling shorts came up beside them.

There were the usual pleasantries, then the front rider of the trio, with lots of freckles and red hair escaping

from under her helmet, looked in towards Daniel. "Brilliant," she said. Daniel nodded and kept pedalling. "What's wrong with your leg?" she asked having clocked the strap across the pedal.

"Stroke," answered Daniel.

"Brilliant," she said again.

Meanwhile, her colleague, resplendent in garish green helmet, which, combined with her T-shirt and shorts, reminded Max of a liquorice allsort, was singsonging in a Welsh-accented conversation with Max. Something about gear ratios and other technical stuff to do with the tandem but for Daniel it was all a flash-back to Ann Beach playing Polly Garter in Dylan Thomas' *Under Milk Wood*. "Oh, come and get me Mr Anybody!" And all the other characters crowding in from his father's old vinyl recording featuring Richard Burton. "Lovely," summed up Liquorice Polly.

An irritated motorist, held up by the five of them hooted his horn.

"Read the Road Code, dickhead," yelled Freckles with scattered other expletives illustrating how much she thought of him.

"Perhaps you'd better go ahead," offered Max.

"Not yet," said Liquorice Polly, "we're taking you up the big hill," with a huge grin.

And sure enough, another half mile or so up the road was the hill, steeper than the rest, and long.

"Pedal like a bastard," called Max and Daniel did. Up the hill they zoomed in convoy two abreast, the women and Max hooting encouragement.

"Almost there," called Freckles.

"Go, go, go," screamed Max.

Daniel just smiled and pedalled, gasping for air as they reached the summit.

And over they went. The racket from the women was immense. It could have been the finish line of an Olympic marathon: whooping, hollering, ringing of bells.

"Brilliant!" called Freckles, and they were off, disappearing in a blur of pink, black and green.

And now everything was infused with Dylan Thomas. The mustardseed sun. Hay as high as houses on all sides. And here Daniel was, green and carefree, famous among the barns … and singing. He and Max belted out Bruce Springsteen, Talking Heads, David Bowie, Queen – not all the words, but enough, and the joy in their voices trailed across the valleys as they rode.

They stopped for sandwiches and thermos coffee high above Rhossili Bay, a few tiny wisps of cloud just adding to the scene as the sun poured down on the beach and headland. His coffee finished, Daniel lay on his back, letting his mind float, listening to Max talking of his plans for the future. These involved buying a small farm and running it as an organic B&B operation, giving Inês and any brothers and sisters the best possible environment to grow up in. "We're on the lookout for motivated investors. Not something you would be interested in?" said Max with a smile.

"I feel well warmed up for an investment pitch," said Daniel, chuckling. "And sure, I would be very happy to look at a proposal. If anyone can make that work, I think you could. I would still need to be convinced by the numbers – old banking habits die hard."

"Sure thing. Thanks, Dad. Maria said not to mention it to you. She was worried it would make us look like greedy kids preying on your vulnerability, but I said that you weren't looking vulnerable to me – quite the opposite. We've got a fair chunk of the money saved and a big client list of people who have stayed with us in Lisbon but wished they could spend some time in the countryside. And we've found a nice place which won't need too much sprucing up. We could probably finance the whole thing on our own if we had to, but we would love you to be involved if you wanted."

Well rested, they headed off again, eventually stopping for pizza and beer at a pub in the middle of the peninsula. Daniel was so knackered by the end of lunch that he could hardly speak, and Max let him doze as he pedalled the tandem back to the campground. He shook Daniel awake for the last climb, after which they freewheeled down the slope towards their tent, the sea beyond and a glorious day behind.

Dinner was a wondrous concoction of braised leeks and pasta with pinenuts, Max unpacking chilly bins from the van that included a Portuguese rosé, and sheep's cheese from the Pyrenees. They finished off dinner with choc-ices from the camp store – redolent of those early days of Max's youth when he and his Dad were a team of explorers, builders, tale-tellers and friends. They played cards just like the old days – two-handed five hundred, scoring fiercely. Both bid extravagantly; better to have tried and lost than not to have tried at all.

The next morning, they video-called Maria and reported back on their tandem adventures, and their

plans for the next couple of days. They were both undone by Inêz's happy gurgles and eyes. For Daniel, it was great just to listen and not feel the need to jump in and make his point. There was plenty of to and fro just the same, and Daniel was able to express his gratitude to both of them for these days of pure magic. "Come see us soon," said Maria towards the end. He would, he promised, volunteering any amount of time looking after Inêz while they scouted out their new project. "Deal. Take it easy, Daniel and send Max back to me in one piece," said Maria, as she wished them well for the day.

Reflection

3rd October

Autumn was here. It was colder, with more wind and plenty of leaves falling all around. The beans were finished, but the dahlias and chrysanthemums still provided plenty of colour in the garden.

The stroke itself was now in his past, no longer centre stage. Was it six months ago? So long? All the inconveniences of his not-so-good right side: hassles in the shower, sitting down to dry his feet, avoiding buttons and laces, were second nature and not something that he thought about much anymore. That was how it was. And he continued to get better at doing things - somehow his brain had adapted to the motor difficulties on his right side and worked out the best way despite those problems. His walking was faster and safer, and although he took a walking pole with him when he was walking on tracks rather than pavements, the rest of the time he left his stick at home. Even his piano playing was improving.

In those six months, his life had transformed in ways he could never have imagined. He had thought about it a lot and tried to describe the whole experience to Max on the phone when they had talked a few days before. "Imagine your life is a series of cotton threads woven together. Before the stroke, my life felt like a few threads of dull monochrome, all a bit tangled and disconnected. But now there are all these new brightly coloured

threads, connecting with other people, making marvellous patterns, pulling me along, going somewhere, flowing into the future, and it feels fantastic. Does that sound crazy?"

One of these threads was the homeless shelter. Ravi's mum, Meera, had taken him down there to pick up all the financial paperwork so he could make a start on the annual financial return. His heart had sunk as she handed over several box files of random receipts, chequebook stubs, bank statements and ledgers that at first glance looked all over the place. But he had smiled and said, "I'll see what I can do."

"Come and meet the crew," Meera said, and he sat down with a group of volunteers and some of the men taking advantage of the shelter's facilities for the night. He was served strong hot tea in a large mug, somewhat bizarrely carrying a one-sentence abridged version of 'Pride and Prejudice'. The volunteers varied in age from Ben, a young man in his twenties - a 'graduate of the street' was how he described himself, through to Val, a woman of about his age who had been helping out in the shelter and soup kitchen for more than 10 years. The men clearly loved 'Auntie Val', and there was plenty of rude banter in both directions. Daniel had been aware of homeless people around the town but hadn't paid them much attention. He had seen the small tents pitched in out of the way places on the edge of town, down by the river. He mainly believed the various media lines that the men and women who asked him for money outside the supermarket probably had somewhere to sleep, didn't really need the money, or drank and gambled it all away.

