

**SUZANNE JAGGER**

**FOR MY  
CHILDREN**

**BOOK 3:  
2018-2020**



*Life would be tragic if it weren't funny.*

— Stephen Hawking

*There is comfort in the strength of love  
It will make a thing endurable which else ...  
Would ... break the heart.*

— from William Wordsworth's 'Michael' (1800)

\*Book Three was written by Suzy in a beautiful hardback notebook with this dedication...

11th March 2018

Dear Mummy

Happy Mothers' Day

I thought you could start your third diary in style with the finest of silk paper - as the only fitting recipient of your wonderful words ...

Love you xx

Jazzy

*Book Three*

*For My Children*

**7th June 2018**

This book is so lovely that I hate to mess it up with my scratchings. And I sincerely hope my hand continues to hold out. But there are many pages so we will go as far as possible with the intention of finishing.

I have called this book "For my children" when in fact all my books are for you. They are memories to remind you always how much I love each of you, what fun we have had and to give you insight into what I have been experiencing so you understand. You three have been with me all the way. You have given me your hearts. I would not have lasted this long without the three of you. And it is interesting that each of you has an intuition about me which others don't share.

When I want or need something one of you often knows or works it out. It's almost like a sixth sense, and I've noticed it with all of you. It's quite uncanny.

I have seen you grow as people through this too. There is a maturity that has surfaced - a strength of character that I wasn't expecting and has made me deeply proud. I want you three to know this. How proud I am to be your mother and how blessed I feel.

I am not planning to write you each a letter to open on my death. Too morbid and I hope to be around for a long time. But who knows? So these books are for you.

Jazzy will be the keeper but I hope you will share them with each other and talk about them together and with your own children. I am lucky to have the time and space to do this. But none of us know when the time will come so I wanted to put a few things down and then I can relax a bit and not worry so much about the future knowing "you've got this".

I can't say this enough - always be there for each other. You know each other - your virtues and faults. Enjoy and rejoice in the successes and be unfailingly tolerant of the failures and faults of each other. Don't let anyone come between you and look after each other for my sake. Be an active aunt and uncle to each other's children. I never had that you and you didn't have it to the extent I would have liked. Family grounds you. It teaches you tolerance and how to love. It gives you security and roots.

The three of you have turned into individuals with depth and soul. That can be painful but use your creativity to release and cope with it. You are all deeply creative - I see that in your songs and writings but also just in your phenomenal problem-solving capability - that is creative and a great asset for you. You will find fulfilment in your creativity far more than the pursuit of a bigger bank balance. Be comfortable but don't let it rule you.

Sorry to be preachy but actually I'm not sorry at all. It's my right.

Another thing – I know my death and the time leading up to it will be painful. It is unavoidable. But remember – it is the right way of things. Be sad but not consumed. And LIVE as I would want you to – happy and enjoying the people and beauty that surrounds you. Jazzy, I know you will be very fragile, but you know you are my girl and I see me in you every day. It is a comfort to know there is a little bit of me in all of you and so when you look at each other you will remember me. My darling girl, live your life with happiness – that is the greatest gift you can give me. And boys – you help Jazzy. And all of you help your father who, despite what he tries to convey as being in control, will be struggling having lost his companion of more than 40 years.

Boys, I know you have a wonderful relationship with the other and Helen and Cristina and this will help you tremendously.

Now, enough of this, although if the mood takes me I will return to this subject. For now, on with the memories to cherish (well, some of them).

### **11th June 2018**

Sunny days and evenings on the patio. My best time basking in the gentle sunshine. Suction to hand – kids coming and going. Yesterday took the waterwheels to the pool with James and Justy's help. Once in, they helped me get off it and we used the noodle to hold me up at the front while one of the boys stayed behind to keep me steady. Even managed to kick my legs and "swim" if you could call it that. Supported at all times of course. Had to get back on the wheels to get out as there is no way in the world I would have made it up the steps. This proved challenging, but the boys worked out a way.

Another lovely day today and Jazzy not to be outdone asked if I wanted another swim. I said when Justin comes. She said: "you don't need him, we can do it". I said "It's no problem getting in, it's getting out." "No," she said: "we can do it". I thought ok, why not?

So another great swim but then it came to getting out. Hugh and Jazzy needed to push the chair far enough down for me to be able to get in from the first rung of the steps. Not easy. Ruby was hanging over the steps, latched onto me, while the other two tried to push the chair down far enough to lever me onto it. Got me half on and then pushed it to the shallow end where they heaved me onto it. Not as easy as they thought, but I did eventually make it out. Worth the hassle (at least I thought so). Shocked I can no longer swim a stroke though. Another one of my loves bites the dust.

One of the best things about these June days is the longness – still light past 9 o'clock. The other best thing is Jazzy and Douglas stay for the weekend which they do a lot. They are so great together and like the same things. God, I hope they get married.

She's kissed a few frogs in her time but Douglas is not one. He is so funny – both have sardonic wit – and they spark off each other. I love the way they set up elaborate spreads on the garden table – bread, cheese, houmous, tomatoes, olives, wine. They make each other iced coffee and real lemonade, and sit in the sun trying to edit their PhDs on laptops. Playing with Truffle, in the morning big brunches – eggs, bacon and exotic salads.

I get the impression he actually likes being here. Not phased by the yucky suction machine and not frightened to converse with me. Initiating conversations and just being a laugh. It helps Jazzy so much that he is happy to be here – and me too.

### **17th June 2018**

What an epic day yesterday! James completed "The Wall" in a tremendous run along Hadrian's Wall from Carlisle to Newcastle. Took him 18 hours' solid running and raised over £4,000 for MND. I swear the efforts my kids have put in to fight this is so great that, if there was justice, I would be free of it. He is an inspiration and if he can go on, so can I.

Have been beset by gallons of [saliva] in my throat. Needing suction almost hourly if not constantly. Was at Garson's Farm and decided to buy a Father's Day card for Hugh. So sent him off to buy herbs. Got the cards and felt that horrible feeling that stuff is building up in your throat. You start gargling your own mucus. But couldn't reach the machine which was hanging on the back of the wheelchair. Raced to the herbs. Starting to panic. Saw Hugh. Made the gesture my whole family and carers have come to know as needing suction machine (to the uninitiated, looks decidedly rude). He quickly got me the tube and turned it on. I hid behind some plant pots. I swear the noises emanating from the pots must have sounded something from *The Day of the Triffids*. I was willing no unsuspecting shopper to saunter in my direction. The kids say I shouldn't worry what people think. I used to walk these floors regularly buying all sorts of things. Now I wheel myself along stooped (because it's hard to hold myself up) and silent. Trying to control the drool – kitchen towel roll at the ready. Fumbling and trying not to choke or something else awful. It was a hard time going there.

### **19th June 2018**

Our usual Tuesday night dinner with James and Eva. Helly couldn't make it as got stuck in London, but we made the all-time favourite chicken pastry dish which Eva liked after some coercion. I knew she would love the pastry once she tried it. Her talking is coming on tremendously. She calls Truffle "Arfarf", which I totally get. It's the 'f's. So then she asks for an apple and points to it on the table. It comes out "ah pull" and for some bizarre reason everyone thinks she's saying "Truffle" when it is so clear she's asking for an apple. She even points to it. How she puts up with these dumb adults I don't know. Then they say to her "Do you want a strawberry?" Then

they start talking to each other and she says “strawberry” really clearly but they don’t hear it! Argh. I try to gesticulate to them that she said it but of course I’m useless. Anyway James says again “Do you want a strawberry?” when she had already quite clearly indicated she did. Then she says it again and Hugh and James exclaim “She said strawberry!!” when in fact, as with “apple”, she was totally in control of the situation and they needed to just get with the programme.

Anyway, how wonderful to see my heroic son after his “Rat Packs” achievement conquering Hadrian’s Wall. Now he says he intends to settle down for Wodgie No 2. Yes! Eva is going to have a little baby brother or sister! What epic news – they are such great parents. And I FULLY INTEND staying round long enough to get to know and love the new addition as much as I love Eva (if that is possible). God willing.

Another plus today was that I managed to use the chicken pastry to entice Jazzy home so she should be here soon! Didn’t work on Just sadly.

### **25th June 2018**

A close friend who was reading Book 2 remarked that it was so interesting to read but why hadn’t I put more of my angst-ridden thoughts into it. Wasn’t a diary where you wrote dark thoughts to “get them out” – like a kind of therapy? But I found this diary has served three purposes and, in that way, it is not a conventional diary. Firstly, and foremostly, as I wrote at the beginning, it’s for my children to remember me by. And so dark thoughts are not appropriate. But also, I use it was a way of communicating. So, because I can’t talk and typing is tiring, if someone says “how was your holiday?”, or I want to just tell people things, I will point to certain pages. Finally, it is a form of therapy, but I don’t want to dwell on dark thoughts. I don’t want to “vent”.

I had never experienced a panic attack before. People told me about them, but I never understood and thought it was feeling afraid. But I get them so easily now and believe me, it is much worse than that. For me it is sheer and utter hell. Firstly, heat, you feel you are on fire. Then tears, and then you can’t breathe and your heart races – thumping your chest like a jack hammer – but the worst is by far the suffocation. Until you take that breath. All the while thinking “is this it?” Heart attack...

I had an attack the other day when one of my carers said she wasn’t sure she could stay because the contract we drew up wasn’t what she wanted and was upset.

Hugh wasn’t [aware] that she was thinking of leaving – obviously that would be sad, but people have lives and I do realise that it is not all about me. It was that we had upset her and that she hand’t realised she just needed to talk to us. In fact, it was a complete misunderstanding and sorted very quickly.

Panic attacks happen so easily when I dwell on the future or think about possible negative scenarios. So venting is not for me. Seeing the funny or ironic side of things

helps. But of course when you are deeply frustrated, in pain or fatigued, it's hard to see the funny side. In fact, it is profoundly unfunny and my joking and out-and-out laughter is far less these days (although family and close friends can bring it out).

