Paola
A warrior's Soul.
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Edited by Kiwi (thank you)

Introduction.

In our lives we encounter experiences that define us, we have moments that change us, people we meet along the way, places we go.

What drove me to write this short novella?

With all that is going on in the world, I wanted to introduce people to the love of my life, to a woman who had dreams and wishes, who faced battles and odds that most of us never have to.

To let people know what really matters in life, to remind people what they have and to cherish it.

Someone so special she changed me into a far better person.

I could fill many books with the experiences of our life but that is not quite what this story is about.

Instead this is about what I felt made her special, this isn't about me that is a book for another time, this is about Paola

It is human nature to believe that our loved ones are special, as they are to us in a personal way what I wish to convey is what made her different than anyone else that I knew in my life.

Many people in the world become "I'll just let many people die in the world" or "I'm more important than anyone else" but some take these challenges and become so much more.

Getting cancer does not show bravery or courage it is like any other bad situation we come across, instead what more defines us is how we deal with adversity.

At the end of this piece I will be giving some tips and tricks learnt from years of looking after an ill and disabled person, hopefully this will help others in this kind of situation.

How we met.

I knew from the first time I met her she was special, sat alone at a table looking slightly lost at this party, it was someone's birthday. Music and drink filled the large rented room above the Albion pub.

A strange rather eclectic group of people, role-players and gamers brought together at a shop long since gone.

I was wearing a Deep Space 9 t-shirt and her first words to me were in the form of a challenge, “DS 9 is okay, but Babylon 5 kicks its ass” I would like to say that acting all suave and sophisticated I sat opposite her but the truth is I was a geek before it was fashionable and not only had a girl just spoken to me she was speaking science fiction.

I do remember sitting on the opposite chair, but I believe that was just luck and muscle memory.

After the shock receded, we began to discuss the matter in depth, four hours later as the party wrapped up, we were still sitting at the same table and chairs talking.

I lived locally but she needed to catch the last bus back to Oakhanger, as I stood there never wanting this night to end trying to build up enough courage to ask for her phone number she asked me if I would like to visit her college and sit in on a club she ran, sure I said a little too quickly, did not even cross my mind to ask what kind.

She would meet me the following day and we would take the bus together to Alsager.

As the bus pulled away, I had the biggest goofiest grin on my face, just about floated home and slept.

Oh my god! She ran the science fiction club, I think 7 people including myself and Paola were there, we watched an episode of Tekwar and Star Trek Original series we had a lot of fun.

Our life before illness

It seems like from the start everything was against us even before she got ill, she had been dumped two hours before the party we met at, my friends warned her not to get involved with me that I was “strange” her parents did not like me and my mum thought she was after my money.

So we did what any self-respecting and quite stubborn person would do.

We became a couple within days, moved in together three weeks later and three months later we were engaged.

Everyone we knew thought we were crazy.

Sold everything to pay for the rental deposit on a drafty mid-terrace house, the front door was so badly fitted you could fit your little finger between the frame and door at certain spots.

Who needs a bed when you have an air mattress that takes an hour to inflate before bed because the seal on the pump is damaged, yes we didn’t even have a real bed for 3 months until a relative took pity on us.

We were happy though, she went to college while I looked for a local job doing something involving computers.

Her course was Creative Writing, she wanted to be a Librarian with a side order of archaeology dreams.

We became involved in all the local tabletop and live action groups, it was a fun time.

Yes I proposed to her in McDonalds, breakfast meal no expense spared our after party being the local gaming shop.

Everything changes

I received a call from the main bus station, Paola had fainted on her way to college, this was the start of the coming challenges.

A friend had brought back glandular fever from his travels, so the first assumption was that. When it got worse and Paola began to get terrible pains in her legs, she was sent to a physiotherapist which just caused more pain.

A visit to the A&E got us shouted at by a young Doctor for wasting NHS resources.

No one took a blood sample, Paola was getting worse and so-called experts even believed it was in her head.

I am ashamed to say that even myself and my mother began to believe them, after all these were Doctors and they knew best.

Time went on and Paola got worse, a week before we got a real diagnosis, I called an out of hours Doctor who took one look at Paola crying on the couch coughing and wrote a quick prescription for Antibiotics accusing us of wasting time like his last call out which was to a girl with nits.

I will point out that this is where our distrust of Doctors started, it took many years for that trust to come back.

It was a Saturday morning, I still remember it well, mainly because at the age of 26 it was the most scared I have ever been in my life, we had recently began to enjoy computer games and having only one computer we shared the time, I came down from my nap to see her coughing violently on the sofa.

