



Personal Story
By Saskia Blumer

Write below was an email I sent out to all my friends and family a few months ago, in an attempt to convey what my situation has been and to raise awareness for this little known illness. Having not seen me and not on social media for so many years, people were curious as to what had befallen me and my family had a hard time trying to explain to everyone what was happening. This email doubles as not only an informative description to those unaware of the severity of this illness, but also as something relatable to my other fellow sufferers. I hope it can bring some comfort to those brave warriors during their battle, and to make sure they do not feel as alone as I have felt for so long.

Dear Family and Friends,

I thought it was about time that I finally opened up about this purgatory that has been my life for a few years too many. I hope this gives you all some insight and can make you better understand my side of things.

I first got sick with Meningitis in May 2015 in Australia, age 19 whilst on my gap year. What ensued I can only describe as a hellish nightmare, that has not yet ended. The first of 3 bouts of Meningitis very nearly killed me, and as I was so weak, another savage illness crept in and has ravaged my body.

Now, as you may have calculated, I have been very ill for over six years now, but one of the hardest things has been trying to get people to understand just a fraction of what it has been like. Imagine trying to explain to someone what salt tastes like when they have never tried it. Even Mum, who has been with me through this whole process and seen me almost everyday and witnessed my suffering, still can't and will never be able to understand. Only a fellow severe myalgic encephalomyelitis (M.E) sufferer will, not even a mild sufferer, as it is such a different illness from stage to stage. Severe M.E is in a league of its own. It is a like like comparing someone who has a cancerous mole removed v.s someone dying of a brain tumour, all under the same umbrella. Some woman said to Mum "oh I totally get what Sas is going through, I can't lift all the weights at the gym and I can only workout a few times a week now". Not helpful. Bless her, she of course didn't realise what she was saying, but she assumed we were the same, as we both had M.E, she had it mildly so our experiences are completely different. I need

to point out that M.E is NOT the same as Chronic Fatigue Syndrome (CFS), it is CFS plus a whole load more. So I guess what I'm trying to say is that people can say offensive or stupid things simply because they are ignorant of someones situation and don't actually take the time to educate themselves on what someone else's illness or situation is. This applies of course to lots of other conditions; anorexia isn't simply the will not to eat, OCD isn't about rearranging cushions and washing your hands, cancer isn't walking around with a scarf covering your bald head. Unfortunately, society has coined up stereotypical images and phrases pertaining to various illnesses.

I have noticed that it is my real friends who have taken some time aside to try and understand or really asked about me and what I'm feeling, what I do all day, how my appetite is or how much physical pain I am in. Many people suddenly turn into experts and dish out random advise as if you haven't been researching EVERY cure and remedy under the sun... in my case the "advice" I have been proffered has ranged from turmeric, coconut oil, to gold cordial, cannabis, hypnosis, horse therapy, stem cell transplant, blood transfusions, kidney transplants, chemotherapy, aromatherapy, acupuncture, acupressure...acu-fuck-off thank you very much.

I understand they only have good intentions and they don't mean to be offensive or sound ignorant, but what may help cure you of a common cold, just ain't gonna cut it for this illness, it is a very complex ailment that goes down to a cellular level, even doctors don't understand fully. Unfortunately because very little is actually known about this illness so there isn't really any advice or help or treatment one can seek, so in that regard one is totally blind and alone and it is simply a case of trial and error, keeping the pain down and trying to improve the quality of life. A leading expert in this field had said that "a person living with severe M.E has the quality of life and experience as that of a terminal cancer patient in their last few weeks of life". So imagine that but with no ending.

As for me, I thought I'd give you a brief update and small insight into what life (or lack there of) has been for me. I have found it hard to open up about what I have been/am going through, feeling like it was shameful and that no one wants to hear about it or that is 'simply isn't discussed' (so bloody English), but I have opened up to a few people in depth about it and their responses were not only appreciative but so kind that it made me feel less alone. This process has been so cathartic, and I only wish I could have had the strength to do it sooner, but this is proof that I am on the up. I am still frustrated that I can't and will never be able to convey the full extent of all this, it really is the tip of the iceberg! My account has by no means been exaggerated for dramatic purpose, but actually dulled down, as I said- no words can really describe the extent of it.