STOP PRESS – SIGHTING – red-headed woodpecker on feeder! And visits from Surrey parrots yesterday evening.

**26th June 2018**

SIGHTING, 6pm: loads of goldfinches and Surrey parrots

Ruby is so excellent caring for me, particularly at night. She seems so awake at 3 or 4am when I call. So much so that I asked her what her secret was, "Ah" she says, "That's my training as a guerrilla soldier in the Rhodesian war". She then related a true story in which she feels God interceded or she would not be here today.

As a rebel fighter life was hard. Her group went from village to village relying on food and clothes from sympathisers. But the food was often poisoned by the Rhodesian soldiers and the clothes treated with some chemical that would burn the skin. Tired and hungry, her group decided to rest in a huge tree. The safest place. Unfortunately, a band of Rhodesian soldiers pitched their tents beneath the very same tree. Three days and three nights followed. No one daring to breathe or make a sound. Not able to sleep, eat (or do anything) because they knew if they were discovered it would be the end of them. On the third day they were near despair – of course soldiers never leave their tents unguarded. On the morning of the fourth day a HUGE black mamba slid out of the very tree they were hiding in and raced through the soldiers' camp. Causing havoc, the soldiers ran in all directions – leaving their food, clothes and ammo beneath. Ruby and her group climbed down and grabbed everything and enjoyed the first good meal in weeks – they knew there wasn't any danger of being poisoned.

At the time she and her comrades thought the snake was the spirit of their ancestors sent to protect them. Now she attests it was God saving her life for a purpose.

When she gets het up by little things, she remembers her time as a soldier and realises these little things are inconsequential in the bigger picture.

I also have discovered little things don't matter and often remind my family that in the bigger picture – little things are *just that*.

I write like it's quite commonplace be looked after by an ex-guerilla fighter. But I have come to see my life as so bizarre, anything is possible. I love her different views and life experiences. Although from completely different cultures, we are the same in so many ways and she is becoming a sister to me.



The same with my other carer, Suresha. I love the smell of her wonderful curries as the spices fill the house. I love hearing about her two daughters and her times at Temple.

Surrey parrots visited this afternoon – they are now a regular occurrence. I am surrounded by colourful talkative immigrants!

As I am one myself, I feel very much at home (although not so talkative these days.)

### **1st July 2018**

I have suffered so much with reflux. It has added to my misery because of the gallons of mucus that assail me – compounded by the disease causing my inability to swallow and general weakness in my throat muscles. It was not the doctors who realised it was reflux, not the plethora of specialists. They all said it was “secretions” (what a word) but although trying to treat, had not established the cure. It was Hugh who ventured to ask at one of the consultations “could it be reflux?”. “Indeed, it could,” was the reply. There followed an adjustment of medication, the result of which confirmed that was the cause.

However, what also became clear was that medication loses its effect after a while. So back to square one on triple doses.

However, my dear husband then came up with the suggestion that, although I clearly have an intolerance for the rich formula, could it also be the night feeds causing the reflux? We set up the machine to drip feed slowly every night, but the fact is I do sleep flat or only a bit elevated. Night feed abandoned and the result is much less gunge. I do hope this works

### **4th July 2018**

Fun times walking with Mcleods and Hollises at the Devil’s Punchbowl, just like old times, except me in wheelchair stopping every now and then for suction. Ruby in hand. Before going back to Mcleods for lunch I thought I would avail myself of the disabled facilities at the tea rooms. WHO MAKES THESE PLACES??! Clearly no one disabled (or seriously so). With effort got onto the loo seat. But so low couldn’t get off. Ruby with me, even she battled. Thought, “This is interesting.” With a bit of manhandling she finally managed to lever me onto the wheelchair. But that type of exercise not good as could so easily twist something or inadvertently pull out the PEG.

Lovely Pouilly Fuisse at Mcleods. Had too much. Felt great!

But most of night had to use suction as I think it contributed to reflux. Don’t care. Was good to feel normal for a brief time.

### **5th July 2018**

Well, they say we're in for a summer like 1976. That was our first summer here and I thought "English weather is great in the summer. We can live here." So we settled down. It took me a few years to realise a summer like that wasn't coming back anytime soon. By then firmly established. But I love England ... despite the weather.

### 9th July 2018

Daughter had the foresight to apply for wheelchair tickets for Wimbledon in April and we got two for today. Best seats in the house. I have been going to Wimbledon for years and with the ballot club tickets have always ended up in the rafters. The players little pinpricks – miles away. These seats were fabulous, and Jazzy and I enjoyed ourselves immensely. Jazzy provided wonderful entertainment – shouting and cheering like a banshee. Getting chatted up by the security guard (Lewis) without even realising it (Lewis coming and looking for us (her) after the match.

Two great matches – the first one a South African, Kevin Anderson against Gael Monfils, a Frenchman. We rooted for the underdog all the way. Kevin won, being the stronger player. And when he took his shirt off we both felt he deserved to win.

The second match was more cut and dried as it was the seasoned Djokovic against a Russian so nondescript. I can't even remember his name although Jazzy was shouting it often enough. And despite the fact the wiry little devil cheated on his wife (at least that is what Lewis said) it is always great to see this magnificent player in action. Of course he annihilated no name in three straight sets.

What a superb day. Thank you darling.



### **10th July 2018**

Slept for eight hours with the BiPAP Machine – that’s NEVER happened! RESULT!

### **12th July 2018**

First-born’s birthday – what a whirlwind of change he brought to our lives 34 years ago. And he’s grown up to be the sort of son every mother would want.

A feast is being prepared. Four sea bass we will cook the Chinese style with ginger and spring onions. Pak choi with oriental mushrooms, ginger garlic chicken, Japanese salad and Chinese noodles with prawns. Ruby has made a beautiful cake with a picture of the three kids on the front.

I think Suresha and I will have lots of fun in the kitchen today. Hugh has promised to do the fish which he always does with great panache.

### **13th July 2018**

Dinner was a great success. For posterity, ‘Pak choi with Mushrooms’ is below:

#### *Pak choi with mushrooms (recipe)*

- Wash pak choi and set aside.
- Chop spring onion and garlic together
- In a separate bowl combine oyster sauce and soy (2 to 1), 1 tablespoon of dark brown sugar, a teaspoonful of cornflour and salt. Mix cornflour first with a few teaspoons of water, then mix with other liquids.
- Boil pak choi for two minutes and arrange on a serving platter. Throw onions and garlic together in a wok – fry.
- Then add loads of different mushrooms. I used shiitake, porcini, oyster, and fry until tender.
- Add sauce and wait for it to thicken. N.B. amount of sauce is for 4 small bunches of pak choi. I used much more because there were 12 of us.

### **15th July 2018**

Every morning without fail there are cheery faces that pop their heads round my door and say “How was your night?” They are willing me to say (or signal) “Better”, “Good”. Sadly unless a liar, I almost always have to disappoint them. I hate having to do that but my nights are always a marathon of interrupted sleep – fighting with leg cramps exacerbated by not being able to turn over and choking fits caused by reflux. I am always tired too. The effort to get dressed so exhausting I often go back to bed afterwards. What sort of life is this? I am always anxious. Anxious about what I have to do in the day – will I be able to get the most out of my time with the

kids? Turning down invites and not replying to friends because I can't face the effort to converse. Because typing is so hard now, as is writing. I feel I'm letting people down. I feel so sad for them because I see how desperate they are to see me keep going. It warms my heart and makes me want to TRY SO HARD. But I have never known such weakness and fatigue.

**17th July 2018**

Beautiful Eva's birthday! Can't wait to see her this evening.

A good day in the woods with Marie. We took the path we used to do often. We would walk the gauntlet sorting out each-other's and sometimes the world's problems. Many an issue aired and solutions found. This time not much talking but wonderful all the same. Powerchair behaved admirably negotiating the ruts and bumps with ease. A few sticky patches where the chair would veer off course into brambles or nettles, but it's the path we used to cycle so doable on wheels.

**18th July 2018**

*Mirror, Mirror*

*Mirror mirror on the wall  
Who used to be my friend  
Show me that person long ago  
Who still resides within.  
Gaunt face, head bowed  
Eye tired and wary,  
Who is this furtive stranger  
Whose burden I will carry?*

*A fleeting glance as I wheel by  
I turn and face you  
Lift up my eyes.  
I raise my chin as if to say  
'Do your worst, come what may'.*

*But mirror mirror on the wall  
I implore you to be kind  
And in the image you deem to show  
Reflect the person who lies behind.*

**19th July 2018**

You would think that going to the loo in a hospital outpatients department where most of the patients are in wheelchairs would not be a big deal. Right? I mean 'having a tinkle' (described by one nurse) should be a common occurrence and with all the nurses running around, if a problem ensues, easily solved right? WRONG!

As with many disabled toilets, the seats are too low. At home I have the trusty “Molift” – looks like a Segway and allows me to stand up to transfer from one seat to another. So nice to stand up too. Well, they don’t have these in hospital but Ruby and I thought with someone on one side and another on the other, I could be shifted onto the loo. After all, at 115lbs I’m hardly a heavyweight. So, when the need arose, Ruby called a nurse to help. However, the nurse looked positively terrified at the prospect and ran to get her superior. Then ensued a discussion on how this could be done. Finally, they decided a hoist was needed so I was wheeled off to a different loo. This loo had all mod-cons and I could see had adjustable heights but no hoist. As usual, I was a casual onlooker as they attempted to get me onto the loo seat. An hour later, there we were: me seated on the loo with three women looking down at me. Needless to say I could not perform. They left but for some reason tried to operate my wheelchair to remove it – not sure why. Their reasoning escaped me. This meant opening the double doors to the loo to navigate the chair out of the room – leaving me on display to the entire ward while I sat with my head in my hands praying for the gift of invisibility. I was like the ostrich. It was not happening. They returned again and we had the whole scenario in reverse, except, I pointed out I needed to flush. No one knew how to flush the thing. Someone pushed a button and I felt a spray of water squirt up from the bowl and drench my dress. Then I felt hot air. It became sauna-like – no one know how to switch it off. I had the driest ass in Christendom.

