Eleven days that changed EVERYTHING

In total honesty it was much longer than 11 days, but the speed of deterioration over those last 11 days was something that I’m still trying to understand and digest.

The thing is my mum Joan Catherine Heath was diagnosed with terminal lung cancer on 12th November 2015.

I remember that day as clearly as if it had just happened.

It was a Thursday, and I was scheduled to instruct a spin class at Bloomsbury Fitness part of UCL.

I distinctly remember mum being adamant before the appointment, that no matter what the outcome I would go and teach the class!

Especially as I was self-employed at the time.

I don’t remember the exact time we were called into see the consultant… I do remember there being an extra person in the room, a Macmillan Navigator and there being a heavy and hot atmosphere in the room.

We sit down, and mum being mum and never one to shy away from the truth no matter how hard or painful to hear, asked… well more like made a statement but presented it like a question… ‘it’s cancer… isn’t it!?

Bear in mind mum had been going for a shit load of tests and cancer had been talked about previously but never confirmed…

The consultant confirmed that mum had lung cancer. Mum and I looked at each other deeply in the eyes and held each other’s hand. The closest way I can describe it is like when a child is scared and reaches out to its parents’ hand for safety and reassurance.

Only this time it felt different, as if I was the source of safety and reassurance.

In that moment I knew, I knew I was willing and happy to, as people say, sacrifice anything for my mum. Unless you have experienced this yourself it’s hard not to see it as a sacrifice, as you personally no longer want anything for yourself other than the happiness, safety, reassurance, dignity and comfort for who you love.

Then came the real sucker punch to the gut that completely knocked the wind out of us both…. There is no easy way to say this, your diagnosis is terminal…

As the cancer has spread to the lymph node in the centre of your chest and as you also have mild to severe Chronic Obstructive Pulmonary Disease (COPD) it is clinically deemed inoperable. Also, we will not be offering chemotherapy or radio therapy due to the location and COPD.

I kept feeling mums grip get tighter and tighter during this onslaught of information.

After composing ourselves, another Macmillan Navigator entered the room.

Now that there were two Macmillan Navigators with us, one took mum aside and the other took me to a different room. While I was with the Macmillan Navigator, she was assessing my level of understanding of mum’s diagnosis and what it meant and asked what I knew about Palliative care.

Strangely enough the year before I had gone back to college to do an access to nursing course and the area, I was looking into was Palliative care, so I knew full well what was meant and the outcome of Palliative care.

With that the Macmillan Navigator asked if I would like to know what time frame they were looking at? Me being me and never being hidden away from the truth, no matter how hard or painful it is, I said yes.

6 – 12 months… if we’re lucky!

Oh, err, ok, 6 – 12 months…. Right.

Then something clicked…. Shit…. The spin class at 17:30.

I think it was just gone 16:00 and I asked the Macmillan Navigator if I could go and make a phone call and to let mum know I was on the phone and would be back as soon as possible and pleaded with the Macmillan Navigator not to leave or let my mum be alone at any point no matter what!

As I stepped outside into the cold, I felt as if I were on fire, could feel my heartbeat as if it was hollow and the trembles from the surge of adrenaline… I had to take a minute to compose myself long enough to put a post on a Facebook page for group exercise instructors to cover classes. I then called the manager at Bloomsbury Fitness and half explained what had just happened, when I say half what I mean is only telling him half the story, only that my mum had been diagnosed with cancer, not that it was a terminal diagnosis. I also told him that I had put a post-up on the Facebook page for class cover.

The manger was fantastic and said not to worry about anything and that they would sort the class out and to go and be with my mum.

When I went back into my mum, I found her sat with a Macmillan Navigator, the same one I pleaded with not to let mum be alone at any point.

We went home, put some of mum’s records on, talked, cried, hugged, and talked some more into the early hours.

Then in January 2016, mum had an appointment with a thyroid consultant/oncologist.

The news was more of the same shit really. But… another sucker punch was that if they had offered treatment to mum for the lung cancer, they would have taken her thyroid out removing the cancer… but as no treatment was offered, they could not offer any treatment either!

A few months later, after talking with mum, we decided to put up a fund raiser to help get a cheap and cheerful run around car to try and make life easier for mum getting out and about, to go to the various appointments, keep her independence, to go shopping and to make memories by going out for day trips or holidays to Haven Caister-On-Sea.

2016.

We had to move temporarily due to damp problems and a rodent infestation, we were moved to a ground floor one bedroom flat with the two cats Miomy and Reka throughout the summer, which was challenging as having normally having the garden to escape to was not there.

I had also started a new job as an Assistant Club Manager at a Spa and Fitness centre at a well-known brand of hotels, it didn’t last long as soon as I was asked to let someone go as they hadn’t done any shifts for a period of time, the reason they hadn’t done any shifts was because they were looking after their mum who had cancer and they were the sole carer. Hence why I didn’t last long after refusing to fire someone because they were doing the right thing. There is more to this story but that is for another day.

Generally, mum’s health was pretty stable throughout 2016.

2017.

It was pretty uneventful really, mum was doing remarkedly well considering the prognosis of diagnosis’s’.

Although I November mum had a trip up to A&E in an Ambulance as she was struggling to breath. She had gotten up during the night to go toilet, she had managed to get to the toilet in the bathroom but couldn’t catch her breath and called out to me. Thankfully, it woke me up and just looking at how mum was, I called 999, about 10 minutes later a rapid response paramedic arrived, checked her SP02 (oxygen saturation) and they were mid to low 90s, after an oxygen driven Ventolin nebuliser mums SP02 raised up to 97% but would drop to low 90s high 80s not long after. So off we went to hospital.

We must have been there for about 12 hours. We were let go after mums SP02 had stabilised at 96% consistently without any medicated nebulisers.

Beginning of 2018 was a very scary time…. January and February nothing much happened but then at the beginning of March mum ended up in Resus with Type 2 respiratory failure with C02 retention. Mum had gone out on one of her usual jolly jaunts with her shopping trolly with a seat on it down to Portobello Market, which she would regularly do! This time though she really struggled to get home, she described it as a never-ending effort of going up a steep hill and felt breathless and struggled to catch her breath. When she eventually got home, she rang the doorbell and played it down and passed off her breathlessness as having gone too far and buying too much. She left her trolly up at the gate and went inside, she sat down and took a puff on her salbutamol inhaler. A few hours later I was getting some dinner sorted for us both and mum said she was going to have a lay down and have a nebuliser and see if that helped with her breathing, which it seemed to do for a few hours. Then it must have been around 01:00 and I woke up to mum calling out for help!!

This was a different type of calling out, you could hear the fear in the tone and pitch of the call, this sounded and felt urgent! I flew into mums’ room and she looked grey and not good at all, she couldn’t breathe properly, and she was scared… very, very scared. I ran into the front room and grabbed the phone and called 999. During the call with the dispatcher mum had started to try and climb up the mattress of her bed that was raised up with the mattress raiser, it was like she was trying to climb up high to get some air. She kept pleading for help, and I could see the fear in her face, in her eyes and all I could do was try to reassure and calm her down by saying the ambulance was on its way and help will be here soon. I tried to get her to do some breathing exercises to regulate her respiratory rate along with purse breathing but nothing would help, mum was in the grips of fear and panic.

When the ambulance arrived, they carried out their assessment and it was a blue light run to the hospital. There was no time to go through the normal triage section, mum was rushed into resus and I was told I couldn’t go through just yet and was shown to the relatives room and told someone would come and see me soon. About an hour passed but it felt like much, much longer and no one had come to talk to me! Nope, I wasn’t having that! That’s my mum in there!! I waited by the locked doors and took my moment when it came, a nurse exited the resus area, and the door was unlocked so I went in. As soon as I walked in a nurse saw me and came over, I explained who I was and who my mum was and she took me straight over to her, as we walked to the curtained area where mum was, she was trying to push the nurses and doctors away and kept calling out for me. As soon as she saw me and I spoke with her and asked her to let everyone help her she did. The doctors and nurses then put a face mask on her, a CPAP (Continuous Positive Airway Pressure) a form of Non-Invasive Ventilation (NIV) to help her breath as she was in Type 2 respiratory failure with C02 retention. Once mum had the face mask on and was allowing it to work. The doctor took me aside and explained just how poorly mum was and due to her health, this machine the CPAP NIV was the ceiling of treatment they could provide and if it didn’t work all they could do then was to make mum comfortable. The doctor also explained why they wouldn’t administer invasive treatment such as, incubation or life support, as mum would not likely be strong enough to be taken off of them. And also, that a clinical decision to authorise a DO NOT RESSUSCITATE order as the trauma of chest compressions would have a detrimental impact on the quality of her life if she survived it.