Now firstly, I have to point out that I HAVE FINALLY MADE SOME PROGRESS! It was always a rapid downhill slope, with no end in sight, but finally after 5 years, the tide started to turn. The very fact that I am typing out this email to you proves it, as year ago I would not have been able to do so. I turned a corner about a year ago. I don't know what happened in order for me to start getting better. I didn't do anything differently, I hadn't started any new alternative medicine or therapy- it just slowly started happening. At first I was most confused, and I did not want to jinx it. The irony is, that just before my turn, at my lowest point, I had actually pretty much given up. I surrendered completely and was just waiting to die and stopped fighting it. Maybe it was that peace of mind and that surrender which kick started something, or which ignited a spark to life. The really frustrating thing is that if I am ever to go downhill again, I would not know what to do

to fix it, or indeed, be able to help anyone else. I can hardly tell them to just give up and be willing to die, as that may not work for them, and I would have that on my conscience.

Slowly, slowly I started to get some energy and the pain dulled down a bit- it hasn't gone by all means, I am still in it every day- but the pain feels more distant and less intense... When I say pain- I mean unending, relentless stabbing, aching, stinging, throbbing, burning, cramping, gnawing, shooting pains all over all day. I didn't realise your eyelashes could hurt- but they did. No medication I tried from serious opioids and panadol to white willow bark, chamomile and cannabis would even touch the pain, so there was no salvation, apart from riding it out until the next lot of pain, one overlapping the other and so forth, the only escape being this few hours of peace in which I slept. My headaches get so intense that all I can do is literally assume the foetal position, and clutch at the nearest object until my knuckles turn white. The headaches never go away, getting so bad I would either vomit, black out or be unable to string a sentence together, forgetting what simple words were. The migraines I got that were concentrated behind my eyes would give me a mini seizure, and my muscles would spasm so much so that one eye would not be able to open for a few hours. My hands would sometimes seize and turn into a crab claw which also took time to release.

I couldn't bare to have the duvet or clothes touch my skin (it felt like a cat scratching a sunburn) and water from my sponge baths felt like it has acid in it (mmmhhmm I had to be washed, as I couldn't do it my self).

The pain was so scary at times, all I wanted was to be held and cuddled by Mum but I couldn't stand to be touched. My skin on fire, and my flesh still feels permanently bruised, so any pressure is uncomfortable. It is almost as if someone has peeled off my skin, soaked my muscles in acid, then sewn me carelessly back together again.

Being in pain of course makes you tired, I am already absolutely exhausted all the time, the word exhausted doesn't even cut it, there should be a whole new word for this kind of feeling. The closest thing I could equate it to, which some of you may be able to envisage, is the almost drunken delirium you can experience after having pulled 3 all nighters in a row, with absolutely no sleep in-between. In a cruel twist of fate however, I am unable to sleep, getting only an hour, maybe two, a night... I even tried sleeping pills but they just made me hallucinate (I mean tripping big time and not in a pleasant sort of way)!

With my illness- the body does not react 'normally' to almost everything. If you're tired, you sleep, when you drink you quench your thirst, when you take pain killers, the pain goes away...not with M.E. The body becomes ultra sensitive and all your senses are heightened. Thats where not being able to tolerate light, sound, smell and touch comes in. I don't just mean that you find it uncomfortable, but I mean it is simply impossible to endure, even for a second. JUST NO.

I was trapped behind black out curtains, with the length of them actually stapled to the wall so not even a peep of light came through, and even mattresses were stuffed into the windows to try and drown out the sound of birds. Every little song of theirs felt like screws being drilled through my ears into my brain- they even started bleeding sometimes. We had to give away two of our dogs as they barked too much, and the sheer pain of each sound they made, was unbearable. It

feels as if everything that emits any form of decibel has been put through a megaphone. The same goes for human voices, one has to whisper around me.

Noise cancelling headphones would be a God-sent, if only, if only. As they are designed to take away one of your senses, automatically all your others are increased, and with all of mine already being in overdrive, it gives me a similar sensation to sea sickness, so, that solution is out of the question for day to day, and they are only used in extreme emergencies. My blackout curtains have now been replaced by regular ones and remain drawn at all times, and I wear sunglasses indoors. Every light fixture and lamp in the rooms I use have been covered in blankets so that only the minimum amount of light required to make out the silhouette of objects is used.

