



A DIARY BY SOMEONE DETERMINED TO FIGHT MND

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# BITTERSWEET

BOOK ONE - THE FIRST YEAR

## ***Dedicatory Preface***

I dedicate this little book to my wonderful family, without whom I wouldn't have survived this last year. My husband Hugh — a rock who has carried the weight of this with love, faith and determination; my eldest son, who with his tireless research, regular visits, big hugs and beautiful songs has made me feel so loved; my daughter, who with her deep empathy and compassion has raised my spirits just by being her beautiful self; my youngest, whose inner strength and steady support and care (and effortless ability to lift me!) has made me feel strong and hopeful; and my daughter-in-law and lovely granddaughter — an absolute joy and delight.

Thank you my darlings for being there for me through the highs and lows of this roller-coaster-ride.

## ***Introduction***

This diary is a chronicle of my first year after being diagnosed with the Bulbar Onset version of Motor Neurone Disease. Although diagnosed in October 2016, it begins in August 2017 because ten months after diagnosis was the first point that I felt able to step back and put some thoughts on paper. The first ten months were a mixture of panic and confusion, as my speech went from the odd mispronounced word to being virtually unintelligible; my mobility went from walking and riding my bike with ease to needing a cane, then a walking frame, and then a wheelchair; and I went from being able to eat anything to eating and drinking nothing unless it goes through my stomach tube (PEG).

When I was first diagnosed, I felt my life had ended. Literally my entire world collapsed. All my dreams and plans evaporated and I was inconsolable — my heart broken. An MNDA volunteer said to me: “It gets better — I don’t know why, but people seem to come to terms with it and cope”. I hung onto those words even though I felt I would never be able to cope. Who I was and who I would become had changed forever. I read posts on the MND websites and thought “How can they talk so unemotionally about something so awful?”, “How can they talk at all? They discuss horrible things like stomach tubes and BiPap, suction and cough-assist machines in such a blasé way”. I couldn’t understand it. My whole world was crashing down, and yet other people with this disease were just getting on with it. But over the past year I have discovered that this is indeed the case. It does get better. You learn and take up the challenge. We are amazing creatures

with the propensity and will to survive. I guess that's why we've lasted so long. Never give up. Never lose hope. Fight to the end.

## **22nd August**

*Remember me as I was  
Someone you could lean upon  
Someone who was strong and quick  
Someone with a ready wit  
Who loved you whatever.  
Who could fix it.*

*Remember me as I was  
My smile, my laugh, the love in my face,  
Never forget I was there for you  
That I wish I could always care for you.  
Think of me as I was,  
Not what I will become.*

*Remember how much I love you  
Even when I won't be able to hug you  
Cuddle me more to make up for it,  
Don't let me become a sad presence  
That sits in the corner in silence.  
Don't hide me away,*

*...shrivelled and wizened —  
Trip over the cord and say it was an accident.*

*Let's dance now while we can!*

*What fun we shall have!*  
*I love you ... my six beautiful beings.*  
*So absolutely spectacular each in your own way.*  
*God I'm so.... LUCKY!*

### **23rd August**

One in three get cancer.  
One in three hundred get MND.

Trust me to be dramatic.

### **24th August**

Had the most fabulous day yesterday with my daughter. Went to Black Pond — one of my favourite places. If it wasn't for the distant sound of the A3 you'd think you were in a Canadian forest. Truffle's (our dog's) favourite place too. I looked into my gorgeous girl's eyes and saw the most beautiful person. Her heart-shaped face so perfect and thought: "Well I did something good!". She is so lovely in every way. The most contrary of children — always with the alternative word — and yet somehow I knew she was so smart she'd find a way to make life work for her. Not easy, but she has become amazing. Sensitive but practical, deep-feeling and kind.

### **Conversation with Daughter and Husband**

Daughter: I hope you are using the notebooks I bought you.

Me: Well yes actually, I've just started.

Daughter: *(Genuine surprise registered on her face)*

*(to Hugh)* You're not to read them. They're private...  
SECRET.

Husband: I will read them! We have no secrets.

Me: You will not! Everyone has secrets!  
*(Hugh if you're reading this STOP now this instant!)*

### **25th August**

**5.25am** Eau de fox shit (Truffle) has arrived on my bed. It's a faint whiff — I will ignore it because I'm so pleased to see her — feel her. Daughter must have locked her out. I love her soft fur on my toes...

**6am** In my grief, my soul has folded up into itself.

### **27th August**

On our way to beautiful La Baule in France with besties Rob and Ann. In Gatwick I'm being wheeled by an airport accessibility employee. Speaking very slowly, she puts a hand on my arm and says: "A-re yo-u al-right de-ar?", as though I am mentally deficient. I suppose I sound that way. As we go sailing past the Armani counter a girl is offering to spray a sample. I fling out my arm and grunt "yes please" (which comes out "yas ple") and am rewarded with a lovely whiff of the new Armani 'She'. My handler seemed rather surprised by my gesture — as though the disabled don't need perfume. The impression I get as a new recruit to the world of disability is that, overall, people are very kind. What a relief that I live in a kind society overall, where legislation supports helping those who need it. I've been amazed at the

extra services made available to me — Lord knows I need them. However, along with that comes a certain dismissiveness. People don't quite look at you — they look at the tall one wheeling the chair, not the one *in* the wheelchair. I suppose they probably think I'm not capable of making decisions for myself. I am ... YES I AM! I want to scream "LISTEN TO ME — LOOK DOWN — I'M HERE!", but it comes out a garble. A smile is universal and yet people don't often look at me to see the smile. If I manage to catch their eye — I can get a lovely return smile mostly (although my smile is a bit hit-and-miss now — more manageable on the left side than on the right). In the old days, people used to warm up when I smiled at them — I could soften the hardest of hearts with a twinkle of the eyes — but these days it's harder because people mostly ignore me.

Us women over 50 have already experienced the invisibility factor. Compared to the spritely years of our thirties and forties, the fifties brings with it (along with other things) a need to make our presence felt a bit more strongly to be noticed. But try being 60 and disabled! Then it's a real challenge to be heard and/or even seen. What an experience for this cosseted girl with the world at her beck-and-call not long ago.

So on to La Baule! How I LOVE the french markets. The CHEESE! If I'm very careful I can eat it — a little bit. Ann and Rob are very indulgent of my persistence to try a multitude of different types — goat's, sheep's, and of course the wonderful brie and roquefort. As we traverse the market, I am saying: "just one more", "this one", and "oh and this one". When I picked out some exotic mushrooms I thought

Rob and Ann were both going to faint dead away. I'll prove to them how delicious they will be even if I can't eat them myself.