That wasn't the scary part, the scary part was as she coughed a bruise seemed to appear on her face moving down her cheek every time she coughed, and her eyes were red almost completely red, I ran for the phone but Paola forced me to put it down she wanted to wait until the surgery opened because of her experience with an out of hours Doctor.

At 9am I called the surgery and the GP arrived at our front door 5 minutes later, that in itself was a shock, it seems this particular GP had experience in many areas.

He took one look at Paola asked to use our phone and I just stood there as our GP rang the Medical assessment unit direct, shouted at the people on the line until he was put through to the dispatcher and literally ordered them to send out an ambulance that second refusing to answer the normal questionnaire.

He then took me aside and said "I can't diagnose this for you, it's not my place but brace yourself it's going to be bad"

The Ambulance arrived, we were on our way to the Medical Assessment Unit, blood tests were taken as soon as we arrived, over the next couple of days 9 pints of blood and alternate bags of platelets were given.

I was in shock, I remember my mum being there and a few others, I remember small pieces of conversation, time spent at the vending machine while my mum took turns at her bed.

Her white cell count was through the roof, but they were immature cells not fully developed so her immune system was shot, her red cells were so low they were surprised she was not in a coma and her platelets were at 0 that meant her blood was not clotting.

The Diagnosis

Acute Lymphoblastic Leukemia (A.L.L) a rather unfriendly type of blood cancer that originates in the bone marrow.

Cancer although in the 90's when this happened most people called it the C word.

A predominantly childhood illness and much easier to fight and go into full remission and cure if you are young.

While myself and my mum were speechless Paola actually breathed a sigh of relief, she had been fighting an illness for 3 months and no one believed her, she finally had a name a label for the enemy.

While I was shaking and trying to comprehend what was going on Paola just asked the Doctor three simple words “Okay what now?”

This was the moment I first saw her strength and her response kicked me into gear, I think that was the moment I decide that I was going to marry this amazing woman.

The shotgun approach.
Chemotherapy is horrible, the idea is simple flood the body with poison because the leukemic cells are less viable against certain concoctions that healthy cells, so you will have some friendly fire but in theory you hit more of the cancer cells.

You are trying to get the person into remission, to a stage where either you get rid of the cancer or you lower it to a point preventative treatment can keep it at bay.

Unfortunately, you are also poisoning a human body, appetite goes out the window, sickness and nausea is common, a lot of people can not cope, your hair can begin to fall out, weakness and inability to sleep even though exhausted.

I believe the moment it really hit me how bad these treatments were, was when I told not to kiss her because it could transfer to me via her lips.

Weeks of this and the plan was simple, get Paola into forced remission and then see what the results were.

To most people getting married is an event that takes months if not years to plan, dreams and wishes fulfilled, friends and family, a romantic and special proposal.
“Jason can we get married, I want you to be my next of kin and if I die you know my wishes”
That is all it took, I rang the registry office and asked when the next free slot was, we organised a few friends to help us, our honeymoon was one night away from chemotherapy laying on a mattress in my mum’s house.

Attack of the chromosome.
One day a Doctor came to see us and quite apologetic explained that Paola had the Philadelphia Chromosome which in the case of A.L.L made it much harder to fight.

Chemotherapy would not do the job; the only chance was a dangerous treatment involving a bone marrow transplant and full body irradiation.

This was the first of many setbacks but Paola even though crestfallen just said okay, we hugged, while the Doctors started to look for a bone marrow donor, family was tested but no match.

Great news we found a match in the USA, so we moved ahead, plans were made we would be moving to a hospital more specialised in this kind of procedure, you have to understand most treatments for cancer are based on a percentage chance of success there is no 100%.

I put the house in order and started making plans for the move, I wasn't going to let her face this alone and rooms were available on the Hospital grounds.

A week before we left for the new hospital news came through that the Donor was not as good a match as thought and had a very good chance of failing, we were heart broken, our hopes once again raised so high, all our energy and fight towards this one goal and then it was taken away from us.

The other option.
You have to understand this was the only option available to us, A.L.L is a killer and quite aggressive, the treatments are brutal, and we were on borrowed time.

Instead of transplanting someone else's bone marrow you take a sample of your own, hit the person with full body irradiation, clean the sample and reintroduce to the body, sort of like a reset to factory default.

It was risky but what choice did we have.

Within the next week we were taken to the new hospital.

Clean room.
I am not exaggerating when I say that the treatment was the equivalent of throwing my wife off a cliff, watching her hit the bottom and then trying to bring her back.

To kill off the bone marrow so that the new sample could be reintroduced your body is irradiated, hair falls out, your body loses the ability to make platelets, white cells and red cells, you have to wait until it's all dead then you reintroduce the cleaned sample and hope yes that is the word hope her body restarts because if it doesn't then you're dead.