Any time I tried to solve a problem, the solution would create new problems. For example I always have really bad tummy cramps and serious swelling/bloating and the only relief is when I use a hot water bottle (more like lukewarm) to sooth it. This helps ease it a bit, but because my skin is so sensitive it burns it, which in turn blisters... come next day, my tummy swells again, so much so that the blisters burst and bleed from the skin being stretched, but again the pain inside my tummy is so bad I have to put the hot water bottle on, which makes the burns worse and so on, the cycle continues... I have some pretty gnarly scars as a result, but luckily I don't have to use the hottie everyday now, only occasionally.

Every time I cry from the pain and frustration of it all, the tears burn my cheeks as they run down, leaving little crimson paths, and my headaches get even more intense, so I cry more, so the vicious cycle repeats. At times I find myself feeling sorry for myself, and I just have to think, it could be worse, I could be going through all this totally alone, without help, without a home, or living in a noisy city. I could be paralysed, or been on a life support machine, so be thankful you are not.

So many things the body does which you take for granted changed or ceased all together. It is so sad being betrayed by one's own body, something on which we rely on for every single thing, then turns around and is the source of all your pain and suffering.

Every little thing feels different now, from the feeling of my heart beat. Similarly, the way breath feels as air is drawn into my lungs, it feels heavy, hot and smoky. The dexterity of my hands- the brain telling it to pick something up, but there being a lapse in time before my fingers actually clench at an object, and I drop things all the time. When I drop something, that little shock, sends adrenaline coursing through my body, and first gives me the sensation of my stomach falling, like when you are on a rollercoaster that suddenly drops, then a wave of dizziness and fainting ensues. That happens at every little fright. Every emotion, sensation and physiological reaction is exaggerated.

Every movement feels as though you are swimming through treacle, as your limbs are not only stiff but heavy. Every day that goes by laying in bed, the muscles deteriorate further, until it lacks the strength support itself. I could go on and on about this. If I were to list every single body part, from eyeballs, to toe hairs, I can tell you precisely what different kind of pain each part feels.

I am constantly aware of every part of my body. If you think about it, you never notice your pinky toe, or ear, or kidney, unless it is injured or malfunctioning, then you are made aware of it

through pain or discomfort. I am reminded every day of every part of my body, and it is always in a state of pain or discomfort.

It is amazing however, what your body does for itself when it is in survival mode. I have lost hair and eyelashes/eyebrows, nails don't grow and all non essential functions get put on hold. However there are a few eyelashes beginning to sprout... but I don't want to jinx it! I lost my period which I had mixed feeling about, joyous in many regards (any woman would agree) as they really are awful, and I would not have been able to handle the cramps and fatigue on top of everything else, but at the same time I really don't want to end up being infertile.. which is unfortunately the case with a lot of women with this illness. However, a few months ago, IT CAME BACK! Sorry, I know you probably didn't want to know that but as I said, we're getting real and raw in this account. To be honest if you are getting squeamish about period talk in 2021, then Houston, we have a problem!

Food, which had always been such a passion of mine, both creating and eating, was somewhat ruined. Obviously unable to cook, but I as I said, I am so sensitive to smell and taste and anything I eat or drink always causes clenching cramps, no matter how bland. I couldn't keep tea down, but I am now able to drink it, and my oh my, never underestimate a great cuppa.. 4 o'clock is now my favourite hour of the day! The teapot is still too heavy for me to actually lift, so I have a wee little one, but that only means I get one cup... One does not simply have one cup of tea.

I never felt like eating due to the constant nausea caused by the pain, and still struggle, but I forced my self to eat most of my meals which were mainly liquid as chewing was too strenuous. Sometimes I had to be spoon fed as I could not lift my arms up, and or the terrible tremors I got made eating a rather messy affair. As a result, I dropped down to a measly 43kg. I have now regained some of that weight and look and feel much healthier for it. Looking a bit less zombie like too as the black circles under my eyes have lightened. I think they were caused not only by a serious lack of sleep but also bruising from the migraines, as my eyes felt like they would pop out at times. My skin is actually a translucent grey colour, with my blue veins shining through, showing an intricate map of my inner workings, a complete contrast to the permanently tanned olive skinned and voluptuous girl I once was.

This illness has shown me that it is not about how physically strong you are, nor how academic or intelligent you are, but how emotionally resilient you have to be. You are stripped bare of your dignity, your confidence, your wits, happiness, fun, humour, strength, physical contact, your hope and your faith in and for life. However sad all this loss may be, I feel so strongly, that I have literally been given a second chance at life. It sounds so cliché, but I now see beauty in every little detail, the pattern on a moth's wings, the taste of chocolate, the smell of rain, and a treasured moment of happiness when I hear of a friend's engagement, or the birth of their child. It has taught me patience, compassion and most importantly compassion and respect for my self.