All the shopping hung on the wheelchair. So pleased to be useful.

### **28th August**

How to eat a french almond croissant when you have swallowing difficulties:

1. Eat it alone — it is not going to be pretty.
2. Have some freshly brewed coffee with it — don't forget to add the trusty thickener given to you by the speech and language therapist to minimise choking.
3. Dig around in the middle to get to the marzipan. Slowly add other bits around the edge carefully. Sips of coffee throughout.
4. Quit while you're ahead. Never try to "eat it all"— those days are over.

### **New Rules**

1. Never buy white tops — choose patterns to hide dribble and spills.
2. Don't wear dresses if you want to have a swig of PEG wine — hitching your dress up to your stomach is not a good look. Choose trousers or skirts.

My tongue is a shrunken stump. WHAT THE HELL?

### **29th August**

#### **Reflection on Time in Portugal in June**

Okay I have some time sitting in a wonderful room in La Baule with a 180° view of the sea and so I'm going to use it to relate the time we



had in June in Portugal with my siblings-in-law. Hugh's brother and wife live in Sydney. His sister and husband live in South Africa (I have no siblings of my own). For the past forty years we have seen them when we can but, due to sheer distance, this has been sporadic. When they heard about my diagnosis they all decided we should be together for a holiday — something that has never happened before. This was a time when the devastation of the diagnosis brought us all together in a way we never expected. It was such a moving time in which the bonds of family — even by marriage — taught me a deep lesson. Everyone rallied: they went to great pains to ensure I could eat when what was on the menu wasn't suitable for me — looking after me in a way that was heart-warming.

My love of swimming is intense — perhaps it's being a California girl. On several occasions we would venture down to the sea to find the rollers breaking ominously. But where there's a will... and we were not dissuaded! They KNEW this was what I loved doing, and went to great lengths to ensure that I got that swim. Timing was key. One had to pick the exact right moment to make it into the waves. With brothers-in-law on each side, and husband behind, we gingerly made our way to the water's edge and at the shout of "Now!" plunged ourselves into the waves — me making sure I stayed above them due to my inability to control water coming in through my nose and mouth.

We made it! Bobbing around in the waves was heaven — the water cool (but not too cold) and clean. Best of all — I felt my normal self, as the weightlessness meant that I did not have to balance precariously to stay up. Eventually I signalled to them that I was ready to come out.

However, by this time the waves had got up quite considerably and were breaking frequently. Onlookers were bemused — the lifeguard busy on his iPhone. We tried to time it right. Getting into position — brothers-in-law again on either side, husband behind and girls flanking the rear, we heard the shout “NOW!” and began making our way through the waves, me being propelled through the water as I furiously paddled.

But it was not to be. As a set of huge rollers appeared from nowhere, we were tossed like ninepins in all directions, and were all unceremoniously dumped onto the sandy sea floor — arms and legs flailing. Coughing and spluttering, we scrambled into position once more, and I was literally dragged up the beach by my arms. I could see they were terrified that I was going to drown, but actually I have never laughed so much in my life. During that time with them, I discovered the warmth and love of sisters and brothers that I had never had, and was glad and yet at the same time sad to discover this so late in my life.

### **La Baule**

God the French can cook — I just had two bowls (yes two) of soup de poisson. To DIE for. Haven't eaten this much in months. No choking!

### **30th August**

What a fab time we've been having — found a gorgeous cove for swimming — unbelievably beautiful water; clear and cool. Glorious!

### **My Night in French Accident & Emergency Department**

The sweet and the bitter. Picked up a throat infection somewhere (probably the plane) and it got its tentacles into me last night. Started

feeling very rough and **COULDN'T STOP COUGHING**. Big racking coughs that kept on until you couldn't catch breath. Taking deep donkey-sounding brays as I gasped for air and then coughing again — like an epileptic fit — no control. And with some coughs biting my poor tongue so a blood-filled mouth. Gunge by the ton load (sorry for the detail but important to understand going to A&E wasn't because we wanted to try out the French health service for entertainment). After rapid replies from the wonderful Caz, an MNDA Volunteer confirming I must go immediately, we made our way to St Nazaire Hospital with me attempting to program the car navigation system while simultaneously avoiding drooling and coughing all over myself in the car.

Note to self: kitchen towel is a crucial accompaniment to have within arm's reach **AT ALL TIMES**.

What can I say? Efficient and kind, we were seen quickly. At 1am it was relatively peaceful with only a few people waiting to be seen.

After various standard procedures I saw the doctor after an hour. She looked at me and said, “Parlez-vous Français?”. Unfortunately, not only was my French ropey, but since my speech is pretty much unintelligible except to the most experienced of listeners (immediate family and girlfriends), there wasn't a hope in hell of being able to communicate with her on that level. But all was not lost! I had my trusty iPhone with Predictable text-to-speech software and proceeded to type out answers to her questions. She was initially sceptical (I know that French look) — I think she may have thought my problem was mental rather than physical as she listened to me grunt away and type.

She didn't know the English words "Motor Neurone Disease" and "Bulbar onset" was WAY out there. When I typed "Stephen Hawking" she said "Ou es zat? Your father?" WHAT? I thought EVERYONE knew who Stephen Hawking was! I quickly scrubbed that out and remembered Caz's text: "Maladie de Charcot". She looked at me: "Ah Charcot?...Charcot?". Eventually the penny dropped. "Oui...Ah Charcot!". The light dawned on her: *this woman is not mad — she's got Charcot and is using the iPhone to speak because she can't — d'accord*. After that, a chest x-ray and bloods, and I was wheeled to the way-station where I was surrounded by other unfortunates awaiting their results. The only part of my experience that could do with some rejigging on the part of the French health service was the bed arrangement. I had a rather unpleasant view of a large and hairy Frenchman's balls (also large and hairy) — as he was across from me (and the room quite small) it was unavoidable. Poor man (although I don't think he minded in the least). But I think something might have happened to them judging by the way he was lying. Anyway, I was discharged before him so I never knew his fate. But for his sake, I hope all is well down there.

### **Reflection:**

A response to any terminal disease is that, in reality, we all have to go sometime, and in some way. There are really VICIOUS things about MND though: like the way it hits young people at the start of their lives — so vile. It's got to me at 60: well, there are awful aspects — truly awful — but I've had a great life. Statistically I should have had at least another ten to twenty years, but things often don't turn out the way one would like. Still, the worst thing is the slow degeneration. Watching yourself literally fall apart but not knowing quite what is going to be hit next. I was healthy and fit — I cycled all over France

and was looking forward to a glittering end to my career, and a fun old age with my husband of 40 years. The worst things? Not seeing all my children married; not watching my beautiful granddaughter grow up; not meeting the ones that come after her. Not being able to help my wonderful husband grow old (I'm the younger) and even worse, contributing to his ageing with my illness; and putting my kids through this.

