

# **Shakespeare's - The Last Leg 2015**

## **“ Parting is such Sweet Sorrow”**

### **A Short Story**

**By Paul Hallinan The Bard of Cheshire**

#### Foreward

What a Sh\*t year 2015 turned out to be, as they say I was robbed even before it started, robbed of my eagerly anticipated trip down to Devon, a few nights on a brand new Tesco special “Put me up” double air bed, and a New Year’s Eve party with a bunch of old friends I really wanted to spend some party time with.

Instead I found myself confined to the bowels of Inverclyde Royal Hospital, in Greenock Scotland, surrounded by surgically battered strangers, sneaking only the smallest tot of Malt Whisky to see in the New Year ,a very small consolation that really didn’t make up for the life changing events of the pervious couple of days.

Welcome to my classic short story, sixteen thousand words or so, OK maybe not so short a tale, but a gripping one of adversity, challenge and triumph, with more than an odd close call with the Grim Reaper. Don’t worry it gets better.

The story is pretty much as it happened as I remember it, maybe not as others may have seen things, but I have purposely painted as positive a picture on events as best I can ,as a reader you can make your own mind up how well I have managed that, considering what has happened it may well be a story I would rather forget,time will tell.

I think it's important to say from the outset that my family and friends have all been just as intimately involved in every second of this medical mystery tour and have all suffered just as much physically and emotionally as I have, if not more, something I didn't appreciate at the time, but now in recovery realise only too well now what they have been through as well.

Enjoy the read X P

Dedicated to:

Jenny, Jamie, Kevin and Lynn and all my family and friends who offered great support by just being there, be it in thought, prayer, text, picture, letter,card, phone call, visit, the lot, you will never know how much you helped me to survive.

Thank you to you all

## Chapter 1

### The Big Surprise

The Big Surprise is that I'm putting pen to paper, my spelling is rubbish so Andy my mate is knocking the scribble into a readable shape.

I think I write more in a blog style and really the only reason for having a go at recording my experiences is to save me having to repeat the story over and over again, dredging up the highs and lows of what went on.

The presentation of my non-sarcoma sarcoma was both a dramatic surprise and somewhat of a severe inconvenience, both in terms of where and when it happened.

I had no idea even what a Sarcoma was, well not until the afternoon of the 28th of December 2014. It wasn't the sort of thing that came up round my dinner table even though my wife is a doctor, but in my case it turned out to be a pathological fracture of my right femur and in the end ,after much of a to do, it was diagnosed as - a Bone Cancer with a long name.

A year on, some life changing surgery, the acquisition of numerous wheelchairs and crutches, and now the real prospect of a prosthetic leg, has caused me to reflect on what on earth happened to me and my family and friends throughout the year that was 2015.

If you were to go through this kind of ordeal, and if you were lucky enough to survive , telling the story of what happened I believe helps in two ways.

Putting pen to paper allows me to tell my story remotely, so as not to have to re-live those times again and again in the telling, it's something I have considered and thought about a lot.

I know that repeating my story time and time again would I'm sure help others, but it would not help me psychologically, as I would find it would become increasingly depressing, each time I repeated the story in the telling.

This way I can tell my story once, then continue to look forward with a positive outlook on my new life and the new opportunity it presents.

Perversely the impact of my situation and condition I notice brought a number of people around me together in a very positive way, which might not have otherwise happened.

It's amazing who steps up to the plate when the chips are down, equally so those who step away.

A good example would be, having had a distance relationship with my brother for thirty years, for no other reason than our own lives got in the way, this ordeal has brought us much closer together than ever before.

## Short Bio

To give you a little background to my story I guess it would be a good idea to tell you a little bit about myself first.

I'm now 57 years old, married to my beautiful long suffering wife Jenny, have a 22 year old son James, and it would be rude also not to mention our mad dog, who is called Tiggi, a soft coated Wheaten Terrier, she's a bit like Dougal from the Magic Roundabout, but on acid.

I have been self-employed most of my life which might account for why the people who know me, would describe me (so I have been told) as an outgoing optimist, those people who know me really well, would say annoyingly so. I think its an important trait to surviving self employment.

So far (apart from this little episode) I have enjoyed good health and have had a great active life ,which has enabled me to travel extensively with the family and enjoy an outdoor lifestyle, that included skiing, sailing, mountaineering and mountain biking.

My personal number one passion is sailing, for the freedom and adventure it offers by the bucketful.

Jenny, my wife, loves the freedom but would like me sometimes to tone down the adventure bit. To my mind there is nothing wrong in having adrenaline fuelled clenched buttocks every now and again, but she thinks otherwise.

I enjoy a diverse group of friends and acquaintances and am always up for a party. So to find myself in this situation with my wings so severely clipped came as a real shocker.

The annoying thing about this particular Osteosarcoma was that it affected the middle to upper part of my right femur and by all accounts had been quietly developing undetected for some considerable time.