Paola had many scares and complications, actually more than most, one of the main consultants came in before we left to go home, opened a text book and said most people get one or two of these problems during the stay, showed us 3 pages of small writing and said you got every single complication, everything that could have gone wrong did except you didn't die.

Was it a cure?

No, you would think all that effort was for a cure but no all that was just to force her body into remission, so she could go on a medication for the rest of her life to keep the cancer away.

Back home beginning a new life.

We were able to secure a bungalow run by the local council which was much nicer than our old place, it was setup for disabled people.

This was one of the only times I saw Paola really angry, one of our neighbours was a devout Christian, we have nothing against any religions everything has its place but when we got back from the hospital, we explained what had gone on and she said
“Oh god must really love you for you to survive”
I saw my Wife tense and then she replied
“Excuse Me! I and my husband fought this with the help of our Doctors, IF you want to give your god credit for my survival then you damn well better accept that he caused the cancer in the first place, you can NOT have it one way without the other.”

I do not think she spoke to us again.

Paola was tired but seemed to be recovering, all she had to do was take this one injection every couple of days and everything would be golden, we got back to living our lives and furnishing our new home.

I even began to make plans looking for a job, life was good we had faced the dungeon boss and won everything would be good now.

Paola started getting more into painting and crafting in general, she never liked to just sit down and rest, she felt a second chance was given to her and she was going to do something constructive with every moment she had.

While most of us would need to rest and recuperate having gone through such an event she poured herself into cooking, writing, needlework, painting and life.

Side Effects.

Imagine being on a medication that keeps death at the door, this medication is your only shield if you drop it you die but every moment you hold it your body becomes weaker.

At 21 Paola developed arthritis in her joints, muscle weakness, fatigue, cramps and pain, she had to start walking with a stick, she developed terrible panic attacks and anxiety, all symptoms of this medication keeping the cancer at bay and the medication offered by the Doctors to help with these symptoms turned her into a zombie.

It was at this point Paola first said no to painkillers and antidepressants a decision she kept to for 18 years, not even paracetamol.

Her view was I need to be able to think or what is the point, I need to know when I am causing myself more pain not hide it away.

I gave up my idea of a career and became her primary carer, my job and future was now making the best of our situation and trying to make her smile.

As the years went by the side effects got worse, a night’s sleep became impossible and even cuddling caused her pain, this is about her not me but imagine that you are with the love of your life and you can’t even cuddle.

Paola was in constant pain but she got used to it, a lot of her crafting and an projects became too much for her but she never gave up, if needlework was too painful she switched to crochet, if jewelry work became too much then she moved to another medium, she never gave up, she fought every single day for what we take for granted.

Every six months we would go for blood tests, every six months we rolled the dice to see if the cancer had come back or something else had happened, after all the initial treatment was so brutal that secondary cancers were more likely and damage to other parts of her body were unknown.

Coping mechanism.

While we all like our time off and enjoy rest days, while most of us enjoy quiet time and sleeping in as anyone who has gone to prison will tell you there is a big difference between staying at home because you want to and being locked in.

Within the first six months Paola became housebound and I as her primary carer taking on more and more of the roles around the house, cooking, cleaning, laundry and budgeting became housebound too.
Friends disappeared, I can’t really blame them after all who in their 20’s wants to be reminded about mortality.

We were lucky that we both had so much in common, not everything I was not a crafter she always amazed me with the beautiful items she created, it's good to have your own thing even in a loving relationship.

I built and continually upgraded our gaming computers, we could no longer explore the outside world, but virtual worlds became our playground, we ran our own game, we explored other worlds together, always together playing characters and classes that supported each other.

I still have vivid memories of exploring Everquest together.

Games matter people matter.

Before Paola became too fatigued and new side effects kicked in we played many games together, from Meridian 59 to City of heroes, we met many people but in all our time one game stood out, EVE Online and one set of people stood out, Goonswarm and more specifically European Goonion and the corporation Amok.

While we all know the outward appearance and actions, those people behind the pilots were part of the most genuine group of online people I ever met, my main character was Quebber my favourite ship the Sabre, Paola played a couple of characters depending on her duties but I think she had most fun with Bei Jaique flying a Vigil.

I met a lot of them at a live meeting and it said something that I trusted them with the truth about Paola, we were not looking for sympathy or special treatment.

When they found out about Paola, without my knowledge they began to organise presents and events for her upcoming birthday, it turned out to be one of the best birthdays Paola ever had, a lot of real life gifts arrived and it ended in a free for all event in EVE.

https://www.youtube.com/watch?v=ELPZIV5N74w

What they never knew was Paola was in tears of joy for most of the event so touched was she by these people who hardly knew her making this effort.