Thankfully after 36 hours in RESUS mum recovered enough to be moved to an observation ward. After another night on the observation ward mum was discharged under the care of the community respiratory team.

Mum seemed to be picking up but then it all happened again at the end of March and again at the beginning of April.

However, on the 24th April the most amazing and wonderful thing happened! I received a Facebook message from a lady called Alison…

It was my big sister, mums first born, her baby girl who she had been forced to give up for adoption.

Was it really her…? Mum and I had done many searches for her over the years, from as far back as I can remember I have always known about my big sis. And then now…. Was this really happening, had my sister just sent me a message on Facebook?

I remember mum standing over my shoulder reading the message, just itching for me to get off the computer so she could log in to her own Facebook account and read the message Alison had sent to her personally…. it’s hard to explain and describe that feeling of excitement, anticipation, it’s like being in the middle of a vortex of a whirlpool, chaos surrounding but still and calm in the centre.

It was just the perfect thing to happen for mum after being so poorly, it gave her a boost of strength nothing else could have!

Again, this is another story for another time, but I will get round to doing so keep your eyes peeled for that.

The rest of 2018 was pretty smooth all things considered.

2019.

Mum kept getting UTI’s (Urinary tract infections) so was on antibiotics a fair bit but generally she was ok, she went out on her jolly jaunt missions with her shopping trolly with a seat and was still very independent! Mum thoroughly enjoyed her freedom and enjoyed making and taking full use of her freedom pass and would often toddle off to Hammersmith or Shepherds Bush.

In February I had started working for a company called Motiv8 who run and manage residential gyms and spas, initially I started part time at a site of theirs near Ealing Broadway. When I went for the first interview, I was up front about the circumstances and situation with my mum, which previously had not in my personal opinion ruled me out of a number of jobs I had applied for and had an interview for would question my commitment to the job/role I was applying for.

Anyway, in the interview with the site manager (Egle) for the residential facility, I had explained that as well as the situation with mum, I had also been experiencing anxiety/panic attacks. When I say anxiety/panic attacks, they weren’t like your typical stereotype description, of feeling like you’re having a heart attack or feeling sick. Mine hit me hard, fast and completely unexpectedly. I could be in the middle of shopping and then bang… my head would spin, start sweating, felt disoriented like I knew where I was yet at the same time had no clue. Then the fear of, if anything happened to me who would be there to look after and be there for mum. That would then feed the fear and full-blown panic mode hit and It felt as if I was going to pass out, that hot flushed feeling you get before the lights go out, but I would never pass out or faint. My way of dealing / coping with it would be to stop whatever I was doing and head straight back home, home was safe, and home was where mum was and to do a finger prick to check my blood glucose levels. I ended up doing over 400 tests in one month, the GP wasn’t to happy because the test strips are not cheap, but I would say they are cheaper than the limited talking therapies they offer!

Even after being that honest, Egle must have seen something in me to have enough belief in me to put me forward for a second interview with an area manager at their head office.

The area manager Grant, a big, tall bloke who obviously went to the gym and could probably bench press two or three of me haha. I have to say here, that second interview was probably one of the best interviews I have ever had. He was extremely understanding and refreshingly honest and didn’t claim to know what it was like to be living with what I was living with. Which to me showed he was respectful, he asked me if I was comfortable talking about my experiences and didn’t assume anything.

I left the company in December that year, as there were a number of different factors involved, mainly looking back now as I’m writing this, there was a progression back then with mum as her voice had started to change, she started sounding like a teenage boy who’s voice was about to drop. It would be normal and then either go deep and husky or high and piercing.

How could I forget the public consultations mum and I went to regarding the closure of the in-patient service at Pembridge Palliative Care Hospice at St Charles Hospital. Mum was adamant to stand up for what she believed in, even if that meant confronting the issue and subject of dying and death at those meetings we went to.

2020!

Covid fucked everything up!

Looking back now I really believe the lockdowns, along with the social distancing and shielding played a part in mums’ deterioration.

I feel like the above robbed people of their freedoms and independence.

Mum was the type of person who enjoyed going out for a walk down the market (Portobello Market) and bumping into people she knew and even complete strangers for a chin wag. And having that taken away… I can’t even imagen what that feels like.

2021 The year where 11 days changed my life.

Mum had started to get tired a lot earlier and her fitness levels had dropped but nothing that couldn’t be accounted for due to the lack of activity due to covid and restrictions.

On the 3rd of March I took mum for a CT scan at St Marys for an Oncology appointment on 23rd March at Charing Cross Hospital.

Sunday 14th March.

At around 23:00 mum was sat on her bed and was coughing a lot and hard. I heard her bring up phlegm and sputum, I was in my room and called out asking if she was ok. I didn’t get a response, so I went to her room and saw her sat looking down into a tissue with a concerned and scared frown. She looked up and over to me and showed me the tissue. There were some specks of bright red blood. I tried my best to reassure mum that it was likely a small capillary that had bled because she had been coughing so hard just before. Inside I was shitting myself, we’ve all seen the movies and tv shows and what usually happens to people when they cough up blood. Also, it was only a small amount, and it was specks, no clots and it was not continuous. Saying that it was a very sleepless night for the both of us, every time mum coughed and spat, we would examine and scrutinise everything! Thankfully, there was no more blood overnight.

Monday 15th March.

Bang on 09:00 I called the GP to let them know what had happened the night before, and a few hours later a rapid response nurse turned up to assess mum and took some bloods for testing, while they were here mum coughed up some blood a couple of small clots and a decent medium sized blob that looked like a clot but also looked like a lump of phlegm that was bright red. The nurses took that away as a sample.

For the rest of the day mum rested and took it easy, she watched some tv in the front room and then had an early night.

Tuesday 16th March.

Around 09:30 10:00 another rapid response nurse turned up and carried out another assessment and let us know that the blood test results had come back and there was nothing to worry about, just that kidney function wasn’t ideal but nothing to be concerned about.

Mum again had another rest day and had an early night.

Wednesday 17th March.

Mum seemed to perk up and went out into the garden and was planning on where to plant runner beans, where to put tomato plants in pots, where to grow spinach the lot…. She warned me how much work we were going to do and reminded me to finish off the Garden Gnomes, especially the flasher with a leaf covering his tackle! HAHAHAHA

Mum even started to continue finishing off a cardigan she was knitting herself.

Again, mum had an early night.

Thursday 18th March.

To be honest it was pretty much the same as the day before, mum was making plans as the news of lockdown restrictions being lifted excited her and she was looking forward to going out for her walks again and bump into everyone she had missed talking to.

Again, another early night but this time it was because mum had two appointments at St Marys Hospital, one a thyroid ultrasound and the other a chest x-ray both routine and regular so it’s not as if they were rushed through urgently.

Friday 19th March, the day it all started to unravel.

Mum found it hard getting up, she was breathless and found it hard to breath, just getting dressed made her breathless and tired. I remember what it feels like giving mum a hard time saying we were going to be late if she didn’t get a wriggle on. Looking back now it’s hard not to feel a sense of guilt having done that.

When we arrived at St Marys, I parked in the disabled bays just before the ambulances turn into A&E, so not that far from the entrance to the main building. As I was packing away the dash cam mum went ahead. I caught her up in the reception area and she was a bit breathless and puffy. She said to me that she couldn’t walk any further, so we sat her on the walker, and I pushed her to the scan and x-ray appointments.

After the scan and x-ray I pushed her back to the car on her walker and tried to make it as fun as possible by making silly stupid noises pretending it was a race car or spaceship. Mum was laughing and joining in without a care.

We drove home and when we got home mum went inside and sat in her red recliner chair in the front room and picked up her knitting. We sat in the front room talking and watching telly until about 22:30/23:00 and mum went to bed.

Saturday 20th March.

Mum was absolutely shattered, the previous days exploits had knocked her for six, she just could not get out of bed. At around 10:00 mum got up to go toilet and just could not make it to the bathroom. She had to use the commode and by even using that her SP02 dropped to 70%! But she wasn’t feeling or displaying any signs or symptoms of a COPD exacerbation or respiratory failure.

