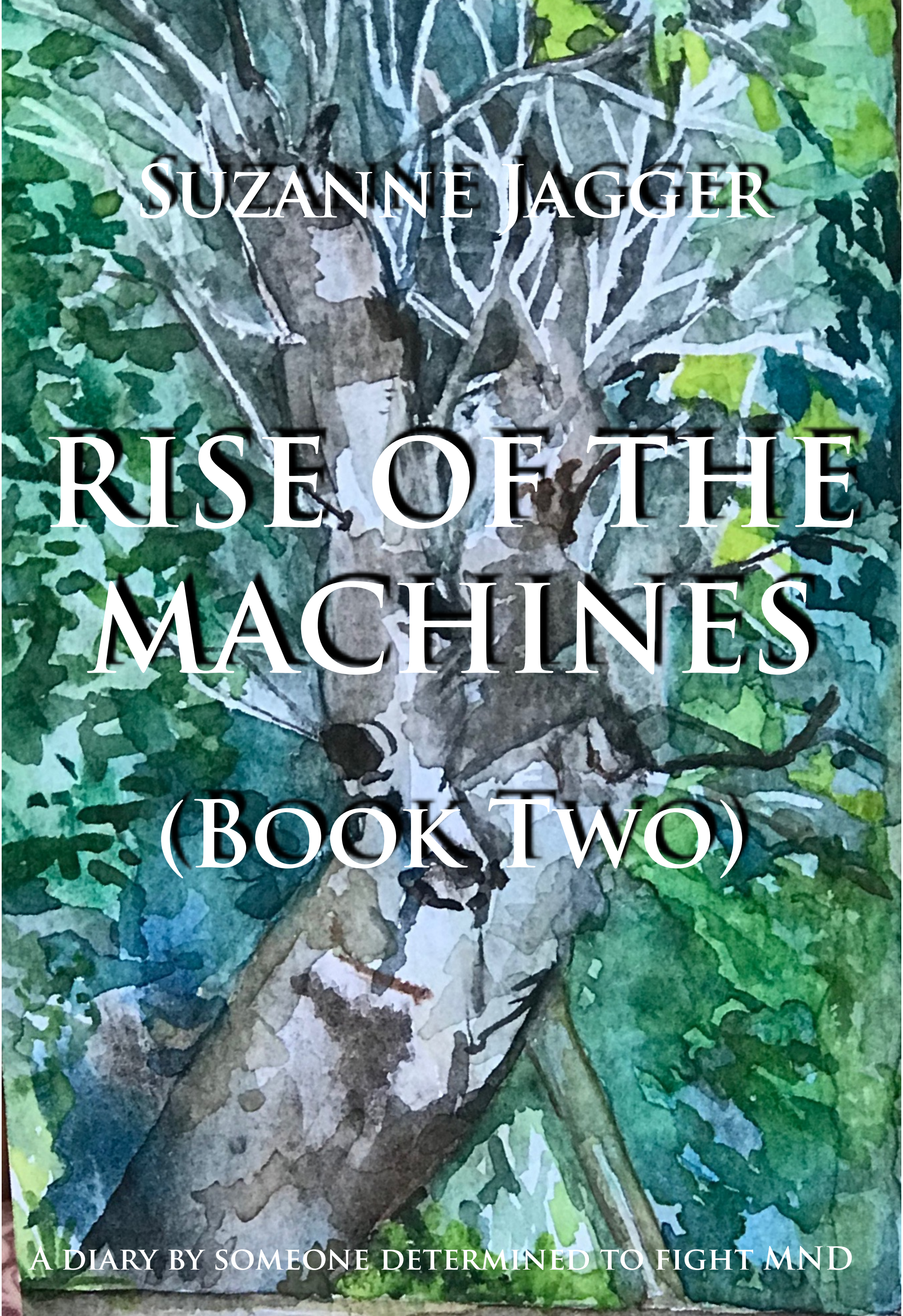


SUZANNE JAGGER

RISE OF THE MACHINES

(BOOK TWO)

A DIARY BY SOMEONE DETERMINED TO FIGHT MND

Tho' much is taken, much abides; and tho'
We are not now that strength which in old days
Moved earth and heaven, that which we are, we are;
One equal temper of heroic hearts,
Made weak by time and fate, but strong in will
To strive, to seek, to find, and not to yield.

— from Alfred Tennyson's 'Ulysses' (1842)

I am now a woman of few words. This book gives me the opportunity to speak. I am grateful for that.

In my dreams

In my dreams
I am healthy
In my dreams
I am talking
In my dreams
I am walking
I am myself as I used to be —
In my dreams, in my dreams, in my dreams.

Book Two

Rise of the Machines

I have become dependent. I have always hated being dependent on anything — hence my decision to have my own career independent of my husband's and to give up smoking. We are all dependent on each other to some extent — that is what a society is. But I have always been one of the strong ones — a contributor. And, to some degree, we are all dependent on our machines to make our lives easier. For instance, I have always sworn I couldn't live without my dishwasher, but of course washing-up would do us all some good, especially when a team effort. No. This is different — what I mean is that I couldn't LIVE without my machines. Or, next step down, my life wouldn't be worth living.

So what are these new entities that have entered my life and have become so responsible for my well-being? A list below:

1. Food pump — having food through my PEG slowly throughout the night so not tethered to it during the day.

2. Suction machine — so good for saving on copious boxes of tissues. Far more efficient at avoiding a choking fit.

3. Nebuliser — designed to ease coughing.

4. Electric chair — no, not that kind of chair — a recliner that tilts me out so I can stand up to go into the Mo Lift (see below).

5. Mo Lift — a contraption designed to transfer me from one thing to another.

6. Power electric wheelchair — brings less dependency on others to get places.
7. Smartphone — yes I know, none of us could do without that, but for me it means I can communicate using a keyboard.

8. Bipap for breathing — designed to correct the amounts of oxygen/carbon dioxide in my lungs.

Let's hope we don't get a power cut.

22nd November 2017
Last week I went swimming again. I am trying to do this regularly as it really helps me both physically and my mood too. Suresha has never swum before and so was pleased she was prepared to try. Had such fun teaching her how to swim. So nice to do something for her as she is always doing so much for me. Got the noodles (floating tubes) and put them around her and she was off! Had some concern she might sink and I would have to dive down and rescue her. Imagine the headlines:

"MND Sufferer saves carer from drowning!" Ha! Ha!

25th November

Can't believe it is only a month to Christmas. Have made the cards and ordered the food. Will still be in control. Everyone coming. Tree will be spectacular as it always is.

Doing my usual insane online shopping. Figure you can't take it with you and saving huge amounts on food bills. At least that's my excuse. But have never needed an excuse to shop, and of course I never ate *that* much!

Had such an amazing reaction to my 'Bittersweet' book from friends and on Facebook. Has encouraged me to continue, although don't need much encouragement as it is a type of therapy for me anyway. But people say it helps them understand what I'm going through.

In John Lewis yesterday, Gilly experienced what I was talking about first hand in relation to people's reaction to the disabled. As we went to the counter to pay for our goods, the cashier kept asking her if I wanted items gift wrapped, price tags off, a bag etc. Each time Gilly said "Ask her". Then she would turn to me. So bizarre that people ignore the one in the chair. But because Gilly had read my diary (or maybe she realised how odd it was) she knew how much it meant to me to be treated as a customer, and so kept pointing the cashier to me. Bless her. In the end I got a beaming smile from the cashier. I think she just needed to understand — that just because I am disabled does not mean I cannot make my own decisions.

26th November

3am. Have begun night feeds. What a strange word — “feed” — like I’m a pet rabbit or zoo animal or something. But this is the terminology in the world I have now become part of.

I had wanted to keep to a normal routine of regular “meals”, but it doesn’t work well with a food pump because you need to be connected to it about eight hours a day to get enough calories. So I have decided to have it on throughout the night. This means I am not tethered to the thing during the day and frees me up a lot. It’s a bit odd to wake up in the morning having been fed for the day. Also during the night it can seem strange, although I am nocturnal anyway.

Dieter turned up today. Hugh and him get on so well. Hugh has a lot of “men friends” but his relationship with Dieter is very special. I hope he shares with him his anxiety as I can see he’s suffering. All of this is so hard for him.

Justy came back from a school reunion pissed as a newt. Insisted on helping with my medication. Needless to say I had my eagle eye on him to ensure I didn’t end up with double doses.

Despite being wakeful, I must try to go back to sleep. Another swimming session tomorrow. Taking Marie and Suresha.

Am finding my left hand is cramping up when I write for very long — oh no. Very worrying.

Thanksgiving Message

A “Thanksgiving Message” was put on the ALS worldwide site tonight from a greek monk with ALS. I found it so wonderfully heartening I am going to repeat it here so I can read it often. The thing I love about it is that he has focused on all the things he has, rather than dwelling on what he’s lost — which is of course what one is prone to do.

Father Sophronios Gouverneto, thank you.

On this day I thank God for the
many things he gives me to ease
the suffering associated with ALS.

I am grateful for my eyesight, which
allows me to take in so many visuals
that bring me joy every day.

I am grateful for my hearing,
which allows me to hear my loved
ones and the sounds of nature.

I am grateful for my sense of touch
which allows me to feel a hug or
a touch of my hand.

I am grateful for my mind
which allows me to think,
Communicate and comprehend
concepts large and small.

I am grateful for my prayer life
which allows me to communicate with God.