So I have taken little steps here and there but huge in the sense of hope and joy. I have also reduced the amount of time I am on the oxygen machine to a couple hours in the morning and evening which is a welcome relief as the nose piece chafes my nostrils rather!

I started being able to shower standing up and by myself. Still only twice a week but the sense of freedom and independence it gives me is amazing. No longer having to wait for mum to finish her work to then seat me in a special chair and wash me like an 9 month or a 90 year old... The washing in itself was painful, from being touched and from the acid like water which left my skin looking burned and blotchy. I used to dread it so much, and afterward I would sometimes throw up, from the pain, and faint from the sheer effort of being hoisted out of bed and into the chair. My independent showers are just so encouraging, I imagine its the kind of freedom feeling one gets when they move into their first home!

Of course I wouldn't know what this actually feels like, as I got sick just before I was ready to spread my wings and venture out into the big wide world. I can't quite come to terms that my friends are all settling down with babies... I find it hard to wrap my head around that fact that everyone else's lives have continued, and the world has kept spinning, as mine feels like it has stood completely still for a very long time. I only really realise just how long it has been, when I say it out loud. Six Years. I still feel 19- which is the age at which my life stopped, and not the 26 I am.

I am getting a bit impatient and sometimes would love to do the simple things that people take for granted such as strolling out of the front door and hopping in the car, throw a ball for your dog, make a pot of tea, have a shower every evening because you feel grimy, float in water, swing on a swing, a kiss, a dance, a walk or singing along to your favourite song...but this is still an improvement from being house bound for over 6 years and entirely bed bound for the 3 years, only getting up to have bedding changed and use my porter potty, or change my nappy. Yes, even at one point I was in nappies, that, I think was the grimmest part, psychologically it was very degrading.

My days used to consist of lying on my left side for a few hours, until it got too sore or went numb, listening to an audiobook for a few minutes, then heave myself over to swap to lying on the right side... repeat, and repeat and repeat for 23 hours a day, everyday for three years. I want you to walk into your bedroom, shut the door and imagine never opening that door and seeing anything outside of it again, not the painting on the wall, the carpet in the hall, the sky and grass outside, for 34 months. A prison essentially. In fact in most cultures across the world, the most sever form of punishment, is solitary confinement. What am I being punished for?!

These days I can sit up in bed (not just lying down), and no longer rely in my zimmer frame to get from my room to mum's (4m away, which is my 'living room/dining room'), just to mix up the scenery as you can imagine I'm rather bored of my bedroom! I have started to potter into other rooms in the house as well as the garden to join Mum and just be near someone else so I am not always so alone. We even managed to watch a couple of movies on a laptop (even with the brightness settings on the dimmest one I could only manage about 15 minutes of screen time a day before, without a migraine and dizziness). I had forgotten how nice watching a good film is. Sounds quite mundane but when you haven't done something in a while, even the simplest of things can bring you pleasure. A lot of the time I have to watch it on mute because, I'm not sure if you've noticed, every bloody film has some form of music in it! I still can't stand noise and haven't listened to a song, even "gentle" classical, since I got sick. I have only just started to be able to read again, like pretty much everything else, it gives me a splitting head, dizziness and nausea, and the concentration required was too strenuous.

But onward and upwards I hope!! And even if I stay in this current state for another year or two I am content, so long as I do not go back to where I was, I honestly could not do it again. I was in a very dark place... very dark. I could actually feel my organs shutting down. Just one example was my liver was really struggling and I turned yellow as a result. Every breath was an actual conscious decision and effort. Every night when I finally managed some sleep, I would actually think 'will I wake up in the morning?', and in a rather twisted way when I did, I was just a bit disappointed as it meant I had to go through another long day of dark, quiet, lonely agony. Mum also thought I was going to die, as many who reach the 'severe stage' that I did, do. Suicide was also a constant companion, but as I lacked the strength to tie up a rope and hang myself, or get to anywhere that had a blade, or access to an abundance of pills, I couldn't even manage dying by myself, but I just did not have the heart to ask Mum to do it for me. I did however have a note for Mum for if/when I did die, telling her that I was glad it was over and not to worry as I was now out of pain.