Easier to look away. Not so easy to look away now. The men and women he was sitting with had stories, uniquely theirs. Stories of families, struggles with addictions, struggles with mental health, struggles with authority. Bad luck, happy times, support from Auntie Val, if only with a cup of hot soup and a laugh. On the whole they were quiet, wary of saying too much. Val and Meera filled in some of the detail after the men had drifted away for the night. Daniel had asked what more he could do and whether he could join a volunteer's roster, but Val had put her hand on his shoulder and said, "Easy does it, Daniel. If you can sort out the books, that would be a huge weight off our shoulders. With proper accounts, we have a better chance of funding, and that's what we really need - some steady income so that we can plan. You're welcome to come down here any time and talk. Lots of these people have had the humanity kicked out of them, and it is a very slow process to heal."

Since then, he had done what he could with the accounts, setting up a simple system for all new income and expenditure, compiling a rough approximation of the finances for the last 12 months and submitting it. He had also started a couple of grant applications for equipment and repairs. He was now officially the 'Treasurer' for the Trust, and the positive response to his efforts from the others on the committee was ridiculously over the top. It had not been a lot of work, and he only wished that he could have been involved sooner.

One of the things he could share with the men and women at the shelter was his invisibility. People in the

street would avoid him, sometimes cross the street to not walk past him, just because he was limping, and his arm looked odd. They seemed to assume some element of mental disturbance as well. So what? He had walked through the centre of town the week before and had seen Linda, a woman from the bank. They had worked together for a few years, not exactly friends but would always say "Hi". He was sure that she recognised him, but she had looked straight through him! Admittedly, he was in a hoodie, sweatpants and trainers (so much easier to get on and off) rather than a suit. However, to his mind it was his physical limitations that she was registering as 'not my type' and moving on. When he went looking for it, there was plenty of literature describing this 'othering' of people: by skin colour, age, religion, physical or mental limitations and he realised he had been guilty of exactly the same thing in his previous life. He hadn't thought much about his life of privilege - white, male, English as first language, no major financial hardship growing up, good education, better than average salary, never unemployed - until now. Even in the subset of people after stroke or with lots of other physically limiting illnesses, he was way better off. He had an income and savings and a house; these were a world away from surviving on disability benefits and overcoming prejudice in the job or rental market. How do you get your shopping up to your tenth floor flat when you walk with a stick and the lift is broken? How do you apply for rehousing when English isn't your first language, you're not computer literate, and the nearest public computer is at the library a long bus ride away?

On the brighter side are what he had started to call his 'angels'. They were everywhere and would always pop up when he most needed help. Ironically, they were more likely to outwardly be 'others' just like him: most often women, often older, non-white. "Can I help you?"(getting on the bus or walking down the non-railed steps at the library). "Let me take that for you" (taking his tray to the table in a café), and even once an older Indian woman helping him put his shoe back on when he got his stiff foot caught behind a pole on the bus. Would he have done that for them when he had been able? It likely would never have occurred to him. It was not as if he usually needed the help, and part of him was too proud to want to accept the help anyway. But he had gradually realised that these were simply acts of kindness - other people 'seeing' him and not excluding him, affirming him as a human being. The kind of world he wished to live in and contribute to.

One of the brightly coloured threads in his new life was about thinking. 'Philosophy' sounded far too grand and abstract. Now he had time to think and read, not something he had done much since university days. His reading before the stroke tended to be newspapers and crime fiction, the latter mainly on holiday. In the last six months he had read a ton of non-fiction: plenty about stroke and disablement but mainly approaches to living well from the Stoics through to Alain de Botton for individuals, and Michael Marmot and Hilary Cottam, amongst others for society. Lots of poetry. He had re-read Dickens, Thackeray and George Eliot as much for the social commentary as the amazingly drawn characters

and humour. On the one hand, he found the reading enriching, filling a hole in his life, something he should have been doing years ago. But more importantly for him, the distilled response to the wisdom and experience of these writers was Action. One must do something. Although physically he was somewhat less able than before, he had never been better able to contribute. He wasn't going to change the world, but he was determined that in however small a way, the world would be a better place when he left it.

The thread labelled 'family' had definitely changed to a brighter colour. He had video-called Max and Maria last week, which was warm, friendly, and natural. Max and Maria sang some songs including Portuguese fado. She had a natural voice and sounded so good singing in her own language. Later on, he and Max had tried to play some piano duets, but it proved impossible to coordinate across the call with a built-in one-beat delay. Nevertheless, it was funny at times, and there was plenty of laughter. Room for improvement, they agreed.

Perhaps the big surprise had been his relationship with Annie. This had been very cool for years - Annie mostly talked to Jayne - and Daniel had accepted that this was the way things were. However, their relationship had taken a major turn for the worse after Daniel's 60th birthday party when Annie had been so nasty to Maria that she and Max had left early. Daniel had been uncharacteristically angry with Annie and her husband once Max had left, and they had hardly spoken since. Annie had visited him in the hospital a couple of times, always with Jayne, and each time he had felt her recoil at

his limitations. She barely tolerated the slowness and intelligibility of his speech, finishing his sentences for him and speaking overly loud as if he was deaf or stupid or something.

But since Jayne had left there had been a few phone calls "just seeing how you are getting on", stilted at first but becoming less so of late. He had found himself talking about his reading, writing and music. Then two weeks ago, she had sent him a package with details of a 12-month subscription to *London Review of Books* and a link to her ad-free music streaming account plus a set of wireless, bone conduction headphones. So now he walked around the house, the garden and the local parks with Dylan, Mercedes Sosa, podcasts and audiobooks playing in stereo. It was magic. The headphones were also fantastic on his exercycle as a way to overcome boredom and keep going. How could Annie have worked him out so well? Who knows? Still, lots of water under the bridge and a truly warm relationship seemed a long way off, but now there was some hope—worth some extra effort for sure.

He thought about all the other explorations in the last six months – the garden, walking, cycling, music – and thought for the thousandth time, "would I have been here without my stroke?" and knew the answer was "No".

Sam

6th November

It was the first properly cold day for a while, intermittent rain and wind smacking against the windowpanes. The trees in the garden were naked and sad, hunkering down for the winter.