I am grateful for the technology
which keeps me alive and allows
me to be in touch with friends,
family and other people living with ALS.

I am grateful for the doctors and
scientists who are on the front lines
of the fight agains ALS.

I am grateful for the donors who
support research to find a cure.

I am grateful for the people of ALS
Worldwide who have dedicated their
lives to helping people living with ALS
around the world.

I believe each one of us has the
gift to awake each morning and be
grateful for something despite
the challenges we face.

I pray your heart and soul finds
comfort in this gratitude.

May God bless you.
Father Sophronios Gouverneto
Chania, Crete, Greece

[N.B. I would add to this that I am grateful for my carers, who work tirelessly to keep me alive, to comfort, wash and ease me, and to help me keep my independence.]

23rd December

It's been almost a month since I last wrote. I have not wanted to dwell too much on my worry. Since that time I have spent several days in hospital having the Bipap fitted. They call it a non-invasive ventilator because it doesn't require an incision in the neck like a tracheotomy, but pushes the air into your lungs using a mask. They said my CO2 levels were too high so suggested I use it at night. Unfortunately I absolutely hate it so haven't used it. Will have to practice during the day to try to get used to it.

Christmas is upon us and I have had to conscript Suresha to help out with all the things I have done myself for the past hundred years. I thought I would be able to make the Christmas Cake but my hands are just too weak. Still, have ordered everything and with Marie and Suresha's help it's done, with the important ingredients which make my cake unique. Should I divulge this closely guarded secret? Why not? For posterity and anyone who's interested.

1) Reduce raisins significantly
2) Add masses of pecans and halves of cocktail cherries and juice
3) Feed for 1 month with almond liqueur

4) Reduce cooking time to 1 hour less

I know words like ‘masses’ are not helpful but I have always done things by eye when it comes to cooking. Fingers crossed this one will be as good as last year — not that I’ll know — everyone will be too damn nice to me as usual. That is a problem these days. Always complimenting me on my hair, or my clothes when (if the way I feel is anything to go by) I must look like shit.

I’ve said to people “come on, I must look weird when I smile?”
“No”, they say, “you look the same”
“Yeah right.”

Tree is decorated thanks to Jazzy. She has been unbelievable this Christmas. Between her and Suresha we have got so much done. Nin looked at our tree and said “I love your big balls.” That raised a snigger.

I am making a list of comments I make and what people think I say. Sometimes it’s so hilarious. People are always trying to second guess me when I don’t use my app to speak. The other day I said “I have my moments” and Jazzy thought I said “It’s really bulbous.” I asked James if I could have some juice and he said “Do you want me to clean your shoes?”

In fact, I’m amazed how my kids and my friends can often work out what I’m saying — *I* can’t!

Well, the most momentous day today. I am now ensconced in my new room. After months of building work — a labour of love from my wonderful husband, I now have my own room downstairs with an adjoining wet room and a spectacular view of the garden. No more risking life and limb hauling myself up and down the stairs — precarious being an understatement, especially in the early mornings. It was only a matter of time before I would have come tumbling down. Now I am near the kitchen but have space and a beautiful outlook. Sad to not be in my old room with Hugh but will get two beds down here — my hospital one and a single next to it for when he wants to stay. The machine can be noisy but I'll try to make it worth his while…

This week has been fun with a trip to the Tate Modern with Marie and Carolyn and a few days later a trip to the V&A to see the Winnie the Pooh exhibition with Jazzy. Such a laugh and so glad these places provide facilities for wheelchair users. Was in the loo at the Tate and was thinking "this is tricky" because the door was far away and my wheelchair was not self—propelling. Marie comes in apologising profusely, to which I express gratitude — otherwise they would have been waiting for me for hours as I couldn't get out on my own.

Even my darling daughter helps me get dressed. It is hard for me though. The roles are strangely reversed and it makes me sad. I've taught her so much, looked after her, comforted her, dressed her, taught her things and now she does that for me. I hope she doesn't feel she's lost me. I used to "fix it" — now I can't fix anything — except advise — I can still do that. I hope she will always want advice from me. Also we still laugh together — sometimes side-splitting laughter that does both of us the world of good (even if it sets off a coughing fit).

5th January 2018
Ruby

I know from things people have written who have MND how carers are often the bane of their existence. To have to rely on someone else to help you with things that you have always done for yourself is something that has worried me greatly. I did not want the family roles to suffer and so have opted for a carer. I have been blessed with Suresha who has been, and continues to be, an absolute marvel. But now, having been given NHS funding for an agency carer, I was concerned who would show up and how we would get on.

About six months ago when we were coming to the realisation that I needed a carer, Jazzy said "I want a woman with a heart of gold and a rip-roaring sense of humour to look after you." Well Ruby is exactly that. A big, strong, black Zimbabwean with a heart of gold. And as well as that I could tell she was bursting to tell me things. Finally, out it came. God was why she was here. A powerhouse of positive faith and hope with a fabulous sense of humour. She has been a wonderful addition to the team. "Praise Jesus, Hallellujah! Have faith!", she cries. From anyone else it would irritate me but from her it is so heartfelt and sincere and full of conviction it is actually infectious.

"You are GOING to get better."

“You are healed.”

Well, whether or not it happens, it is wonderful to have someone who truly believes it. It gives me hope and makes me try just a bit harder to believe and work towards that goal.

8th January 2018
Momentous Day

Today Jazzy handed in her PhD. There was a time around my diagnosis when I was not sure it would happen. I would have been devastated if she hadn’t finished because of me. What an incredible feat. We are all so proud of her. I had the privilege of proof reading it over the last week. Such a beautiful and inspiring piece of writing. I hope the examiners give it the credit it deserves. What a talented daughter I am blessed with. So there will be two Doctors in the house.

13th January
Subtle Beauty

There’s an old apple tree
In my garden
I look out and see it
From my window

Gnarled, bare branches
Still trying to reach the sky,

Yawning mouths which
Were once boughs
On which a tree-house stood.
And children played
And from which
Every year bore fruit —
Big green apples for cooking.

It takes me back
To my children's laughter
To fun and happy sunny days,
To swings and slides
To high-pitched little cries
To smiles and squabbles.

It still stands proud
And lives on tho' half its size;
It is not so beautiful now to some
But to me it is
Majestic in its resilience:
Every bough hole
A testament to its previous strength
Every gash a history
Of a life lived.

Now it's propped up
By posts to help it stand
And it still goes on
Some fruit though not as much

A different and more subtle beauty.
Particularly for those
Who have loved it so.

12th January
Chris

Thank God for understanding friends. I have been going to my hairdresser Chris for over 20 years. Hard to believe we are that old. Now when I arrive he is there, waiting to negotiate the wheelchair and help me in and out. We converse well — me with my phone and keyboard and him doing his usual banter over the sound of hairdryers and Beyoncé.

Today, sitting there in all my foils, playing my computer game, I suddenly feel warm liquid soaking, seeping into my side — I look down over my chair and see a dripping puddle on the floor. I lift up my jumper and see the contents of my stomach gushing out of my PEG tube. A whiff of bananas (Jazzy had made me a banana smoothie before I left). I was mortified. Frantically trying to close the valve, fingers slipping and sliding, I finally managed it and surveyed the scene. Jeans soaked through. Chair dripping (luckily plastic). I grabbed one of my hankies and started mopping the floor with my right hand. No-one had noticed. I typed a message to Chris.

“Sorry, accident. Nothing nasty but need some towels.”

What a gentleman, not bothered in the least; but I was reminded how nice it is to have friends from way back — you know they are with you.

I said to him: “I bet that’s a first for you in here.”

He graciously replied “Oh we’ve had everything in here — people being sick, passing out, you name it.”

I still know it was a first.

14th January
The Husky

I love our walks with Truffle and Hugh pushing me in the wheelchair. Beautiful views over the South Downs at Box Hill and Newlands Corner; majestic stags and bambi-like deer in Bushy Park. Truffle is completely unruly. However, she is a good husky, pelting along pulling the wheelchair, with me holding the lead. I’m sure Health & Safety wouldn’t be keen. Sometimes I give my handbag a ride by pushing the chair myself for a few metres. But less and less these days. Balance and leg strength not so good.

Without Truffle the walk seems a bit tame, so I suggested yesterday we go to the Hampton Court Antique shops. We have been going to these shops for over 20 years. I am convinced we have a painting from there worth far more than we paid (although have no idea really).

So, for the first time for a while, we went down there only to discover the places inaccessible in my wheelchair — either couldn’t get in them at all, or the aisles were so small I couldn’t get past the door.

Thought of going back with my walker but had visions of tripping over and taking down a few glass cabinets with me.

A problem these days — what can I risk? Every day is a challenge because the disability is not constant — well it is — it is constantly progressing. So you can't say “I can do this”, because maybe you could last week or last month, but who knows now?

We soldier on.

Pots and Pans

Before I got ill I was a busy lady but was proud of my kitchen and ensured it was always clean and tidy. When I cooked I would say: “I cooked, so you wash up.” Not onerous with a good dishwasher you might think. “Of course, Mum.” And yet every morning I would come down and be greeted with a tidy kitchen until I looked in the sink. A proliferation of pots, pans and implements that needed to “soak.” Why does a pan that boiled pasta need to soak? I would come home from work and still they sit soaking. I would ask “for how long do they need to soak?” I swear if I left them for a month they would still be there. What is this deep aversion to pots and pans? They are not burned with charred remnants and do not require elbow grease.