But by far the hardest thing to handle is the relentless destruction of my poor body — bit by bit — muscle by muscle. Thinking “What’s next?” and “Oh, I can’t do that now”. Thinking “Am I reading into this? Is this hand really withering?”. I examine the hands and legs of all of my friends who are my age to see if any of the changes are age-related, but sadly there’s no getting round the fact that mine didn’t look like this a month ago.

And of course there’s the fear of the future and what it might bring — but we will face that when it comes. With help — lots of it from the people I love and “THE PROFESSIONALS” who are very good at what they do; oh, and not forgetting ANTI-DEPRESSANTS. Thank God for those.

The other point is: isn’t *any* disease truly awful? Anything that is capable of killing a human being has got to be gruesome...

Anyway, enough of this morbidity.

## **THE PEG**

### **(The Percutaneous Endoscopic Gastrostomy)**

(Thank you, Mr Google)

The PEG is my friend — yes! My reason for having to get one is based on my loss of weight due to the simple fact that one of my most beloved pastimes had become arduous, dangerous and frankly no longer the pleasure it had once been. I was an ardent foodie and loved cooking, so it may seem strange to be reacting so happily to the insertion of a stomach tube. But when every mouthful becomes like a military exercise in strategic planning, and every swallow a dipping of the chin and crossing of the fingers, the joy of eating is lessened considerably. A choking episode would bring gasps of air and, in response, concerned offspring would jump up from the dinner table and attempt all sorts of methods to alleviate. Always saying (bless them) “What do you need, Mum?” when it was clear I was in no condition to actually reply. There would follow wild gesticulations from me — like a form of macabre charade. Pointing to the kitchen towel between heavens, “water?” — uh...no... (water is the enemy). Madly trying to understand and mind-read. But we’ve now more or less cracked it. The easiest way to reduce the spasm is to stick one’s head in the freezer. So my sons or daughter, whoever was the fastest, would now jump up when a choking fit starts and literally drag me to the icebox — much to the alarm of any unfortunate dinner guests.

But with the wondrous PEG, these incidents are far less frequent. I have learnt to sit at the table and eat, but not (so to speak), unless I am pretty sure it will go down. And this is because...I don’t *have* to eat to stay alive!! Yay!!

My initial reaction when shown one of these contraptions was, “Ew, gross” (in my Californian way). One end has two valves from which you can screw in syringes, which contain anything from medication to milkshakes. The other end sits just above your bellybutton and a very long tube extends in between. I initially balked at the tube, which does not look great under my pink swimming costume or other items of that nature, but now I couldn’t care less.

The installation could have gone more smoothly. At the first consultation before agreeing to go ahead, the surgeon (did I detect a bit of a gleam in his eye?) said:

“Well, you won’t feel too great for a while...I am effectively STABBING you in the stomach” (gleam gleam).

“Uh...right”.

And afterwards, when I was complaining of pain, again: “Well, to be fair I have just STABBED you in the stomach.”

“Yes, I know...can you stop saying that please? It’s a bit creepy” (actually I didn’t say that, I just thought it.)

But ALL IS FORGIVEN.

It is wondrous. I have sat with friends in the garden having a drink — them with their G&Ts, beer or Pimms and me yes also with my G&T, Pimms, beer, or, my favourite, red wine (full of anti-oxidants). Them with their glasses and goblets and me with my syringe saying “Cheers!”. I particularly like smelling the wine as I drink it and can detect a good or average bouquet. But I am a cheap date because good old plonk is fine — can’t taste it anyway, but still hits the spot. Yes I know we are advised not to use the PEG for alcohol consumption but

hey, who's going to stop me? No one wants to be a killjoy — especially when joy is on the decline — you have to take it where you can get it.

I have my “food” to make up the calories I need but do not have to hack and choke my way through a meal. I eat if I want (as you've read previously). No more numerous attempts at getting pills down...all provided in liquid form or crushed, dissolved, and put down the tube.

I am convinced that the PEG has added to my life's quality and expectancy — with this throat infection I would have continued to drop more weight off, which is now not going to happen.

### **31st August**

**5.20am**

*My body fights against this pernicious attack:*

*It has no mind — that is separate,*

*It doesn't reason “why is this happening?”,*

*It just adapts and fights to preserve itself.*

*But it does not attack the cause.*

*It adjusts, and in that way it has lost.*

*Why can't it win?*

*Why can't proteins fold correctly?*

*If I could will it right,*

*If God would turn it around,*

*If life gave life instead of death.*

*If, if, if...*



Woke to another donkey-braying episode. Dawn breaks.

Darling daughter thank you for suggesting I write this book and for giving it to me. Have never had the inclination to have a diary — too busy. But as I become silent and no longer able to audibly say and share my thoughts and experiences, this little book becomes invaluable. It keeps me sane. Bless you darling.

## **1st September**

### **4.30am**

When you're in a long dark tunnel, you have no option but to keep moving forward towards the light. There is no way to go but forward. If you stop, you're really in trouble. I must keep praying and hoping for help — healing or learning to cope (preferably the former).

Yesterday had a fabulous time on a rowing boat with Ann and Rob at a beautiful nature reserve in a glorious part of the world. I discovered that I am still an excellent rower (if not better than previously). This was curious, and then I realised it must be all that pulling myself up the stairs at home. Although my right grip is going, my upper body strength is good.

Anyway, we began the trip in glorious sunshine, but 3/4 of the way along the heavens opened and we got completely and utterly drenched. We all raced back to the car, climbed in, turned on the heat to full-blast and stripped off (except for Hugh), with everyone politely averting their eyes. Getting into the flat from the car park in our underwear was done with great skill, with only one nervous Frenchman (fixing his bike) beating a hasty retreat.

**Note:**

Sadly, one of my greatest talents of shuffling playing cards like a pro is 'no longer', because my right hand doesn't have the strength to bend half a pack of cards. It was one of my party pieces. People looked on with great admiration as I effortlessly shuffled a deck with aplomb. Oh well, I suppose the PEG wine is also a party piece, so have replaced one with another.