Soon after Paola became too tired and had to stop playing.

I too had to stop playing as Paola got worse I was needed more often without any warning.

One point to add, when Paola found out that The Mittani had personally broadcast rallying people to help with all of this, she worked on a new thank you card for three days and we sent it to him, couldn't use her hands properly for a week after. If she wanted to do something she was going to do it, no one especially me was going to stop her.

We loved B-movies and anything science fiction or horror our music tastes were all over the place, this was the start of our DVD collection which numbered over five thousand, in time I was able to transfer all of the movies and series to hard drive putting the physical copies in storage and as technology especially wireless evolved laptops and phone meant that no matter where she was in the house she had access to entertainment.

Sad was the day when she no longer had the energy for us to explore online worlds together, she could need to log off or take a break with no warning.

Short term games like Left 4 Dead or Warframe, still group orientated but a session could last less than 15 minutes.

As with every challenge we adapted, single player games were chosen, it was always nice to see the different ways we played, in Skyrim for example, I usually powered through the main quest line and by the time I had done all of that she would own every house in the game and collected all of the items.

I remember her sitting next to me while I played through all of the Mass Effect Games.

Recently we took turns playing Forza Horizons 4, one of my best memories is of her laughing and racing around the British countryside in a Jag.

When you have pain and mortality surrounding your life these things really matter, it is no longer leisure or luxury it's an actual lifeline.

A window onto a world you can no longer be a part of.

Mobile gaming and phones in general came into their own in the later years, with Paola not being able to sleep most nights her phone and the games available became a life saver, Bloons became her favourite and when too tired even to mobile game she would watch her favourite YouTube channels.

Those 18 years passed so quickly her side effects slowly getting worse but so slowly that we just adapted.

Technology is your friend.

When you are stuck in a small bungalow or any kind of house for a long period of time you need to adapt, online shopping became a life saver, Amazon, Tesco, Asda, because of Paola’s weakened immune system limiting contact with people was a necessity it wasn’t about being antisocial, a cold could lay her out for 6 months.

Plex, as you can imagine we collected a lot of DVD’s we owned all our favourite series and films, always looking for rare B movies, we ended up with 6000 plus films and roughly 4000 episodes from different series, these began to take up too much room, so I began the 2 year ongoing task of putting them all on hard drives and then Paola could watch anything she wanted at any time or place.
Echo from Amazon changed our lives, with one next to her bed she could control the lights, listen to music, control our plex.

At some point in time her eyesight got worse and books which she loved became impossible to read, audible helped a lot.

She always wanted me to be able to game and have fun, so we developed a system whereby I could be upstairs and sleep upstairs and not worry too much.

Our system was this, if she needed me and it wasn’t an emergency, she could turn my bedroom light on and off, she could then broadcast a message through the downstairs Echo to my Echo. Letting me know what was going on. If I was dead asleep, she could send a song to play.

We also had multiple mobile phones one on me at all times, one upstairs and one with her at all times as a backup.

Trevor and Mum.

My mum was amazing, she supported me, brought me up on her own and allowed me to be me, she taught me right and wrong, never forced her beliefs on me and she was there for Paola as if she was her own daughter.

Trevor and mum got to know each other over the fence, they lived next door to each other and fell in love he is a great person and as good a surrogate father as we could have.

Unfortunately, my mum was diagnosed with early onset dementia, so after a discussion with Paola we left our little bungalow and moved into Trevor’s house and he moved in with my mum, that way we could help him to look after her.

We managed to look after her for 4 years before she became a danger to herself and had to go into a home.

The wonder drug.

The original medication for an unknown reason stopped working and another medication a newer medication was chosen for all purposes this was a much better medication.

All new medication has risks and side effects, it is never the same for everyone.

Unfortunately, the new medication hit her like a truck.

It was at this time when we got concerned that things could go badly so last year, we did some crazy stuff like visiting firing ranges, bought a little boat for the canals which promptly broke down and died after 2 days, we visited wildlife parks and went on 10-mile canal walks with me pushing her wheelchair.

As the year went on and actual damage to organs started to appear especially to her kidney’s and diabetes type 2 started, I did all I could to raise funds, so she could do anything she wanted to try.

She humbled me in so many ways, weakening as she was, we went out every day, sometimes she would even fall asleep in the wheelchair as I took us exploring, we called the wheelchair “Adventure Chair” and we went everywhere.

It had big tires and suspension, so we could go off pavement, we would go out day and night, I knew she was hurting, I knew every little bump jarred her bones but when you know it's only going one way you fight for what you still have.

Those are some of the most special times we had together.