Still the problem of how to transfer me back. Finally, Ruby said “take an arm” and they got me on the chair.

The moral of this story is:

1. Machines are useless if people are not trained how to use them.
2. My Molift will be part of my entourage from now on.

Thank God for a strong bladder.

## **22nd July 2018**

Lily, the daughter of my dear friend Ninette, organised an MNDA event which included a screening of her new film, *Mama Mia! Here We Go Again*. She sent such a sweet text asking if I would come to it that I felt I really should. The challenge being that I would have to: sit through the film which for me is not easy without suction, drive to the cinema which was in North London, and be there by 10am!! However, the suction had been easing and so I made the journey and, much to my relief, was able to sit through the whole film without needing suction! Result!!

I had hitherto avoided MNDA events because I’ve been unsure how I’d react to meeting others in the same boat. However there didn’t seem to be many with MND, although the cinema was packed out. There was one woman and it was hard to see

her. Stick thin and bent over in her chair – I thought: “Will that be me soon?” But overall, it was a great event and Lily was such a little trooper selling raffle tickets and doing a Q&A at the end. How she has stayed so grounded and normal is a mystery but a real credit to her. Jamie (her late father) would be so proud of her success but more importantly how she is still so sweet and unassuming. I know Ninette is.

### **23rd July 2018**

Can't believe it but I actually managed to do our cycle route Black Pond ride in the chair! With some pushing over rough patches did the whole 5-mile journey! Truffle in heaven.

### **29th July 2018**

So fragile these days. Carers had arranged to cover each other which meant one working non-stop for 34 hours. When I found out I was furious. It's all very well arranging these things but I'm the one in danger of something happening due to tiredness. So many things could go wrong. I am conscious of how vulnerable I am, dependent on others – it is unnerving. In trying to explain, my face began to crumple – I could feel the panic rising as I tried to grapple with the impact of being without a carer or an exhausted one. Found myself shaking. Jazzy saw what was happening and took control but it made me aware of how my emotions are on a knife edge.

### **5th August 2018**

My inventive husband has really excelled himself this time. We have a plunge pool at the bottom of our garden. But I can no longer climb the steps to get in and out. Knowing how much I love the pool, he researched outside hoists and was unhappy with what he found. So he decided to improvise and got hold of a small industrial crane and cemented it into the pool patio. Then rigged up a sling. In this hot summer, the pool was the best place to be – so, after waiting four days for the cement to dry, I invited two friends over to assist with the initiation: Marie, a bubbly ex-teacher, and Liz, a wry ex-intensive care nurse. The dialogue between the three of them as they attempted to work out how to work the thing was entertaining in itself.

Hugh and Lizzie's conversation has always been forthright as both have strong views and think they know best. Hugh being an ex-senior partner in a management consultancy firm is not used to being questioned.

*Lizzie* - Hugh it's not good to have electricity so near to the water

*Hugh* - It's OK Liz it's a 12 volt battery

*Liz* - Are you sure? Won't that still give you an electric shock?

*Hugh* - Yes, I'm sure.

*Liz* - Hugh you should be in the pool when Suzy is lowered in. One person is not enough.

*Hugh* - Marie can hold her.

*Marie* (tactfully) - I'll wait for you to get in before we remove the sling.

Having rigged it all up they thought I would just agree to get in. But I have a policy to never try anything until I have seen it work on other able-bodied friends or family. Particularly new inventions. So Lizzie gamely became the guinea pig, or as Marie called it "the victim", and was strapped in. "All my weight is going to be held by that bit of velcro," she said doubtfully. As the sling ascended, there was some discussion as to how it should be lowered into the pool. As Lizzie remained suspended over the pool, they debated the point – a comical sight.

"Oow it's cold!", she screamed as she was lowered in.  
"Actually it's fine", she relented.

She was then hoisted back up for them to work out how to undo the sling once again on terra firmer.

"Well, that was great! So easy to get you in and out!"

Praise indeed from my down to earth friend. And she is right, a feat of engineering that has meant I have been able to float about (with someone holding me up and buoyancy aids), kick, and even walk in the water. Such a great feeling.

*Pied Beauty*  
by G. M. Hopkins

*Glory be to God for dappled things –  
For skies of couple-colour as a brinded cow;  
For rose-moles all in stipple upon trout that swim;  
Fresh-firecoal chestnut-falls; finches' wings;  
Landscape plotted and pieced – fold, fallow, and plough;  
And all trades, their gear and tackle and trim.*

*All things counter, original, spare, strange;  
Whatever is fickle, freckled (who knows how?)  
With swift, slow; sweet, sour; adazzle, dim;  
He fathers-forth whose beauty is past change:  
Praise him.*

**9th August 2018**

As I sit in my room listening to music and watching the myriads of birds vie and swoop to feast on feeders full of goodies we have prepared for them, it's hard to believe I could be so low as I have been the past few days. Beset by gallons of mucus so I could hardly breathe. Leg cramps at night resulting in interrupted sleep – the exhaustion was so severe I thought I couldn't go on. It began three days before with

a cough that would not allow me to catch a breath. I began to panic as I tried in vain to sit forward in my wheelchair. With each short breath, another series of hacks, the like of which I had not known up to this point. Then copious amounts of phlegm that even the trusty machine couldn't suck up fast enough. An evening of misery that left me fatigued and full of fear. Even lorazepam failed to quell my anxiety. Frightened that an incident like that might repeat itself. After three days of drug-fuelled exhaustion as I attempted to numb the pain and foreboding, I decided if this is what my future held for me, I had better book into Dignitas in Switzerland. It would be best for everyone.

But the cough and gunk has subsided and for the last two nights I have had the best sleep (drug free) in months. I have been able to use the BiPAP (non-invasive ventilator with mask) throughout the night and have awoken not feeling like I've been run over by a train. This says to me that these episodes do end. That it's a question of peaks and troughs. And to not give up when you're in a trough but try to remember it is not the only reality. And worst of all, don't make life and death decisions when in a trough!

#### **10th August 2018**

Several months ago, I put together a simple webpage so that friends and family could download my diary books easily. What has my lovely daughter done? Only edited both books and made them look beautiful and then piece de la resistance ... a separate page with six of my old songs from the glory days (well, sort of glory days). James had painstakingly got them remastered with the help of darling Gary and Patrick but we had then come to a halt – not sure what to do with them. Perfect solution have them on the diary website. And all linked to iTunes and Spotify. Thank you my darling girl.

#### **11th August 2018**

It's amazing how long nail polish lasts when you don't use your hands. The right hand is pristine, the left a few small chips. Sadly, the right is pretty much useless now but I am still writing with my left hand. However very slowly, and I have to hold the pen in an odd way. Time to get the eyegaze guy in sadly. Can still type with my left, and hope this will last but better learn the eyegaze to be prepared. N.B. Eyegaze is software for tracking letters and words selected by eye to make sentences that can be spoken. It is the same software I currently use for typing text to speech.

#### **17th August 2018**

Fun and games at the NHNN where I was asked to come in for an overnight assessment. They want to see how the BiPAP is working and deduce whether I need a cough assist machine to help clear my throat. Having my own side room ensured I was spared the noise of a busy ward. Being a specialist hospital for very complex needs, the equipment is state of the art, including a loo that raises and lowers and



self-cleans. Hugh decided to use the loo and was gone a while. We heard a lot of splashing and Hugh emerged and then said he needed to go to “beat the traffic”. I said why not stay until the after the traffic and he conceded that his underpants were soaked through as he had attempted to use the self-clean system. Suresha also got baptised by the toilet which seemed designed to do everything other than what it was supposed to do.

The hospital determined that the cough assist machine wouldn't help me because my thick secretions are in my throat, not my chest. CO2 level significantly raised which is a real blow as I had thought, having got used to using the BiPAP all night, that if anything, the level would be lower. Sadly it appears my breathing is becoming less and less efficient. So I am trying to use the BiPAP during the day for a few hours. Not easy as I am still drowning in mucus! Yuck.

### **22nd August 2018**

Jazzy and Douglas have now arrived in LA. I sent them on a mission to establish how my ageing parents are coping, having had to be moved to a nursing home. It wrenches my heart not to be able to be there but Jazzy will feed back to me what is happening with regard to them. It's not the right way around – me not being able to look after my parents. Feels so wrong. But Jazzy going feels right. Thank God for her.

Sighting – Nuthatch.

### **3rd September 2018**

It has been a while since I've written anything. Dealing with mixed emotions. Everything from sadness at not being in a position to go and sort out my parent's transition. Taken from their free existence in their own home to living in a little room in a care home with little help. Hallways smelling of piss and being occupied by dementia patients, bed pan by their bed (how do they do that?). No bath or shower for two weeks. They have always been scrupulous about their appearance – this must be killing them. My mother has rejected invitations to be washed. I totally understand that. I have had the privilege of getting to know my carers with a gradual introduction to what is expected of them ... eventually. By the time we got the 'bare all' scenario, we had formed a trusting relationship. Now when Suresha is bathing me, I let her scrub me down and enjoy the fantasy that I'm an Egyptian princess being bathed by her handmaiden. However, the amount of soap and scrubbing undertaken is synonymous with a manual worker doing hard labour rather than an Egyptian princess. But I do come out squeaky clean.