Anyway, I don't venture into the kitchen at mealtimes these days. I do some cooking but tend to make myself scarce while they tuck in as I don't enjoy watching people eat. I have to stop myself watching their every mouthful with a mesmerised longing.

However, this afternoon I wandered in to look for a bowl Ruby wanted and … guess what I found? A sink piled high with pots and pans!

Some things never change. Quite comforting in an odd sort of way.

15th January
Wonder—full

Jazzy has given me the most wonderful book. *This Sunrise of Wonder* by Michael Mayne. In it, verse four of a poem by W. B. Yeats, called 'Vacillation':

My fiftieth year had come and gone
And I sat a solitary man
In a crowded London shop
An open book and empty cup
On the marble table top

While in the shop and street I gazed
My body of a sudden blazed
And twenty minutes more or less
It seemed so great my happiness
That I was blessed and could bless

I feel the past year and a half has been a mixture of fear, sadness, but also moments of joy and wonder. The sharp relief I have experienced of how precious life is, and the people in it. The beauty of sunsets — particularly my birthday sunset — and nature.

In my room I never tire of looking at the trees and sky from my window — I am riveted and notice colours and textures I never saw before because I didn't really pay heed. This time is so special to me. A time of space and reflection with and by myself. Where will I go? What have I done (or not)? What will I leave behind? I hope it is something good and lasting for the people I love.

More comments from Ruby (in her Zimbabwean accent):
"You naughty, naughty girl — you are doing my job for me." She often spills my water or meds on me, at which we both crack up. "I am baptising you in the name of the Father, Son and Holy Ghost", at which point I make the sign of the cross.

She has me in creases and I her — I think we are good for each other.

She did a big prayer over me yesterday and got louder and louder. She said when she prayed for her friend on the phone he told her he always throws his phone in the garden, she's so noisy. I burst out laughing and said she can make as much noise as she likes, but not when my friends are here. That brought another guffaw.

16th January

Explaining to Ninette today how it is difficult to type the letter ‘P’ with my little finger because my right hand is getting so weak. As a touch typist, and with typing as my main method of communication, this is mildly frustrating. “Same with my right foot”, I said. “Can't type the letter ‘P’ with my little toe either.”

17th January

One of the most awful symptoms I have is constant, involuntary yawning. I have to type often to people: “Don’t worry, you’re not boring me” (even when they are).

The worst is that I yawn at night, sometimes waking me up, and then my jaw locks and my teeth grind. I hope it doesn’t crack my teeth. It’s really aggressive and gives me a headache.

At the dentist I typed: “Be careful, don’t put your finger in my mouth, it might get bitten off”.

“Don’t worry”, he said, “I have the reactions of a mongoose”. And sure enough, as my jaw clamped, he whipped his finger out like lightening — thus being spared a nasty bite. He told me the story of a woman he treated with dementia. She clamped down on his finger and wouldn’t let go. He needed six stitches.

The occupational hazards of being a dentist.

Morning Coffee

Smells are very important to me now — oils for the bath and massage, creams and lotions. One of my greatest pleasures is my morning PEG coffee. The smell takes me back to my days as a lecturer: I used to arrive in the early morning, pick up an Americano from the campus Costa, and take it up to my office. I would organise my day and the coffee smell would fill my little room. I miss that.

As I pour the coffee into my tube I take a whiff from the jug and close my eyes. I am there again. Busy mad days of students, lectures, seminars, and colleagues.

21st January

Why so low today?

Little things, like:

1) Not being able to clean up after yourself.
2) Not being able to paint your nails because fingers curling (wanton hussy).
3) Not being able to have your favourite chocolates from LA while everyone else does.
4) Not being able to bear having the Bipap mask on.

This day is full of "Not being able to's."

I am not even able to cry without knowing it will set off a chain reaction of secretions I wont be able to cope with. But do it anyway. Snot fest.

Woke up with neck pain which makes me scared. Won't be able to lift my head soon. Oh God please not that.

Everything seems unbearable.

I am so sick of this.

Was determined to wash my own hair today. Got to the bath and got the shower head water on (after some effort) — drenched myself and pyjamas and wet room but did it. Made it back to bed exhausted and soaked. Got into bed and slept till Ruby came.

Going to stop now. Full of self-pity, so pathetic.

Saw in the MNDA magazine someone using a recumbent bike. I would LOVE that *so much*. I miss riding my bike in the woods with Truffle. Oh that would be such joy to do again. Wonderful if I could manage it. Will look into it.

22nd January

Just read my entry yesterday and "Not being able to's." Yes there is so much I can no longer do. But equally let's adopt a glass half-full approach.

I can still:

1) Carry my weight. Yes, maybe I need a frame inside and a wheelchair outside. But I can still get around even if slow. In and out of the car which is essential.

2) Write! I am still writing this by hand. Although right hand more and more useless, my left hand still OK and can type so can still communicate.

3) Smell — although I can no longer eat, I can smell lovely oils and food — blessing and a curse — but quite the connoisseur of different coffee blends and the aromas they have. Less so with wine, simply because the last few glasses through the PEG have given me terrible headaches. (Probably shouldn't drink with all the meds I am on.) So avoiding wine as will want to PEG it.

4) Laugh! Brays and snorts that may be off-putting for some. I have noticed odd looks from some folk when out but am getting used to that. They're probably worried I'm going to jump up, rant and rave and run amok. *But,* this is the biggest blessing. To be able to laugh with my family and friends, my lovely carers too — no matter how odd it sounds.

5) Music! How I love listening to it. *All* types. I can't sing or play, myself, any more but can still listen.

6) Reading — another joy.

Of course there are many more "able to's."

For instance … a rowing machine. See next entry.

24th January
Thought about the recumbent bike, so decided would go to the gym and try one out to see if I could use it. Also thought about a rowing machine as still have some upper body strength.

Well, rowing machine was total success. I really enjoyed using it. Bike less so — right foot just slipped off the pedal — no push. So will add rowing as a number two weekly activity.

Exercises
Jane the physiotherapist (who comes about once a month) has been showing me exercises to help keep me flexible. I previously did yoga almost every day. So depressing, can’t do *any* of it now other than the Table Top, Cat and Reclined Twist. Can't even sit cross-legged. Absolutely kills my legs. These new exercises are so tame but not for me these days. So the rowing is a definite goer.

Went to a yoga class for the disabled a few months ago, which was a total disaster. The final bit that did me in (along with the “ohms”) was being told to visualise a tree in the distance. Yes I can do that, I thought. Now visualise yourself walking towards it. It’s getting nearer and nearer. OK … now you’re in the tree . OK … started to yawn. Kept yawning. Bored. “Listen to your body.” Started to feel all the horrible fasciculations that accompany this disease — muscles jerking and twitching — a constant reminder of your fate. I thought: “I don’t want to listen to my body. It has betrayed me. Why the hell would I listen to it?"

Needless to say, the session was not a success.

But the rowing machine…. yes! As long as I can stay balanced on the little seat (which is a bit of a challenge.)

Am so sick of being fed through this tube. How cruel that someone who is such a good cook and eater is reduced to this. Still, there are worse things, I guess. Like having nothing and starving to death, which would be the case without it.

25th January

The Sunday Times editor turned up today to do an article on me. They really like the diary "Book One." At first it was a bit unnerving using my keyboard and I-phone for the interview. Then a photographer arrived. I thought it would be a few snaps, but no, it was the whole shebang — lights and posing. Always was a bit of a poser so pretty at ease with it. Took me back to my band days and the photo shoots for that. Only now rather decrepit and wrinkly. At one point the photographer said "now look a bit serious." I couldn't explain to him that that control of my facial muscles is hit and miss. We'll see how it turns out. A bit scary when you have no idea what's going to be in it. What take they'll put on it and what photos they'll use. But my days of really caring that much are behind me — I just hope it helps the MND cause. They seemed kind and sensitive.

27th January

Tethered to the bed with the food pump on one side and the Bipap on the other. Trying desperately to get used to the Bipap which I despise.

Played a mean hand of bridge tonight. Justy and I wiped the floor with them.

30th January

Usually I don't close my blinds at night because there is enough light around to see the outline of the trees and also, later, to see the stars in the sky. I often watch the dawn break and the light slowly herald the new day. Last night I woke at 4am (maybe 4:30) to the most amazing sight. The moon golden and massive through the tops of the trees. The sky lit up in the most dazzling cloud display. It was wondrous and I lay there for a long time watching it as it slowly disappeared behind the trees. What a magnificent way to wake up!

I do love the dawn. All the birds are out. Winter dawns are beautiful with its stark gentle awakening.

31st January

Last night all the kids were round, and Eva of course — the youngest kid. I love it when she sits on my bed with me. When I break into a coughing fit, she looks at me curiously. Not alarmed — just trying to understand why Grandma coughs so much. She loves my keyboard and my remote. She got a surprise when she pushed the bed remote and we all went downhill. With Suresha's help, we made the family favourite: artichoke chicken. Need to do a recipe book. They told me it was the best yet. Did taste the sauce (third of a teaspoon) and agreed it worked out well. Secret is the thyme and stilton in the sauce (and of course the frozen artichoke hearts).

I feel like Beethoven composing his best symphonies when he was deaf.

1st February
Raw

Raw, raw nerves and feelings throughout the night as I deal with limbs that don't want to move and a cough that cannot shift. A sore hip — had to turn over. Even with the special mattress. Hand stiff and claw-like. Face fixed.