I have touched briefly on the illness itself, I know it doesn't seem so, but if I were to go into all the details on the physical side of this illness, I would be writing a full on book. As for the emotional and psychological aspects, as you can imagine it is pretty grim. The total isolation and lack of contact creates a sense of loss, loss of friendships, loss of everyday life, loss of identity. The sadness feels similar to that of grief, the feeling that sits heavy in your chest. Grieving over the life you left behind, and knowing that the new life to come will not be in anyway the same as the previous one, and not what you had imagined when you were young.

I have been writing more and more about my illness, trying to focus on every aspect of it, and the way in turns your life upside down and how it affects those around you. It is such a monumental task, to try and get down every little detail, but there are still aspects I am uncovering and realising aren't in a normal healthy person's life. I have actually forgotten what normal is, and what it should feel and be like. When I see Mum carrying a bucket of water, I am in awe that they human body can lift such a weight, or when I see my sister outside with no sunglasses, I forget that she doesn't feel immense pain at the sight of the light. It scares me sometimes, how I am adjusting to my new life, and beginning to think that the limited way I have to live now, and the constant pain is just normal. One should not have to settle for this, and I am afraid that I will stop trying to fight for a better life, and just be content with the one I have now. I am not sure if it is because I am exhausted by the battle I have had to face, or whether I am, deep down, coming to the realisation, that realistically, life will never be normal and healthy again.

It saddens and scares me that I may not be able to carry my own child, as the rate of miscarriage is much higher than in healthy women. If I do manage to get pregnant, will I have energy and strength required to create and sustain another life, without diminishing my own? Once that baby arrives, will I have the energy to care for it, be able to tolerate its cries, and give it the attention in needs and deserves? I wouldn't want to go through all that, just to have a child I am only able to be around for a few minutes a day, and miss out on their lives. These are some of the questions that haunt me.

Being given any normalcy is a blessing at this point, but just because I now know how precious life is, doesn't mean I can't be disappointed and upset I didn't get to have the one I had envisaged for myself.

The insidious knowledge that it is not a foreign entity attacking you, not cancerous cells or a bacterial infection, but your very own cells, fighting themselves, a civil war if you will. Thus there is no way of getting rid of the 'corrupt' ones, without killing off you, as they are one in the same.

I haven't been able to have visitors since December 2015, as it is exhausting and at one point I could barely speak so there was little point. I can't wait to have my first visitor and sit down with a cuppa and have a good old natter... People have been complaining of their 'social isolation' since COVID but they are able to Skype, call and text to go shopping and to leave the house, so when you have actually been starved of hearing another person's voice or seeing their face, you realise just how social we creatures are and how important actual contact really is to our overall well being.

Another little conundrum is that I have had some serious memory problems, or lack thereof.... From all the swelling in the brain from 3 bouts of meningitis and the inflammation of the brain lining and spinal cord from the M.E. Pretty much short to mid term memory, so the last 10 years or so are very hazy or just blank... It was not as if I woke up one morning and they had all disappeared, but it was a gradual takeover. It wasn't as if my life were a film and someone switched off the television, but rather a static interference which blurred the image, gradually getting stronger until there is nothing but that pepper static on the screen.

Can't remember secondary school and/or the people. I struggle even now to remember some of my best friends from that time. But luckily my early childhood is all still there with vivid clarity, and made all the more precious to me. I hope it comes back by the time I am able to be out and about as I am dreading the day of bumping into people I should know very well and drawing a complete blank as to who the f*ck they are! No doubt it will be very tedious having to explain to every single person why I look so baffled and surprised that a person who I think is a complete stranger has just hugged me, knows my name and struck up a conversation.

I really want to help others in my situation somehow, I still can't manage it in the state I am in, but in the future. I need to find some light out of my darkness. Well I should say 'more light', as I have actually had a few positives arise from this illness. One of which is that Mum and I are now so close, so close that I personally think no other mother and daughter are as close as we are! Of course there are but the love and respect I now have for her is so immense I can't explain it. She has looked after me so amazingly single handed after my Father left 4 years ago... so dealing with me, a full time job and a divorce is quite frankly astounding. **What a Goddamn Rockstar**. I always make sure to thank her and tell her just how wonderful she is. Of course, Mama being Mama, says 'any parent would do the same', which in a perfect world should be true, but unfortunately it is not. I know I am very lucky to have such a caring patient and kind woman as my Mother.