Jazzy was described as a 'tornado' the way she arrived on the scene and tried to help remedy the problems. She brought pictures and some of their things (they had arrived with nothing). She even researched other homes, not quite realising that Sarah, a close personal friend, had painstakingly done it already. But she put the cat among the pigeons by being forthright in giving her opinion of the home and the result was

that on her last visit things had improved. She is surely my mother's grandchild who also has never shirked from saying what was on her mind. Indeed, Jazzy reiterated my 94 year old mother's comments on seeing her. She had been told my mother had more or less lost the plot so was not expecting the ensuing conversation. On being introduced to Jazzy's boyfriend...

"Grandma this is Douglas"

"Oh really?" (*casting a very suspicious look over in his direction*) "Is he ten years older than you?"

"No five years younger"

"Oh well (*grinning*) that's not so bad. (Her fourth husband was 20 years her junior).

And on a repeat visit:

*Grandma*: "Where's the boyfriend today?"

*Grandpa*: "He's right there honey next to me"

*Grandma*: (Undeterred by this) "Are you gonna marry him?"

*Jazzy*: "I think so"

*Grandma*: "Oh that's nice. (To Grandpa) I'm sure she knows what she wants. (To Jazzy) I'd like to be there."

You and me both Mum!!

So, Jazzy and Douglas returned with items my parents had in the house. Pictures of me and her that I have always loved and some ornaments. They seem out of place here and signify the end of an era. How sad that I will never see them again – very hard to write that.

### **12th September 2018**

There is something very traumatic about watching and feeling your body shrink and bend. Swellings at joints, skeletal hands and forearms. Dominant hand now stiffening and fingers beginning to bend. Dropping things, not able to do simple tasks. Losing independence. Cannot transfer without help. At times everything uncomfortable. This is where it gets really hard, particularly as I can't tell people what I want or need easily. Suresha seems to know, instinctively pre-empting my requests. But this weakness is leading to a faintness of heart. Panics in the evening soothed by lorazepam. A reluctance to "go to bed" knowing I will be cruelly awakened every two hours either by coughing, or leg pains. Watching the clock till 6am when I can ask for porridge or just to sit up from the night carer. My world shrinks along with my body. My big heart tested for endurance as I struggle with the fear that makes me breathless or is it the other way around? The breathlessness causes the fear? Whatever, it's real and it's scary.

### **17th September 2018**

Been looking through old black and white photos Jazzy brought back from the States. So many of my brother who was estranged from us. Michael had a lot to contend

with having been the son of husband number 1. He went through a further three – my father being number 3. But the love of her life was definitely number 4. A big giant with a heart of gold, 20 years her junior.

**21st September 2018**

*Dignity Takes a Battering*

I will not go on about the indignities one has to suffer as your hands become useless. The reader must use their imagination and I confirm: “Yes, even that”.

My poor dear parents are suffering similar fates. Odd that we should all be grappling with the lowest level of survival from lives that focused on lofty ambitions for the world – reduced to needing help with the daily essentials – keeping clean, fed and watered.

I am not brave. People say I am amazing but that’s because they see a side of me that appears to be OK. They don’t witness the person inside who’s crumpled in a heap at the bottom of my heart. Continually asking myself ‘why?’. Veering between conversations with God and a rebellious atheism. Looking for answers from anyone I meet but encountering either stock phrases that dissolve when examined, and the honest “I don’t know” which throws into sharp relief our vulnerability in the face of the unknown.

This disease is unbelievably nasty the way it robs you. You lose one ability like walking and come to terms with it. You think, ‘OK, I can do this’. Then your right hand starts to curl and weaken. You work out left-handed methods for doing things. Then the other hand starts to go. Pushing buttons hit or miss.

**29th September 2018**

*My Birthday Adventure*

What a momentous day – the Saturday before my birthday. The whole family off to Woburn Safari Park. Any trip now a military operation. Suction machine, BiPAP, molift in tow, we ventured forth for a two-hour drive. I used the BiPAP on the journey to keep energy levels up. Suresha there for food and meds as well as everything else. What a show we were presented with. Big black bears. One perched high in a tree a master of all he surveys. Naughty monkeys all over the cars – clowning around. Tigers, lions, wolves, giraffes. What a wonderful array of animals – everyone in good spirits. Not like our African safari obviously but the animals seemed to be well cared for in large areas to roam. My favourite? The meerkats! I have seen them on TV but never in real life. Such comical little creatures, standing to attention on the lookout. And what teamwork! I could have watched them for hours.

**1st October 2018**

Lovely presents from family. Personal and thoughtful. Beautiful books from Jazzy. A telescope from Jazzy and Douglas so I can do videos of the birds in the garden. Bath oils from Just and Christina— Neal's Yard no less. A frame for Truffle picture – perfect. And gloriously comfy pyjamas from James and Helen. Today, friends turned up with gifts and flowers. Wonderful poncho from Suresha.

### **3rd October 2018**

First suction-free night in ages. What a difference it makes to get a decent night's sleep. But have to admit energy levels very low. Just moving my arms takes tremendous effort. Writing is not easy as this script shows. The fact that I'm so puffed doing anything is scary. You'd think that having had all that sleep I'd be up for anything but on the contrary I'm really battling to move. Still the relief from not having to suction is great.

### **\*[Date unknown] 2018**

I have not written for a long time because I have been challenged just to survive. A lot.

### **\*4th November 2018**

A new phase which centres on the BiPAP as a central player in keeping me alive. My left hand weak but still able to hold this pen. Kept wanting to write to record my thoughts and progress but so tired it's been hard to write. Haven't wanted to see anyone because my old life now dead and gone. House has two new carers for round-the-clock care. Now have to hoist to get out of bed for the loo or anything.

I know having a sense of humour is important but far harder to have with this level of disability.

\*(These were Suzy's final *handwritten* entries, both in a very fragile hand.)

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*The following entries were written by Suzy via eyegaze technology.*

### **29th January 2019**

No entry until now. And a very different entry using eyegaze to write. October and November were very cruel. Everything conspired against me. Each sign of progression harder to bear. Breathlessness forcing me to use the BiPAP 24/7. Needing to be hoisted to loo or wheelchair as I can no longer support my weight. Severe loss of independence. Useless hands so can no longer write, operate wheelchair, or phone.

Didn't want to see anyone and everyone was worried I no longer texted. They started calling Hugh and he relayed messages that my friends wanted to see me. But to me they weren't seeing me but a pathetic broken woman. The mask I have to wear distorting my face, my stomach distended from peg use. Stick thin legs and arms. Involuntary noises, sighings, and violent yawning. My kids still saw me as mum and Christmas revived my spirits as I organised the lunch which Justy cooked with great success. Jazzy bought a tree for my room and we had our usual eleven foot tree decorated from a collection of ornaments I accumulated over the past 30 years.

### **22nd February 2019**

One of my closest friends rang Hugh to find out how I was -alarmed that texts had stopped. I just didn't feel I was the same person. I relented for her to visit because she was so close to me. A friend of many years standing. As soon as I saw her face, the concern, the tearful relief I realised how much she meant to me and I her. That my situation had not changed that.

### **2nd March 2019**

I rallied in January. With the help of my family. Things are different now. I spend most of the time in bed. Preparations to go out with all the paraphernalia I need are exhausting. Bridge games are fun with the kids but most of my time I spend watching TV, listening to audio books, and writing this diary.

### **8th March 2019**

I now have conversations with myself. Little quips I always voice resound in my head. I do amuse myself. But it's sad that I rarely enter into conversations anymore. People are slowly learning to wait for my comments and not be afraid of silence. Everyone has to chill when they see me and slow down. Master of the quick repartee no more. I often respond to questions or comments only to find the dialogue has moved on and no one knows what I'm talking about. Puzzled expressions not wanting to let on they worry I'm talking nonsense me worrying at their inability to connect the dots.

### **15th March 2019**

So tired my days largely spent in bed desperately trying to get comfortable. Alternating between suction to remove the thick secretions in my throat and masks with weak seals that belch and fart. It is hard to have a sense of humour in these circumstances but the family and carers do well in keeping my spirits up. And if the pain is too great there is always trusty lorazepam to take the edge off and blessed sleep. Where I am always my old self, having parties, eating and talking.

### **23rd March 2019**

I have never had anything to do with the disabled. I never had elderly grandparents or people in my family who were disabled. Maybe what has happened to me would have been a shock for me anyway but I have not had a point of reference on which to draw. Disability is so alien to me. I'm not proud of that just being honest. The diagnosis hit me like a sledgehammer and with each new manifestation another knock. Now I mostly live in my bed. It is the most comfortable place to be. Every now and then hoisted to the loo or wheelchair. BiPAP connected to me always. Fighting with the mask which I have a love hate relationship with. Suction machine always within reach. Two carers always available. Privacy abandoned. Neck unable support my head so sitting up not an option. Hands useless. Eyegaze my only way of communicating. Thank God for technology.

### **27th March 2019**

Up till now, my diary has recorded things I've done with my family. Some amusing anecdotes along with coping with this disease. Times that were bittersweet. But being so tired and consequently spending so much time sleeping and listening to music, I have all but abandoned this diary. Unsure how much I could write with eyegaze. But I am finding I'm a real pro at using it. Another talent to add to the list. Also small pleasures that before were pretty much taken for granted mean a lot. Sensations heightened. The smell of coffee still entices. Lips being wet with a teaspoon of hot chocolate. Jazzy took me to a farm shop towing BiPAP and suction machine. What a mission to take me anywhere now. We raided the farm shop and got wonderful cheese and antipasti. I enjoyed myself immensely even though not a morsel will pass my lips. I remembered they sold root beer. We bought six cans. I just had a teaspoon in my mouth. Wow! How it took me back to my Californian roots. What a taste.