Daniel's phone pinged. It was a message from Sam: *Daniel. Pls visit tmrw 2pm? 66 George Ave. Door is open. Bring Dylan T. Sam*

He hadn't heard from Sam for ages and didn't know what to make of the request. Was this the promised chance to meet Miriam? And why the poetry? There was only one way to find out.

He found the place without too much trouble, a lovely cottage on the edge of town which fitted Sam's description of Miriam's house. He knocked on the door. "Come in," called Sam from somewhere inside. He opened the door and walked a short way down the entrance hall. "This way." He followed her voice and eventually spotted her in a room on the other side of the house. She was sitting in an armchair next to a huge window looking out over a garden to trees and a brook. She was much thinner around the face, but a large woolly jumper and a beautifully colourful, woven blanket across her legs made it difficult to tell what the rest of her looked like. Her big smile hadn't changed.

"Oh, Daniel," she said, "it's so good to see you again."

He didn't know what to say. He knew something was wrong and guessed Sam would tell him in her own sweet time. She gestured for him to pull up a chair, and he sat down.

"I'm sorry to spring this on you, Daniel. Things caught up on me a bit quicker than I thought. My kidneys are blocked by the cancer. They wanted to stick tubes and stents in, which would drag things out for a while, but I wasn't keen. I've moved into Miriam's place, and the community hospice team are helping look after me here. Miriam's got a whole stack of business to catch up with in town this afternoon, so I said I would ask you to come and sit with me for a while. Is that OK? Isn't it an amazing view?" So matter-of-fact.

"But why me?" he blurted out. "And why now?" Realising this sounded a bit rude, but Sam didn't seem to mind.

"A shared love of Dylan Thomas? No, really, I just wanted to know how things turned out for you. It felt to me like you were at a turning point, and I selfishly wanted to see if it worked out. Are you flourishing? Do you mind me asking?"

Of course he didn't mind. He told her about the garden and Ravi, the cycle trip with Max, his piano playing, retirement, all the reading. "Max asked me to thank you from him. And from me. You've changed my life. That Take Charge stuff changed my life."

"Oh, Daniel. It wasn't me. I'm sure Take Charge helped. But it is only the start. You needed something like Take Charge to properly look at yourself and start filling

up your tank with stuff that mattered to you." She paused for breath, taking lots of time between each sentence.

"Where you have got to is fantastic. I am so happy for you. But there is still lots of hard work to do. Do you know the Christina Rosetti poem?

Does the road wind up-hill all the way?

Yes, to the very end.

Now is not the time to take your foot off the gas, Daniel. Keep going. It is so lovely to see you again."

She stopped speaking, needing to catch her breath. Daniel became more aware of the music in the background. He could see the speaker on the bookshelf with its blue ring pulsating and assumed that the music was coming from Sam's phone on the bedside table. The music was orchestral and so soft and low that he could hardly hear it. And then there was just a solo piano with a very simple, slow melody picked out in the right hand accompanied by broken chords in the left, instantly recognisable to him as the slow movement of the second Shostakovich piano concerto.

"Since when did you like Shostakovich?" he asked.

"Is that what it is? Beautiful hey? Miriam put all the music together for me in a long playlist, and I just leave it going. Some of it is happy, some peaceful and soothing. She has a thing about Bach, so there's quite a lot of that. She played me some Bach yesterday with a high voice and a solo violin that was totally gorgeous. I could listen to that all day."

"Sounds like *Erbarme dich* from the St Matthew Passion. Very beautiful. "*Have mercy, my God, for the sake of my tears*". Peter is pleading with God because he has just

forsaken Jesus to save his own skin. Human frailty and all that."

He went round to her bedside table and scrolled through the playlist on her phone - an eclectic range of classical, blues, folk and others like *Happy Together* from The Piano Guys and Coldplay's *Fix you*.

"Where does she get all this from?" Daniel asked.

"Oh, Miriam's a magpie. The young people down at the homeless centre send her playlists of stuff, and she just picks things she likes and adds them."

"You're lucky to have her in your life."

"I know. You'll meet her at the funeral. You two would have so much in common." There was a glint in her eye.

"Are you matchmaking?" Daniel asked with mock horror.

"Not at all. Miriam is a grown-up woman and used to living on her own. When you start looking properly at your life Daniel, you realise that there are not many grown-ups in the room. So it is good when you meet one."

"Anyway, she's organising my funeral. We want you to read something. Is that OK?"

Daniel was too choked up to talk.

And now, inexplicably, the music was Billy Joel's *Goodnight my angel*, a song that was released when Max and Annie were small and which he used to play and sing to them. In those days, he had thought mainly about the line "I never will be far away" in the first verse, although it was the lines:

Someday your child may cry/ And if you sing this lullabye
Then in your heart/ There will always be a part of me,

that consistently choked him up.

But now, it had a completely different resonance. It was as if Sam was talking to him as the parent. *Goodnight, my angel/ Now it's time to dream/ And dream how wonderful your life will be*.

"Are you OK, Daniel?" she asked when he hadn't spoken for a while.

"Sure," he said, fighting back the tears. "It's hard thinking about a funeral, that's all."

"Dying is the easy bit, Daniel. I've had a beautiful life – plenty of ups and downs, but I wouldn't change a minute of it. So, you'll read something for the funeral?" she asked again.

"Of course I will. I would be honoured."

"Speaking of which, read to me now, will you?"

"What do you want me to read?" He looked at the pile of books by her chair. "A novel?"

"I've no time for novels now, Daniel. Too many words. I can't concentrate for long. Read me poetry. Did you bring Dylan Thomas?"

He pulled the slim red volume of poems out of his satchel. "Where shall we begin?" he asked, smiling, but heaving inside.

"Read *In my sullen craft,* then *Do not go gentle*."

He started reading, a little surprised by her first choice.

"God, he was such a show-off!" she murmured, mainly to herself when he had finished. But she was smiling.

He read *Do not go gentle*– all that raging, raging against death. He looked over at Sam.

"Don't die like that, Daniel," she said. "Dying doesn't matter. It's living that's important. No point in raging. I

just wanted to get that off my chest, you see. Just to explain that I'm happy and not raging. Now, read something joyful. Of life. How about *Fern Hill*? It's a *Fern Hill* kind of day."

And so he began … *As I was young and easy under the apple boughs ….*

Reading the poem reminded him about the Welsh cycle trip, so he recounted the Dylan Thomas moments to Sam. She laughed. When he described the three women cyclists she laughed again. "You're making that up," she said.