**3rd September**

Had youngest son here and eldest son and family for Sunday Lebanese food. Granddaughter shovelling tomatoes into her mouth just like daughter used to do! Youngest son said he firmly believed I'd get a revolutionary new drug in time — I love his optimism and pragmatism. Seeing them all keeps me going.

**4th September**

First drug-free sleep in a while. Nice to wake up not feeling groggy. Had a lot of coughing fits yesterday. One was so bad I thought I had taken my last breath. Heart pounding, throat closed. Afterwards, I realised that bending over brings it on. I was bending down and sorting out the laundry. Solution very clear — don't do the laundry.

**6th September**

Wonderful day with two very close friends TOGETHER. Yes! After an altercation several years ago, they both told me they've set aside their differences because of me. Good result! Glad I could be useful in my own weird way again. So wonderful to be back to old times. This propensity females have for falling out is such a pain, but we all do it. You don't have Hugh walking in and saying: "I'm not seeing David

anymore — we've fallen out!". He rarely falls out with anyone. But I think it's because we rely on each other more and in this way make ourselves more vulnerable. The result is often deeper relationships with each other, and that can lead to more disappointment if we don't meet each other's expectations. ...Dr Suzy's musings! I hasten to add: I'm not saying that this is true for "all women" or "all men" — I know some men who have extremely deep relationships and wonderful friendships. But, in my experience, we women are close...and also vulnerable.

The main point is: when adversity hits, people rally. The beacon is focused on a greater need and we put aside our differences — a sign of great strength. I've seen a side to humanity I've not really seen so personally before. The compassionate side. I only wish I could do for my friends what they are all doing for me. It is so sad that I won't be able to do that; but one thing I've learned and didn't realise before is that it's not about reciprocity — I can't do that — it's about kindness and being 'human'. What a lesson.

I'm trying so hard to enjoy my life despite this foul disease, and it means accepting help at every opportunity. I've always been proud and resourceful — not needing help. My, how the tables have turned. How the mighty can fall.

### **9th September**

So worried about my daughter taking on too much — the love from my family is immense but it's wearing on all of them. Not fair.

New carer starting today. So needed! Suresha is Sri Lankan and has a wonderful calmness about her. I hope she can help us get back on track. Although they've all been committed to helping me by providing me with needed food, water, and a helping hand, I need/want to do the fun things with them. I don't want them to see me as a drudge and duty.

### **13th September**

Saw an old friend who I haven't seen in over 20 years. Why did we lose touch? When a diagnosis like this happens, people want to reconnect. I think it's genuine heartfelt sadness for you. Nice to see her.

### **Times I am most happy:**

With my family and close friends. Everyone was together at the weekend — to make macaroni cheese (with help from youngest) and a green salad with lovely Japanese dressing. Felt like old times (except of course I didn't eat any of it, but I had my tube wine while they all tucked in).

Have managed to regain control of the house with Suresha's help. Was such a mess and made me miserable, but is back to normal with Suresha as my legs and lifter. Everything clean and pretty again! Laundry sorted, dusting, etc.

Still losing weight — need to up the bottle feeds. Coughing GONE thank God. Was such a rough time.

Stephen Hawking says his work was one thing that kept him alive. But the idea of writing a research paper couldn't be less appealing to me. I

want to spend every minute having fun with the family — laughing and enjoying life — leaving positive memories. Maybe it's because it's only been a year since the diagnosis. Maybe I'll be content with writing research papers using my eye scan when (or if) I can't do anything else.

Right now I'd rather plan a Mediterranean cruise — how shallow of me. What happened to my career and my burning desire to “move the needle” in regards to business ethics? Oh well — maybe that drive will return, or maybe that period of my life is over for good. Right now, the world of academia and all the associated stress it brings is the last thing I'm interested in.

Made the most glorious pear and stilton soup yesterday. Absolutely delicious!

### **15th September**

Now that I can eat practically nothing, I realise that I would rather be fat than not eat. I miss food so much. The smells from our kitchen when my family make some delicious lunch or dinner kills me. But as soon as I try to have a mouthful, I regret it instantly. No matter how small, the tiniest morsel lodges halfway down my throat and either sets off a choking fit or threatens to do so. The Professionals are all kindly saying: “Perhaps you shouldn't eat now — we don't want you aspirating do we?”. “No we don't.”

### **My Arse**

I have always been known for my arse. Regardless of my weight, the arse was always there — sometimes smaller or bigger, but *always*

THERE. Imagine my surprise to note that it has disappeared! This is not good. It is my trademark. It seems this stupid disease has shrunk my beautiful arse. I've always had a love/hate relationship with it, but now that it's gone I want it back. My backside is FLAT. It's never been flat.

Saw Sarah Ezekiel on the news. She's lived with MND for seventeen years. Such a long time. She was diagnosed in her forties I think. I hope I can live a long time.

Had an intense prayer session with some very caring, well-meaning friends. They have been desperate to pray for me and so I agreed. But of course I've been down this road many times, and so it's hard to go through it. I would love to be healed. But the reality is that very few people are. I have to cope with this, and that means some acceptance.

### **Tirade about Devices for the Disabled**

I asked the occupational therapist for some support rails to help me get off the loo. I've been levering myself off using the wall on one side and pushing off a magazine rack — not very stable. The prospect of falling over with my trousers and knickers around my ankles and having to call for help is not a pleasant one. The hospice has sent over two loo rails. They are vile and I have decided to risk the magazine rack. They consist of a raised plastic seat with a hole in the middle and two rails on either side. I would rather die than use them. It's so UGLY (and I must add extremely uncomfortable.) I'm finding out that devices to aid the disabled are very functional on the one hand, but all made out of plastic for hygiene, and all aesthetically hideous. Attractive ones are needed — a good business opportunity? There are

a lot of us out there and I can't believe that how it looks isn't important to them. Do people think when you're disabled you no longer care about how something looks? Do they think that aspects of style and beauty go out of the window? Do they think that because it has a purpose what it looks like is irrelevant? What nonsense! If anything, to be surrounded by white and grey plastic and black black black is depressing, and it's even more important to put some thought into aesthetic design. Why are all wheelchairs BLACK? Things can be attractive and still cheap and cleanable.

**2am** I'm drowning in my own saliva. This is so awful. This slow death. No one knows how long I have, but the way I feel at the moment I can't have long. In fact I hope not if this is what I'm consigned to. I know it will get much worse than this. This is nothing. I can still use my hands to bring some relief — to crush a lorazepam tablet into a powder and put it down the tube. It would be better to die now — to let everyone get on with their lives. It's not self pity, I'm just being practical. Why have I been given this burden? Why me? What have I done? Have I been that awful in my life? What is required to save me from this? How can I cope at times like this?