### **31st March 2019**

Had a wonderful poker game with the troops. Dieter doing his usual sob stories about not having the cards. However, unlike previous sessions he didn't clean up at the end. I was blessed with good cards and on one hand reeled him with a full house. He had 3 queens and so kept on going. I didn't raise too much because I didn't want to scare him off. I love it when a plan comes together

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*Suzy's diary entries from April 2019 until now were lost by her eye-gaze technology when it was updated. She has done her best to reconstruct them, below:*

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I have used eyegaze to write this diary ever since the loss of my hands in January 2019. A blow that defined me as needing help every day. Little things you take for granted like pressing the call button and scratching! I had developed a rash to the medication and it's excruciating when you can't scratch. Every little thing has now

have to be done for me. If the eyegaze doesn't work I am cut off. There is a alphabet board that I can use but most of the carers can't get the hang of it. It's very slow compared to the eyegaze. But the eyegaze is sensitive to light so it doesn't work outside. So we try to use the board. Anyway I had various entries in this diary from April 2019 to December. But during an update the stupid software lost them all. I was so disheartened I stopped writing. But my lovely daughter rescued me. She told me I shouldn't stop writing and helped me get going again. So the following is a synopsis of the highs and lows of 2019.

## **May 2019**

### *To Trach or Not to Trach*

I visited the hospital where they had given me the non-invasive mask and ventilation machine. Which I used at night. Increasingly I found I needed it the day as well. That horrid mask. The doctor was shocked at my progression. I asked for a prognosis. He said everyone was different. I persisted. I wanted to know what I was dealing with. He said in his experience three to six months. I wheeled myself out of his office shocked to the core. The mask was uncomfortable. I had to suction constantly. It filled up with saliva. I remember Eva called me bubbles. She was wary of this person with the mask. I felt like Darth Vader. When I took the mask off I was shocked at my appearance. The mask had added lines and deformed my face. With that prognosis I thought about a tracheostomy. Major throat surgery where they cut a hole in your neck and attach a ventilator to it bypassing your mouth and nose to breathe. The consultant advised against it. The family researched it and found positive stories about it from America where it seems common practice for MND patients. I felt I didn't want to live like this. I still had my smile but it was useless behind the mask. So I decided to go ahead with the operation. If it didn't go well, so be it.

## **June 2019**

### *Joaquín Sorolla Exhibition*

Went to the Sorolla exhibition at the National Gallery with Jazzy: 'Sorolla: Spanish Master of Light'. Absolutely stunning, huge artworks towering over you. I loved looking up at them. I bought me and Jazzy pillows of 'Sewing the Sail' (1896) in the gift shop and a print of one of my other favourites.



Joaquín Sorolla, 'The Return from Fishing', 1894, © Musée d'Orsay, Dist. RMN-Grand Palais / Patrice Schmidt

### *The Operation*

I awoke breathing without the mask! What a relief. I thought whatever happens this is worth it. I could communicate with a smile and felt free. I spent two weeks in a high dependency ward. With strange bedfellows. Opposite was a woman who had MND. She just stared into space. Clearly terrified. It was a bit off putting but I felt for her. The other was a drug dealer called Jerome. Who had a wealth of followers. Collecting and delivering packages. He used to disappear to the toilet and Ruby said there was a distinct smell of hash. I don't blame him if I could get to the toilet and stick my head out of the window and have a good long drag. But I haven't got any lung power to do that. I thought of ingesting it through the PEG but I have found lorazepam works just as well. Maybe I should have told Jerome. The one thing I found extremely irritating about Jerome was that the nurses had found him a TV. And he had it loud day and night. It was his choice of programmes. Game shows and cheap soaps with lots of adverts. I got weary of advice of the best toilet paper or adverts for funeral insurance to ease the distress of your loved ones when your time comes.

### *Recovery*

I couldn't do without my lovely carers during that time in hospital. I was hooked up to a monitor that measured oxygen saturation levels. 93% was considered to be borderline. I noticed I was breathless. Then my oxygen began to plummet. There was no nurse in the room. The alarms were blaring. The last I remember was hearing Ruby running down the hall crying "help us!". Then I heard Ruby praying. And people



urging me to wake up. It appears I had a reaction to the antibiotic that was given to me through a nebuliser. As soon as they took it off, I began to recover. Apparently my saturation went down to 40%. This figure was confirmed by the nurses. Ruby's quick action saved my life, for which I am extremely grateful to her.

## **July 2019**

From July to September I was trying to get used to the trach. The stoma was raw and sore. Debbie kept coming from the hospital to try another trach. A lively effervescent woman, she always makes me laugh even as she's replacing a great tube in a hole in my neck. I can't pretend that it wasn't agony, but it was shortlived. Jazzy organised tickets to plays and art galleries. I had always wanted to see the stage version of War Horse. And it did not disappoint.

### ***Cornwall***

We usually go on holiday abroad and Portugal is our favourite destination. But with the tracheostomy, no airline would take us. And we haven't the cash for a private jet. So Jazzy looked at options in this country. I had never been to Cornwall. I wanted to go somewhere I'd never been. So Jazzy researched accessible places in Cornwall and found this amazing old house by the sea and a little cottage nearby for James, Helen and Eva. The whole family drove in convoy after dropping me off in with two carers at Reading to take the train. The train was far more comfortable than driving for me. We arrived to glorious weather. James and Eva immediately went down to the beach. Where Eva, an adventurous two-year-old, announced she wanted to go swimming. James reasoned with her that they would have to go up to the house and perhaps it was too late. By this time she was halfway to the water shedding her clothes as she went. James had no choice but to go swimming fully clothed as he rushed in after her. They had a great time and that was the start of a stupendous family holiday. The property was called Bosloe House, built in 1903, with views across rolling lawns and the Helford River. You can amble right down to the sea in 5 minutes along the wooded coastal path. Sunny Durgan beach, where James and Helen stayed, was just a few minutes' from the house, and Falmouth was 10 miles away. We spent our days outside in the magnificent gardens or down by the sea at a little pub, where we would while away the hours in the sunshine.

We had amazing family holidays during my illness. Before the kids wanted to holiday with their friends. The stark realisation of what this dreadful disease can do has shocked us all to the core. It has helped us appreciate what matters to us when one of us is slowly being taken away. I am grateful that it is me, who has lived my life, and not one of the others. But my family has shown me that there is still a lot to live for.

## **October 2019**

### ***Birthday***

I have always exploited my illness. Using accessibility shops. Having discounted tickets etc. This extends to my husband as well. I have always wanted chickens. Hugh was not so keen because they tend to wreck the lawn. Now that I live downstairs with a view of the garden I asked for chickens for my birthday. How could he refuse?

### *The Chickens*

The kids entered the project with gusto. On my birthday providing four beautiful bantams eight weeks old. And Hugh providing an igloo house with pen. I love them. They create a great deal of entertainment. Although the African carers initially couldn't understand it and were convinced they were destined for the cooking pot. They even offered to do the honours. We named them after Hugh's aunts: Mavis, Elma, Dolci, and Hugh's mother Verna. This was too much for the Africans. But they have learned to love them. Although Ruby joked she is like a python: entices them, and then pounces.

And it's true they have wrecked the lawn.



### **BATH!**

I always had had a hot bath every night before the illness. Since I cannot get in the tub anymore, I have been reduced to showers in a commode chair. How I missed my daily ritual. The NHS said it was too dangerous because of needing to be hooked up to a ventilator. But I was persistent, and on my birthday I got given a bath hoist. I no longer have showers but just soak in a luxurious bath. It is heaven. A fabulous present

by my darling husband who has stayed by me. Next birthday I'm going to ask for diamond earrings...

## **November 2019**

### ***War Horse***

Hugh was driving and Belinda and I were in the back. He was getting irate because of London traffic and we were late. It is always a mission for me to go anywhere. A whole lot of paraphernalia has to be taken with me. Two ventilators. A suction machine. Various assortments of drugs and syringes. And me hoisted into the wheelchair. We are always late for everything. None of us can believe how long it takes for me and all my clobber to be organised. On this occasion we were very late. After an hour's drive Hugh pulls over and Bel and I thought we were there. She got out of the car. Hugh consulted Waze, put the car into gear and sped off. I remember Bel frantically trying to get back in. She failed and I saw her in the rear-view mirror standing in the middle of the road, a disbelieving look on her face as we receded into the distance. I was frantically trying to tell Hugh through the eyegaze that Bel was no longer with us. I sounded the alarm on my eyegaze over and over again. Hugh said 'Belinda, see what is happening with Suzy'. We turned a corner. I thought we'd lost her for sure. I typed the words 'she's not here' with difficulty and pressed the speech button. He looked round and saw the empty seat. 'What the fuck', he said, and pulled into a pub forecourt. 'Where is she?' he shouted. As if by magic, Belinda reappeared. She had been chasing the car running down the middle of the road. She got back into the car gasping for breath. I have never laughed so much. Needless to say we arrived late and we were hustled in to my disabled seat, which was totally unsuitable with a metal railing which obscured my view. We left. But I still maintain the journey was worth it.

## **December 2019**

### ***The Tale of the Fish Head***

I have experienced different cultures through my carers. Which have enriched my life. Suresha is an animal lover. But if there is a fly in my room she shoos it out. Same with spiders. On the other hand Ruby has the African view towards lower life forms and kills insects dead. I tend to favour Ruby's treatment of insects. But Truffle has stolen Ruby's heart. When Truffle used to sit at her feet, she used to resist the urge to kick her out of the way. But she soon realised how Truffle was a comfort to the whole family. She now loves Truffle.

On New Year's Eve, we had a big whole salmon. I am always mindful of the carers getting their portion. They often are tending to me during dinner. And so miss out on the big dish up. I asked Suresha if she had got her dinner. And she explained that she was having the fish head. I was incredulous. Why would you want the disgusting head? I said she had better ensure it doesn't get thrown away. She had already put it in the fridge. I asked Ruby if she had had a sufficient meal. And she said she was

going to have the fish head. I saw a fight coming. They were both adamant. I saw a solution. It was Ruby's birthday the day before, so I told Suresha Ruby should have it. She agreed reluctantly. Crisis averted.