Do you want the bad news or the bad news?
Late in 2017 they did something called taking stock, a lot of medical tests over multiple departments to find out what was going wrong and if anything could be done.

It was 27th of December at 2:30pm when we entered the consultant’s office, you know something is wrong when the consultant’s whole demeanor is apologetic in nature.

“Your Kidneys are failing and there is nothing we can do to stop it happening”
I asked about dialysis.
“Don’t worry about dialysis, your kidneys will last at least a year maybe 2 we are forming a team from Renal, Nutrition and Haematology we will keep them going as long as possible”
Okay we said let's get started.

It wasn’t meant to be, we followed all the advice Paola did everything they asked we were used to it, we would adapt and overcome or, so we thought.

She almost died at this point because the plan was to get her weight up because she was only 49kg and her legs and arms were like matchsticks she started gaining weight and her BP came down, we were so happy, but Paola started to have chest pains and her legs inflated.

She wasn’t gaining food weight her kidneys shut down a lot faster than anything thought it was all liquid weight.

Her kidneys went down to 8% within 2 months and they still do not know why.

In March she was rushed to the renal ward with 22kg extra liquid weight on the body, her legs were leaking liquid so much she left watery footprints and the liquid was filling her lungs.

It usually takes months to prep and setup for dialysis, they had to do it in weeks, they maxed out on water tablets and other medication trying to get rid of the liquid.

It was at this time when Paola took it upon herself even though she was tired, in pain and suffering to visit the other people in the ward while I was at home and keep them company, because in her words “they looked lonely.”

We took the Peritoneal Dialysis option because that can be done at home, her days would be free, and she would just be on dialysis every night from 9 to 8.

During all this she was her amazing self, never giving up, never complaining just getting on with what needed to be done.

Home time.

While she was in hospital, I turned our lounge into a bedroom, I made it so she could watch TV, go on her computer, play on the Xbox and do her crafting from the new riser recliner chair I bought, the bed came from the social services, home nurses were in place and everything was ready for her to come home.

Once at home things got back to normal, removal of the excess fluid was a very slow procedure, you can’t take out too much at a time so 0.1kg at a time, we kept score, we had access to her blood results at all times, every day visits from either the District Nurse or the Home Dialysis team, they were all amazing.

Paola never got better after each of these setbacks she just adapted to her new norm, I was fully trained on setting up the Dialysis and the house had to be surgical clean because her exit wound needed cleaning daily by me.

We had 6 different cleaning solutions for different situations.

I set up a camping toilet because while on dialysis she would not be able to get to the bathroom.

She could only have washes with wipes because if water got into the exit site it could be deadly.

You adapt, dry shampoo, body wipes, we had visits from private nurses 3 times a week but mainly that was for conversation.

Her feet had been badly damaged by the water blisters that burst and dialysis plus diabetes meant very slow healing rate.

She started to craft again and play Forza Horizons 4 with me, it was great to see her laugh and enjoy herself.

Dialysis is an ongoing treatment that needs to be tweaked, Paola ended up back in hospital again due to the cycle not working right but once again we made it home and things actually started to get better.

Thursday 8th of November

On Tuesday and Wednesday we had been to our two monthly check up with Renal and Haematology to make sure everything was on track.

Thursday morning, she woke feeling nauseous and with heartburn, we thought she had picked up a stomach bug and treated it accordingly but on Monday after putting her on Dialysis at 10pm I went upstairs and heard her coughing and it didn't sound right.

I came down and spent two hours with her, we called the non-emergency service to ask for advice and ended up in the hospital emergency room via ambulance at 4am.

Within hours she was moved to the Coronary Care Unit, it seems last Thursday she had what is called a silent heart attack, if you are female and have diabetes you can have a heart attack without it showing any kind of normal symptoms.

I was in shock, whereas Paola just dealt with it.

Darker times.
It is very hard to understand let alone accept that sometimes things just happen, the universe isn't biased against you, it's not personal it just happens. The universe is indifferent.

As the week passed by it became a blur of time spent at home and time spent with Paola, each day was the same, I would arrive at 6:30am, if nurses were not busy I would ask how the night went, then off to her room, we would chat and make small talk while we waiting for the final cycle of her dialysis to finish and then I disconnected her from the machine and did the prep work so that the nurses could take away the used items.

Because of my training I was allowed to do much more than most and I was put down on the staff list for the room as her Nurse, I could even call for new medication.

After organising her dry weight being taken and then her breakfast, she loved Rice Krispies with cold milk, the Doctor would arrive, then we would discuss the days plan.

We talked about how her night was and how she felt but mostly I talked because she was so tired.

At 9:00am or there about I would go home get something to eat feed the dogs and chat to her via WhatsApp, she would keep me informed as to tests happening and if she needed to sleep.