I'm tired of being a burden on my friends and family. I want to help them, not to be the victim. I have always fought against being a victim. Stamped my foot and said 'no, I'm strong'. But finally I admit defeat. So low.

## **21st September**

This time last year, I was in the middle of a test to determine if I had MND; although, from the moment the specialist saw me in August

2016, he knew. I saw it in his face. He tried to be kind, but he is young and I could see he was certain. A positive EMG and brisk reflexes with his little hammer, plus the state of my tongue told him all he needed to know. So the next 3 months were going through the motions of checking there was no other cause and giving me and Hugh time to come to terms with it. I remember Hugh saying to him: “But it’s so rare — she can’t have it”, and him saying: “It doesn’t matter how rare it is if you have it.”

On my 60th birthday I knew the diagnosis and this was confirmed a week later. What a rotten birthday that was.

So... This year is going to be different. I have had such wonderful support from family and friends and have decided to have a party of my daughter and girlfriends (and dog), women only — the ones who have been really amazing — the core ten. I’m going to give a speech which I’ll programme into my phone to speak using my voicebank software. Yes, back in October, I did a voicebank. Ten hours of recording my voice while it was still relatively unaffected. I’m so glad I did that.

Birthday speech:

“Thank you my gorgeous friends for your amazing support for me this year. This year is better than last year because I’ve discovered what true friendship really is. You have not left me to wallow in self pity, but have texted, rung up, been available for coffee, taken me out for retail therapy, taken me on holiday, lifted me up (sometimes literally), helped me to find a carer, buy a fridge, plant rose bushes, get fabric to cover my lovely special chair, chose bathroom tiles — the list is endless. But



most of all you have brought me yourselves to help me feel cheery and normal. I don't know how many more birthdays I'm going to have, but having the privilege of you as my friends, I know I'll get through them. And if I can't communicate so well, please remember this: I am so grateful and really love you all. I'm so lucky to have you as my friends and I'm only sad that I probably won't be able to return the favour — unless of course we have a miracle, which is always on the agenda.”

Lovely homemade Sri Lankan curries made by Suresha. I'll probably be on tube red wine — always a winner.

## **22nd September**

**3.30am** It is only when your life is being slowly taken away from you that you realise how precious it is. It throws what you have, the people you love, into sharp relief. And what matters becomes clearer. I have always wondered what the purpose of my life is and was driven to discover this. I thought, “If there is no purpose, there is no point”. But now I realise that the purpose is to **BE** — to realise that what matters is being able to persevere with love. To love and be loved. To rest in **BEING**. That's all. Not to be the best — to have the most money or power, or to be the most popular, but just to enjoy **BEING**. To appreciate the life given to us. To accept the gift and cherish it. To never give up and to live fully.

On 20th daughter-in-law sent a video on WhatsApp of granddaughter's first steps! Momentous!! She almost managed it with us on Tuesday, so they decided to set up a camera in the hope she would, and she did a proper walk! What a wonderful thing to have on film. She is the most adorable little girl. I love her to bits. I never knew that being a grandma would be so amazing. A continual reminder of my eldest when he was that age. The most perfect, sweet, happy, beautiful little being.

Have discovered a wonderful thing. The Professionals have put in a hospital bed downstairs so that I can adjust my posture for more comfortable sleeping. Result? No more coughing! I was wakeful but not due to coughing, and today my voice is stronger and I feel so much better.

### **23rd September**

Eldest has done a shedload of research on causes of ALS and has identified a buildup of ammonia as a possible factor that exacerbates it. So my new supplements will contain elements to reduce ammonia buildup. He has spent so much time on it — what a sweetheart he is.

### **25th September**

Party went well. I delivered my speech via my speaking app on my phone and everyone understood it. They said it sounded like the old me. This was a great comfort. To be able to communicate with my voice really matters. So glad I did the recordings way back when I could talk so that they could create a good simulation. I've listened to English voices and American voices, and it would have been less satisfactory to have to use one of those (although better than nothing).

My mid-Atlantic drawl is sadly not catered for by those off-the-shelf apps.

### **Birthday presents!**

Two beautiful paintings of old memories, a wonderful furry blanket, scarves, and an amazing cake with an icing sculpture on the top of me in my little pool with our dog Truffle and my granddaughter. What talented friends I have!

### **Reflection**

An old friend thinks I need to not “accept” this disease. To not let it become part of my identity. This is tough. Not accepting it makes it hard to live, because at every turn you are thwarted by some new symptom and bashed by reality. Accepting it brings some relief. Being aware of what may come next helps you cope. And thinking: “I have this, but I will live each day to the full” is easier than to deny it. To say “NO!” is...I don’t know. I did that early on, but it was relentless. It didn’t matter that I said “NO” — it kept right on coming.

### **Preparation for Portugal**

Never realised how complicated it is going abroad when you have tons of medical bottles and stuff to take. Marie has kindly offered to help me pack, and boy, do I need it! Am amazed at her organisational prowess. Everything folded neatly, and all meticulously arranged. Never realised the true art of packing and the sheer skill and orderliness of mind required.

Virtually a truck load of food has arrived for our trip because I’m now only on ‘Nutricia’ food bottles. Also a pump and associated bits and

pieces. I think one needs a PhD to work this out. Thank God I have one in Computer Ethics — *really* helpful at this point in time...

## **PORTUGAL (Algarve)**

### **2nd October**

Had a stunningly special evening on the beach on my birthday last night. Asked God if I could have a beautiful sunset and he obliged with the most glorious display I have ever witnessed in all my years of coming here. Spent hours on the beach with beautiful family — incredibly special birthday. Sadly youngest couldn't make it which was hard indeed.

### **3rd October**

I have had no cough for three nights. What a difference it makes to get a good night's sleep. No choking fits either (which are related). It's so restful here. I've decided to completely steam-clean the carpets and curtains at home in the UK as I'm wondering if dust might be making things worse for me.

Lots of granddaughter time! I think she really loves her grandma! I hope we can keep our relationship going even if/when I become incapacitated. I hope so — she is such a dear sweet girl.

The way I'm feeling at the moment I'll be around for a while. More birthday presents! The most beautiful photo book from daughter, a sound system and fluffy towel from Hugh, and eldest has said he wants to make an album of my old songs from my previous life as a singer/songwriter to put on Spotify or iTunes — what a thoughtful idea.