### *Christmas*

Christmas was a time when everyone was here. I don't think they realise how they lift my spirits. I remember visiting my Mum in California. My stepfather always said she was not too great. But when I arrived, she seemed fine. Animated and talkative. I now understand. Whenever my kids come, which is often, I rally. I feel different. More like my old self. Instead of Hugh and I doing everything, they got together and contributed dishes. Christmas Eve was the usual oyster stew. Perfectly done by Justy. We had two trees: one in my room and the usual eleven-footer in the lounge. It was a tremendous time coupled by the fact that Jazzy and Douglas announced their engagement with a stunning ring. They are made for each other.

### **January 2020**

#### *A&E*

January was a cruel month for me. I was having trouble with my trach tube, which was painful. Debbie came and put in a softer one which was so much better. But I began to suffer bouts of plummeting of oxygenation stats and a raising of my heart rate to over 100. It was scary. Breathlessness and A heart pumping through my chest. Hugh called an ambulance. Four paramedics arrived and debated amongst themselves. How many paramedics does it take to change a lightbulb? I would say at least four. Meanwhile, symptoms had subsided. I eventually went to A&E at Kingston, Where I was monitored and discharged. I was thrilled to get out of there. I was concerned that being in hospital would expose me to viruses and germs. I am much more happy at home. A week later? Check. It happened again.

I couldn't breathe. The only thing that alleviated the lack of air was the cough assist machine. A machine which forces air into your lungs dispersing mucus. I used it every other day. But now I needed it permanently to keep me breathing and I used it all the way in the ambulance to the hospital. On arrival at A&E, the following is a series of events as I can remember. It was truly a nightmare for me.

I had arrived relieved that now I was in the hands of professionals, who would look after me. Little did I know it was far from the case. I have never in all my time been subjected to the absolute torture that was experienced by my visit to A&E on that occasion. From the moment I arrived I had asked for lorazepam which would ease my suffering which I could be given at home. They didn't give a dose for many hours. Making me suffer all that time. My kids were asking them to, but their requests were ignored. I saw the tracheostomy consultant Mr Kumar. Who did a probe of my trach and announced there was nothing wrong with it. I knew he was wrong. The probe

didn't go far enough down. He said he was on call till 6am and if the trouble persisted to call for him. I couldn't set up my eyegaze, so I couldn't communicate.

We were into the early hours. I was repeatedly requesting lorazepam through my carer. I repeatedly requested Mr Kumar. But they said he was gone. I watched a change of shift. A female doctor announced she was in charge and proceeded to ignore me. The whole team ignored me. I concluded they had given up on me. I got some lorazepam finally, but it was a miniscule amount and it was through the PEG rather than the canula which would have caused immediate relief. I was finally transferred to a bed in ICU.

Unbeknownst to me, Jazzy had contacted Debbie and pleaded for her to come to Kingston hospital. As the daylight dawned, I saw Debbie standing over my bed. She put in a new trach and I suddenly was able to breathe! I immediately fell asleep. I later learned that the trach had kinked halfway down. They had indeed written me off and the kids were traumatised by the events. They were forthright in not giving up and would sit with me all night. I know how much they love me during the past three years. They have kept me going.

#### **20<sup>th</sup> March 2020**

Had a wonderful poker game with the troops. Dieter doing his usual sob stories about not having the cards. However, unlike previous sessions he didn't clean up at the end. I was blessed with good cards and on one hand reeled him with a full house. He had 3 queens and so kept on going. I didn't raise too much because I didn't want to scare him off. I love it when a plan comes together.

#### **25th March 2020**

I live a quiet life. My children are self-isolating because of the coronavirus. Lots of videos and FaceTimes. But I spend my days watching *Star Trek* and *Judge Judy*. And listening to classical music. Watching the birds in the garden (the goldfinches are back). And watching my chickens lay their eggs through a live video cam Justy set up for me. They are so entertaining, each with their own characters. Elma is the noisiest. Announcing to the whole street when she's laid an egg. The district nurse watched her laying but had to go. She wasn't disappointed though – she heard Elma halfway down Albany Crescent where she had another patient!

#### **31st March 2020**

##### ***Coronavirus***

An absolutely bizarre virus. Where the government has put the entire country in lockdown. I miss everyone dreadfully. We have conference calls where we try to keep spirits up but it's not the same obviously.

Today I heard that my mother is near death. I spoke to my stepfather who is not well either. They have been together in a nursing home for the past two years. What a sad end to a vibrant lady. She was a religious leader who travelled the world preaching. And then on the strength of a dream went to South-East Asia to be a missionary with my stepfather and me in tow. I was thus a missionary child with all the conflicted feelings that kind of life can bring. Living in a mountainous village in Java outside of Malang. A village with no running water or electricity. And then journeying to Taiwan and ultimately Hong Kong. Where I completed my schooling. I always felt I had to share her with the whole world. I just wanted to be a normal kid. Not with triad members living in our small flat trying and succeeding to get off heroin. I always felt bad about that. I missed my life back in Southern California. But when we went back there when I was fifteen, I battled to fit in. I was not the same person. Even my accent had changed. I battled to make friends. We went back to Hong Kong and I was enrolled in another school. I couldn't wait to leave Hong Kong. I came to England. Married Hugh and settled here.

Now forty-five years later, I am sad that I didn't spend more time with my mother. We came to see them in California but now that she's near death I am devastated that I can't be with her. A really sad story. With a tracheostomy, the airlines wouldn't take me and now with coronavirus all flights are grounded.

**1st April 2020**

*My mother died today.  
Silent wail  
Past memories crowding in  
Upsetting equilibrium  
A multitude of regrets  
Not being there.  
Things unsaid things not done.  
If you can hear me now  
Know that I love you  
With all my heart.*

**4th April 2020**

You have all tried but this story does not have a happy ending. I am so plagued with suffering now that I don't think I can go on. The worst is the face and throat spasms which make me clamp down on my tongue. Which is excruciating. Another is the constant suction both oral and deep. There is no respite, even at night. I mourn for the use of my hands and legs. I dream about being an able-bodied person again and I cry when I wake up.

**7th April 2020**

Sunny days in the garden. Lock down but we have a nice garden. The sunshine does me good. As do the chickens. We let them out on the lawn while vigilantly watching for foxes and the neighbours' cat.

My emotions got the better of me with the death of my mother. The funeral was exclusively about her achievements in the world of religion. And nothing about her achievements as a wife and mother. A virtue that fares lower than her religious exploits over her lifetime. But mattered to me above all else. Hugh had set up a live FaceTime link to California which worked well. And the kids defying the COVID-19 regulations were all there with me. The only time I was truly moved by the service was when each attendee was asked to put a red tulip on her coffin and the holder of the phone put one on for me. I broke down at that point. The kids then did reminiscing about her which I found much more comforting than the funeral service. Stories they told about her last days and a poem that Rick (my stepfather) wrote about the love of his life.

**By Rick Willans about his wife Jean Willans**

The following untitled poem is a reflection, written after a number of years of marriage, on this "progressive revelation" of Jean which I experienced, perceiving her first as a distinctly anointed servant of God, then as a close friend, and finally as my beloved.

*The one who softly burst upon my life  
Like sunlight veiled behind an autumn cloud  
Above a canopy of colored boughs,  
Revealed by stages as the cloud passed on,  
Its gaps and thinning edge allowing through  
A modulating, ever growing flood  
Of brightness, which in turn was gently screened  
By shimmering lattice-work of redding leaves  
Until, emerging to an open field,  
I stood in warmth and brightness without shield.  
So you began to shine upon my soul  
That Hanoverian autumn long ago;  
Though clouds and trees then hid you from my gaze,  
The warm light of your love now fills my days --  
My love  
My one love,  
My one true love.*

Funny stories which I had never about her. Old age had made her talk openly although she was always one to speak her mind and had a wicked sense of humour. One time when Jazzy was visiting her in the care home with her boyfriend Douglas. She was partially blind and said "who's that guy standing over there in his

underwear?" Douglas was wearing light coloured chinos. Not a great introduction. I'm not sure if Douglas ever wore them again.

Another time, Justy was visiting her and brought her See's chocolates – a favourite of hers. She was blind and deaf. But when Dad wanted to give her supplements, she wanted the chocolates and gingerly grabbed them. Justy maintained his distance so she didn't recognise him but recognised the chocolates.

Hugh regaled the time we went grunion hunting in Baja, California. In a little village called Ensenada on the outskirts of Tijuana. We used to go there in my childhood. It was a short walk to the beach where we would see magnificent-coloured starfish and all manner of exotic sea creatures among the rocks. Sea anemones. Big crabs. And sea cucumbers. And abalone shells that when you turned them over showed a rainbow of colours on a polished surface. We found sand dollars on the beach. And rocks glistening in the sun. Hugh and I took a trip down there with my parents to hunt for grunion. There was a time during a full moon where the little fish like sardines would all jump on the sand to lay their eggs and then the male grunion would jump on the sand to fertilise them. It all happened in a minute. You never knew which night it was going to happen.

We dutifully went down to the beach when it was dark with our buckets. On the third night we saw one fish jump out of the water and then another and another. Soon the whole beach was teeming with them. We ran down and started scooping them up into the buckets, laughing as we did. You had to be quick as in the next ebb they were gone. The whole thing was over in a minute but it was so exciting and we had our dinner. I wished I could take the kids down to Ensenada but the whole of Baja is restricted to travellers due to the drug cartels. Sadly it is not a safe place to travel anymore. Those were the times I remember my mother as an instigator of creative fun things. With a zest for life and great company. She taught me so much and I have missed her. Goodbye mummy.