So we called 111 to speak with an out of hours GP, we didn’t get that far as after completing the telephone assessment an ambulance was dispatched. When the ambulance crew arrived, I met them outside and explained the situation and history, when they went in to see mum the paramedic in charge asked his colleague to grab the life pack. I had to then Advise/inform them of the clinical DNR in place.

We explained that we had called Pembridge Palliative care for advice and all they recommended was to take oral morph (Morphine Sulphate oral solution).

Which mum had explained on numerous occasions she was not happy and fearful of taking it.

With that the ambulance crew called Pembridge and were given the same advice regarding/taking the oral morph.

Mum asked the ambulance crew if they would/could stay while she had some in case, she had a funny reaction and was worried about me. The ambulance crew were so kind and happily agreed to stay while mum took some.

Over the next two and a half hours mum had taken 3ml/6mg of morphine sulphate and had settled, she was also given oxygen driven Ventolin nebulisers at 60 second bursts or until her SP02 raised to 96%. This was given 4 or 5 times as mums SP02 would drop from 96% to 82%. Eventually it stabilised at 93% and it was agreed that it would not be in mums’ best interest to be taken into A&E.

As the ambulance crew were leaving, mum gave them both a mini knitted teddy bear she had made.

About 30 minutes after they left, mum fell asleep, and I went to bed and listened to her breathing all night.

Sunday 21st March.

Mum was pretty much bed bound and really struggled to use the commode, so I ordered a couple of bed pans from Amazon.

Monday 22nd March.

Thankfully, the bed pans from Amazon were delivered early and we had a call from Pembridge Palliative care, it was a bit of a weird conversation as they kept emphasising and asking when was the oncologist appointment was!? Which was the following day. After that call we got a call from oncology confirming the appointment the following day and that it was an in-person appointment at Charing Cross.

I explained how mum was and it was agreed to change the appointment to a telephone consultation instead, still at the same time 11:00, but it could be an hour either way.

Later on, that day and having been in contact with the GP and as mum was still feeling breathless wanted to send mum in for a Pulmonary Embolism test via A&E so she called out an ambulance.

When the ambulance crew arrived, mum and I explained what was going on, they carried out their assessments, during their assessment I overheard one of them say ‘I cannot hear air entry or exit from the left side. Taking everything into account it was agreed that again it was not in mums’ best interest to be taken to hospital for the PE test via A&E, especially as I would not be able to go with mum meaning she would be alone!

Tuesday 23rd March.

It’s a bit of a blur as by 13:00 we hadn’t received the call from oncology that was due at 11:00. Pembridge Palliative care called a few times asking if we had had the appointment yet. At 13:30 I called the Macmillan Navigator service to find out what was happening and if mum was still due a telephone consultation. The age-old reason was given and that was they were running behind schedule and they apologised for the delay.

Then at 14:30 we got the call from oncology, during the call they gave us the results of the latest CT scan mum had had on 03/03/2021 shows there has been progression since the scan previously in October 2020. The lesion in the right upper lobe had grown from 15mm to 20mm, but what was causing them the most concern was the growth on the lymph node in the centre of her chest, it was pressing against blood vessels, had block main left bronchi and had grown around the voice chord nerve.

They also said they were discharging mum from regular oncology into the full care of the palliative care team at Pembridge Palliative Care Centre from here on.

After the telephone consultation we called Pembridge and it was agreed that the Clinical Nurse Specialist (CNS) would visit to undertake an assessment of mums needs the next day 24/03 mum’s birthday.

We both had a restless night and mum had 1ml of oral morph at around 02:00 and that settled her until around 09:00 the next morning.

Wednesday 24th March Mums BIRTHDAY.

Happy Birthday MUM!

I got hold of Alison mums first born and my big sis and let her know what had been happening and what was happening, and we arranged a time for her to give mum a call and wish her a Happy Birthday.

A while later Alison called us and we had the most beautiful and lovely call and arranged a visit for the coming Sunday 28/03, mum was so, so happy knowing she was going to see her special little girl again, something dear to hold onto and look forward to! After the call we opened mum’s birthday cards and read her Facebook birthday messages on her wall, my only regret now is not using mums phone to log into her account using her mobile phone on the day and type the replies out to everyone with what she actually said when I read each message.

Mum asked for a little bit of oral morph and I stupidly asked if she wanted 1.5ml instead of the usual 1.0ml? Mum agreed, but not long after mum said she was feeling a bit sick. I’m not sure what time it was but the CNS arrived and carried out her assessments and gathered information such as preferred place of care and preferred place of death if different. Mum also let the CNS know that she was feeling nauseous. The CNS said she was going to speak with the GP to get some medication to help with pain, breathlessness, agitation, secretions, and an anti-nausea.

After the CNS left mum asked for a little bit more oral morph. So, I gave her 1ml this time as giving her 1.5ml made her feel nauseous. It must have been about 45 minutes to an hour later mum said she felt really sick, and she wanted a bucket. I manged to get a small empty salad bowl and mum threw up. It must have been about 3 or 4 litres of dark green bile, it totally knocked mum out and she drifted to sleep, as soon as I could I gave Pembridge a call for advice and to see how the prescription request was coming along.

It was 17:30 when the prescriptions were finally done and sent through to the chemist, but they were closing at 18:00. I put a post-up on Facebook and called a few neighbours, but it was such short notice that at 17:45 no one had answered my post or my calls so mum and I agreed that I would run my arse off and go get the medication as she really needed it. And that’s what I done, ran my osteoarthritic hip backside down to the chemist and back again, but the chemist didn’t have everything needed! So, in reality it was a pointless exercise.

At 17:53 Lauren from a flat above sent me a text asking if all was ok? I gave her a call and explained what was going on and she told me to call the GP and get them to send another prescription to Boots in Queensway and she would go and collect it no probs! So, that’s what I did and that’s what was done, When Lauren got to Boots, they too didn’t have everything! Lauren was absolutely amazing and called around to the other Boots chemists in search for all of the medication. Each one had different meds but not all of them. She then got them to print out a copy of the prescription and went to several chemists in the area in search, but nowhere had the complete prescription!

By this point mum had woken up fully and was in discomfort so I called the district nurses and explained that mum was in discomfort and I hadn’t been able to get the injectable medications she needed!!

The night district nurse arrived around 21:20 and gave mum some injectable medications they were able to get from an out of hours GP and Pharmacy. Within about 30 minutes of them giving mum the medication she fell asleep and looked comfortable and peaceful.

Earlier throughout the day I had moved a tallboy wardrobe from the hall into my little back bedroom, a 7-draw chest of draws and a sewing work desk from mums’ room into the hall to make space for a hospital bed to be delivered.

By making the space for the hospital bed delivery on the 26/03 there was enough space to put a duvet down on the floor with some blankets so I could nap in between keeping a watchful eye on mum throughout the night. I would set my alarm hourly so I would fall into a deep sleep-in case mum needed me or needed anything like help using the bed pan, or helping her hold a glass of cold London tap water to help quench her thirst or to call the district nurse to come back and administer more end of life medication.

Thursday 25th March.

Mum was so, so, so thirsty all of the time but whenever she tried to have a big gulp of water to quench her thirst it would make her cough and wretch leaving her feeling nauseous.

I kept asking her if she wanted me to call the district nurse so they could come and give her something to help with feeling sick, but mum was adamant she didn’t want much of any of the medication until Alison’s visit, she wanted to be with it when she came, she wanted to be able to have a conversation the best she could before she couldn’t.

Mum was still kind of ok, as in her mind, her soul and spirit was still mum, it was her body failing her and shutting down. Whatever mum wanted, I tried my hardest to do for her.

We also had a video consultation with our GP, during the call mum wanted some water, by now we were also using pink sponges on hollow sticks that we would soak in a glass of cold London Tap, place the sponge in mums’ mouth with the stick poking out as if it was a lollipop. Mum would then use her tongue to squeeze the sponge against the roof of her mouth to get little bits of water at a time. So, when we done this with the GP on video call, mum started coughing and retching, she tried to sit herself up in the bed but didn’t have the strength to do so.

I dropped the phone and gave mum a hand by helping her to sit up with my arm wrapped lovingly and caringly around my mums back for support and reassurance. Once mum had settled, I then placed the phone so we could all see each other again, not long after doing that mum started to try and cough again but she wasn’t strong enough to finish the cough completely.

Then mum tried to shift herself up in the bed as her mattress was on top of a bed raiser, she had slipped down and was uncomfortable. She just didn’t have the strength to do it on her own, but she wanted to try, to keep her independence! Mum tried a few times but just couldn’t, she looked at me and didn’t have to say a word, I knew she wanted and needed a helping hand.