Justy and Cristina left yesterday for a month in Canada, skiing. Amazon sabbatical. I howled — emotions so raw. Couldn't stop floods of tears. Felt bereft, partly because I wonder what a month will do in terms of progression. How I will miss them.

The nastiest choking fit in the bath. Couldn't get air. Kept biting my tongue. Blood dribbling into the bath — horrid.

5th February

Sunday Times Article

On 28th January, *The Sunday Times* published an article of the interview with me. I have been wrestling for the last week as to what, if anything, I would write about this article. Initially, on reading it, I was disappointed. I felt used. This is because the article expressed the funny things I had written without conveying the deep angst that led me to write it. Why do I make light of bizarre episodes that happen to me? Why do people laugh and cry? Because of the extreme levels of emotion I am battling with. The only way I can cope with my huge all-encompassing feelings of loss and helplessness is to stand apart from it and acknowledge the ludicrous situations and be able to crack a smile. Also to embrace the profundity of the experience and, to some degree, the uniqueness of it. Being able to laugh at it helps to get me through. But what the article failed to do is show why the laughter is important. Unintentionally it runs the risk of making light of a disease that is truly devastating and as such did me and other MND sufferers a disservice. At the same time, I know that wasn't the writer's intention. The final article was edited down. Because the media is a blunt instrument whose main priority is to sell papers, I will think long and hard before accepting any more invitations of this kind.

The Radio 4 interview (*The Digital Human: Authenticity*) was far more sensitive and is perhaps a more suitable mechanism. The article was, however, very well received and, as Caz said, all publicity is good publicity to raise awareness.

Woke at 2am feeling just terrible. Coughing and hacking. Lonely too, although faithful hound by my side. Tried to sit up, which is hard these days. Rolling over in bed is a logistical skill. Rough night. This morning Ruby said she woke at 2am and felt she needed to pray for me.

9th February

In the week leading up to a hospital visit I am always on edge. Worried about the outcome. This week was no different. Having a few serious meltdowns. Sometimes I see Jazzy looking at me and wondering: "is she losing it?"

No, I think my meltdowns are totally appropriate and are usually frustration — overwhelming frustration at not being able to do something or say something. I often listen to people struggling with something when I know how to fix it. Or they will have conversations where I am in earshot and ask how to do something of others. Ask me! I'm here and I've been doing that for years.

13th February

Well, the hospital visit was fine. I was told that the carbon dioxide levels in my lungs had not got any worse in four months, which is great news. Had botox treatment on my saliva glands (made the obvious jokes about extra for the forehead). The idea is to paralyse two of six glands to reduce the copious amounts of saliva I have to contend with. Can't use the Bipap machine because of the saliva — end up drowning in it. Waking up in a pool of my own spit pouring out of the mask is not very pleasant.

Went to Garson's Farm with Marie yesterday, and realised getting out does me such good. Temptation is to sit on the bed in my room all day because it's comfortable and SAFE. Every time I go down the front door steps I am prepared for a mishap. But CAN'T WAIT for my electric wheelchair! Will bomb about the place. Driving test next week.

15th February

Speech is completely gone now. Just can't move my mouth to form the words. My top lip has a will of its own. When I try to close my mouth it looks like I'm pouting: sticking my lower lip out like a petulant child.

Tried out the leg braces today. Ankle splints that strap to your shins. Plastic things that go into your shoes. I think they help a little bit by reducing foot drag, but I still have weak thigh strength, so lifting my leg while standing is hard. Still manage to snail-walk pushing the wheelchair for a bit on the recreation ground. The weather was like Spring — I loved the sun on my face — healing. Sometimes I just sit here and think what the hell has happened to me? This is so bizarre. Our family had been untouched by adversity until now. I have always felt incredibly blessed that we had been spared any major mishaps. Felt for my dear friends who have and wondered how long will I escape? After all, life is not just sailing through — I know that trials can be incredibly enriching if you don't let them break you. Certain things could — the death of a child is one. Being hungry, poor, cold and/or unloved. We have been lucky and the bonds we have are strong but this could break us — especially if it goes on for years. I worry so much about that.

I could so easily end it. I have the drugs to do it and would be simple to put it down the PEG — but I would never do that. My kids would be so deeply hurt. Hugh too. They would see it as a form of betrayal. So will have to go through it and take what comes. Ruby would be furious if she knew I was writing this.

"You must claim it! It is your right as a child of God. You will not die. You will be healed! You will live to declare the goodness of the Lord in the land of the living." I look at her face and her complete certainty and think, if it's dependent on my faith, I'm doomed. If it's dependent on hers, I might have a chance.

When I think of being healed I think of eating. When I watch TV and people are eating, I want whatever they're having. I was watching a programme the other day and some kid was eating Cheerios. I have always disliked Cheerios for many reasons.

1) Tasteless
2) Absolutely no food value
3) Represents America at its worst

But watching that kid eating those donut shaped rings, the milk dribbling down his chin, the slurping, the crunching, I was there with every mouthful.

17th February

Every exercise I do is aimed at trying to keep the little mobility I have for as long as possible. I don't expect to improve but hope for no change.

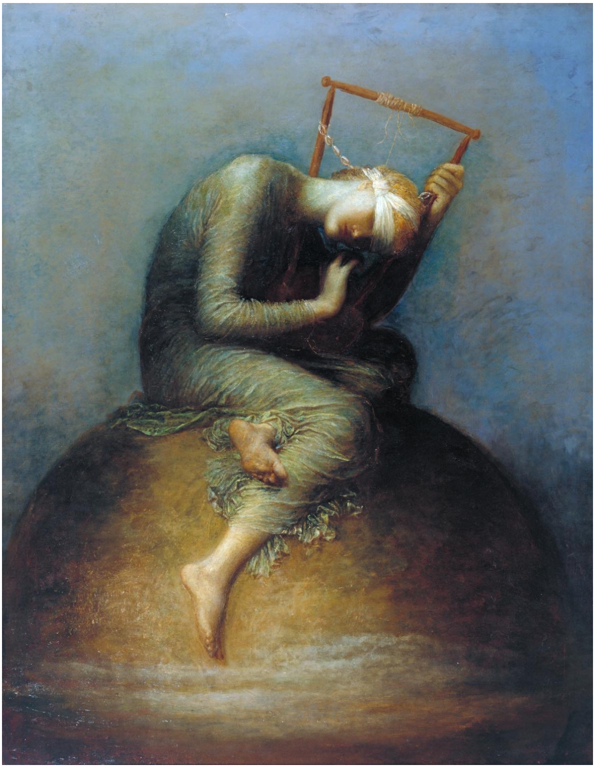
Imagine my delight yesterday when I discovered I could do something I hadn't been able to do for several months. I was actually able to sit cross-legged. Up until now my muscles have been too stiff so that when I tried to sit cross-legged on the floor, they screamed at me and refused to oblige. But last night I was able to do it! I forgot what it felt like for your body to actually respond to the exercise. Made me wonder what can be done with hope and determination.

21st February

Had a fun-packed two days with my darling daughter. She had a brainwave that we should visit Watts Gallery — not far from us — and I had never heard of it. What a find! G. F. Watts was a magnificent painter and sculptor. Particularly memorable was an enormous statue of Alfred Tennyson examining a flower seed with his dog at his side looking up which towered over us. It was inspired by Tennyson's short poem, 'Flower in the crannied wall' (1869):

> *Flower in the crannied wall,*
> *I pluck you out of the crannies,*
> *I hold you here, root and all, in my hand,*
> *Little flower—but if I could understand*
> *What you are, root and all, and all in all,*
> *I should know what God and man is.*

There was also a beautiful painting called 'Hope' (1886) which we especially loved. According to some blurb from the Tate, Watts has painted 'blind Hope seated on a globe and playing on a lyre which has all its strings broken except one. She bends her head to listen to the faint music'. I bought us two kimonos in the shop — one blue, one pink.



'Hope', by G. F. Watts

The next day I thought we should go to Wisley and visit the butterfly house. We had a blast on the mobility scooter. When out of view of any officials, Jazzy climbed on my lap and we went careering round the grounds. The butterflies were spectacular and I was the only one I saw who was blessed with a beautiful large blue beauty alighting on my arm. Everyone crowded round me to take pictures. I felt very favoured by this wonderful creature.

Today I passed my electric wheelchair assessment with flying colours. six months ago I would have been horrified to think I would want/ need one of these big black mechanised monsters, but now it's a solution to dependance. I am tired of being pushed around. I just wish there were nicer colours. Purple or Chartreuse.

So are there any upsides to having this vile disease? Well, in *Bittersweet*, I mentioned how it has brought my family and friends closer, but on a more practical note there are a few…

1) How lovely it is to have a bath run for you. Luxuriating in a concoction of oils and suds prepared by a loving carer.

2) I no longer do the laundry — I have done the laundry all my life — this is indeed a luxury.

3) One of my carers is obsessed with ironing — result, ironed sheets … ironed everything — wow — like a movie star!

4) Beautiful view of my garden from my new bedroom — always wanted this.

5) Room tidied beautifully, not by me!

6) No washing up!

7) Massage every day!!

Of course I would give a million bucks to be able to do all these things again.

24th February

Last night I prayed that God would heal my swallowing first. I thought that, just in case it happens, I would make my wishes clear. Although (obviously) I'm not that fussed in which order it happens — but I would love to eat something. Dreamed I devoured a whole bowl of crisps. Woke up feeling pretty good.