My little sister G spent the last 6 months out here which was fabulous. For the last 5 years I have only been able to see her for 10mins a day, once a year. Comprising of mainly just her lying next to me in silence, maybe a few words exchanged, so being able to chat and laugh with her once more, is just so incredible, and is just as well as she so very amusing and we always used to wind up in stomach clenching, gasping for breath, thigh slapping laughter. Something I

haven't done in a very long time is laugh, I was unable to... I actually lacked the physical strength to contract my diaphragm and abs, and the motion of moving my head felt like my brain was being bruised from rattling around my skull, much like shaking an onion in a jar. So my word to the wise, laugh, and laugh as much as you can in life, its so underrated!

Talking about my illness in retrospect is still difficult, and whilst I was in it's clutches I know that I tried my best to shield my darling Mama and G from the emotional struggles. I did not open up, as I can see how hard it has been for them to see me this way. I am under no illusion that I am the only one who has suffered. It must be very hard for them to stand by and helplessly watch me disappear under their nose, the look reflected back in their eyes of desperation and anguish, that they were rendered completely helpless in aiding me. For a while Mum was under the constant fear that she may have to bury her daughter, something no parent should ever have to do. Although I could not hide most of the physical side of this illness, one could see it all over my pale, gaunt and desolate face, my lifeless stare and my hunched and crumpled demeanour, but I always tried to play down the pain, and if I could, brush off their concern.

The analogy of being like a duck on a pond, appearing calm and collected on the surface but paddling for dear life underneath did not quite fit my situation. That would imply I was managing to rather gracefully stay afloat. Think more along the lines of drowning rat with an anchor weighing down off its tail... I did and still do try to limit the amount of my mental suffering with them. I know this is not the healthiest way to deal with it, but having always been a mothering and nurturing person, I find it hard not to still try to take care of them, and if the only way I can do that is to spare them more heartbreak, then that is what I will do.

It is difficult to be the one who has to be taken care of, and I had to really try to embrace it and let go of that loss of control. I tried to maintain some authority over my life by sticking to a very strict routine. Even if most of it was wake up at this time, eat at this, listen to this book at this time, lying on my right side, then at an allotted time, listen to a different book, lying in a different position. Just that tiny bit of scheduling has helped keep me sane, and meant that my days, weeks, months and years had some form of structure, and not just a never ending abyss of servitude to the agony and lassitude.

I still stick to a routine, which helps me distinguish week days from weekends and actually quells some of the boredom, as I can look forward to certain times of the day, just like a regular person going about their daily activities.

I have been meditating for a few years now, and at first I admit, they were just a means to pass some time, but now I really feel the difference in my mind set if I skip them. They range from five minutes to sometimes over an hour, depending on where my mind wanders during them, and if on that day I need to particularly focus to sadness or anger or grief, or whatever is plaguing me. I wish I could say that it took the physical pain away, but that would be a lie, and a misconception to other sufferers who turn to it in the hopes of finding some relief. The physical pain was far too great. If pain receptor blocking medication specifically designed to help couldn't do the trick, a few deep breaths and soothing thoughts of waves and beaches certainly wouldn't. I am by no means dismissing meditation, it has helped me in many ways and mended many mental wounds, but not with any of the physical pain.

If you have a friend or family member who is suffering from any illness, or injury, or simply not having the best time, please reach out to them. Anything is better than nothing. Even if they are unable to reply, or can't read your message at that time. It is very easy to feel forgotten when you are so out of touch with the world and I feel I have lost some friends as they haven't ever written/texted me, but all the ones who have, I shall never ever forget. You can't feel the love and support from people's silence. The smallest gesture, even just 'Hi, thinking of you' can literally make their day, and make them feel less alone. Just do it, don't put it off for later as you will probably forget. I understand that everyone gets busy, and just because I don't hear from them all the time that they aren't thinking of me, or wishing me well, but they simply forget to convey it. Any little anecdotes or gossip or tales of your weekend antics or voice messages and videos would be most welcome, nothing anyone could send would ever be boring, as it makes a welcome change their situation, as for me, from counting the number of flower patterns on my curtains... there are 46 by the way.

Love, Sas

I had to be physically helped up off my bed or sofa, very slowly as the sudden change in 'altitude' I called it, would always make me sway and my knees would literally buckle from the wooziness. This was likely due to my incredibly low blood pressure paired with a rapid resting heart rate of over 110bpm, which is chaos.