After more gentle chat, Sam seemed to snooze, so he started reading *Poem in October.* Sam opened her eyes and interrupted. "I'm not going to get to my thirtieth year to heaven, Daniel. But I'm not sad." And she asked him to repeat the second verse, mouthing the words along with him.

and the birds of the winged trees flying my name
Above the farms and the white horses
And I rose
In rainy autumn
And walked abroad in a shower of all my days.

And although he started to read on, she went back, repeating, "and walked abroad in a shower of all my days, a shower of all my days, all my days, all my days". He looked over at her, ecstatic, eyes focussed in the middle distance. "Oh, Daniel," she said after a while. "When you've only got days left, everything becomes lighter, softer, calm. Like silk. Cool on your skin. So lovely. Read me Rumi now. I'm getting tired, and I might

fall asleep. Do you mind reading me to sleep? Thank you so much."

He found the book of poems in her pile and opened it. "The one about the couple on the verandah," she said.

A moment of happiness,
you and I sitting on the verandah,
apparently two, but one in soul, you and I.
We feel the flowing water of life here,
you and I, with the garden's beauty
and the birds singing.
The stars will be watching us,
and we will show them
what it is to be a thin crescent moon.
You and I unselfed, will be together,
indifferent to idle speculation, you and I.
The parrots of heaven will be cracking sugar
as we laugh together, you and I.
In one form upon this earth,
and in another form in a timeless sweet land.

"Oh, Daniel, I'm so happy you could read that for me. Don't you love the parrots of heaven cracking sugar? Read it again." Her voice was only a whisper.

And on he read as Sam gradually drifted off. Occasionally she murmured "lovely" or simply "oh". The last thing she said was "the moon thief", which he took as a request. He eventually found it on a particularly well-thumbed page. Sam had been here many times before. He started reading.

At the twilight, a moon appeared in the sky;
Then it landed on earth to look at me.

Like a hawk stealing a bird at the time of prey;
That moon stole me and rushed back into the sky.
I looked at myself, I did not see me anymore;
For in that moon, my body turned as fine as soul.
The nine spheres disappeared in that moon;
The ship of my existence drowned in that sea.

Sam, too, had disappeared, playing with her moon. Just her gentle breathing and a hint of a smile remained.

Daniel rearranged the blanket over her legs, squeezed her hand and left.

Miriam

7th November

The next day, Daniel received a text from Sam. *Thanks. Come tmrw evening. S*

Daniel got to Miriam's house around 6pm. Miriam answered the door. The first thing that Daniel noticed were her eyes. They sparkled with a gorgeous blueness and liveliness. The edges of her mouth twitched upwards in a half-smile.

"Lovely to meet you, Daniel," she said. She accepted his outstretched hand and, to his surprise, leant forward and kissed him gently on the cheek. Conspiratorial. "Come in."

Daniel followed her down the hallway noticing her height - a full head shorter than he was - and her lightness of step, like a dancer.

"How is she….?" asked Daniel when they reached the kitchen.

"Very peaceful. It won't be long now. She is such a wise woman in such a young body. I guess living with cancer can do that. She asked me to give you this and for you to read them aloud to her," she said, handing over the slim book of Rumi's poetry. "And she said that you must keep the book when you go. I'll be out here if you need a chat after."

"Thanks," said Daniel, and he went to Sam's room.

She was lying in bed, eyes closed, breathing slow and deep. Outside it was dark, and he left the main light off

but turned on a small bedside lamp so that he could read. There was a syringe pump on a stand with a plastic tube heading under the covers towards Sam. A few occasional whirring noises from the pump and her music playing softly were the only sounds.

Daniel held her hand and read aloud. Poems of love, of death, of dying, of living well. Poems that made his heart ache with their beauty. Poems that made tears pour from his eyes.

After some time, he stopped and listened to the music playing in the background. It was *Simple Gifts* with a single high voice and traditional accompaniment. When Annie was very small, she loved to dance. This song was her favourite: Daniel would play the piano introduction and then stand up, take Annie's hand, and follow her directions. She would sing the words while they performed a version of a Shaker dance. They would bow and bend and turn at her direction. She would scold him if he turned the wrong way or was insufficiently serious in the performance of her dance. At the end, each time he would lift her high in his arms, let go, and catch her again. She would laugh and giggle and ask to dance it again. At that time, Annie's favourite thing was her 'rainbow ribbons', long thin ribbons of multicoloured material attached to a long stick. She would play with it for hours, first as a famous horsewoman, ribbons trailing as her mane, then as an indomitable sailor, braving fierce storms 'round the Cape'. But mainly, she would just dance, waving her ribbons above her head, colours tangling together in ever-changing patterns, flowing into a glorious future filled with possibility. He wondered

whether he might dance again with Annie, however figuratively. Remind her of her rainbow dreams. Join the Dance.

'Tis the gift to be simple, 'tis the gift to be free
'Tis the gift to come down where we ought to be,
And when we find ourselves in the place just right,
'Twill be in the valley of love and delight.
When true simplicity is gained,
To bow and to bend we shan't be ashamed,
To turn, turn will be our delight,
Till by turning, turning we come 'round right.

He sat for a while pondering the words from the song about gifts and simplicity. Sam's gift to him - Take Charge, her wisdom, her thirst for living - had sent him on this journey, which he knew he had only really started. And maybe he would eventually find his 'place just right'. Was that where Sam was right now?

He read her *Moon thief* poem again.

From time to time, her breathing would change slightly, and he would look to her eyelids for some sign that she could hear him. There was none. But he could imagine her soaring, communing with the poet, talking to the moon, laughing with joy. Climbing her highest wall, both hands on the top hold, whole body swaying, triumphant - then leaping free.

After a long time of just sitting, he let go of her hand, kissed her forehead and whispered, "Goodbye, Sam, thanks for everything."

"Are you OK?" asked Miriam when he got back to the kitchen. She was sitting in an armchair; a book open in her lap and string quartet music playing at low volume in the background. "Come and sit with me a while," she offered.

"Thanks," said Daniel, voice thick with sadness, happy not to be leaving just yet.

"Sam told me about you, Daniel. She said you had a good heart, and she is a fine judge of character. It means a lot to her that you could come today."

"But she didn't know I was there."

"Who's to say? Maybe it was the most comforting thing of all, just a few fragments of words and your voice, feeling loved."

Daniel wept. Miriam held his hand and let him cry.

After some time, she made him tea, and they talked of other things, music mainly and books, poetry and films.

"Tell me about a film you love," asked Miriam.

"Paah, *Diva*, I guess. I've seen it lots of times."

"Nice choice."