I stood by the side of her bed, lent over, slipped my arms in between her arms and body, put my head next to her head, slid my arms around and behind her back to support and comfort her, mum rested her head on my shoulder with her forehead resting on my neck, and after the count of three we both worked together as a team like we always had and moved mum into a comfortable position. I caught a glimpse of the GP watching all this happen and it looked as if she got a lump in her throat. Seeing mum like this I think hit the GP hard as it was not all that long ago mum had been in contact with the GP for repeat prescriptions and seemed fine. We spoke for a little longer then ended the video call consultation.

Mum had two carers’ come into help with personal hygiene washing, changing incontinence pads and a little bit of support. Up until this point it had only been me helping mum with everything, changing sanitary pads, washing, trying to help with small bits of food, being on call with fluids whenever mum wanted, absolutely anything mum wanted or needed it had only been me. Don’t get me wrong we had enormous help and support from friends and family with things like picking up prescriptions, bits of shopping like Lucozade for me when my blood sugars would drop, my diabetes control at this point was non-existent they would go to both extremes. My blood glucose levels would shoot up to 26.8 but would drop to 3.2 within an hour of giving myself a correction dose of insulin but my body wasn’t doing what I was used to it doing. And I didn’t really pay much attention to it either my priority was my mum. To make sure she wasn’t suffering. No matter how hard it was for me, I only cared about mums welfare, dignity and comfort.

Not forgetting the emotional support from the family in New Zealand with heaps of messages and video calls.

Even though the carer’s where there to give me a little rest or break to be able to do other things like keep on top of any bills that needed paying, doing dishes, putting a load of washing on and hanging it up to dry, the everyday small things that make a household tick. I just couldn’t leave them alone with mum, its not that they were untrustworthy, but I didn’t trust them as there was no history there between us. When they were leaving, it would have been mid to late afternoon, they asked what time I wanted them to come back, we agreed 20:00.

They returned at 20:00 and changed mums pad so she was dry for overnight as they wouldn’t be back now until 08:00.

At around 23:00 mum woke up and asked me to call the district nurse as she was in pain and uncomfortable. I called them and they came and gave mum some medication that done the job.

Friday 26th March.

After a relatively restful night, mum woke up around 09:00 asking for some water, she wanted to drink from the glass. So, I helped support her with one arm around her back and shoulders and the other hand holding/supporting the glass, mum took a good few small sips and made that nsst…ahhh noise that everyone does when they’ve had a thirst-quenching mouthful of water.

Around 10:30 the district nurse team leader arrived to check in on mum, which was good timing, as by now mum was starting to feel some pain, discomfort, and agitation, so the district nurse team leader gave mum some meds to make her comfortable and at ease. While the district nurse team leader was here Medequip arrived to deliver the al singing and all dancing hospital bed. I asked how and who would help me move mum from her old bed that wasn’t appropriate for her needs into the new hospital bed that was ordered specifically because of mums needs. Not forgetting the bed was ordered on the 24/03/2021 so you would have thought giving enough time to sort bed transfer as well. The district nurse team leader assured me someone will come and help get that done today 26/03/2021.

At around 16:30 the personal hygiene care workers came by to check in on mum, while they were here a district nurse dropped by with some slip-on sanitary pads to make things easier for mum not having to worry about any leaks. As the district nurse was here mum started to feel uncomfortable and was feeling some pain, with that the district nurse gave mum a booster of meds. At this point it was coming on to 16:45 and I asked what was happening about getting mum into the hospital bed. The district nurse then told me that they might have to call the London Ambulance Service (LAS) out to do a bed transfer! The district nurse then said that the office would call me back to let me know when that was going to happen and left. About 10 minutes later the district nurse office called and told me that the LAS has refused to come and do the patient bed transfer as they were an emergency service not a patient transport or bed transfer service! The district nurse office then asked me for my mum’s social service details as they would need to put an application in on Monday for mum to be moved from one bed to the other! To say I was pissed is an understatement. Total lack of respect, dignity, compassion, and care… what wankers!!! I rudely told them to get stuffed and id do it my damn self! Just like I had done everything else on my fucken own!!!! And hung up!!

Immediately after hanging up, I got a call from a district nurse who was in the office and overheard the telephone exchange and offered his help with moving mum from one bed to the other, which they came and done.

As the district nurse who came in their own time to help mum get from one bed to the other was leaving he said to me to be mindful of them setting mum up on a continuous syringe pump drive that would give mum medication constantly of a 24 hour period, that she would most likely be out of it most of the time if not all of the time, so enjoy and make the most of any and all conversations you can.

(Looking back no moving mum the way we did may have made mum uncomfortable and agitated due to being in a bed that she was not used to and the physical effort it took moving.)

It was a pretty restless night and I had to call the district nurses out a few times for them to come and give mum some meds.

Friday 27th March.

Mum woke up around 09:00 and wanted some help with drinking some water from the glass, so I got up from sitting on the duvet on the floor in mums room and tried to help, but using the glass was too much effort, so I refilled a Sippy cup that a close family friend had brought specially for mum the day before. A massive thank you Cheri, mum loved having that cup to use as it meant she could still have her independence and dignity.

But just by trying to keep her independence had caused mum to feel discomfort, pain and breathlessness. The time was 09:46 when I called the weekend district nurse. When the district nurse arrived, she asked mum if she wanted to have the continuous syringe drive pump set up. But before mum could answer I piped in and said that mum didn’t want to much medication until after Alison’s visit which was the next day as mum wanted to be ‘with it’ when her special little girl came.

But as soon as I had finished, mum managed to speak and said, ‘yes that’s right, but set it up, I want to be away with the fairies!’

The district nurse looked at me as if it was my choice and decision to make. I looked the district nurse dead in the eyes and I could feel them start to sting and burn, like after you’ve been to a swimming pool that has too much chemicals in it. And said, ‘It doesn’t matter what I or anyone else wants, its all about what my mum wants and needs, so if she wants and needs the pump drive set up, set it up.

So, the district nurse gave mum a booster shot of meds and set her up on the continuous pump. After the booster shot mum fell asleep and looked comfortable. The personal hygiene care’s came in twice during the day but as mum was dry and peacefully asleep we decided not to disturb her.

Then at around 20:00 the personal hygiene carer’s came for their final visit of the day, as mum had been asleep for most of the day she hadn’t had much fluid intake and had not long woken up and had only just had a few sips of water. So, mum was dry and didn’t need changing! Although mum did ask if she could have a wash and a change of pyjamas. As the carer’s went to give mum a wash they didn’t check the temperature of the water as well as they could have and mum certainly let them know about it! Lol!!

When they had finished giving mum a good wash and had a good laugh with her as she was still cracking jokes, they left and said, ‘see you in the morning’. With that mum dozed off back to sleep. Mum was asleep for about an hour and a half before she woke up feeling agitated and breathless. As I was calling the district nurse at 22:22, mum said, ‘she didn’t know how much more of this she could cope with and it was getting too much, and she was worried I was doing too much with no real help and that going into a hospice might be for the best. I looked at mum deep in her eyes and I said, ‘mum there is no such thing as doing too much for you, I would go to the ends of the earth for you, love has no limits to what I would do for you, just as you have done for me!

I asked mum if that’s what she really wanted, to go to a hospice?

Mum replied that she could see how much I had done already and she knew her needs would increase and she was concerned and worried that I had no real help especially during the night and maybe it was better for me if she was in a hospice where they could give her meds without me having to call out the district nurses.

I asked mum if she would be happy to stay at home if we could get the hospice at home service we had been told about on the 24/03/2021. It was a hard sale but mum agreed. During this conversation with mum I had got through to the district nurse and they were on their way.

The night district nurse arrived at around midnight and gave mum a booster of the meds. As it started to take effect I was telling/letting/reminding mum that Alison was coming over tomorrow and she would have both her babies and her all together again, mum smiled contently and delicately put her thumb up and fell asleep. As the district nurse was leaving she said, ‘ mum is going to be asleep for a good while, probably until the morning, you should get some sleep yourself, you are doing so much for your mum, more than most families I’ve seen do and you’re doing it all on your own! Your mum is very proud of you, but she wants you to rest as well!’

I explained I had a system that was working. My system was to put my mattress down on the floor at night in mums room when I felt really tired, I would then set my alarm at hourly intervals and snooze. But in reality I would lay there staring at mum, scared stiff I would fall asleep, then I wouldn’t be there for her, no matter what she needed, help with trying to have a drink of water, a mouthful of twister ice cream, help sitting up to try and cough, help sitting up if she felt nauseous, but most importantly to be there to reassure, comfort, and let her know how much she was loved and never alone.