## **20th April 2020**

Easter was a muted affair. Hugh and Suresha cooked a stupendous Easter lunch but the kids came and took it away to eat on their own. Everyone is so afraid of COVID-19 that I don't get hugs and kisses anymore. They are so afraid of getting the virus and giving it to me. James is frightened for his children. Which I understand totally. But I miss them so. Eva is shy with me again where she had overcome that. The weird grandma who doesn't speak, eat or move. Hugh goes round to their house (in tiger outfits and cat boy masks) and Helen takes a video which she posts on Whatsapp. Eva thinks it's hilarious and laughs her adorable giggle. And runs to him to get a hug but he has to stay three metres apart. It is heartrending the way she cannot hug her grandpa. This virus has got the whole world frightened. It is a scourge. I spend my days with Hugh and my chickens in the garden. We let them out to roam, always looking out for the neighbours' cat or fox that I have seen sniffing around.



Verna is broody so she isn't laying. Every morning I have her in my room in a play pen to allow the others to lay their eggs as otherwise she hogs the nesting bowl. In the afternoon we let them out and close the door. Verna keeps running back to the hutch to nest but then the others find tasty morsels in the garden which entices her. So she spends her time running backwards and forwards. Good exercise. The chickens love Suresha who is the purveyor of food. When she appears, they follow her about. She looks like the pied piper. The four hens running after her like miniature Charlie Chaplins. Because of the feathers on their feet and legs they waddle like comical ducks.

**2nd May 2020**

*The Terrier-Within*

Major disaster averted. The hen house door latch was not properly put on and Truffle managed to get in. Chickens squawking and flying in all directions. Truffle intent on catching them, oblivious to our calls. The 'terrier-within' calling. The primal urge. I looked on as Jazzy, Hugh and Suresha ducked and dived trying to catch Truffle. She was amazingly fast, having eyes only for the plump luscious feathers that heralded a plump luscious dinner. Much better than the dried dog food these humans offered her. Unhearing to our calls of "treat treat"! Or "Truffle, no"! I was scared to see Elma in her mouth. But a still small voice inside must have told her to not clamp down. Elma escaped from the jaws of death. Jazzy caught Truffle and the hens were herded back. All except Elma, who was cowering in the bushes. Suresha retrieved her and after some coddling she was no worse for wear after her ordeal.

**4th May 2020**

Sometimes I break down. The carers rush to see what is hurting. But sometimes it is not physical (although I always have some pain) it is more the mental anguish that a photo or song provokes. The visualisation of me enjoying the Spring evenings with my friends in the garden or walking across the lawn. Some little catalyst which sends me into floods of tears. I have become a real cry baby. An emotion that everyone understands though not the reason behind it. They rush to my aid. Worried that they have done something wrong. But I cannot explain that it is nothing that they have done but my own internal fight with trying to live with this illness and still retain my soul when everything else is slowly being robbed from me.

**10th May 2020**

The family had their COVID-19 tests done and Cristina's was negative so Justin felt he could give me a hug! He put me in my chair which is more comfortable than being hoisted. The girls try to be gentle, but the tubes invariably get in the way being rolled in the sling. And the trach is disturbed, which makes me cough. Justy just picks me up and a carer disconnects the ventilator and he puts me in the wheelchair. No being rolled in the sling. Then a carer reconnects the ventilator as I can breathe on my own.

The Saturday was sunny and warm. So I was wheeled out on the patio where Eva and Alex were playing. The chickens were out and it was comical to see how Alex ran after them. His one-year-old legs tottering along. Pointing as he went, then gingerly stroking them. Eva checking for eggs and finally being rewarded. It was good to spend the afternoon with them. I organised mac and cheese for them all (Eva's favourite) and a shoulder of lamb. It was like the old days before the virus.

I have my issues going out, but it is nice to get outside. The purple wisteria covers the back of the house and Jazzy and Hugh have provided wonderful Spring pots full of pansies and the camellias are in full bloom. Red pinks and white. The roses are opening now. Neil and Ken have given me a lemon tree which has pride of place on the garden table full of big juicy lemons and my orange tree which survived the Winter much to my astonishment.

As I have said, I have issues going outside. The paraphernalia that has to accompany me. The suction machine. Obviously the ventilator. The nebuliser. The board with letters on it – the eyegaze doesn't work outside. Hat. Sunglasses. My eyes battle outside because of the medication I'm taking.

But most of all it's the mental stress just sitting there. Not playing with the children. Not being able to communicate. This ugly person in the corner who is an oddity. Who can't converse and just has to listen to their amusing conversations. I remember a time in the long Spring evenings when we used to play croquet and have Pimms. Now I just sit there totally inert. I don't want them to remember me this way. I have entertained the thought of having them not come round. To spare them my gradual disintegration. But I know they would not agree. At least spare the grandchildren. Eva is sensitive and I know does not understand this funny person who does not talk to her and who grimaces (attempting to smile).

Jazzy came on the Sunday. She also tested negative and gave me a big hug. I'm hugging her back in my mind. The boys worry about the tubes but she nestles right in and I can lean my head on her soft blonde hair. The only demonstratable thing I can do. It means so much to me when my children hug me, but it tears me apart that I can't hug them back.

## **20th May 2020**

Simple pleasures. The gold on a goldfinch's back and breast glistening in the sunlight. The chuckling of the chickens. Classical music which I just got into. Spring flowers, presents from good friends. All of which I didn't have any time for in the hustle and bustle of normal existence. I was too hyped up to appreciate the simple pleasures. Ambitious. Driven to succeed in my chosen field.

Others I have got to know that I couldn't have otherwise. The comical scene of Ruby chasing Truffle around the chicken coup as Truffle barks at the hens. Ruby barking at Truffle. Suresha's hugs. My grandchildren's excited laughter as they play on the trampoline. The contentment watching them all eat one of my recipes followed by

blueberries and ice cream. Alex and Eva licking their bowls and spoons clean. Alex chasing the chickens into the flower bed. Eva collecting eggs. All of which are pleasures to me I have not previously known. A reason to stay alive amid the deep suctioning and facial spasms. The discomfort. The endless thick saliva clogging up my airways. Hankering after different foods. Dreaming about walking and holding a pen. The exhaustion from existing.

#### **4th June 2020**

I live on memories. The memories of Portugal. The memories from South Africa with the kids. Memories of California and a boat with hundreds of dolphins jumping alongside the boat showing off their swimming skills. Cycling and rollerblading along Santa Monica beach. Seafood outdoors in Malibu. Wine tasting in Carmel. Cycling over the Golden Gate Bridge and then taking the ferry back. Snorkelling in Hawaii, myriads of colours and strange creatures. These were gifts. Snippets of happiness. And being with my beloved. We have shared such fun.

#### **6th June 2020**

I have had trouble with my tracheostomy. Choking in the night and day. Infections which don't heal. Needless to say, it is far better than the BiPAP mask, without which I don't think I would have survived as long. Still, having a hole in your throat brings problems. My neck is small and the skin is quite weak. It is not a robust neck. Delicate I would say. Scrawny in later years.

One of the delights in having a trach is the joy of changing it every month. Which facilitates yanking the thing out and shoving a new one in. As a person who has had three children the pain of changing the trach is definitely more painful than childbirth without having the resultant prize at the end. Just the sheer relief that it's over.

Imagine my consternation when Debbie the tracheostomy nurse said the new one wasn't taking well and we had to put a second one in. A lot of pain later and copious amounts of blood and it was done. Dosed on paracetamol, oramorph and lorazepam, I managed to sleep the rest of the day.

#### **26th June 2020**

##### *Pet Phrases*

##### **Suresha's pet phrases:**

Bump equals bum.

Oyster equals hoist.

Flug equals plug.

Cotton button equals cotton bud.

##### **Ruby's pet phrases:**

Thank you Jesus.

Hallelujah.

Sorry.

Everything's ok (when it isn't).

### **28th June 2020**

I value my privacy. I don't have much. Sometimes I have to tell my carers to get out. I don't mean it personally, but sometimes I just inwardly scream. No-one understands. They think I'm in physical pain. I am, but by far it's the emotional that is more soul destroying. A case in point: a new carer kept reading my texts. I tried to tell her, but she didn't understand. She then started to read messages I was writing to my daughter on the phone and answering them! I get so frustrated.

Sometimes I yearn for being left alone but they can't do it. Otherwise I could have a mucus plug which when it happens is unannounced and could be life threatening. Even the loo is not sacrosanct. I keep thinking of the times when I was pregnant and that it is a basic human condition that we have to be helped at various stages in our lives. It has just happened sooner for me, and I have to be helped in a big way. Enough said...

### **20th July 2020**

Five days before the big day. Exciting. Flurry of activity in the garden. Getting all the rubbish out, moving the chickens and trampoline. Cristina and Helen doing a rearrangement of the lounge to accommodate a dressing room for the bride and bridesmaids. The boys helped gallantly too. Suresha is making Truffle a dress fit for the ring bearer. Caterers are Rubbarb: the best. The tent will look glorious.

I had a good cry when the team went yesterday. It seems my emotions are on a knife edge. I cried because I couldn't be fit and able for my only daughter's wedding. I worry that I will be needing suction through the ceremony. That my carers don't know what I mean as my gestures go. I can no longer raise my brows to indicate 'yes' and shake my head to indicate 'no'.

I want the wedding to be perfect for my little girl.

### **27th July 2020**

The wedding went swimmingly. Literally as Jazzy come down the porch, Hugh holding an umbrella, it poured, but that didn't dampen the proceedings. My little girl looked beautiful – the most beautiful bride I had ever seen. I felt so proud to be there. The boys looked so dapper. Douglas with his tartan trousers. And Hugh and the boys with their Macpherson ties and morning suits. Richard gave a blessing, Tom did a reading of 'O Tell Me the Truth About Love'. There was first Corinthians 13 by Adam too. When I saw her walk out on her father's arm, my heart burst – I was so glad to make it to this day.