"There's the moment near the beginning when he turns off the cassette player on his scooter, and the music just stops. It always gets me. The night-time walk in Paris to Satie? Oh, and the car journey to the coast in the 15W Citroen. A friend of mine at university had one of those cars, and I loved to ride in it."

Miriam nodded. "Well, the main aria in that movie is on my playlist that I call 'For weeping'. The playlist in Sam's room is full of beautiful and calm music, but I put my weeping playlist on at night when I'm in bed so I can cry my heart out. Strauss *Four last songs*, Mahler *Songs on*

the death of children, Schubert string quintet slow movement, Beethoven 7, Barber *Adagio*, lots of things."

"Quite the list," commented Daniel.

"I find I can be stronger during the day with Sam if I've had a good weep at night. Of course, we still cry together, but it's easier somehow. Does that sound wrong?"

"Not at all. Sounds totally understandable to me. It must be very tough for you?"

Miriam gave a little shrug of her shoulders but didn't answer the question, heading instead back to their previous conversation. "One of Sam's favourite films is *Ratatouille*. She mainly identifies with Colette, the female chef. We watched it together a couple of times, and she knew all the lines. Something about 'haute cuisine is an antiquated hierarchy based on rules made by stupid old men'. Ha! Hallelujah. Not just restaurants either. And, 'Keep your stations clear… Or I will kill you!'" Miriam laughed. "Sam would do that thing that Remy the rat does with vegetables when we cooked together - "clean", "not clean", "clean", not clean" and when someone asked her about a flavour she would often say "It's….lightning-y". So many happy moments. There's one about listening to bread."

"A symphony of crackle," responded Daniel, doing a tolerable Colette impression on "symphony". He smiled.

"You know it!" said Miriam, delighted.

"Exactly. But I related best to the kitchen-hand-turned-chef."

"Linguini," interjected Miriam, laughing.

"OK, I didn't remember his name. Anyway, I know that feeling of having your hair pulled and always being told what to do."

"Well, maybe you need to watch it again. Gusteau said always to do something unexpected. That's what you are doing now, isn't it?"

Daniel looked at her. She was right. He had come a long way since the stroke, since before the stroke. The future was uncertain but seemed a lot less scary.

They talked some more. Miriam told him about the plan for the funeral that she and Sam had worked out together. He agreed to read Gerard Manley Hopkins' *Pied Beauty*.

"That poem is very special to Sam. She considers herself just like that: counter, original, spare, strange, and it took her a long time to accept that she was a beautiful person. She loved to read the poem out loud and point to her freckles when she said "rose-moles". And those 'f's': fickle, freckled, fathers-forth, always made her laugh."

"Do you need any help here?" asked Daniel.

"Thanks, but no. The hospice nurses come and sort out the syringe driver, but I think we've got everything else sorted. It would be nice to talk some more after the funeral. She is going to leave a big hole in my heart."

"Mine too. I'd like to talk again. Thanks for talking to me today."

This time the farewell kiss on the cheek seemed entirely appropriate. They were friends with a shared love of Sam. He picked up the book of Rumi poems and left.

Celebration

15th November

Daniel sat in the garden, looking at the dahlias, yellows, pinks, whites, some spiky, others like pom-poms, bees exploring noisily. Mizuna, rocket and mustard leaves blanketed his salad box. But he was thinking of Sam. She had died a week ago at Miriam's house, the day after his last visit. Since then he had tried to make sense of her death, wrestling with the tension between thankfulness that he had met her at all and feeling cheated at losing her so soon. Perhaps unsurprisingly - as Sam always talked so much about him - it was reading Richard Rohr that helped the most. Rohr wrote about the modern dis-ease of disconnection: from ourselves, each other and our world. Hadn't that also been Daniel's problem? Rohr's solution was to re-connect with people and ideas that were important to us and recognising that 'we were all in this together'. That had been Sam's special gift – through her, he had made and re-made so many important connections. Through them, his life had purpose once more. What's more, Sam and others had shown him that there was a goodness to people that he hadn't properly appreciated and, a year ago, might have been reluctant to admit.

The funeral was held at a crematorium on the outskirts of the town, and to Daniel's surprise, there was a big crowd. Sam had said that she didn't have any close

family apart from Miriam, and he wondered who all the people might be. The second surprise was the music - plenty of it and loud. Nothing maudlin - plenty of joy, strong rhythms, and abandon. Music to dance to. And colour - sure there were some people (like him) dressed in black, but many people were in the gayest bright dresses and headgear - again more like a party than a funeral. The service was led by a young woman called Amy, a canon from a nearby Anglican church who had worked with Sam in a women's refuge. There were plenty of fellow refuge workers in the crowd, along with women who had stayed there. Amy spoke eloquently of Sam's quiet humility, penchant for hard work and capacity for laughter whatever the situation. A climbing buddy also spoke describing Sam's prowess (she was in the national women's team - who knew?) before she became sick but mostly about her mentoring of young women climbers. There were plenty of tears. Miriam spoke of her 'special daughter' and the gift of her love when they found each other again. She talked movingly about Sam's last days and how beautiful the time had been for them both. She mentioned Daniel's visits to read and introduced him.

Daniel stood up, stick-less, and walked steadily towards the lectern at the front of the seats. He could hear the unevenness of his steps on the wooden floor and the thudding of his heart against his ribs, terrified that his speaking voice, practised so hard these last few days, would let him down. But mainly he was thinking of Sam, hoping he could avoid crying until after he had read the

poem. He passed the photo of Sam on the coffin, freckles and red hair and ocean-wide smile.

"Thank you," he said. "I only met Sam five times, all of those in the last six months. She changed my life after my stroke. I can see that she touched the lives of so many other people here too." He recited *Pied Beauty* from memory, slowly but clearly and looked towards Miriam when he said 'rose-moles'. She smiled. Almost as soon as he had spoken the last line - "Praise Him" - a young Afro-Caribbean woman stood up and yelled "Hallelujah Sam-girl", and the call went up around the room, women clapping and shouting. Daniel had never experienced anything like it. As the hubbub died down just a little, the music came on again, a slow intro with acoustic guitar and drums that Daniel recognised. The people were moving in their seats with the beat, swaying, some clapping, some humming the harmonies. A middle-aged woman in a spectacular blue headdress stood and started singing a Joan Baez version of *Forever Young* directly from her place in the congregation with her enormous, rich voice filling the room. The crowd joined in each time with 'May you stay, forever young' and free harmonised the chorus, gospel style. Daniel caught Miriam's eye and saw the tears streaming down her face, another woman wrapping her up in her arms. Daniel, too, wept on his way back towards his seat. He let his hand sweep down the side of the coffin as he walked by and mouthed, "Bye, Sam."