I realise how so much of my life has revolved around food. Probably my upbringing — a mother who has an entire wall devoted to cookbooks, I have travelled the world and remember places partly defined by their cuisine. Grew up on sushi in Taipei at the age of 11; Dim sum in Hong Kong all through my teens, along with other culinary delights. The battle I am facing to abstain from my favourite morsels is overwhelming. In Portugal the sourdough bread, green tomatoes, garlic clams, and Marufo's CHICKEN with Peri Peri. As everyone tucked in tonight I couldn't help myself and decided to have the odd bite. Thought I'd spit it out, but having no control of my tongue, before I knew it, it was in my throat causing a coughing fit in the middle of the restaurant — *so* embarrassing. Was it worth it? Not sure. But I consoled myself with a fair bit of tube wine and now my writing is probably a bit screwy.

Anyway, we had a lovely day at the beach. With eldest on one side and Hugh on the other, I made it into the waves and had a dip. I was aware that my swimming is no longer strong, so they stayed with me. Such fun. I hate the thought of not being able to swim in the sea — or swim at all for that matter. It's such a very special thing for me. I've seen a wheelchair ramp on one beach — so maybe it will be possible...

A main issue on the beach is that, once I'm on the sand, I battle to get up again. I watched my little granddaughter struggling to balance and thought how similar we are. At one point, she was doing her shimmy crawl to try to get to where she wanted and face-planted right into the sand. Came up with a face full of sand but was unfazed. When we were packing up, I was trying to get up and also face-planted! The

whole side of my head covered in sand. I really relate to my baby granddaughter. We're like on convergent paths, but will then deviate as she comes to full maturity — who knows what her future will hold? Athlete? Musician? Artist? And I...well, my challenge is just to survive as long as possible.

#### **4th October**

#### **CONUNDRUM**

People with MND often choose to end their lives in Switzerland or somewhere like that — to be in control, I guess. My real concern is the burden on my family if I stick around too long. And also of course being “locked in”. So the burden falls on them in terms of when to end my life. This is one of the worst things about the disease. Anyway, hopefully I have at least a few years to go before this issue requires attention. I must concentrate on living until then — not on the method of my dying.

They're all sitting downstairs having my FAVOURITE FISH — Garupa. The King of fishes. I first had it in Hong Kong. I have decided to avoid a torture I've been putting myself through every night by sitting at the table while everyone tucks into my favourite dishes. Invariably, I decide to “try a small bite”. But now I'm going to excuse myself. Why put myself through it? It's just not worth it.

Had a rapturous massage by the lovely Rita this afternoon. The woman has magical hands. I found some feeling in my right foot that has not been working too well. So nice to feel that.

I miss my youngest — so noticeable when everyone is together but he isn't here — it feels weird. There's something very comforting about him. He makes me feel...calm and OK.

### **7th October**

Some rough coughing fits over the last few days.

Went to beautiful Fabrica beach for razor-clam rice. One of my favourites, but sadly was unable to eat it. Took the boat over to the sand bar and had a superb time on the beach. However, I am doing all of this walking supported by family. If I'm not in the wheelchair, they are literally holding me up. It is exhausting and rather precarious. I am conscious that my balance is really bad and I could go over at any moment. I think I may need to cut my activities a bit. Am loathe to but if I fall and do damage then that's me really out of action.

Despite myself I can't help thinking about the fact that things are going to get worse. It's very sobering and my joie de vivre is really taking a hit. Can't help thinking: "In six months, what will I do?"; "When will I no longer be able to support my weight?"; "When will my breathing start to go?"; "How will I cope with day-to-day things?"; "What is happening to me?"; "I'm no longer the person I was."

I want to be in bed and to do something distracting, not thinking. I don't want to try anymore. I'm not strong.

*Why try?  
Why persevere when its clear  
The time to go is coming?  
I've been given a sentence,  
It's just a question of when.  
What a battle to fight  
With the odds stacked against you,  
It's just a question of when.*

*I wish I could stay  
Be healthy and strong again  
Live out the rest of my years  
Watching my beautiful family grow.  
Being there for them  
Oh well, that's life,  
It's not about fairness  
We already know that.*

*I am grateful for the time I've had  
But this is hard.*

### **Similarities with Granddaughter (at aged one year)**

We both:

1. Have feeds (although mine isn't milk and is through a tube).
2. Have mashed food (although she's already overtaken me on this. I don't really have food at all now).
3. Are quite unintelligible, although she is a lot cuter than me.
4. Need help walking.



5. Face-plant in sand on the beach.
6. Drool.
7. Cry when unhappy.
8. Like honey-yogurt.
9. Choke on some food (but win in the end).
10. Have cool punk hairstyles.
11. Like Roy Orbison.
12. Have fat cheeks.
13. Like shiny objects.

### **8th October**

*Blessed are those who trust in the Lord  
whose confidence is in Him  
They will be like a tree planted by the water  
that sends out its roots by the stream.  
He does not fear when heat comes;  
its leaves are always green.  
He has no worries in a year of drought  
and never fails to bear fruit.  
(Jeremiah 16:7)*

I would like to have that level of confidence in the Lord to be able to operate even in difficult times like these.

### **9th October**

Oh joy! A GLORIOUS swim in the Algarvian sea. Calm, clean, cool, sunny and turquoise blue. So heavenly. Hugh took me down and, despite the rather treacherous path to get there, with his help I made it

into the gentle waves. Once I'm in I'm fine, but it's getting there that's the challenge. Walking on sand is not conducive for someone with a balance issue and a rather floppy right foot, but it was worth the risk. My wonderful husband is so strong both in spirit and physically. This morning I was lying in bed with him thinking how beautiful his hands are. They're rugged and strong. I've always loved his hands. And now they hold me up as does he with determination to help me get through this. I am blessed to have him by my side for the past 40 years.

### **15th October Kingston Hospital DAY 2 WITHOUT THE PEG**

After fourteen wonderful days in the Algarve, disaster struck on the last day and here I am, having returned to the UK, in Kingston Hospital. My PEG tube is blocked. This means that I've had virtually no food or drink for two days. Not good.

It began in the morning. When putting supplements in, I noticed it just stopped working. We spent literally hours trying to unblock it — we even tried gin! But it's like concrete. So my homecoming is admittance to the Acute Assessment unit — Bay 6. Surrounded by people snoring and playing the TV loud (why is that allowed?!).

I am here to get the PEG unblocked as quickly as possible. If they can't unblock it the only other option will be surgery to have it replaced. In the meantime, I have been a pin cushion as they insist on taking blood ALL THE TIME and of course installing a drip to rehydrate. Taking blood when one is dehydrated is problematic, as my poor arms and hands will attest to — now covered in bruises from unsuccessful attempts.