The flowers and decorations were superb. Nikki and Charlie arrived on the Friday with their box of tricks. Lanterns, fairy lights. And put them up. What good friends they are of forty years. Cristina and Helen did a lovely job on the dressing room. The boys did a superb job of cleaning up the garden. Dismantling the trampoline. Moving the chickens. The carers helped as well. It was a real family affair, more so than the hiring of a place. The marquee was totally spectacular, and I hear the food and wine was great. Hugh staged-managed the garden and Jazzy and Douglas everything else. Eva, Alex and Wren looked so lovely in their little outfits and Suresha made a little dress for Truffle with a pocket for the rings. But in the end we thought it was too risky having her being purveyor of the rings. A wise decision as she veered off at the last moment from the wedding party. I was quite concerned and had visions of the wedding party chasing Truffle round the garden in the rain trying to retrieve the rings.

The band was great and there was dancing into the night culminating in a firepit with everyone smoking cigars. I of course went to bed early but I could see the firepit illuminating through my blinds and knew it was a great day. And I really do appreciate the time and effort my family put in. The house is perfect for weddings. A Victorian with lots of high ceilings and spacious rooms. With a beautiful garden which Hugh has lovingly tended the whole of the twenty-five years we have been here.

Jazzy defied convention and spoke at her own wedding. I have sometimes wondered why the bride stayed silent in this day and age. And what a speech it was too: witty and loving. Jazzy wanted me to speak too. So Justy helped me programme it into my eyegaze. Here it is for those who couldn't make it as the wedding was limited to thirty people due to lockdown.



### *Suzy's speech at Jazzy's wedding, 25<sup>th</sup> July 2020*

I first saw Douglas when watching a video of burns night, he was singing a drunken Scottish tune. 'He's cute', I said, although he was singing way off key. I put that down to the alcohol they had consumed. Jazzy said, 'oh that's Douglas, he is always around'. I thought that was a good thing. She referred to Douglas more and more. They talked. They shared the love of food, wine, golf and Truffle. I noticed their conversation was like they were speaking another language, and I didn't know what they were talking about, but they knew. Jazzy doesn't want me to talk about her previous boyfriends, which is fair enough, but I drew the line at the Mohican haircut. Enough said. Hugh was impressed by Douglas's handicap. Unlike Jazzy's other boyfriends, who didn't play golf, Hugh warmed to Douglas immediately. That and the fact that Douglas was Scottish, and South-African, it seemed to Hugh it was too good to be true. As far as my beautiful daughter was concerned, known for being feisty, I saw that she had found a real friend. So, when they said they were going out, we were thrilled. And when they announced their engagement, we were over the moon. She has found the perfect match, and a normal haircut too. Events transpired to make their original wedding plans impossible, but they persevered, culminating in this day, and what a wonderful day it is too! I love you both, and wish you love and happiness for all your years.--

Douglas and Hugh did short speeches and then deferred to their wives, which is entirely fitting.

### **16th August 2020**

Looking out of the window from my hospital bed at a hot humid overcast day. The stone clock tower hovering over the view. Four grey walls, nail holes where pictures long gone, I recall Justin's wedding last Saturday.

A sunny day outside a medieval church in the New Forest. The bride looked beautiful, with an off-the-shoulder gown. A garland of white roses around the church archway, it was worth a rollercoaster ride to get there. Did them proud. First putting the finishing touches on Jazzy's wedding. How glad it made me feel it was at home in that I found it easy to get involved with the preparations. It is all about the bride. It's her day. A window appeared during the time when the government relaxed their restrictions on coronavirus and both jumped in and culled their invitation lists to a maximum of thirty guests. Making people take a test. Cristina, Justy's wife, opted for a stunning Manor House in the New Forest and an old medieval church. A marvellous setting. My job was getting to it. A two-hour journey both ways. A good friend Rob volunteered to drive me there so that Hugh could enjoy the party. The A-Team was established: being Suresha, Ruby and Kim. They had a room set up for me where I could lie down. It was a spectacular event.



### **21st August 2020**

I suppose I had better elaborate how I was in hospital. The doctor said I should come in for an MOT as I was battling with secretions. They announced I was healthy as a horse. Which is ironic. But welcome news. They kept me for five days with a battery of tests. With a blood test every day. My veins are very fragile. I cannot flex my arms so they had to administer the test in my hands. After several attempts they invariably got blood after much pain. The visit was successful. I have always been ambivalent about going to hospital especially with COVID around. But they ruled out infections and adjusted my medications. I feel much better having gone in.

It is amazing what palliative care there is for this terminal illness. The NHS is great. They never write me off. Something I frequently do myself.

### **23rd August 2020**

Memories keep me going. Fun memories. Sometimes my carers ask why I'm smiling. It's because I am thinking about some distant memory like deep sea fishing with my mother off the Dartmouth coast. She really was fun in the old days. Before she got health problems. She lived a life. Four husbands. The last was twenty years her junior. This one stuck although she did say to me 'I suppose it's too late to get another one'. She was in her eighties at the time. She did say to me 'don't get old it sucks'. She regaled stories about her childhood. How sadly her mother died in a hotel room when she was three. And she was raised by her grandparents, who she hated. When she was six her father kidnapped her at gunpoint. She travelled around the states changing her name and dyeing her hair. Her father's wife was the only mother she knew. When the wife was lying in hospital bed with terminal cancer, she informed

the hospital staff who little “Nancy” was. She told my mother with her dying breaths that she didn't trust her father to look after her. The police brought her back to her grandparents. She said to me in one of her more thoughtful conversations with me that she didn't know how to be a good mother to me. Those conversations I treasured; it was rare she let her guard down. Being a spokeswoman for God, she could not show any weakness.

### **26th August 2020**

Continuing my mother's story. When she was seventeen she married a soldier – she maintains it was to get away from her grandparents. She had a son called Michael. When she was invited to a dinner party of another couple, it soon transpired they were swingers. Yes, back in the forties they had them too. There followed some lewd suggestions about four in a bed. She left him. Afterwards, she discovered piles of love letters from girls where he was stationed.

Next, she landed a job working for the Pentagon. Where she met her second husband. A captain in the navy. She found out he was having an affair with her best friend's husband. Thus number two bit the dust.

Enter my father. A lieutenant commander in the navy. He left his wife and eight-year-old daughter for her. A fact I am not proud of.

I was born in Coronado navel base in San Diego. Amid cocktail parties and chevys. My mother the socialite. She was a raving beauty. Olive skin and a brunette she looked like a young Elizabeth Taylor. We moved to Los Angeles. And there she found God. I grew up in a wave of revival spearheaded by her magazine, Trinity. But my Dad could not cope with all the attention being married to a paragon. She tried to get him involved speaking at her conventions but it just wasn't in him. And he started having affairs. It was a difficult time for me. I remember rows permanently etched on my memory I would choose to forget. Thus number three bit the dust. Then number four came along.

A kind, gentle twenty-year-old. Six foot three. And clearly adored this woman who came to speak at his college. During the summer he worked on the magazine and never went back to college. They married and I was the flower girl. He has been by her side for the past fifty years. Supporting her. Adoring her. Nursing her through her long illness. She finally got it right.

### **27th August 2020**

You know that game kids play where one person stands behind you and then you fall back hoping the other person will catch you – the thrill of it when you feel yourself toppling backwards when for one brief moment you feel you are placing yourself in someone else's hands. Magnify that feeling a hundred fold. And how I feel twenty-four hours a day. It's exhausting. For it is not just falling backwards, it is the placing



of your life in someone else's hands. There is obviously the tracheostomy. They have to drain it and provide suction. And a myriad of other maintenance jobs. Each time they do these jobs you have to disconnect, and during that time I can't breathe. There is also the problem of moving me. Where my body is vulnerable. I can't hold my head up so turning and putting in a hoist is fraught with disaster. Either a stray hand or foot at an odd angle causing a sprain or break. And I can't even call out, I just have to suffer in silence.

## **20th October 2020**

I've had another wiping of my notes. Luckily, I have been sending them to Jazzy. I have lost the Deal holiday. And my birthday. I will try to add this from memory.

I have always suffered a certain amount of trepidation going out. Imagine that effect magnifying a hundred-fold when Jazzy found an accessible house in Deal by the sea.

Jazzy says I need to get out more. I always feel more alive when we get out. But the military operation to get there is exhausting to get packed up. I am seriously disabled now. And the breathing apparatus is extensive. Plus the drugs and accoutrements that a week while away needs compounds things. Suresha has a good heart and arranged the packing with aplomb. Forgetting nothing. Ruby provided four carers. They really wanted me get out instead of being in my bed the whole day. I am so tired I prefer to stay in the comfort in my own room. But that's not living.

I remember a programme about an MND sufferer who had said that "my mind was so centred on my dying, I had forgotten how to live. It's been seven years I've missed." His words echoed in my mind. The kids and Hugh have really been my rock. Providing fun and support. As I am entering the last stage of the disease, I'm battling to live with the pain. The oxygenation stats going down. The choking. The muscle aches. The itching (that you can't scratch), the saliva. The tongue clamping. The wasting of limbs. The turning where I am in agony. The pain from the tracheostomy stoma. Not eating or drinking. Above all its a tremendous fatigue. It is hard to enjoy people's visiting when I feel like this. Much less going anywhere. But Jazzy would have none of it and the kids entered the Deal holiday with gusto. So I caught their enthusiasm and vowed that I would give it a go.

The house was amazing. There was a lift to the living space. A tremendous view of the coast and you could go out on a boardwalk along the sea which was wonderful. To be wheeled along the coast lifted my spirits. Watching the grandchildren play skimming stones with their father was a delight. Going for long walks with the family. I was glad we booked it. And am grateful to my children who don't have the word "can't" in their vocabulary.