Afterwards, there were drinks, food and more music and singing at a local Community Hall. Daniel talked to lots of different people who had known Sam, most of

them much younger than him, but it felt easy and comfortable in a way he hadn't experienced for years. There were climbers, physios and other therapy colleagues, co-workers and women from the Women's Centre. One elderly couple seemed out of place - she in a wheelchair, and he standing beside her.

"Sam was a miracle," Alan explained. "They (by which he seemed to mean the hospital rehabilitation service) had given up on Gwen (his wife) and thought she would be better off in a 'Home' because we 'wouldn't be able to cope'. So, I said I was taking her to our home, and that was the end of it. Her stroke meant she couldn't walk, and she struggles to get many words out, but she understands what you are saying. Sam came and showed us the Take Charge book. We realised we were concentrating too much on Gwen getting better from her stroke and not enough about using the time we had together. Our 'new normal', Sam called it. Gwen has been much happier - we both have. I think we would have given up by now if Sam hadn't come along. We saw her death notice in the paper and felt we had to pay our respects. We never knew she had cancer. But maybe that was why she was so adamant, telling us to make the most of every day."

"Great read, Daniel." He looked around to see the young woman who had called out "Hallelujah" after his poem reading. She had two other women with her, one white, one black, both in their twenties. The singer of *Forever Young* soon joined them. They chatted, eager to learn Daniel's connection with Sam. He, in turn, got to enthuse about the singing and his lifelong passion for

Bob Dylan and Joan Baez. He asked them about Sam's role at the Women's Centre.

Sanaa, the "Hallelujah" woman, had been going to the Centre off and on for a few years, taking part in support groups and helping out where she could. She explained that Sam had come initially to do some exercise classes but then came more often and just hung out with the women.

"We used to call her 'Shrink', 'cos she was always asking us what we dreamed of doing. She used to get big sheets of paper on the floor and get us to draw stuff with crayons and paint. Good stuff, bad stuff, get it out of your head stuff. It helped though. Then sometimes, she would just strip down to her climbing gear - you know a couple of those battered vests and shorts, and start stretching in the middle of the room. "Come on, ladies, move your bodies," she would say. And we would always be a bit slow to join in. So, then she would say, "OK, beautiful arses on the floor, now!" Everyone would fall around laughing 'cos truth to tell, there weren't a whole lot of beautiful arses between us, but it always got us going. "Feel good about your bodies, ladies," she would say. Man, I miss those sessions. Even when she started to get sick again, she would come down and talk. She was a real sister." The others nodded and added their Sam stories. How she had dropped food round to one family for a few weeks because of some balls-up with their Universal Credit payment. How she used to give the best neck massages in the whole world. How she would just listen, unconditionally.

"Here's my favourite Sam story," began Lily, who was probably in her early thirties and looked as though many of those years had been pretty hard. "Sam straightened me out, you know? Drugs, alcohol, bad men. Couldn't have done it without her. She was my guardian angel. Anyway, like Sanaa said, we knew she was a climber, but she never told us how good she was. She would sometimes say she was going off for a week or two climbing somewhere and come back again without saying anything about it. She didn't have a bragging bone in her body. Anyway, a couple of years ago, Sam said she would take anyone who wanted to come for a session on a climbing wall. No experience necessary. Give it a go. So a few of us did. It wasn't her regular gym - just a place close to the Women's Centre. We walk in there, all of us in sweatpants and T-shirts, most of us carrying too much weight, and Sam, cool as a cucumber. Then we realised she was like famous - a rock star or something. The guys that ran the place came over and treated her - and us - like royalty. Sam-this and Sam-that, high-fives, you know. She said "hi" to everyone, no big deal, sorted us all out and got on with it. She was so patient with us, showed us what to do, some very simple stuff. It was great. Anyways, there were a couple of jock-types, you know? Muscle shirts, speaking too loud, always looking for an audience. They were giving Eric - he was the manager - a hard time because they reckoned one of the climbs he had just set was wrong. As in not-doable. "The holds are way too far apart. No one can do that crap." They had been trying and failing to get anywhere up the wall on this particular climb. Clearly very pissed off

dudes. Falling down, swearing. So they were taking it out on Eric. Sam must have been watching ‘cos she just went over to Eric, put her hand on his arm and quietly asked him a few questions. He said something about it being a competition-level difficult climb. She just said, "Ok if I have a go Eric?" - real polite and gentle. He said OK and motioned the jocks to stand back. Sam went over and stood in front of the wall, just looking for a few minutes, eyes going left and right and up, using her hands in the air -left then right- to mime the climb. After some more time, a few minutes maybe, she said, "Hey, Eric, I like it", and gave him this big, big smile. God, she could schmooze that girl. By this time, all the other climbers had stopped and wandered over to see what was happening. Some guys behind us were saying that she was in the national team and had climbed in competitions in the States and Europe and was well famous. So there is Sam, all 5 feet six of her, tatty old vest and shorts and tiny shoes on her tiny feet, covering her hands with chalk, and these 6-foot muscle-bound jocks in their fancy gear standing to the side, waiting for her to fall off. Well, she just springs up onto the wall and goes up a wee way and then pauses. Then she does this thing where she swings herself out and along and uses her momentum to keep going to the next hold, a million miles away and hold on with, like, three fingers of one hand. And there is this sound like everyone sucking in their breath thinking, 'how the hell did she do that?' But she doesn’t stop - her body is moving the whole time, and she uses those three fingers and her movement to swing up and find the next hold. By this time, the eyes of the jocks are out on stalks.

Priceless. I could have wet myself, I was so happy. God, I love that girl. Anyway, a few more handholds, and she is at the top, two hands, letting her whole body swing free right and left, easy as pie. She looks over her shoulder at Eric and us, face full of freckles, sparkly eyes, smile like she is just in heaven, you know? And winks at Eric. Then just chucks herself off the wall and lands. Wow. High five with Eric. Didn't even look at the jocks. Said, "come on girls", and we went back to our bit of the wall. You would think it was ego and bragging, you know she is this insanely good climber, and she just wanted to put the jocks down. But it wasn't that at all. She would always find opportunities to be kind, that Sam. Eric was a good guy and she could help him out, so she did. Just like with us. If I ever have kids, I hope I can bring them up to be kind like Sam. The other women just nodded. "We were lucky to have her," one said.