After the first two days I stopped visiting in the afternoon unless she felt well enough because it was far better that she got some rest.

At 6:30pm I would be back on my way to the hospital either Trevor would take me, or I would order a Taxi, money was tight, as I was burning through funds quickly but if something like this ever happens to you or a loved one you will quickly realise just how low money factors compared to love.

We would chat about what meals she ate and how she was feeling, I talked to the Nurses and voiced any concerns.

At this time, I would like to point out a harsh fact, Paola was in pain at all times during her stay in hospital, all the illness she had combined meaning lying in bed was agony, staying still was painful, moving was painful.

I would let the Nurses know when it was time to help her position for the nights Dialysis, at that time I took over and set it all up.

Once everything was working, Dialysis machines can be a little twitchy sometimes, I would stay for a little while usually till about 8:30pm and then leave so she could sleep.

Monday 19th November was the day when mission “get Paola home” was to begin, it started off normally with me waking up at 6am, giving Trevor call so he had time for a cup of tea before driving me to the hospital, give both dogs some love and let them out while I showered and put some clothes on.

Humans have an amazing ability to adapt to any situation, for it to become the norm, for it to become routine.

Ate half a banana and drank some water then out the door a cold morning not quite a frost but close.

Our drive to the hospital was uneventful not many cars on the road at that time of the morning, I found myself looking into each house’s windows as we passed by, wondering what kind of life lay beyond that pane of glass were they happy did they have health or were they in pain.

I arrived at the hospital and made my way to the ward, looking forward to seeing Paola, hoping she had at least some rest.

As usual the doors were locked and so I pressed the buzzer, it's hard to explain but even after 20 years a special kind of excitement rose inside me every time, I waited for that door to open knowing I was going to see her, every day I had to restrain myself from running to her room.

Entering her room, she was laying on the bed already looking towards the door a slight smile on her lips, at that moment I was reminded of the simple fact that with her at my side I could handle anything life threw at us.

She said “I feel more sick than I ever have before” and before I could even think I replied “dear love you just had a heart attack I think that's expected” then I laughed, I think that is what is meant by gallows humour, she was worried I knew but what could we do but put one foot in front of the other.

While we talked, I disconnected the dialysis machine and did as much as I could because Paola told me it had been a busy night for the nurses, in the coronary ward that usually means bad things.

I could also tell that Paola had hardly slept and was completely exhausted, after her breakfast I told her to let me know if she wanted me to come up during the day or if she needed to rest, I would be back as normal at 6:30pm.

She tried to rest during the day, we chatted on the phone, kept each other company, I binge watched a series of Scrubs and played with the Dogs, logged on to Amazon and ordered a few items for when Paola got home.

That talk.

When I got back to the hospital at 6:30pm I could tell something was bothering her, we had our normal small talk, she told me what she had tried to eat, as well as any information Doctors had passed on.

“Jason, I don’t know if I’m going to win this time”
“We have faced so much and won the dice roll so many times when we should have lost”
“I don’t want to go, I don’t want to leave you”
“I just don’t know how much fight this body still has”

I put on a brave face, I smiled and told her we will fight this together and if it is the end then I expect you to haunt me, then she mentioned hot ghost sex and we laughed.

She played me the two songs she wanted to be played at her funeral while I setup the Dialysis for the night.

We then changed subjects to ideas for her to keep busy and occupied while still in hospital.

We had no money for a laptop, but I would burn a couple of credit cards without a second's hesitation if it would make her time in hospital any better but as always being the wiser of us both she said “I’m too weak to hold my phone for long I couldn’t use a computer at the moment”

You know it doesn’t matter how much you prepare for something so amazing to end, it doesn’t matter that for 20 years you have lived under the threat of death.

Rest without pain my love.
On Tuesday 20th of November at 6:30am I went into hospital to disconnect Paola from her dialysis, things were looking up it was working well, we smiled and talked really wanting the treatment to get a move on, both of us wanted her back at home, no one ever wants to be in hospital, no matter how amazing the nurses and Doctors are we heal best at home.

After I disconnected her and we pushed the machine out of the way, we chatted as we waited for the nurses to come and give Paola her dry weight, a dry weight is when something you take first thing in the morning before eating or drinking, it is how you keep a record and watch on fluid build-up.

The Doctors and Nurses in the coronary care unit were amazing the best I have ever seen, every night I went home knowing Paola was in good hands.

The main Doctor came around and told us the plan of action an Echocardiogram and a big meeting of all the specialists, then tweaking of Paola's medicine and maybe home by the weekend.