2nd March

My heart was broken
My heart was broken
Sorrow, sorrow, sorrow, sorrow,
My heart was broken
My heart was broken
You saw it, you claimed it,
You touched it, you saved it.

My tears are drying
My tears are drying
Thank you, thank you, thank you, thank you

My tears are drying
My tears are drying
Your beauty and kindness
Made tears clear my blindness

While I'm worth
My room on this earth
I will be with you

While the Chief puts sunshine on Leith
I'll thank him for his work
And your birth and my birth

by Charles Stoke Reid and Craig Morris Reid
('Sunshine on Leith', The Proclaimers)

3rd March

Work party has arrived to assemble the new ramp to go out the back doors of my room into the garden and then around the side of the house and out the front. It means my no longer having to brave the front steps. Hugh has done an engineering feat building the framework with wonderful buddies, David and Paul. Jeb, a longstanding friend of James (and me!) has a new company supplying all organic materials for the decking. And he and James are helping to assemble it all today. So, big work party and, to cap it off, darling Justy arrives in half an hour after a month skiing in Canada. He will be roped in to help despite his jet—lag. Home-made Persian soup and brown bread on a cold winter's afternoon after a morning's manual work — what's not to like?

Wonderful poker night last night with me winning right up until the end when Dieter did his usual trick of getting a good hand after terrible cards all night. I stupidly fell for it and continued betting, convinced he had nothing, as usual. Wily old fox took it on the last hand.

Such a great night again. Can't wait for the next one in April.

Continuing with new rowing machine. Core is a mess — hoping it will improve.

8th March

Trip to Oxford yesterday for beautiful daughter's birthday. Such fun to see her college and a fantastic walk on Port Meadow. Truffle had the time of her life. Incredible flocks of birds flying over the pond. So pleased she is living in such a nice place.

Some friction between Father and Daughter. They always have these spats. Hugh reacting. Her reacting — cyclical and I sit there and think what will they do when I am gone? I always try to help them understand the other. Such a shame on her birthday but seemed to end OK. Dougal's arrival always a bonus — I do hope she marries him — he's so lovely and would put my mind at rest to know she has someone nice like him rather than some of the jerks she's gone out with. Not everyone needs that, but she is definitely someone who needs a companion through life to help ground her and give her lots of love. Such an exceptional person with her ups and downs. Douglas seems to understand her so well.

9th March

Yesterday my power-wheelchair arrived. We have named it Pat. I had thought I would have mixed feelings about having this big thing in my room — a reminder of how things are deteriorating. But I LOVE IT. I have freedom. I can get places without the constant worry that I might tip over. And when the power is off it is sturdy, so you have something solid to lean on if needed. I can get to the loo without thinking: careful, careful, careful… concentrate… one lapse and you're over and, particularly when it's backwards, it always results in cracking your head against the floor — mind numbingly painful, literally. This wheelchair has become a necessity — it's that or a crash helmet.

20 minutes on the rowing machine today. Only on the lowest tension and a bit snail-like, but I can do it.

11th March

Mother's Day

Remember the Mother that I was
How I fed you; clothed you;
Cuddled you; played with you;
Protected you; helped you;
Taught you; comforted you;
Encouraged you; advised you;
Dropped you off; picked you up;
Egged you on; stopped you short;
Never gave up on you;
Believed in you;

All because
I love you.

Wonderful Mother's Day cards and gifts from kids and flowers from Hugh.

12th March

Ramp going down from my bedroom doors into the garden and around to the side of the house completed today. The ceremony fitting on Mother's Day. A ribbon was cut and I slowly descended on the ramp to the fanfare of 'God Save the Queen'. A beautiful construction masterminded by Husband with many man-hours put in by friends and family. A work that all can be proud of.

13th March

Family Holiday in the Isle of Wight for three days. A great treat having everyone together. Beautiful National Trust cottage in Cowes. On the sea, wonderful views. Has, however, brought home to me how dependant I am on my home environment. Everyone has worked so hard to get that working for me.

Items such as my hospital bed, handrails, remotes and gadgets all very missed when I stay in a "normal environment." Was brought up short on this holiday when I tried a simple task of turning over in bed. Realised absolutely stuck without hand rails and head-elevation to help. Totally at the mercy of others. How I hate that! Yes, folks, even going to the loo is tough without my rails, as I found when I crashed down onto the seat and hit my back on the front of the cistern.

Suresha to the rescue. So it has been made clear to me that my progression has worsened considerably from six months ago, which is a sobering thought. I keep wanting to think progression is slow but I can't type easily with my right hand now and it is pretty useless in general. Can't lift my legs easily like I could, and my feet are limp fishes. I am also finding it hard to sit up, and I have a permanent stoop like an old lady, which I am *NOT*!

14th March

Stephen Hawking died today. 76 years old. Lived with MND for over 50 years. What an incredible inspiration he was.

Bombing along the seafront in my electric wheelchair was such a blast. The sun on my face. Dog, daughter and her boyfriend trying to keep up. How nice to be setting the pace for a change and going where I want.

15th March

The Sunday Telegraph are doing a tribute to Stephen Hawking and want to interview me today. Initially reluctant after *The Sunday Times* article, but as it's about Hawking I feel deeply humbled to be mentioned in the same context. Much more serious and longer article. Have decided to go ahead. Hope I don't live to regret it. I just want to contribute. Don't want to fade away. Have always been outgoing — vocal. No usable vocal chords now — does that mean no voice?

16th March

Caught a cold on the Isle of Wight. Miserable. Can’t stop coughing. Painful sore throat. Back home. Will weather this with the help of trusty machines — particularly suction and nebuliser. A simple cold is magnified 100 times.

Beautiful verses from gorgeous daughter, Tennyson and Wordsworth — both very apt.

Tho much is taken much abides, and tho
We are not now that strength which in old days
Moved earth and heaven; that which we are, we are;
One equal temper of heroic hearts,
Made weak by time and fate, but strong in will —
To strive, to seek, to find, and not to yield.

from Alfred Tennyson (‘Ulysses’)

There is a comfort in the strength of love;
’Twill make a thing endurable, which else
Would […] break the heart.

from William Wordsworth (‘Michael’)

18th March

So sick from this cold.

21st March

3am. This cold has knocked me back. For the last three days have laid in bed with pounding headache, sore throat and cough, but the worst is the drowning and gagging. Can't bear being separated from the suction machine for any length of time.

Today was better in the morning and I made my first foray into Claygate in my new electric wheelchair to take Truffle to the vet for a rabies jab so she can come to Portugal. Claygate is a small village where everyone knows everyone else. Was worried people would see me and be shocked. It is pretty shocking — how I have been reduced from my former glory.

Face has lost weight so a bit more haggard. Mouth definitely lopsided with odd smile. Stooped even in the chair. Claw for right hand. Hair and nails still immaculate. Oh well — what can you do? (As Freddy would say with a shrug of the shoulders): 'It is what it is'.

Couldn’t believe the state of the pavements — so bad at one point I was tipping over 45 degrees. Decided to drive on the road. You’d think a council with so many posh houses could afford to keep up the pavements. Where is the tax going?

Justy and Jazzy have been looking after me so well. Jazzy helping with baths and generally on the case. Justy steady as a rock.

They have been making me smoothies. Jazzy made me a fruit one with fresh strawberries, banana, apple and coconut water. The smell was heavenly and I wet my lips. Yum. Sieved and down the PEG — almost as good as drinking it…. almost…. Justy made me a tzatziki one for lunch with yoghurt, cucumber, and garlic. Again felt I was experiencing almost eating as I breathed in the wonderful smell —

taking me back to the days of crisps and crudités, six o'clock wine and nibbles with girlfriends. Really lifts my spirits to experience some semblance of normality. James, Helen and Eva round for dinner. How they all keep me going.

But yes, it's 3am and I'm writing this. Had to keep turning on the suction. Waking up choking is not conducive to a good nights sleep. May have to pop a Lorazepam. Dark thoughts swooping in — I thought better to catch up in the diary.

23rd March
Did another perambulation down the Parade with Marie and the dog. Really enjoying the independence. Bought a card and present for beautiful Suresha's birthday. Met a few people along the way with the usual pitying smiles. Some saying "I'll pop in for a chat" which, bless them, is the last thing I want. A chat for me is exhausting. Offer to water my garden or dead head my roses… forget the chats.

Jazzy and I joked that I should programme a new phrase into my speech computer — when people ask "How are you?", it replies: "Never been better".

Getting very good at avoiding tree roots and broken pavements, and spend most of my time travelling on the road. There was one minor incident on our return when I misjudged my speed and ended up in the hedge. But I am quite familiar with Foley Road hedges. Took me back to one episode with a Foley hedge that happened about 15 years ago. After a particularly fun lunch party at a neighbour's, I decided to walk home. But having had rather a lot of very good wine, I went past my house and ended up in a hedge further down the road. Much to my embarrassment, who should come along but my daughter's then boyfriend. "Suzy are you OK?" He asked. (I was hoping he hadn't noticed me.). "Fine" I replied brightly, like it's perfectly natural to find your girlfriend's Mother in the hedge in the early evening. "Do you want some help?", he asked, to which I replied (inwardly mortified) "No thanks, I think I'll just lie here for a bit." He had the delicacy to accept that reply and went on his way, at which point I picked myself up and staggered home.

Different situation — similar hedge.

I looked out of my garden doors today and saw my bike propped up against the fence. A wave of emotion hit me. I went everywhere on it and it looked so rusty and forlorn. How I wish Hugh, Truffle and I could ride again. I broke down. These are hard times.