Daniel thought about Sam high up on the wall and realised he had seen that look on her face too - when she was drifting off to sleep to the Rumi *Moon thief* poem. It was tempting to think of it as communion with someone else - some higher being perhaps - but it was just Sam being truly happy in herself. The real me. Oh, Sam.

Daniel looked around. What felt a bit weird was that there was no family he could see except Miriam. Then he stopped himself. Family was exactly what this was. No blood perhaps, but deep connection. These were people Sam had chosen to spend her life with, and their lives, as well as hers, were richer as a result. He could see Sam's life in an exquisitely bright series of threads, stretching out forever, one of which joined his like some miracle,

flowing forward. Sam inviting him to her own funeral was one more way for her to open his eyes to possibilities. One more gift.

When Miriam saw Daniel, her smile lit up. She thanked him for the reading and gave him an envelope. "This is from Sam," she said. “Open it at home. Maybe give me a call next week?" She glided off to speak to some of the women from the Centre, and Daniel didn’t speak to her again before he left.

The next morning, he took a cup of tea and the envelope out to his favourite seat in the garden. To his left was a commotion of autumn flowers; dahlias just finishing, and chrysanthemums in all shapes and colours postponing winter. The fruit trees had shed their leaves, the bean vines brown, winter cabbages defiant.

He opened the envelope cautiously, right hand pincering one corner while his left thumb broke open the top edge. He fished out the letter, not knowing what to expect. The writing was remarkably strong and alive, as if Sam had harnessed every piece of remaining energy and poured it into these few lines.

Dear Daniel,

Thanks a million for everything. You gave me more than I could possibly have expected. Be kind to Miriam for me. And talk to me Daniel. Whenever you want. Everyone needs a Wise Woman to help get them through the hard times and I am volunteering to be yours. You are a lovely man and I love you to bits. Share the love. Be generous and kind. Be who you really are. Keep getting back up on the wall when you fall. I’ve drawn you a picture. Hope you like it.

Love always, Sam

He unfolded the second sheet from the envelope, gently spreading it out flat in front of him. It was 'My Best Day' from the Take Charge booklet. Sam had drawn herself sitting in an armchair by her window, looking out towards trees and birds and sky, her favourite blanket across her knees. Daniel was sitting next to her, reading out loud from a book. He was holding her hand. She had scribbled across the bottom, "Thanks, pal."

He cried, deep, shaking, sobs of grief. For Sam, for his old self, for everything. But after some time, as the sadness settled, he looked again at the picture and the "Thanks, pal" and started to laugh. "Oh, Sam, you lovely woman. Thank you for being part of my life."

Later that morning, Ravi came over to do some tidying up in the garden. He was his usual industrious self, and between them they turned compost, mulched plants, raked leaves into a pile, then stuffed them into bin bags to make leafmould. All the while they kept up a dialogue – well, Daniel contributed a few words here and there - mainly Ravi unstoppable on cricket, Indian food, poetry, songs, school. Daniel listened, happy that Ravi had read and enjoyed some of the poetry books he had borrowed, and happy also to feel the amazing energy that Ravi had for life.

Now Ravi was talking about the future and how he didn't want to disappoint his parents but wasn't sure that Engineering was what he wanted to study at university.

"Intellectually, I get it, I guess," he said. "But it doesn't feel right somehow. What do you think I should do?"

Daniel said, "Wait here," and went inside. He opened his laptop, searched for the Take Charge website and printed off a copy of the generic booklet that was designed for anyone (and not just people with stroke) to use. Then he headed back out to the garden with the booklet and some pens and called Ravi over.

"I think this could help you sort out some of your ideas," he said to Ravi. "I did this with Sam after my stroke, and it changed my life. Maybe it will do the same for you. You're the boss; I'll just show you how it works."

He opened the booklet at the first page.

"OK, here is where you write how you feel now," he said, pointing to the circle on the left-hand side of the page labelled 'My issues'. "You aren't medically unwell, of course, so just put down anything that feels not right to you. Anything you like."

"And over here," he said, pointing to the circle on the right-hand side, "this is where you write about who you really are. Deep down, Ravi. What lights your fire. What makes you, you."

Daniel looked away, back to his flowers, some of the morning sadness lingering. Next to him, Ravi's eyes were on fire. Daniel could hear the pen on the paper, at first hesitant, but then dancing, happily, big sweeps of arrows and circles and dreams. Daniel was thinking of Sam, but Ravi could see the whole world.

Afterword

August, 2021

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Sam's Gift is a work of fiction, and any resemblance to actual people is unintentional. Thanks to Kathryn Mannix for her helpful suggestions on an earlier version, which I've gratefully incorporated.

For more than 25 years, I have had the privilege of working with people with stroke, and I thank you all. If one person with stroke benefits in some way from this story, I will be happy.

If you haven't read the whole book and simply turned to this page, Take Charge can be used by anyone – you don't need a 'rehabilitation professional' to act as facilitator. In the Taking Charge after Stroke study, most sessions were facilitated by people who were not therapists and had no previous rehabilitation experience. It is possible that outcomes reflected that. Links to the Take Charge evidence base and materials are further down this page – use them!

I wish to acknowledge all the people involved in the Take Charge journey. The term was coined in an early qualitative study led by Kath McPherson and Penny Brander. Matire Harwood was co-principal investigator and did most of the heavy lifting for the Māori and Pacific Stroke study (MaPSS), developing some of the Take Charge ideas in her PhD. The collaborative team that ran the MaPSS study largely stayed together for the Taking Charge after Stroke (TaCAS) study. Viv Fu and

Judith Riley, and the backroom team at the Medical Research Institute of New Zealand were mainly responsible for delivering the TaCAS study.

Grants from the Henry Cotton Bequest, the Ministry of Health, and two project grants from the Health Research Council of New Zealand helped fund the research.

None of this could have happened without the support, over more than 20 years, of Professor Richard Beasley, Director of MRINZ.

This book would not have been written without the support and generosity of Amanda, my wise and forgiving muse, the brightest and most enduring thread of my life.

Further research using Take Charge

Proceeds from sales of this book will be used to support further research about Take Charge and other interventions like it. To my knowledge, there are now two funded new randomised controlled trials in Australia using Take Charge (one with Indigenous people following stroke, one with people with mild cognitive impairment and early dementia), and one planned in Canada for people with stroke, using a virtual platform.