But there is a determination to get it unblocked, with surgery only a last resort. One nurse is particularly proactive, remembering a patient whose tube unblocked with the aid of a type of enzyme with bicarb. We'll see if it works — I hope so.

## **17th October**

### **DAY 4 WITHOUT THE PEG**

Two nights now in AAU. A complete nightmare. Wish I could find something to find amusing, but sadly my sense of humour has taken such a battering. All through the night, beeping machines going off every time someone disconnects to go to the loo. Lights blaring when someone calls (surely the nurses don't NEED to turn ALL the lights on?) — poor people so sick. Feel particularly sorry for a girl with cancer who's ended up in a bed near the loo. Every time someone goes to the loo, the light and fan switch on. She must be well and truly fed up. But I think she is so sick she doesn't care.

I have developed a raging strep throat which is of course like being kissed by death for someone with Bulbar Onset. Surgery was put off yesterday because the Registrar wanted to try to unblock the peg himself first. But, as I suspected, he was unable to do so. I had been given nothing to eat ever since I arrived as I am scheduled for surgery. But because no one really wants me to go through that in my condition, it keeps getting postponed. So I am literally starving. Of course there is very little I can eat, but I would have tried soup or something. I'm losing more weight I'm sure — which is the last thing you want to happen with MND because you lose muscle.

Surgery scheduled this morning — I can't see how I can go through an endoscopy with this terrible cough and sore throat.

### **Maggie**

Several days in, a new inmate arrived on the ward. Maggie seemed incredibly old — I would have ventured about 100 (turns out she was 99). Everything she said she shouted so we couldn't help but become involved in her day.

Maggie: (To all the male nurses) Love your hair. Hee hee hee (very high and very loud) (Loud cackles)

At dinnertime she proved recalcitrant.

Nurse: Maggie don't you want your dinner?  
Maggie: No — take it away — TAKE IT AWAY!  
Nurse: But Maggie you need to eat something  
(coaxing with a spoon)  
Maggie: NO! — now bugger off  
Nurse: Please just try it — look! It's very tasty  
Maggie: Don't fucking want it now why don't you just  
leave me alone and piss off? Hee hee hee!  
Maggie: Wheeeee!! (more loud cackles)

She finally ate some when a male nurse she found particularly attractive sat down and gave it to her. He was the only one she would let feed her.

Maggie was great entertainment on a ward that was otherwise abysmally depressing. She didn't care what anyone thought of her. Okay, she was a bit demented but she seemed happy and was being looked after. Daughter and I decided she was the most fun of them all. I have to say everyone was so sick that it's understandable no one felt up to being friendly — including me — but Maggie helped us all to crack a smile. She said what we were all thinking.

### **19th October**

Miracle of miracles: at the eleventh hour a wonderful woman (nurse) named Ann Marie arrived for a last ditch attempt to unblock the peg. Using a rather ingenious method involving the insertion of a smaller tube inside the PEG she then flushed it through to get right to the source of the blockage. After about 45 minutes, with daughter assisting, I suddenly felt a “pop” in my stomach and eureka! The fluid flowed. Blessed Ann Marie — may she live long and prosper. Will nominate her for sainthood.

Meanwhile while all this is going on there was a bit of a kerfuffle on the ward. Nurses suddenly started appearing looking like something out of *Breaking Bad* — complete with masks, gloves and plastic aprons. So on instructions to begin feeding me up, nothing happened. I later found out this was because the woman in the next bed to me had suspected flu. And the ward went into lockdown. We were all isolated and it became pandemonium. Sick people who had had no sleep due to the constant changeovers from A&E were struggling with limited care. I was tethered to my drip and needed the loo desperately but couldn't get the nurse's attention (partly due to my inability to speak).

I noticed my throat becoming increasingly sore and I knew I had caught something. I was desperate to get out and was discharged that night — daughter arrived to the rescue.

On arriving home had a lovely bath and went to bed. Woke at 1am unable to breathe. So much gunge in my throat — and breathing like my old asthma — long since gone. 999 had to be called and I ended up back in hospital. This time (having come from the locked-down ward) given my own room, complete with masks, aprons and gloves for all nurses and visitors. Discharged this evening — two nights later.

The moral of this story is:

1. Do not put anything down the tube that has the potential to block it — no supplements in granular form. **NOTHING.**
2. If hospital is unavoidable, beg, borrow, lie or steal to get a room on your own.
3. If a nurse has trouble getting blood, physically *pull the needle out*, don't let them keep digging. For them, it's the pride of succeeding. For you, it's the state of your arms and hands and the pain it puts you through.

When you are disabled you have to find another voice to be heard. It's tempting to shrink into oneself. But we have to be **BIGGER**. Everything is such an effort, but it's important to persevere or you sink. I sound terrible when I speak. This is particularly difficult for me because in my earlier life I was a singer and later a lecturer — known for my ability to project my voice but also to express with a melodious tone, full of character and feeling. Now it is rough and garbled. But I

am learning not to care — otherwise the danger is to retreat into yourself and that leads to a lonely life. People often don't let you finish typing when you use text-to-speech. They even walk out before giving you time to answer. They ask a question then don't look at you. All very frustrating, but this is the new me. Will make it work. This is reality.

During my time in hospital, the family rallied as they always do. Everyone with me. Everyone helping me. The nurses were so impressed with our solidarity. What a lucky person I am.

### **20th October**

First day home. Had a good night and woke up feeling much better. Created an extremely impressive spreadsheet of all the medication I'm currently on — more added from the hospital. I have a multitude of bottles covering tables. Could open my own illegal pharmacy or become a drug dealer — hey, there's an idea!

I now have a suction machine. Really gross but it is so good at getting the gunk out of my throat, so I'm thrilled to have it. Funny how one's priorities change. Whoever thought a suction machine would float my boat (or my phlegm)? Also have a puffer (inhaler) but I'm not so good at timing to inhale — apparently I need a 'spacer' which is now on order.

You will notice, diary, there's been nothing about food in the last few pages. This is because I've given it up. Just not worth it. Result? No choking for ages.

## **23rd October**

Relapsed with:

1. a cracker (what was I thinking?)
2. Ice cream

Neither attempt went well.

I MISS FOOD!

## **24th October**

Now on a food pump that sends liquid from 500 or 1000 ml bags into my stomach via the PEG. Rather than a ritual of five bottles a day, the pump dispenses the required calories over an extended period of time. I thought it rather complicated when I first saw it, but actually it's very easy and saves a huge amount of hassle. I can walk around with it — connect and disconnect — and it means no more syringes to be filled and manually administered...other than to flush the tube, extra water, meds and supplements.