Black Pond

"Shall we go for a ride?"
Twitch, shiver and shake
Jackets, gloves, lead and trainers
Confirm the intent
The electric whirr of the garage door
A frenzy of barking
Our chariots await.

We mount and are off!
The sheer joy of it —
Fur flying, ears back

A race to the bridge
Stopping for nothing
Panting and puffing
Down to the fields
Past hedgerows and pastures
To the dark shadowed wood
Cool and enticing
But no time to stop
A wave to the walkers
And on till we drop
The road past the farm
Over track, field and brook
Startled horses look up
Then a brief second look —

Lead on, we cross
As kind drivers await
The race on again
Over tree roots and sand
Past the pylons and left:
A well-trodden dirt path

And 'woo!', in she leaps,
We made it, Black Pond.

29th March

2am. Howling, yes literally howling at the injustice and indignity of it all. I sound like a wounded animal. Indeed I am. Over and over. My room is far enough away. Hugh can't hear me.

It’s the fear of sleeping — waking up gasping for breath which you can't catch. I swear I will probably die of a heart attack just from the stress of that.

Must try to sleep.

31st March

Clever Justy has bought me wristbands with a hook so I can still use the rowing machine even though I can't grip with the right hand. I am starting to feel much better so will get back to that. He has also created a bolster at the end of my bed so I can push myself up easier — clever boy, definitely his father’s son.

2nd April

What an up-and-down winter this has been. Wonderful times with family and friends whilst also struggling with horrible viruses and throat infections. However, thankfully have avoided the dreaded chest infection, often a precursor to pneumonia. So overall have survived the winter well.

Great Easter Day with whole family. Organised Chinese duck with pancakes and had Easter eggs and presents around the table. Kids all did a splendid job of putting the dinner together. Had marinaded the duck the previous night with maple syrup, vinegar and filled cavities with star anise and ginger. Justy made his wonderful Chinese vegetables and was overall Head Cook. Jazzy did splendid coconut beans and everyone else mucked in.

Jelen (Helen and James) did the honourable and often thankless task of washing up while we all played with Eva in the lounge. Eva on tremendous form, running about the house so happy to have her independence as she has fully mastered walking. Her mischievous cheeky faces as she tries to get everyone in the room to give her the Easter eggs on the table just out of reach, that Mummy and Daddy had already said no to having (having had loads already.) She almost got Uncle Justin to succumb with those pleading eyes and coy smiles, but at the last minute he checked with Mummy and that was that. Still, she took it with good grace.

4th April

About 20 years ago I filled in an online career assessment test which identified that, with my particular talents, the top occupation suitable for me was an "Industrial Relations Officer." Seemed quite bizarre to me at the time, but those skills are becoming very useful in helping my two carers to develop a team mentality. Both professional in their own ways, but very different from the other. Enough said. It has been educational discovering the different perspectives and priorities each of them has. Spoken like a natural industrial relations officer.

8th April

So I have been on this PEG tube drink for over a year now and the last six months exclusively — no other food, just that, water and coffee in the morning. It contains all essential calories and vitamins for me to survive.

As a result of taking it without variation for that long I have developed a total aversion to the stuff. I hate it. I hate the smell of it. I hate the look of it. I hate the after-effects when I have it. And I have got to the point where I cannot face it any more.

There’s no getting around it. It’s not fresh.

Thank God for the smoothies and soups. There’s quite a lot that can go down a PEG tube if you have a mind.

9th April

Went to the hospital on the 5th for more botox and talks with respiratory doctor. Made a momentous discovery. Hugh asked if the coughing could possibly be a result of reflux. “It could be.” “But,” I said, “I’m taking something for that." “Double it,” he said. Result? First good nights sleep in months. All this time the coughing seems to have been due to reflux.

10th April

Had a serious meltdown yesterday. Just am so SICK of not being able to do the simplest things. Hate asking for help. I have never been helpless before. This really is a physical and emotional nightmare. It is what I was afraid would happen. Where everything centres on my health at the expense of everyone else’s well being. Just want people to remember the old person I was — not this horrible caricature. I can see why people think of ending their lives. It does seem to me to be the kindest way. What a dilemma.

Hope has flown
out my garden door
That beautiful bird
with rainbow coloured feathers,
Singing her melody
of love and laughter,
How I miss her.

11th April

Two days of horrible depression. James, Helen and Eva came yesterday for dinner. Just organising the dinner and conversing with Eva helped to pull me out of it. Her frank look and then that twitch of a smile, just like her father when he was a baby — that little twinkle. I remember it as though it was yesterday. Also taking Truffle for a walk helped. So better today. Collected her Pet Passport at the vets so she is now going to be a travel dog!

21st April

It has been a rough time, but the glorious weather has helped hugely. Having the sun on my face and the garden doors open. Boisterous bird song and if you sit, watch, and listen to what is going on it is quite amazing. The garden full of life. So lovely to be surrounded by beautiful plants, some of which we planted over 20 years ago. The magnolia with its large purple flowers and, of course, the wisteria will soon burst into colour and cover the whole back of the house. That will be a spectacle.

Meanwhile, the planned trip to Portugal is going ahead like a military operation. Justy has devised a spreadsheet of tasks which have been allocated to everyone. So many things to do. Hugh and Rob are taking the ferry from Portsmouth with Eric (our name for the wheelchair adapted vehicle we now have) which will contain equipment and MOST IMPORTANTLY, Truffle, who will be coming for the first time. A two-day ferry ride and ten hour drive through Spain. ROAD TRIP! But I will fly with Ruby. Just hope I don't freak out the passengers when I use the suction machine. Seriously hope I don't get a coughing fit on the plane. It can be alarming to witness.

Although excited about the three-week holiday I am also anxious, but I love the place so much I want to go again.

Had a lovely day of cooking with Suresha a few days back. One of the pleasures I enjoy the most. She is like my hands. She knows instinctively what I mean and together we make the most wonderful dinners. This meal was Persian lemon chicken with roasted vegetables served on a bed of couscous with pine nuts.

Of course the feedback was very positive. I think Suresha enjoys it too because she loves cooking and my recipes are very different from what she knows. Of course, her curries are legendary.

22nd April

One of the most shocking of the many shocking experiences I am having is when you are lying in bed and begin to cough. Normally what's the first thing you do? Of course, you sit up! So I try to do that but … I can't. The cough gets worse but there is no core strength to sit up. It is a horrible, helpless feeling when you realise you can't even turn over, much less sit up. At the moment, with the aid of the hospital bed, I can raise my back and still have strength enough, once in that position, to grab hold of the left bedrail and heave myself up onto my elbow. From there I can still lever myself into a sitting position although, in the early hours, it's quite challenging. It can lead to a panic which I have, I hope, got the better of.

Jazzy, Hugh and I went to Garsons Farm today and bought two bird feeders which we are hanging by my bedroom garden window. I do hope the parrots turn up. Although interlopers to this country, they are very bright, noisy and comical, and I have always loved parrots. There are gangs of them all over Surrey and the way they have adapted and, indeed thrived, in our climate is surprising.

Our family had a pet cockatiel for 18 years. Twiggy (short for Twiglet) was very tame and would sit on us while we watched TV. He felt it his duty to check our heads for mites. One day he made a daring escape out of the window, over the rooftops and was gone. We were devastated, knowing he was too tame for the wild. After searching everywhere, we gave up but rang the police the next day. They said someone had called in about a lost cockatiel. We couldn't believe it and rang the number. The people on the other end were a bit reluctant to hand him over at first and said: how would they know he was ours? I said, his name is Twiggy and he says "Hello Twiggy." They said, "come and get him." It turns out he had got himself stuck in a Hawthorn bush on the recreation ground, and the groundsman, who was mowing the lawn, rescued him. He then sat on his shoulder for the whole afternoon. We were thrilled to have him back.

As a child I had parrots in Indonesia and Hong Kong. Now I would no longer have one as I think caging them is not fair — even though our birds all roamed free and were members of the family. Still, in hindsight I think birds belong outdoors. I suppose that is why I love the Surrey Parrots. They were once caged but have made good lives for themselves, adapting in a climate very different from their natural habitat… like I did.

My Mother was an evangelist and, as a result, my childhood was spent travelling all over the world. I remember going to a Mexican school in a town called Pueblo, outside Mexico City for a month. But by far the most notable move happened after a dream which she felt was from God — this meant uprooting from suburban life on the outskirts of LA, and travelling to the island of Java in Indonesia. I was 10 at the time.

Indonesia in the 1960s was far different from what it is now. As a child of 10 from a middle class American family, I had never witnessed this level of poverty before and it left a profound impression on me. I remember the heat where the sweat dripped off you, and the beggars. Lepers with stumps for hands and noses rotting off their faces, crowding us as we got on a train. "Treemakase tuhan." Holding out their pitiful ragged hands. I remember beautiful lush countryside and stretches of barren hillsides where terrible landslides had occurred because of over-logging. The dirt tracks as we travelled by jeep and the squelch of a chicken or two, determined to cross the road just as we passed. It was like they had a death wish and the saying "why did the chicken cross the road?" became more than just a rhetorical question.

My Mother wanted to see her missionary friends who lived far up in the mountains in a village outside Malang, called Nonkajarjar (after a fruit called nonka). Even now the sickly smell of that fruit brings back unwelcome memories. But the intestinal experience of that nonka taught us all a valuable lesson about the importance of washing fruit (particularly from an Indonesian street stall).