More information will be posted to our Facebook page: https://www.facebook.com/TakeChargeRehab and/or on the Medical Research Institute of New Zealand website (stroke page): www.mrinz.ac.nz/programmes/stroke

Please let me know about new projects, links that are not working, other errors and any feedback (positive and negative are both OK)

email: harry.mcnaughton@mrinz.ac.nz

Reading list: (sadly some of the journal articles are not freely available apart from the abstract– your local library may be able to access them for you)

Take Charge

1. The first study describing the concept of 'Taking Charge' and how it is important to people with a range of medical conditions, including stroke.
   [McPherson, KM, Brander, P, Taylor, WJ, McNaughton, HK.Consequences of stroke, arthritis and chronic pain–are there important similarities?Disabil Rehabil2004; 26:988–999.]
2. The first randomised controlled trial. The Māori and Pacific Stroke Study (MaPSS, n = 172). Māori and Pacific people discharged to community living and within 3 months of stroke who received one Take Charge session in addition to usual rehabilitation, were significantly more likely to have better physical health, more likely to be independent and their carers reported less strain at 12 months after stroke compared to those who received a control intervention.
   [Harwood, M, Weatherall, M, Talemaitoga, A, Barber, P, Gommans, J, Taylor, W. et al.Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life – a randomised controlled trial. Clin Rehabil2012; 26:493–501.]
3. The second randomised controlled trial. The Taking Charge After Stroke (TaCAS) study (n=400). Predominantly European-ethnicity New Zealanders, 2-16 weeks after stroke and living in the community, who received one or two Take Charge sessions in addition to usual community rehabilitation, were significantly more likely to have better physical health, performing more advanced activities and more likely to be independent, 12 months after their stroke compared to those who received a control intervention. Meta-analysis of the MaPSS and TaCAS trials together (n=572) showed the number needed to treat (NNT) with Take Charge for one more person to

be independent at 12 months after stroke was only eight (8). [Fu, V., Weatherall, M., McPherson, K., Taylor, W., McRae, A., Thomson, T., Gommans, J., Green, G., Harwood, M., Ranta, A., Hanger, C., Riley, J., & McNaughton, H. (2020). Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention.*International Journal of Stroke*,*15*(9), 954–964.] [Open access]

4. How does Take Charge work? An analysis of secondary data from the TaCAS trial and some of the theory behind Take Charge. Some soft evidence that Take Charge acts on baseline 'ability to Take Charge' to affect outcome. No evidence that Take Charge acts through improving mood. [McNaughton, H., Weatherall, M., McPherson, K., Fu, V., et al (2021). The effect of the Take Charge intervention on mood, motivation, activation and risk factor management: Analysis of secondary data from the Taking Charge after Stroke (TaCAS) trial.*Clinical Rehabilitation*,*35*(7), 1021–1031.]
5. Thoughts on using Take Charge for people with COPD. The concept of Take Charge can be applied to many medical conditions, not just stroke. A recent randomised feasibility study, using Take Charge for people with recent hospital admission with COPD is complete but not yet published. [McNaughton A, Levack W, McNaughton H. Taking Charge: A Proposed Psychological Intervention to Improve Pulmonary Rehabilitation Outcomes for People with COPD.*Int J Chron Obstruct Pulmon Dis*. 2020;15:2127-2133] (Open Access)
6. Economic analysis of the Taking Charge after Stroke study.. Headline figures of cost/QALY of £-25,000 (ie health utility gain AND cost saving) and point estimate of cost saving of about £1,000 in the first 12 months for each person treated with Take Charge. [Te Ao B. et al Economic analysis of the 'Take Charge' intervention for people following stroke: results from a randomised trial. *Clin Rehab* 2022;36(2):240-250.

doi:10.1177/02692155211040727

And more in the pipeline including a qualitative study run in tandem with TaCAS

Take Charge materials – all available for free download at https://bit.ly/3ysp1KM

1. Booklet for people with stroke. As used in the TaCAS study
2. Booklet (generic) for people, not specific for stroke. Not yet tested in a clinical trial, modified from the original
3. Take Charge manual (tips on how to use it). Used by the facilitators in the TaCAS study.
4. Webinar on Take Charge hosted by the World Stroke Organisation, April 2020. https://bit.ly/3tqGaAq
5. A sample baseline assessment (17 questions, takes a few minutes)
6. Translations of the Take Charge booklets and manual in Estonian, Russian, Portuguese, German and Slovakian (so far)

Thanks to Hedvig Soone, who investigated Take Charge for her Master's thesis using qualitative methods to show that Take Charge was acceptable to people still in hospital after stroke in Estonia. [Soone, H. 'Sessiooni „Taking Charge After Stroke" Testimine Ja Valideerimine Eestis', Master's Thesis, Tallinn University of Technology, 2020]

Calculating risk
Q-risk calculator: https://qrisk.org/three/index.php

Some of the books mentioned in *Sam's Gift*
Richard Rohr

Rohr, Richard. 2013.*Falling upward: a spirituality for the two halves of life* San Francisco: Jossey-Bass

Rohr, Richard, and Mike Morrell. 2020.*The divine dance: the trinity and your transformation*. New Kensington, Pennsylvania. Whitaker House

Robin Vickers-Willis

Vickers-Willis, Robyn. 2008.*Navigating midlife: women becoming themselves*. Cottles Bridge, Vic: Wayfinder Pub.

Stephanie Dowrick

Dowrick, Stephanie. 2014.*Intimacy and Solitude*. Crows Nest, A: Allen & Unwin.

Thomas Moore

Moore, Thomas. 1994.*Care of the Soul: a Guide for Cultivating Depth and Sacredness in Everyday Life*. New York, New York: HarperPerennial.

Moore, Thomas. 1994.*Soul mates: honoring the mysteries of love and relationship*. New York, NY: HarperCollins Publishers.

Michael Marmot

Marmot, Michael. 2019.*The health gap: the challenge of an unequal world*. New York, NY: Bloomsbury

Hilary Cottam

Cottam, Hilary. 2018. *Radical help*. Little, Brown Book Group UK.

The Stoics

Holiday, Ryan, and Stephen Hanselman. 2017.*The daily stoic journal: 366 days of writing and reflection on the art of living*. New York. Portfolio/Penguin

Dylan Thomas

Thomas, Dylan 1972 *Collected Poems* 1934-1952. London: Dent. Many available at https://www.poetryfoundation.org/poets/dylan-thomas

Rumi

Rumi, Mewlana Jalaluddin. 2004. *Poems*
Poemhunter.org – The World's Poetry Archive (both the poems 'A Moment of Happiness' and 'At Twilight', mentioned in the book are here: https://www.poemhunter.com/mewlana-jalaluddin-rumi/ebooks/?ebook=0&filename=mewlana_jalaluddin_rumi_2004_9.pdf)