Her weight was taken and then she sat out in her wheelchair, I tried to brainstorm new things to distract her, at 9am I left after making sure the Nurses ordered her a protein drink, before leaving I told her that I loved her, and waved through the door to her room, I called Trevor to come pick me up and stood outside the hospital main entrance, Paola messaged me on WhatsApp and mentioned Minecraft for the phone so I bought it for her from the google store and told her to download it.

I was so excited to tell Trevor Paola should be home by the weekend, even started making plans.

From looking at her phone I could see the last thing she did was start playing Minecraft and listening to the new song Hold on to Memories by Disturbed, I got home and fed the dogs, went up on my computer and started typing out all the updates to let people know how Paola was, I then looked at rings online, Paola wanted to swap her ring for one with less edges, I found a lovely band with a Dragon, it was 10:07 when I sent a message to her phone asking for her ring size.

She never replied, I got a call a minute later from the nurse looking after Paola, saying she was in a bad way and I needed to get back to the hospital, I felt right then like my world was ending, everything went cold, I put the dogs in and ran over to Trevor's house next door, we were in the car in minutes and he found a parking space while I ran to the ward, I was trying to talk myself out of the pit that had formed in my mind, I was shaking as I pressed the buzzer into the ward, a nurse came to me and told me they were working on Paola, would I like to go in or go wait in the waiting room, I went in with them.

I now understood why the coronary rooms are so big, 12 people were in there, a lot of machines and they were taking turns on Paola's chest, if you have never seen a cardiac arrest and how they respond it's not like in the movies or TV series at all, it is so much more violent, they compress the entire chest, they had the echo ultra sound , 2 mins of chest compressions plus she was already ventilated then they would stop check for a pulse, (unlike tv there is no sound from the machines they turn the sound off) do a quick echo scan of her heart and start again.

They managed to bring her back once just before I arrived, she had a second cardiac arrest, her heart was unresponsive, not working at all, they gave adrenaline they really did try everything, they let me tell them when to stop.

They then told me to hold her hand and talk to her as she slipped away which I did.

Paola was in no pain at the end, after that moment of playing Minecraft and listening to her song once she said her chest felt funny by the time, they lay her on the bed she was listless and unfocused. But as the Doctors explained her body fought to the end.

I went back to the hospital the next day, I visited the wards took some chocolates and thanked all the amazing people who looked after Paola, I sat with a nurse and we talked about things. Making them all promise that they would pass on my thanks and thoughts to others who were not in that day.
Walking the halls of the hospital, places that together me pushing her wheelchair or holding her hand as she used the walking stick in the past we had travelled together for many years.

I miss her so much, I can do anything that I want now, go to bed early, not go to bed at all, sleep in, play computer games all day or go for long walks, I could travel and explore but all I want to do is look behind me and see her smile.

We are not put together to truly understand our mortality, we are not built to accept that one day it will end in some ways it is harder to live knowing we will die, my thoughts go out to everyone around the world who has to cope with something like this but remember this if love is involved then you can cope, you can deal with it and you can take one step at a time not for yourself but for them.

As a carer without realising it you put your own life on hold, it isn't a conscious decision if you love that person it just happens, she or he becomes your focus in life, it affects every part of your life, you live to a schedule set out by their needs even down to what you watch on TV.

We loved doing things together but Paola was so ill and tired most of the time that we had to consciously limit what we did, watching a film or more than one episode of a series would tire her out, so we kept to our favourites Forged in Fire, Arrow-verse, Marvel Films, Agents of Shield, Task Master, 8bit, Mr. Robot, Preacher, I got use to watching a film in four or five parts.

Games were the same, as she got worse, she could only spend time on those games that were really special, I was sad when she became too ill for us to play MMO’s together, I will always cherish those times spent exploring EverQuest and Anarchy Online, we never usually joined a big guild because it was hard to with her situation.

The song that she always said best spoke of us both was Sad Song by We The Kings (prepare to cry if you listen to it or maybe that is just me).

A realisation.

Before I wrote these pages, I already believed Paola was amazing but as I sit in this empty house, as they take away the medical equipment and I organize the funeral I can see just how much she lost.

I am in awe of her, that during this for 20 years as all her dreams, most of her hobbies became too much for her she never gave up, when her eyes became too bad to read books she started listening to audiobooks, when her muscles in her hands and arms wasted away, she leaned on me to warm the modeling clay.

She never once fell back into old routines, be that her liquid intake limit, her diabetes control or her medication.

She kept a detailed log of all her results from blood pressure, temperature, o2 stats every day so that the Doctors had the data they needed.

And she made time for me every day.

Yes, I did all the heavy lifting, I cooked, cleaned, looked after the budget and kept things going but she never slipped, never stopped fighting until the very end.