To get there we hitched a ride on a milk cart — all of us sitting on kegs the diameter of side plates. As a skinny 10 year old I didn't mind that, but for my mother and step-father it must have been a painful ride. Several hours later, shaken up the mountain for miles along cobbled stone-rutted paths, we arrived dishevelled and disorientated and were greeted by the missionary family.

I remember sour looks from the village inhabitants, unhappy with my blonde hair — too much like the Dutch colonialists who had ruled them for decades. I remember a beautiful tree in the middle of the village. A table at the foot of it was piled high with all manner of delicacies — offerings to the Tree God, while the people went hungry. That village had very fat birds. I remember going to the village school and being in the English lessons. The teacher asking me a question which I thought was in Indonesian but, much to my embarrassment, I realised (after she kept repeating it and looking expectantly at me) was meant to be English — unintelligible to me. The only way we could converse was writing (and even that was touch and go). No electricity or running water, the flies, the frugality, the lack of what we would consider basic essentials, was the best education I could have had about the haves and have nots. About the other world beyond our own sterilised cosseted existence, where everything is on tap and we lack for nothing.

24th April

Lancashire Hotpot

I wanted to write down these two recipes which Suresha and I did so as not to forget them. One from today and one from last week. Today's one was a variation from the Lancashire Hotpot. I have never seen Eva shovel it away so fast (except maybe Suresha's curry). We used diced lamb, which we browned well, then set it aside and fried 2 onions, 1 garlic, 1 carrot, added 1 aubergine — all cut small and some cubes of sweet potato. Fried that up and added 2 teaspoons of Lea & Perrins, and salt and pepper, sprinkled with flour (25g) and fried a bit more. Then added 500ml fresh beef stock and the lamb. Made very thin potato slices (used a magimix) and layered them on top. Spooned a bit of gravy, then potatoes. Put in a 160 degree oven, covered, for 1 hour. Took off cover and cooked a further half hour with oven on high.

Middle Eastern Meatballs

This used lean mince but I added onion salt, cumin, grated ginger, garlic, breadcrumbs (sourdough with cranberries or something like that) lemon zest, one egg. Make into balls / patties, either fry or bake. Serve with yoghurt / chutney.

26th April

One thing I dread is meeting people I haven't seen in a long time. It is stressful as I know what they are thinking and I hate being the object of pity. It is not their fault but I tend to avoid people I haven't stayed in touch with because of that (I'm also just too tired most of the time).

SAID	**NOT SAID**
Hi! How great to see you.	OMG you poor woman.
How are you?	How is it progressing? You're now in a wheelchair and can't talk, so can't be good.
Is there anything I can do?	There clearly isn't anything I can do, what a bitch this disease is.
You're looking good.	For someone with what you have, you have not fallen apart as much as you might have.
Keep in touch.	I don't know what to say. It's so awful.
I don't know what to say.	I don't know what to say. It is beyond my experience to know how to be.

What to say when we meet after months… a few suggestions:

1) Don't ask how I am.
2) Don't lie about my looks. Best to stay off the subject.
3) Don't look sad, concerned, piteous or cry (there are exceptions).
4) Be normal — I crave normality.
5) Try and remember the old me and talk to me like that. I'm no different on the inside.
6) Don't say "I don't know what to say."
7) Don't say "Cheer up." That comment usually goes with "things could be worse", when actually they couldn't be much worse.

7th May

Hugh left last night with Truffle and Rob on their exciting road trip to the Algarve where I will meet them in two days when Ruby and I will take a plane.

Initially it was my idea to do the road trip — I have always wanted to, but when it came to two nights on the ferry and 10 hours of driving, I just didn't think I would manage it. So in the end we decided I should fly. Very disappointing. I would have loved travelling through Spain and down through Portugal, but that's the way it goes. Most importantly all the kids have taken time off to come down for some of the two weeks and, for the first time, Truffle will be with us. AND Hugh has bought me a beach wheelchair that … get this … ACTUALLY FLOATS! So I can travel on the sand and go in the water if it's calm. It also looks great. Big fat yellow wheels and a blue and white striped seat like a deckchair. Very cheery and "un-disabled looking." I can't wait to try it out. It was such a lovely thing to buy me and cost a fortune — he is using up his pension fast. If you are reading this, thank you darling with all my heart for all the things you do to try and make it more bearable, it helps so much. You help so much. My friend, advocate, lover, heart of my heart. You have never tired in looking out for me. I love you so much.

I have not written much because I have been grappling with this disease. I didn't feel I could detach myself enough to record anything or put any coherent thoughts on paper. It has just been a muddle of stark realisation hitting me over and over again and the resultant turmoil. I don't want this diary to be too dark — what good is that to anyone, including me? Dwelling on dark thoughts just makes you more dark, so I try to wait until I can temper things or see things more objectively.

A few days back, we were looking after Eva. I watched Hugh and Eva sitting on the garden step talking to each other. It is lovely how they communicate and she adores him, whereas Grandma is a bit strange. Always silently sitting in a big black chair — enticing with its dials and buttons, but still a bit off-putting.

Watching Hugh and her from the window I couldn't help shedding a few tears. I will never be able to talk to her like that. She will never know me and love me like she loves her Grandfather but I am so glad for him that he will have her.

After wallowing in some self-pity for a while, I joined them in the garden and for the first time she put her hands up to me indicating that she would like to come up to me and sit with me in my chair.

Hugh put her on my lap and we went motoring around the patio. She loved it, honking the wheelchair horn. What fun we had!

12th May

I am in Portugal sunning myself on our patio. James, Helen, Eva, Hugh, Ruby and Truffle all here. What a result! Hugh and Rob did an epic non-stop 10 hour drive from Bilbao and made it in one day! Ruby and I came on the plane which I have to say was a living hell. Compounded by being two hours delayed. I have never needed assistance to my seat before and was curious how the airlines get round the little problem that I can no longer walk down the aisle. Quite an innovative way of doing it. They have a very narrow chair that actually goes down the aisle — the seat arms go up and they scoot you in. However the actual plane seat practically killed me — like resting your back on a board — and I realised how weak my back muscles are in that I struggled to sit up. Why don't these flight companies let the disabled sit on the front row where they won't feel even more crushed? Kids insisted I wear a mask to avoid cold germs but had to take it off. Too claustrophobic. I couldn't wait for the journey to end. Trying to stay upright, using the suction machine surreptitiously. Luckily the noise of the plane drowned out the sucky yucky noises. Such a love-hate relationship I have with that thing. Ruby, always such a bright spark, kept me going.

When they came to take me off after everyone had gone, two strapping Portuguese men appeared with the thin aisle chair. One of them was so good looking I thought "Yes! Picked up by a gorgeous Portuguese hunk, things aren't all bad". I swear he was like a movie star. The other one stayed with us all the way to the car park. Sadly the hunk went off somewhere else. Little does he know how much he brightened a very bad day. Marie and I wondered if he was recruited especially for this purpose.

It has taken me three days to get over that flight. We arrived in the early hours because of the delay and my feet were like ice-blocks. I hardly slept that first night. Ruby, bless her, stayed up all night with me. I think I slept for two days after that. But am now more or less recovered.

13th May

Just like the last time I came here, it is a kind of pleasurable torture smelling the wonderful food. Even the smell of frying garlic is different. And the Chorizo sausage — heaven. Last night Hugh saved me a bit of juice from the clams they had for dinner. The aroma was amazing. Even Ruby admitted it smelled delicious and she hates even the idea of clams. Obviously not a delicacy in Zimbabwe. The Algarve — long stretches of sand as far as the eye can see. Truffle was in heaven — running around like a lunatic — putting her face into the wind — ears flapping back as she lifted her nose to smell the sea breeze. Hugh throwing sticks into the sea and she bounding in. The surf helping to bring her in but when a small wave enveloped her, Hugh had to run in to fetch her and drag her out. At that point we realised throwing sticks into the sea was not such a good idea. Then she disgraced herself by barking like an idiot because we wouldn't play with her. Then she went for Eva's snack which didn't go down well. So I finally tethered her to my beach chair. This chair got me onto the sand so I could sit on the beach. It's so comfortable and when the waves are less we will try it in the sea. James valiantly dragged it across the sand. Not easy but doable if you have a bit of muscle.

As at home, one of mine and Hugh's greatest pleasures was biking in Portugal along the Ria Formosa. A stretch of coastline that is a nature reserve along a large portion of the eastern Algarve, protected from development — long may that be so — an area of outstanding natural beauty.

Ria Formosa

Take me back
To that time
On the Ria Formosa
The sun beating on our faces and shoulders
The crunch of our wheels along the gravelly path
Yellow warblers perched on the hedges
Grebes and cranes, lazily wading in the ponds
Brimming with fat carp, some the size of serving platters
A stork flying overhead.

Take me back to our
Sweat soaked t-shirts
As we stop on a shady ledge
Congratulating ourselves on the miles we've done
With a lunch of Algarvian almonds and egg salad sandwiches
Made with sourdough bread.
Finished with Sharon fruit,
Custard apple or whatever we had in the fridge.

Sometimes making it all the way to Faro Island

Where we would have a cocktail
And throw ourselves in the sea
Take me back to that time.

14th May
Modesty

I have always been a very shy person when it comes to nudity. Not one to flaunt my booty — even when a rock chick. I still was modest — perhaps overly so — having come from mid-western American parents, we did not bare all and bordered on the prudish.

One of the first things that concerned me was how would I cope with losing my privacy when I could no longer dress myself? Or even get to the loo without help? Or have a bath?