Hospice nurse called today. She had heard about my hospital visits and wants to visit me with a doctor to discuss DNR (do not resuscitate) wishes. When Hugh told me I burst into tears. Such a shock when other people bring it up, although Hugh and I have talked about it and have prepared a Living Will and Lasting Power of Attorney.

The beautiful downstairs bedroom with en suite wet room they are building for me is coming on so well. I hope I will be around to enjoy it!



## **26th October**

Long day at Hospital in Queens Square, London, to visit my neurologist and a respiratory doctor. My neurologist is lovely — so positive and supportive. Says progress is very slow. She says it feels fast because it's affecting muscles I use a lot, but that's not the reality. She says I should be around for quite a while. I hope she's right. Respiratory doctor says CO<sub>2</sub> too high and that I should go on BiPAP (which is a machine to help breathing) at night. I will be scheduled in for two nights in November to have it calibrated for me. So, some good news and some not so good.

Beautiful beautiful day yesterday — fantastic weather and Hugh and I went to Box Hill. Used to climb it, now we drive to the top and sit on the ridge. What a stunning view. Used to love going to the pub in Mickleham afterwards for lunch and drink. Miss that.

People always comment on my outfits. It's true I enjoy looking nice, but for me it's more than that — it's a form of expression — a craft, to give an insight of who I am and how I feel on a particular day. When I was young I dressed for men. Always wanted to be attractive. When I hit middle-age I dressed for women — colleagues or friends. NOW I dress for me. At last. Took me long enough not to be so concerned about what others think of me. For me it's:

1. Comfort above all else — must be soft not scratchy, loose or at least not too tight.
2. Often a bit of sparkle somewhere.
3. Colours that often reflect my mood.

Maybe it's because I don't create much professionally or cook now, that what I wear is even more important to me.

### **1st November**

Wonderful husband suggested I use an external bluetooth keyboard with my phone. Wonderful number two son helped to set it up. I had been using the Predictable app and have found the predictive text selection method quite slow. I'm an extremely fast typist (or I was) so once we connected the keyboard suddenly this sped up my conversation dramatically. It's amazing — I can now type my answers quickly and be part of a conversation with my Model Talker voicebank. Only fly in the ointment is that my right hand is getting weaker (I'm left-handed) so I don't know how long I'll be able to type for — but a wonderful freedom to be able to converse much more easily. Long may it last.

### **4th November**

Nasty fall yesterday. Was just trying to get a cup from the sideboard. For a normal person, a harmless enough activity. I turned around and misjudged the step. Went over backwards and took down the dining room chair with me. Cracked the back of my head on the wall. Lay there bruised with the pain pounding in my head. Hugh came running. The simplest thing is so risky now. I literally can't trust my feet or right hand. Very unhappy to feel my freedom ebbing away. This house was my domain. I kept it in order — will be hard to do that but will find a way. Lesson to be learnt — don't be stupid trying to do things that involve:

1. Steps

2. Turning round in tight places
3. Small areas where a frame can't go
4. Uneven surfaces
5. Slippery floors

### **6th November**

Nin took me to Colets for a swim today. Just what I needed. Physical exercise makes me feel so much better, but it's shocking when you realise what you can no longer do. I was such a good swimmer, but today I battle just to stay afloat. I've been known to do over 100 lengths of a 50 meter pool easily, but today even one was so hard. However, I persevered and it got easier. Also the club had these webbed gloves which helped a lot because I cannot keep the fingers on my right hand together. Legs rather dis-coordinated too, but had such a great time. Told Nin I felt almost normal! She commented that she hoped I wasn't becoming normal, saying I've never been normal in my life — why start now? It's excursions like this that keep me going — thank you, wonderful friend.

### **New Approach to Brushing Teeth**

Yes, who would've thought the most mundane of tasks could become such a trial? Have been struggling with this for a while because my jaw often jerks and closes (which results in biting the brush) and because my swallowing is so dodgy. Electric supersonic toothbrush made it worse as the water splashed back into my throat. I have found a combination of normal brushing and clamping my teeth together with the brush on the outside so that it doesn't trigger a coughing fit, and putting the toothpaste on my teeth but rinsing it off so it doesn't sud when I brush with the supersonic.

## **7th November**

Well it has been over a year since my diagnosis. I'm still standing (just about — with help). No longer eating or drinking or speaking (other than in my strange dialect that only the initiated can decipher). But I'm alive and kicking and I thank God for that.

I posted on Facebook asking if anyone would like to type up this little notebook for me. Who knows? Maybe it will be useful to someone. I had some lovely replies and volunteers. But first come first served... And the winner is... Rob! Thank you so much; I hope it isn't a trial and that you have some laughs (and maybe some tears) as I have done. In the meantime, I will begin my second notebook.

If you are reading this and feel disappointed that you are not mentioned, please don't be. I hope there will be plenty more notebooks to come where all my dear family and friends will continue to feature highly. As you are indeed the stars of this show.

## **Most exciting development**

After extensive research by all of my family we have come to the conclusion that the most promising medical advances in MND are coming from Brainstorm in Israel. They have just announced the start of a phase 3 trial in the States and Israel, and earlier trials are actually showing a halt in progression and... in some cases, actual reversal. This is extremely exciting. Results will be in early 2019. Perhaps too late for me, but how amazing for all those coming after. And who knows — maybe — just maybe I'll make it to get the benefit. We can but try and hope.

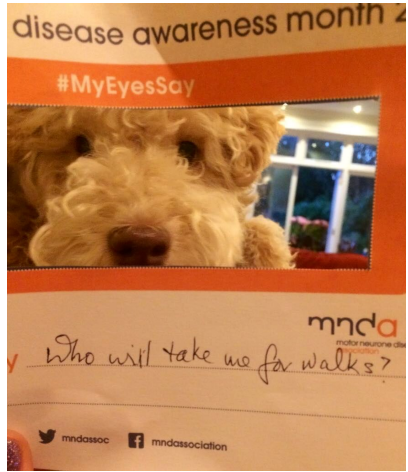


Walking the Coleridge Way, March 2017



South Africa, April 2017

















SUZANNE JAGGER IS AN EMERITUS FELLOW OF ROEHAMPTON UNIVERSITY IN LONDON. RAISED IN CALIFORNIA AND HONG KONG, SHE NOW LIVES WITH HER FAMILY AND DOG IN SURREY. 'BITTERSWEET' IS HER FIRST BOOK.