I was probably getting 3-4 hours every 24 hour period, not a lot but it was working.

With that the district nurse left and said, ‘if you or your mum need anything to call her again.

Sunday 28th March The BIG day was here mums special little girl was coming to see her.

The big day was here! Mum gets to see her first born, her special little girl, the daughter she was forced to give up for adoption!

Mum woke up around 08:00 and was as thirsty as a flock of animals at a watering hole!

During the night I had been using the pink sponges on sticks to try and keep mums lips and mouth moist to stop her lips from cracking and mouth and air way from drying out completely.

We all know what a dry cough feels like but could you imagen that but with only 27% lung function and the one good-ish lung blocked by a tumour leaving the other lung, the one with the 20mm lesion to do all the work.

Not long after 08:00 the personal hygiene carers arrived and mum wanted a wash and her slip-on pad adjusting, as during the night mum needed to go loo and I tried to change her, well…. Putting a slip-on nappy pad thing on is a lot harder than you think! When the carer’s saw my attempt after mum had managed to tell them what we had done overnight, and made a joke about it we all had a giggle and they gave mum a wash and put a fresh slip-on on.

The district nurse arrived around 11:30/11:45 to change the syringe drive pump.

They increased the hourly dosage a little bit as mum had needed numerous booster shots in the last 24 hour period.

By now we had heard from Alison and she was well on her way!!

At 12:18 I got a text from my big sis saying she was outside with Frank her hubby, mums son in-law getting masked up and ready to come in.

When Alison and Frank came in the district nurse had just hooked up the pump and was about to give mum a booster of meds, by now she had an additional sub cut cannula inserted as not to keep giving mum invasive injections repeatedly.

I went into mums room and let her know Alison was here, mums face came together as if she had perfect clarity and train of thought!

As Alison entered mums room, mums face lit up, her eyes sparkled, her mouth forming the biggest, happiest smile you could ever imagine. The type of reaction when seen by others would bring tears to the eyes, let alone under these circumstances.

WOW!!

As Alison walked over to mum, mum reached out with both hands as did Alison, mum held on to Alison’s hands lovingly and proudly and said something like, ‘My special little baby girl’, It was heart-warming and heart breaking at the same time. Mum was deteriorating pretty quickly and she had gotten to see her first born again and it meant so much to mum, but selfishly heart breaking as often mum would get frustrated at losing her independence and at times I really struggled to understand what she was trying to tell me or let me know, and with the medication she was on, she would lash out or pull away from me in frustration. The district nurses and the team at Pembridge Palliative care all told me it was not personal and mum didn’t do it to hurt or upset me, which I knew and understood but it was still painful.

Mum wanted an Aloe Vera drink with the bits in. So Frank and I went for a walk down to Poundland along Portobello Road and gave mum and Alison some one on one time.

When Frank and I returned, Alison was sat in with mum and mum looked so happy and as content as she could be, but I could see she was getting tired. It is surprising how tiring excitement can be.

A little while later mum had dozed off and Alison, Frank and I ordered a cheeky Nando’s off of Deliveroo. It arrived about 20-30 minutes later and we sat in the front room, which was an absolute tip as I had move so much stuff for equipment, create a space with a desk for the district nurses and other services to work from to help mum that the front room became a dumping ground. While we were eating, I kept nipping in to check on mum in case she wanted or needed anything.

After we ate Alison and I went into mums room and we all had a conversation as best we could as mum found talking difficult and frustrating but mum done so well, and I know how important it was for mum to be able to have a conversation with Alison.

Alison and Frank left coming on for or just after 19:00 as mum had been drifting in and out of sleep for a while and was obviously exhausted. As Alison and Frank were leaving, she spoke with mum and said she would call and try to visit again later in the week, mum was pretty out of it but nodded and smiled then went back to sleep.

Then at 19:18 I had to call the district nurse out as mum was in pain, discomfort and struggling to breath. The district nurse arrived pretty quickly and gave mum a booster shot of meds. As it took effect there was something different about it, the speed and impact it had on mum was total, something deep inside of me knew that this now was really the beginning of the end, the way mum was just laying there zoned/spaced out, like the phrase the lights are on but no one is home.

I knew, somehow I just knew I wouldn’t have many conversations if any with mum from this point on. All I could do now was just be there, support, talk and pre-empt anything mum wanted or needed.

I had been warned by people in end of life care that mum may deteriorate rapidly after Alison’s visit. I didn’t believe them at the time as they didn’t know mum like I did, mum was tough, she was a fighter, if you knew half of what she experienced in her life you would be amazed and surprised at how she was with people, caring, kind and full of love to give.

But I could see it happening with my own eyes for real! It was just the way the medication took effect, it was as if mum wasn’t fighting to stay awake, its as if she was happy to be ‘out of it’.

However, mum didn’t stay settled for to long and at 23:24 I was on the phone to the district nurse asking them to come and give mum something as she had let me know she was in pain and discomfort, by her facial expressions, wriggling in the bed to find a comfy position but couldn’t, trying to speak and say pain but found it hard to speak. While we were waiting for the district nurse to arrive mum wanted some cold London tap water to rinse her mouth and have a refreshing sip of water.

The district nurse arrived, I cant remember the time but it must have been close to 01:00 and gave mum a booster shot of meds and increased the hourly dosage on the syringe pump drive as it was clear and obvious that mum was needing more end of life medication to make her comfortable as the cancer was destroying her body.

After the booster mum was out cold and looked as at ease as could be.

Again, I used a mattress on mums floor to have naps just like every other night.

Monday 29th March.

I must have fallen asleep and not set my alarm, as I woke up really abruptly and sat straight up and looked over to mum who was awake and kind of sat up looking over at me smiling! I shot over to her and asked if she was ok and she nodded to say yes and lifted her arm over to me and touched my face softly with her hand, which was so frail and delicate. As anyone who knew mum, knew she was never big and was always slight and dainty, but she had a big personality and character.

I looked at my phone and it was 07:00, the last time I remember looking at my phone was 05:45, I couldn’t believe it, I’d fallen asleep for 1 hour and 15 minutes. And I have no idea how long mum had been awake for watching her last born, her youngest baby sleep for. Looking back now it must have been for a while as when I woke up and saw her smiling it was like a loving parent sat watching their child sleep and resting, which I know mum wanted me to do so much. I hope by mum seeing and watching me sleep gave her comfort and reassurance.

For the next few hours mum was dozing on and off, asking for water and helping her use the pink sponges to try and quench her thirst.

I received a call from Pembridge Palliative care asking if the hospice at home service had started yet and how it was going? I said that they hadn’t yet started and I was awaiting a package from them they were couriering over for the start of hospice at home from 20:00 that evening and it would be continuous 24 hour care.

By now it was nearly 24 hours since mum had the syringe pump set up and was needing to be re-done, so I called the district nurse at 11:44, it was the team leader who answered the call and said he was about 10 minutes away and wouldn’t be long. He arrived about 10 minutes later and readied another syringe to put into the pump drive but there was not enough meds to complete it so gave mum a booster and I ran down to the chemist to pick up a prescription, but they said they didn’t have one sent to them and started to give me hassle, I asked if I could take what mum needed and I would ensure they received the prescription for it that day, after begging and pleading they finally agreed and let me take the medication and I ran back home so the district nurse could complete the syringe and connect it back to the pump.

As the district nurse team leader was here the personal hygiene carers arrived to check on mum, and he advised them not to disturb mum if they didn’t need to, they checked if mum needed changing and she wasn’t so they left.

As the district nurse team leader was leaving we had a conversation about mum and I said I didn’t think mum had much time left and he confirmed and he said something to me which im eternally grateful for, ‘Your mum may look like she is asleep but she can still hear everything going on around her, if you need to make or have any difficult telephone calls or conversations with people and she hears it, it could upset her even more.

While mum was asleep due to the medication, I was able to call the GP to get prescriptions sent to the chemist, call the chemist to check they had received them and find out when they would be ready to collect, which was the next day 30/03.

Mum was pretty settled and slept for most of the day until 16:33 when I tried to call the district nurse to come and give mum something to make her comfortable again, then at 16:43 they called me back and said they were on their way. At 17:37 I called them to see where they were as mum was getting very uncomfortable and breathless, they were at the gate, so I went and let them in, and they gave mum some medication and it settled her and she went back to sleep.