Would I manage to preserve my dignity?

I now think differently about my body. It is just something I live in — and it is failing me. I am above it. I have to live with it. I have to look after it as best I can as it deteriorates. And I have to suffer the pain and heartache it gives me every day. I am like an astral projection looking down at this strange version of myself and thinking: "that's not me — it's just a body I am tethered to". So I don't really mind when I need help. Getting dressed, going to the loo, baring all — it's a necessity and I am blessed with people who are happy to help. My boundaries have narrowed as I allow more people into my life to support me. My walls have had to come down but, by consenting, I am still in control. I have not succumbed.

15th May
Fab Fabrica

Yesterday we went to my favourite place, Fabrica just outside Taviera A sleepy beach hamlet overlooking a tidal lagoon. When the tide's in a motorboat ferry takes visitors across to a sandbar — a wild and windy deserted beach where many a kite has been flown. Hot competitions to see who could do the most spins or hit a vertical stick strategically placed for that purpose. The far side exposed to the Atlantic waves and crystal clear water. And miles of white sand.

The hamlet and lagoon a picture of tranquility. With a small kiosk serving chicken and tuna pastries, sweet melon and ice cream. And a restaurant with surly waiters serving the best seafood rice in the Algarve. Looking out over a bay of sun-bleached red, yellow, green and blues boats in various stages of disrepair. The sky a deep azure blue. The water ever-changing shadows, denoting different depths as the tide ebbs and flows. Sandpipers pecking for morsels, gulls watching from the sky and at low tide men and women with rolled up skirts and trouser legs, digging for clams in the squelchy mud.

It's the colours. Indescribable in their vividness. Sharp relief and shadows as the sun hits the water and glistens, fish darting beneath. And the lagoon the perfect spot to launch my floating beach wheels. I had accepted I would never again set foot on the sandbar — no way would I be able to get in the ferry boat. But then we thought James could pull me across the lagoon in my wheels, at times swimming. But it would have been hard. Then Hugh asked the ferry man if he could tow me across. The kindness of this young boatman was wonderful.

So they roped the wheels to the boat and I was towed across. When the wheels hit the water half of it submerged. It was cold! Wow! A bit hair raising at times when a wave hit and threatened to topple it but was a very fun ride and I sat again on the sandbar. I hope not for the last time.

18th May

Deep breaths of the sumptuous aroma of Algarve fish soup. Essence of clams, sea bass, prawns, and tomatoes and pimento — yum — at the same time down the tube it went (strained of course). Felt was almost eating it.

20th May

Justy and Cristina, arrived yesterday and we all headed to Val Beach and spent a great afternoon — playing in the sand, having games of Boules, a sumptuous picnic and…. serious highlight for me…. surfing the waves in my wheels. Justy and James on either side, we hit the beach, wheeling out the chair into the waves. Initially it seemed quite unstable and so I had a momentary regret that maybe this was not such a wise activity for someone who can no longer swim ….. but realised "too late now"…. and a gasp as I hit the cold waves! Soon acclimatised. Rushing over the swell, at times, the front dipped under and I thought "this whole thing could do an underwater flip and leave me upside down". We went far out. Then tried to time our return with the wave breaks and ended up surfing in. Again, as we were surfing in my feet dipped under, but the wheels remained upright much to my relief.

21st May

Quinta Lake today. Hired a pedalo that looked like a pink Cadillac, and Justy and Jazzy towed me out on the wheels. Lake water far warmer than the sea, which meant we could paddle around for longer.

22nd May

Justy and Cristina have gone. A fleeting visit but he says he will come out for more time in September. He felt bad, which is not what I want. Guilt is such a negative emotion and, where I am concerned, I want my children to just feel positive and know how grateful I am and how immensely happy they make me with all that they do for me. They have literally pushed the boat out (ha ha) for this holiday. They have rented a hospital bed, and a special raised loo seat with handles; bought a bathchair, and helped lug the waterwheels and my own power chair from place to place. They have sieved and juiced food, run for the suction, helped put in ramps, the list goes on… It is quite a project to transport me anywhere. There have even been times when both boys have offered to take me to the loo and close their eyes, but luckily that has not been required — I hope it never is.

23rd May

Market day! The gypsy market in Quarteria is always good for a bargain. The stall on the far left at the very back has been run by an old guy and his wife for as long as I have been going and I'm sure longer. His belts are pure leather and of the highest quality. Beautiful work that would cost a hundred at home. And he monograms them while you wait. Got a nice one for Justy's birthday. The rest of the stuff is a mixture of tat, seconds, and rip-offs, but always an event to go. The Peruvian pipers still piping their tunes (I have my doubts about their antecedents).

In writing all the fun stuff we do, I would be lying if I said it has been idyllic. I have struggled being away from my comforts despite everyone's efforts. Ruby has gone the extra mile by getting up with me in the night. Doorways too narrow for the power chair; bed hard to get in and out of. I think Ruby could enter a weight-lifting competition and win after her regular sessions with me. She has made me fresh porridge every morning and been truly diligent with administering the meds and supplements.

Jazzy has been such a support too. Her soup is delicious (at least the smell) and she has cleaned and decluttered my room. What have I done to deserve such a fabulous daughter? I worry I am no longer able to be the mother I was. Makes me sad but she seems ok. Always makes me laugh. How I love her.

Arrived back from the market feeling terrible with pounding headache and that drowsy feeling I get a lot where it is almost as if I've been drugged. Not sure if it's the neck or breathing causing the headaches, but went to bed and didn't really get up again except to have a bath, some soup and then crashed again.

It is at times like this that I think it's not worth it. I think — "is this it?". But today I feel comparatively ok again and am sitting outside writing this. The ghastly thing about this disease is that, when I breathe in and my chest hurts, I think: "oh no, my chest muscles are weakening". But today it's ok, so maybe I just strained something.

It's the uncertainty of what's coming next….and….when. Last evening I wanted to die. I felt so rough. Today I want to keep going — up and down, up and down. Yoyo-ing between thinking about the hereafter and how they will all cope without me, and thinking I can fight this. I may not win ultimately, but am strong enough to keep going.

25th May
Last night was the first night since we arrived that I needed a sleeping aid. I don't know why but thoughts were swirling in my head. Like: "What happens when I can't breathe, and can't signal to anyone? What happens when…" — awful, and called Hugh down. I said if it got to that I didn't want to go on. He understood.

26th May
James just sent me a song he wrote today — "Back Home". I love it — so beautiful and poetic. His voice has matured so beautifully too. I wish he'd get his songs out there. People would love them as I do I'm sure.

I am so blessed with children who have hearts. All three of them have deep empathy and awareness. I am not sure how that happened, but it's wonderful and I have been able to experience their love so much through this ordeal. I never thought I could say some good has come from this vicious disease but I can.

Although I always believed in them as people, through this they have shown me first-hand what love is. Something many parents don't get a chance to see.

30th May

The last day of our holiday was pretty intense with lots of packing up. Hugh heading off back to the ferry at Bilbao with Truffle and the waterwheels — Jazzy, Ruby and I to the airport. Arriving, we were told our flight was delayed by three hours (which turned into five). There followed a fraught time as we tried to give me water, medication and food in the middle of a packed airport with no place for privacy. Ruby finally set up camp at some chairs and a table near the ice cream shop. She tried to shield me from being on show — an object of curiosity with my tube and suction machine. In the end I couldn't face it so didn't have anything.

In the airport shops I found Jazzy some pretty sandals and she fancied some sunglasses she saw on the mannequin. However, when she asked to buy them, the salesgirl said they were "old stock, and not for sale". She pleaded with her, but to no avail. Even the sight of the disabled mother in a wheelchair wasn't enough to tug at the old heartstrings (yes we have been known to resort to that tactic on occasion).

We went back to our base where Ruby had been guarding the bags. I mentioned how Jazzy loved those sunglasses.

"Which shop?", Ruby said.

I turned to Jazz: "If anyone can get you those, Ruby can."

Ruby, always one for a challenge, sprang up and sashayed off to the shop. She was ages, and Jazzy and I had visions of her being arrested for harassment. Jazzy hid behind a kiosk to see Ruby and the shopkeeper deep in conversation. More time went by, and Jazzy returned, saying they'd gone into the shop.

Suddenly, Ruby appeared, handing over the sunglasses with a smile. Jazzy was amazed — me less so, as I knew the force of Ruby's personality when she wanted something.

"That girl was not budging, what did you do?!" Jazzy asked, incredulous.

"Ah it's simple," said Ruby, "I asked to try them on and then said "I like these, don't they look great on me? How much are they?"

"They are not for sale", said the salesgirl .

And I said: "Why do you have things on display and don't sell them? That's not right. I want them. I want to speak to your boss. She said her boss was not there and she wasn't allowed to sell them. And I said: 'Well, I'm not taking them off, so I suggest you do'."

So the girl sold them to Ruby, along with a lovely colourful bag, saying that she was clearly a "very important person".

Of course we always knew Ruby was very important. What a legend.

After a gruelling wait, we finally boarded the plane. Made it home at 6am where Suresha was waiting for us in a state of some worry. As soon as I wheeled myself up the ramp and into my bedroom I was so happy. Comfort! Doorways wide enough! Space to turn! A bed with a rail, wet room with a comfortable bath chair. I was in heaven. Pretty flowers on the table and fresh clean sheets. It's good to be home.

Pictures from our time together during the writing of Book Two:

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