Think about it for a few seconds, she had multiple life-threatening illnesses and absolutely no chance of a cure, only one direction right from the start this could go, imagine how terrifying that must have been.

Each time she almost died, each time it took away something else, removed her ability to walk or permanently gave her a throat problem that for the last 2 years eating anything caused her to choke.

A woman who was living on 2 hours sleep a night for the last 4 years on top of the fatigue caused by the illness.

She still never stopped smiling, never stopped helping others and never gave up.

So, I leave you with one question you tell me, was she a hero, was she a bad ass, was she something very special or am I as her husband just biased?

A thank you.
In no particular order there are those whose creations helped my wife in so many ways, I have over time contacted many of you sending thanks and, in some cases, received replies and even gifts most of these gifts are small things like a beanie hat were never announced and went unnoticed by all.

On Dark nights full of pain and suffering you were a light.

YouTube subscriptions

Yogcast
Ashens
Ask a Mortician
Ten Second songs
Mental Floss
Drew Lynch
MrMattyPlays
Gone to the Snow Dogs
Wildlife Aid
Snow Dogs Vlogs
Quirkology
Extraashens
Vet Ranch
ThreadBanger
Talking Kitty Cat

Worlds of the imagination where escape was possible problems solved dragons slayed and death just meant a respawn.

Minecraft
Meridian 59 server 102
Everquest
Anarchy Online
The Secret world
Final Fantasy games (10 was her Favourite)
Eve Online
Bloons Tower Defence
Daggerfall
Oblivion

Skyrim
Fallout games from 1 to 4.
SkyrimVR
Fallout 4 VR
Assassin’s Creed games (black flag was her favourite)
Warframe
Forza games (Horizon was her favourite)
Unreal Tournament
Counter Strike
Left 4 Dead 1 and 2
Half Life
The Witcher 1-3
System Shock 1-2
All of the many hidden object games.
Elite Dangerous
European Truck Simulator 2
American Truck Simulator.
Plague Inc

Television shows and Films that made her smile.
Prey
Now and Again
Firefly
Star Trek
Babylon 5
Arrow-verse
Marvel films
Tremors (all of them)
Librarians (films and show)
8Bit
TaskMaster
Time Team
Dog soldiers

Online communities all over the world too many to name.

Thank you to Audible, when it became too difficult for her to read, we started purchasing Audio books, she was reading the Dresden Files books, I bought her all the ones available, she was on book 12 when she went into hospital and was also looking forward to reading Monster Hunter Inc set of books.

You all made a difference to a very special woman.

Now for the real reason this is a lot shorter than I planned, 7 days after her death I had an appointment for a colonoscopy, my red cell count was dropping, although we still have to wait for the results they found what could be bowel cancer samples were taken and an emergency CT full torso scan was taken in case it had spread, I am still waiting for CT results and sample results, so I want this story to get out there because they say as long as one person remembers someone they are never really gone and I believe Paola deserves to be remembered.

As I stated at the start of this short novella, I wanted to share someone who was amazing, to let people know our story and in some way let people know what true love is and what really matters in life and death.

I would also like to point something else out, the week before the heart issues happened, we had a bombshell which meant even if she had survived this, she was in for a lot more pain and the path looked very dark.

Her cancer test count was rising, they were concerned it was because the dialysis could be removing the medication before it could work, we couldn't stop the dialysis, so they were thinking of raising her medication or transferring to a different version, which we both knew would mean more side effects.

One minute she was happily playing her game and listening to music the next she was gone, no pain, no suffering.

Thank you for reading.

Who knows maybe it would make a good film.

Please feel free to share this story in any non-commercial way as long as nothing is changed or charged.

I know Paola would be so happy to know her story touched people.

If anyone wants to donate to the funeral costs and her charities or to keep me in books and games my PayPal email setup for this specific reason is jason@deviantedge.org

Her favourite charity was Animallifeline.org.uk if you wish to donate in her name to them that would be amazing.

These are the posts I started with Pictures of Paola that inspired me doing this, thank you to all those that encouraged me.

https://imgur.com/gallery/JSggx0v

https://imgur.com/a/dgFe4fH

Now I promised to give some ideas if you are facing anything like this.
Take one day at a time, do not focus on what you have lost, focus on what you still have, make friends with nurses and doctors, most of them are not in this for the money, are overworked and underpaid doing what they can with limited resources and time.

You are as much an expert about your illness as the Doctors, you are living it.

It is okay to ask for help, a lot of resources are out there, get yourself a Social care and Occupational therapist who will fight for you and look into what is available.

You are not weak because you asked for help.

Adapt, you're going to have to change and try not to isolate yourself.

Appreciate and live for every day because you have no idea how many more you have.