I’d been sat with mum from when the district nurse left at 18:00 and it was nearly 20:00 and was expecting the hospice at home care worker (HHCW) to arrive.

At 20:03 I got a call from a mobile number and it was the HHCW letting me know she was running late due to traffic and she was on the number 7 bus at Paddington now and wouldn’t be long.

She arrived about 20:30 and when she walked in she went to walk straight into my mums room! I had to tell her to stop, take of her jacket, wash her hands, put on the appropriate PPE and read the briefing notes of the patient that had been couriered over earlier that day before she goes anywhere near my mum or her room!

She looked at me as if I was some kind of dick head but complied with my requests.

Once she had done what I had asked she went into mums room and asked if there was a comfortable high backed chair for her to sit in, as she was doing the night shift and it was a long 12 hours! Not the best thing to say to someone who is already physically, mentally, and emotionally exhausted from doing what she was about to for 12 hours for 24 hours a day every day since it all went south. The only two types of chair I had to offer was a comfortable pick nick / fishing chair with a hole in the arm rest for a drink or a hard back dining chair. She reluctantly chose the pick nick chair and took a seat positioned looking at mum.

As she was a professional hospice worker and I needed to do a shop to buy some bits and pieces, food, more Lucozade and most importantly cat food and cat litter I asked if it would be ok to run down to Tesco quickly, she said that was fine with her, so I went over to mum and spoke to/with her and told her what I wanted to do and asked if it was ok to go, mum moved her head to look at me and slowly nodded yes and mouthed OK, LOVE YOU. I told her I was going to get ready and will let her know just before I go and gave her a kiss on the head and told her I loved her to. I went into the front room to get myself ready and once ready I went back into mums’ room to let her know I was off to Tesco. When I walked into mums’ room, she was sat bolt upright reaching out in front of her! I looked at the HHCW and she was sat in the chair staring down at her mobile phone!!

I rushed over to mum and held her hand and asked if she was in pain and she shook her head, I then asked if she was thirsty, and she nodded her head and opened and closed her mouth as if to highlight how dry her mouth was. I reached for the pink sponge on the stick, but mum didn’t want that... she wanted a sip from the glass, so I helped her do that.

While I was helping mum with the glass the HHCW came over and I said to her, ‘I was not impressed, and I did not want it to happen again!’ The HHCW apologised profusely and promised it would not happen again and put her mobile away in her bag.

Reluctantly, I had no choice, I needed to get out myself for a walk and I needed to buy some shopping, to feel some sense of normality but before I left, I made sure mum was ok with it first, which she was. So off I went to Tesco, while there I bumped into a family friend and I let them know what was going on and how things were! It was hard to do but I think I managed to keep my shit together.

The walk back home seemed to take longer than it normally would. When I got home I went straight into check on mum after taking my jacket off and washing my hands first! She was sat up with the HHCW having lots of little sips of water, but mum seemed to be restless and agitated so I asked mum if she was comfortable and she moved her head side to side like ears to shoulders side to side, the HHCW was flapping around, banging on that mum was sounding bubbly! I asked mum if she wanted me to call the district nurse and mum nodded yes, she did. At 21:36 I called the district nurse and they arrived not long after, they gave mum a booster and mum fell asleep again.

By this point it was nearly midnight and I was feeling exhausted, and I needed to get a bit of sleep, I asked the HHCW if it would be ok if I went and got a bit of sleep and she said yes and if anything were to change with mum she would come and wake me up. So, I went over to mum and let her know I was going to have a sleep and gave her a load of kisses. I then went into my room and crawled into bed. I knew that another HHCW would be arriving at or around 08:00 as well as the personal hygiene carers so I set my alarm for 07:00, the time now was coming on for 01:00.

As soon as my head hit the pillow, I was out cold.

Tuesday 30th March the day my world fell apart.

SHIT what’s the time, where the am I, what’s going on? It was 06:00, id been asleep for a solid 5 hours and felt guilty for it. I felt guilty for sleeping straight through, I didn’t wake up once, not even to check on mum, it was the first time id spent more than 30 minutes away from mum and out of her room since the 20th March. My world had shrunk to her bedroom, the kitchen and the bathroom. I know I shouldn’t feel guilty for getting the rest I desperately needed but….

I tried to get up but could only mange to sit on the edge of my bed and even that took a ton of effort. I could feel my chest getting tight, but it was like a light tightness, my breathing was a bit shaky, and my eyes burned. It took everything I had to pull myself together and remind myself of what I had been saying since day one. ‘It does not matter how hard or painful it is for me, all that matters is mum and making her comfortable and letting her know she is loved!’

I got dressed and went into mum and said good morning to her and gave her a few kisses on her forehead and one on each cheek and told her I loved her as I did almost every time, I went into her.

I sat on the commode next to her bed and talked to her, at one point I rested my head on her mattress nest to her arm, so my head was gently resting against her arm and hand. Miomy the little girl cat jumped up onto mums’ bed and settled by mums’ feet to keep them warm. Reka the big boy cat also jumped up on to mums’ bed and gingerly walked up along the mattress next to mum’s torso to her shoulders then inline with her head and face. Reka gave mum a sniff and a little very gentle headbutt which mum used to call ‘loves’ and then jumped down off of mums bed and Miomy followed him into the front room.

At about 07:50 or so, the doorbell rang DING DONG. I went outside and opened the gate to answer it and it was a HHCW for the day shift and to relieve the night shift HHCW. As we walked into the flat the cats both ran out of the open door and the day shift HHCW screamed out loud, ‘CATS!!! I’M SCARED OF CATS!!! CAN YOU LOCK THEM IN ANOTHER ROOM?’

WTF…. Really… did this just happen? Did this so-called professional ask if I could lock my cats away in a room? Is she nuts??

I bluntly and plainly said to her, ‘This is obviously not going to work, there is no way I will be locking our cats away in another room and stop them from going into mums room, they are more than just pets, they are family. You better give your line manager a call and request a replacement HHCW for this job and you request a different job with no pets in the household!’

As soon as I had finished my little rant, the HHCW that was here over night, the one who was late came belting out of mums room leaving mum unattended and proceeded to berate the day shift HHCW for coming straight in and doing a hand over. She then emphasised how hard and long the night shift is!

This was all taking place in the hall by the front door and close enough to mums room so she would have heard it all!

I momentarily lost my shit. I told them both to leave as they were causing more problems than they were worth. I told them that they were sent here to help not hinder a very emotional major life event that was playing out. I said ‘your causing unnecessary distress with their behaviour and actions. Get your shit and bounce!’

The night shift HHCW took off real quick, like no joke, you blinked and she was gone.

The day shift HHCW on the other hand and credit where credit is due, she said. ‘I understand and respect your wishes for me to leave but I really don’t think you should be alone at the moment. And I promise you I will be ok with the cats even if they come into your mums room. But I really don’t want to leave you alone.

I felt stuck! I did need someone here so I could go out and pick up mums prescription from the chemist when they opened at 09:00, I also had someone come and do a risk assessment of the flat, well mums bedroom. So, I reluctantly accepted her offer to stay. And wow it was a hell of a bust day, being on the phone to various service providers and organising the multidisciplinary care team to provide mum with what she needed when she needed it and collecting mums’ prescriptions. Not forgetting the risk assessment.

When I completed all the tasks I needed to I went and sat with mum for a few hours and held her hand and talked to her, I told her what I had done, passed on messages from people I had seen and spoken to. It must have been about 13:00 as the HHCW asked if she could use the microwave to heat up her lunch. I showed her where the microwave was and how to use it, once she heated her food up she took it outside and ate it, then came back into mums room.

Once the HHCW was back I then went out for a walk around the block, I need to move, I was feeling restless and needed to be active. I was gone for about 10 minutes but before I went I told mum what I was going to do and wouldn’t be long and gave her a kiss.

When I got back I went straight back into mums room and sat with her again. I told her quite a few times that I loved her and had a little cry while sat there, the first time id really let go in front of mum since her diagnosis on the 12/15/2015. It felt right at that moment as I’d been so focused on being a source of strength for mum I’d not allowed myself to show any vulnerability to or in front of mum.

The personal hygiene carers came by a few times but as mum had been asleep she hadn’t had much fluid intake and didn’t need changing during the day.

What I had unfortunately witnessed was the HHCW talking on her mobile phone organising her work schedule for the next few weeks, so again another one who I have questions over how focused were they on my mums needs while on their mobile phones?!

At 20:00 it was all change, there was yet another different HHCW for the night shift and the personal hygiene carers came at the same time, as the two HHCW were doing their handover the two personal hygiene carers checked mum and she had urinated, only a small bit but still enough for them to change mum very gently and delicately. I stood there like, I don’t even know what I was like, but I knew I was making sure the treated and moved mum with care, respect and dignity!

When mum was changed one of the personal hygiene carers was standing next to mum gently stroking her hair settling her. I went into the front room and grabbed two photos of mum. One photo of mum when she was 21, it’s a black and white photo and mum is absolutely beautiful. The other photo was of mum and me when I must have been 8 or 9. As I was telling them about the photos of mum I said, ‘no matter what mum looks or looked like, past, present or future she will always be the most beautiful person inside and out that I will ever be blessed enough to know and I feel extremely lucky and privileged to have a mum like I do! By this time the new night shift HHCW had joined us.

As the personal hygiene carers were leaving, I was going to give my aunty, mums little sister a call in New Zealand, we’d been in pretty much constant contact since mum started to go downhill. But as I was about to go outside the little girl cat Miomy darted into mums room with her tail down and jumped up onto mums bed and lay down length ways along the side of mum with her head resting on mums stomach. When I saw that and noticed mums breathing had changed, I decided the call could wait and went in and sat with mum.

As I sat next to mum, I reached out with one hand and held hers and used my thumb to gently stroke the base of her thumb, the part that looks like a chicken drumstick.

Miomy the girl cat who mum called nurse-y because if either of us were unwell, poorly or feeling blue she would come and curl up next to you and purr and give you headbutts that mum called loves!

As I was sat with mum I was telling her/asking her if she could feel Miomy purring gently?

Then out of the blue Reka jumped up on the bed and walked along the mattress and gently smelled mums’ cheek and then touched his nose on her cheek, sat for a moment and then jumped off mums bed and headed towards the living room. As he was going off, I told mum what Reka had just done and asked if she felt it?

It may have been my imagination or wishful thinking but I’m positive I saw a flicker of a smile.

What wasn’t my imagination or wishful thinking was the tears forming and the reflection of soft lighting in those tears of my mums half open half-closed eyes.

And I knew, it was like a trap door giving way and in that split second of a moment before you fall of realisation you’re about to be engulfed in darkness and free fall into the abyss. It’s deeper than being scared, it’s a hollow emptiness yet every sense. Sound, smell, sight, vibration, atmospheric, every part of you is a receptor ready to receive.

Seeing the tears and the enormous effort it was taking mum to breath, I could see the fight mum was putting up, she never, not once stopped fighting, no matter the odds she stood tall!

I leant over gave mum a few kisses on the forehead and one on each cheek and one on the tip of her nose, sat back on the commode still holding mums hand, and I started to gently and delicately stroked mum’s hair and said.

‘Mum, I love you so much and I wish you could live forever, you have been not just the best mum, but the best person I have and will ever know. Your teachings have helped shape me into the man I am today and that is all down to you. You have been my mum, my dad, my everything. I am so thankful for all you have done, all the silent sacrifices you made do I could have wanted for nothing. Mum I am proud and privileged to be your son and that will never change.

I know you are worried about me, but the amount of love and kindness you have given to people, our family, friends, neighbours, locals down the market, will keep an eye on me, and so many people have been in touch checking on us. That’s all because of you and the positive impact you have had on others! You are loved by so, so many people who care so deeply they will make sure Reka, Miomy and me are ok.

I held her hand a little tighter as I could now see her heart beating ninety to the dozen and I said.

‘Mum you’ve fought so hard for so long, you’ve shown the doctors they were talking out their backsides back in 2015 and even after our trips to A&E with respiratory failure you fought your way back then as well! But as hard as it is to say, It’s ok to rest, and if now is that time to rest, its ok, I love you with all my heart. We’ll see each other again one day when its my turn to rest. Love you mum, its ok to rest and go to sleep now.

Then there were a few short shallow breaths, then two or three gasp type breaths and then nothing…. No movement from breathing or attempt at breathing, I could no longer see mums heart beating under her frail chest.

I must have sat there for a good few minutes, hoping, praying, willing there to be signs, a sign of life, but no, there was nothing.

All this happened with the HHCW sat in the corner of mums bedroom. I then said loudly enough for her to hear. ‘I think mums gone’ I think the time was 20:35.

The HHCW came over and carried out a few basic signs of life assessments such as sternum rubbing, and earlobe pinching for pain response and pinched the nails on mums fingers for capillary return. All of which pointed to one thing. My mum had just died in front of me.

The HHCW then said, ‘yes your mum is dead, lets put her flat!’

I told her not to touch mum until it had been confirmed by the GP.

The really strange thing is earlier that day I had spoken to Pembridge and asked what happens or what should I do when mum does die. As in a care setting such as a hospital or hospice there are policies, procedures and protocols to implement and follow. They said to just all them and they sort it all out.

So at 20:45 I called the 24 hour advice helpline and the call went something like this.

Pem: Hello Pembridge 24 hour help line so and so speaking.

Me: Hi so and so, its Jamie Heath, Joan Heath’s son.

Pem: Hello Jamie, how can I help?

Me: mums just passed, I think my mum has just died.

Pem: Oh Jamie, I am so sorry, you need to call 111 and ask for an out of hours GP to come and confirm death and then call the district nurses to come and disconnect the syringe pump drive.

Me: What… Huh… I’ve got to do that? I gotta call 111? Really? Someone from you guys earlier today, told me to call you and you would sort it all out and now you’re telling me I have to call 111 and then the district nurses?

Pem: Oh… oh.. we can do it for you if you would like?

Me: Nah, its cool, don’t worry, I’ll do it myself, I’ve done pretty much everything else for my mum why should now be any different!

I ended the call and began to call 111.

All the while the HHCW was just sat in the chair chilling.

Calling 111 to request a GP to certify/confirm death is a real bitch! There’s no magic short cut to speak with someone, you have to listen to all of the pre-recorded messages about all sorts of things and the covid messages go on for what seems like an eternity!

After about 20 minutes I finally got through to someone. Before they had a chance to say anything after hello I explained why I was calling, that my mum had just died at home and it was an expected death and what I needed to happen, have an out of hours GP confirm death.

The 111 operator replied he needed to complete the questions on his screen to then get the correct help arranged for me.

First question: Is the patient still breathing?

Are you taking the piss? I asked, I dun told you my mother has just died at home, it was an expected death otherwise I’d be on the blower to 999!

Just my luck to get a jobsworth!

He was adamant he had to go through the questions on his computer screen!

And that’s what the dickhead did, asked all the questions pointlessly!

Finally he said. ‘I’ve managed to get the appropriate help arranged for you, but just to let you know, we are very busy this evening and it could take up to 6 hours for the help to arrive, if after 6 hours you have not heard anything, give 111 a call again.’

He started to blabber on some more and I cut him off and said. ‘All I need to know is that the appropriate help is on the way and could be up to 6 hours, correct? He replied, ‘yes’.

With that I ended the call and then called the district nurse at 21:09.

The district nurse I got through to expressed her sympathy and told me she couldn’t verify/certify/confirm death but her colleague could and would call them for me.

Within a few minutes a different district nurse called me and was lovely, she said all the right things I needed to hear at that moment, and as she had been to see mum the night before it felt more meaningful.

The district nurse said that shoe would be with us as soon as possible, but she had two patients to see first. I said that was not a problem and that if anyone else called and needed their help to ease someone’s pain and suffering to go to them first, as mum was no longer in pain or suffering. I know that’s what mum would have wanted.

About 10 minutes later the district nurse called me back and said she had spoken to the out of hours GP and he was on his way and shouldn’t be too long, as she was still with the first of the two patients and didn’t want me waiting long. While I was on the phone the HHCW was sat in mums room. I’d also sent a text to my mate across the road from us, he’s ore like a brother from another mother. Mum and him (Toni) got on really well and Toni used to call mum Marj. The message I sent was short and to the point, ‘Bro she’s gone’.

When he saw the message, he came over and was outside in the passage to the front door. I didn’t know what to do, I was going back and forth to mum, as if I was still checking on her in case she needed anything!

At 22:50 the out of hours GP arrived, already in full PPE.

Plastic face shield.

Blue surgical mask.

Blue Gloves pulled up high over the elbows.

White plastic apron.

Blue overshoes.

The GP was here for about 20 minutes. He done what was needed to be done to certify/confirm death on the tick box worksheet and signed it off. He explained everything that he was doing at the time and recapped when he had finished, asked if I had any questions, which I didn’t. The GP left around 23:10.

As I’m stood there with this documentation of my mums death, the HHCW had seen Toni and asked me if wanted her to do anything? … I… I don’t know what I want! She then asked me if I wanted her to stay longer?

In a very mater of fact way, I said, no not really, mums dead and there’s nothing you or anyone can do to change that… so no, there’s really not much point now!

As soon as I had finished speaking she was halfway out the front door, I over heard her say to Toni.

‘Keep an eye on him and look after him, I’ve got another job in South Croydon starting soon’.

Mum looked peaceful and as if she was just asleep, although her eyes were half open half closed, which was a little strange, but she looked at rest and at peace.

I went into the front room where Toni was, and we both had a drink. One of mums faves, Russian Standard Vodka with Pepsi. I also let family know both UK and NZ.

While Toni and I were sat in the front room, I saw a post pop up on Facebook. I’m not going to lie and say I felt good about it, because I didn’t, it hadn’t been all that long since my mum had died and someone else took it upon themselves to then broadcast the news on Facebook, tagging mum and me into the post!

That now meant I had to rush in telling people about mum before they saw it on Facebook, something I wasn’t really ready to do, but now had no choice but to be ready to have very difficult conversations with people.

Yet at the same time I understood that people grieve differently and that the post came from a pure place, a place of love and compassion, and in the grand scheme of things maybe it was needed to give me the push to actually start excepting that mum had gone and I had to let people know, otherwise you all may not know at all. As I said grief is different for everyone.

I sent my cousin a private message thanking him for his beautiful words.

It must have been about 03:00 when it hit me… mum had been left exactly as she had been when she died. As I asked the HHCW not to touch mum until the out of hours GP had confirmed mum was dead, just in case there was still a small spark of life and her last memory would be being laid out flat like a slab of meat on a butchers table. And the HHCW left pretty much right after the GP had signed off on mum being dead.

Question: Do you know what happens when someone dies?

Answer: Their bowl and bladder release anything in them.

What that meant was my mum had been left for almost 8 hours laying in her own excrement!

I cannot even describe or explain how that felt. All I knew is that I was not going to leave my mum undignified!

It took me back to one of our trips to Resus back in 2018 when mum was going through respiratory failure and she had an accident and not one nurse or member of staff seemed to care about it, and I had to sort mum out by drying and changing her while the nurses tried to get the CPAP mask on, but she was resisting because she was wet. As soon as I dried and changed mum, she started to respond to the treatments they were giving her. It’s the simple things like keeping your dignity can bring magical results in helping someone feel cared for and loved.

When I went into mum and lifted her duvet, it was clearly obvious mums bladder had released, and wow… it is surprising just how much fluid had been released. I honestly thought the syringe pump drive had been leaking for how wet the bedding and mum were.

The room was a wee bit cold as I had had the window and the main door open, (the cats were locked in the front room so they didn’t escape and give me an extra thing to have to think about) as I didn’t want mums spirit, soul, aura, whatever to be trapped. It feels stupid to type out but it’s what I did. So I closed the main door and closed mums bedroom window so it was just open enough for a gentle breeze to come in and boosted the heating. I gave it about 15 minutes to warm up and got a bowl of hot-ish water, mums favourite Dove body wash, 3 face cloths/flannels, mums super soft fluffy towels, clean bedding and a pair of mums pink pyjamas with little black cats on them and a pair of warm fluffy bed socks.

As I entered mums room I spoke to her, it was weird as I knew mum had died but I still wanted to talk to her and let her know what I was going to do and talked through everything before and during what I was doing.

To give my mum the respect and dignity she deserved/deserves I had to:

* Remove soiled bedding.
* Take mums soiled pyjamas off.
* Wipe and dry the hospital air mattress.
* Gently wash mum using her Dove body wash and three different flannels. One for privates, one for her body and the other for her face.
* Move and manipulate my mums body that had started to go stiff numerous times.
* Softly and thoroughly dry mum, making sure the mattress was dry as well.
* Put mums fresh clean pyjamas on with her fluffy bed socks.
* Put fresh clean bedding on.

All this on my own and mum remaining on the bed throughout!

When I had done that and put a duvet over the top of mum, just up to her shoulders and I lowered the incline of the bed as if she was in bed asleep, and that’s exactly how she looked. Like she was peacefully asleep. I then gave mum a kiss on the forehead and she was cold, I could feel there was no life left in the body, she had transcended into a Guardian Angel and would be looking out for as many as she could. That’s my mum, always looking out for others before herself. I told mum I loved her and always will and then left mum to rest.

Before I had done that I had called the funeral directors, they said that they could come straight out and pick mum up and they could be with us in an hour, but as it was out of hours there was a fee of £250.00 or they would come first thing in the morning.

As at that point mum had been left undignified and I didn’t know how long it would take me to make mum dignified and financially £250.00 is a lot of money when now I’m responsible for all of the household bills alone. I asked if they could come in the morning and explained why, They Brooks Funeral Directors were amazing, kind, compassionate and most importantly understanding! It’s a bit weird to think of doing but I would recommend them highly!

It took me about an hour and a half to make mum dignified on my own. When I had finished, I went and sat in the front room for a bit and then went to bed at around 06:30.

Wednesday 31st March.

DING DONG, DING DONG, DING DONG!

What the… Where am I, what’s going on…?

I jumped out of bed, DING DONG, DING DONG.

The doorbell, shit, what time is it?

07:55 I’d been in bed for an hour and 25 minutes.

Who the … is this DING DONGING my doorbell, I opened the door and shouted up to the gate… ‘Who is it…?’

No reply but I could see feet under the gate.

I went and opened the gate, ‘hello, can I help you?’ I said.

Hello, I’m a HHCW, I’m here for my shift! Said the woman standing there.

Pardon… I replied… what do you mean here for your shift, my mum died last night!

The damn HHCW then said, ‘Oh really… no one has told me. Let me in to see.

WHAT! I replied.

I need proof to tell my boss!

I told her that that was not going to happen!

As I went to close the gate she put her hand on the gate to stop me from closing it, and was about to say something but before she had the chance I told her to let go of my gate and if she didn’t it would be the last thing she ever held!

With that she let go and I closed the gate and went inside.

I then sat in the front room and waited for the funeral directors to arrive. Who mum had spoken with herself not all that long ago, mum wanted something simple, cheap and no religious based service. Plus with the restrictions of covid she didn’t want to leave me in a position where I had to choose who to ‘invite’ and who not to ‘invite’ so mum chose a no service simple cremation or as she said. ‘Collect, Burn, Return’ and wants me to do a gathering in the back garden for a celebration of her life and life in general. And for people to wear bright colours, but if they felt the need to wear black to show their respect then she asked if a splash of colour be added even if it was a bit of ribbon, a scarf, a handkerchief anything with a bit of brightness! While I waited for the funeral directors to arrive, I called our GP to arrange and organise getting a death certificate. I also kept going back and forth to mum again, like I was hard wired to continually check on her.

When the funeral directors arrived to pick mum up, I showed them into mums room where she was still in bed as if she was just asleep. They asked if mum had any tubes or cannulas attached, I said no, but wanted to double check and went to lift the duvet off of mum. What I saw next shocked, surprised and hit hard! From what I could see was mums bladder had released again. She was soaked and so was the bedding! I couldn’t believe it. After taking my time and being so careful in making mum dignified only a few hours earlier, I hadn’t thought to put another nappy pad on.

I didn’t know the dead pee a few times!!

Stood there with mum wet and the funeral directors, I asked if they give the dead a wash? I had explained on the phone to them the night before, well the early hours when I called them about making mum dignified. The funeral director said that they could if I wanted them to, and I said yes, I don’t care how much it costs as long as mum isn’t left laying in a puddle of her own piss even if she was no longer alive. The funeral directors said not to worry about that and took a clean set of pyjamas away with them when they took mum away.

I couldn’t watch them put mum into the black body bag or as they carried her out of the flat, but I did watch as they put her into the private ambulance. Which was a very surreal moment.

The only real thing I was thinking was… shit I wonder how many curtain twitchers are peeking through their windows having a gander!

There are far more details to this story and this is just an overview to share some of what its like being a sole carer to a terminally ill parent.

By focusing on the love we should all have for each other, we can all make the worst times in our lives bearable.