The condition it turns out is seen as a young person's decease, something 17 - 24year olds get , which flatteringly I guess must mean I'm a late developer.

## The Drama and Severe Inconvenience

So to the dramatic surprise and the severe inconvenience my non- sarcoma sarcoma caused on that bright and crisp 28th December day 2014.

I am both fortunate and mad enough to be able to own and keep a 35 foot sailing boat at Largs Marina, just south of Glasgow in Scotland.

It's my pride and joy and her name is "Dutch Courage", not necessarily a name I would have chosen myself, but sailing tradition and superstition does not encourage many sailors to a boat name change, because bad things can happen.

So it's winter 2014 and the sails on the boat need to come off both for safety and winterisation servicing. As my good mate Dave Williamson (now Chairman of the RYA Royal Yachting Association) would say, "Standards old boy, Standards".

The weather in late 2014 in Scotland had been particularly appalling, with high winds and lots of rain, far more than normal. I had been watching and watching for a suitable weather window for almost three months to get up to the boat and Christmas was fast approaching.

Then came the perfect opportunity, a high pressure weather system parked right over the centre of Glasgow. This meant a bright sunny day and calm conditions ideal for the service job I had to do.

It was going to be a mad dash from my home in Cheshire all the way to Glasgow, a 510 mile round trip, which with daddy's little helpers, we would attempt to do in the day.

What was supposed to be a job that would take no more than a couple of hours at the marina turned into something quite different and lets say special.

I can tell you that no one in my family is happy with or appreciates an early morning start, especially my A Team - Tiggi our mad Wheaten Soft Coated terrier and my student son Jamie.

5:30 in the morning the alarm sounds a flask of coffee is made and in no time we are ready to hit the road, with an expected arrival time of 10:30am at Largs Marina, a journey we had made many times before, taking on average 4 hours 20minutes on a good day.

The car was packed with all the kit we needed and off we roared North up the M6 . Soon I could hear a snoring noise coming from Jamie in the passenger seat and Tiggi offering percussion support snoring from the back seat. The A-Team was in good form.

The journey up the motorway was uneventful, both the M6 and M74 motorways were clear and we pretty much arrived on time as expected.

Happily as described by the previous day's BBC weather forecast we were greeted with a still wind , a picture perfect crystal clear day, and ideal conditions to get the sails off the boat.

A quick breakfast in the marina cafe , a full Scottish ,and we got started.

Dutch Courage was parked in her berth K16, a narrow finger pontoon allowed access to her Starboard Right hand side, I opened her up to the world, and ran a few well rehearsed safety checks, firing the engine up for good measure; it was all looking good.

There is something about owning your own boat ,it's silly but there's a feeling, almost a bond, you get once you have had a few adventures and a few close calls, the sense you can go anywhere and be safe, Dutch Courage gave me that sense of comfort and safety and far more.

Removing the sails from a boat is a reasonably straightforward affair , some undoing and pulling on a few ropes, which I have to say Jamie did admirably, all that was required to finish the task was to simply bag the sails and hand them over to the local sailmaker for winter servicing and scoot home.

## **What could possibly go wrong?**

With the sails laid and neatly flaked on the dock Jamie bolted below deck to recover the sail bags to allow us to complete our work and even consider a second breakfast before setting off home, bish boff biff as they say, job done.

I must admit I was feeling very pleased if not smug with myself ,but in a split second that was all about to change.

## **The Moment of Surprise:**

Picture the scene, I'm standing on the beautiful wooden deck of Dutch Courage , I look like an extra out of the film Master and Commander, I'm on top of the coach house roof just by the mast, I simply turn my hips to recover one of the ropes which had been attached to one of the sails, then bang, in a split second I hit the deck like the proverbial sack of potatoes.

It takes a moment to realise what has happened, I'm confused and I think in shock, I find myself lying across the coach house roof with the upper part of my right leg clearly bent in the most un-natural position - oh shit.

Strangely at that moment I was in no pain although that wasn't going to be the case for long, clearly I had just become the owner of one badly broken leg.

Stunned is now a word I completely understand the meaning of, I felt a surge of adrenaline and started taking some very deep breaths as I processed the situation in my head as best I could.

I count myself lucky that I fell inboard and not outboard, if I had fallen into the water things again would have been very different.

In as calm a voice I could muster I called to Jamie , I remember that he came back with a retort that he was still looking for the sail bags.

Again I remember requesting his presence on deck a little more forcefully, when his little head popped up above the companionway hatch with a quizzical look on his face, asking me the obvious question, "What are you doing lying on the deck dad"? I could see he hadn't grasped the gravity of the situation, but why should he?

Taking a second to gather my thoughts so that I could take charge of the situation, whilst I was both still conscious and before the effects of shock really started to kick in, I had the presence of mind to instruct Jamie in a very clear and concise voice, that I was badly injured and required an ambulance and some first aid. That he was to tie the dog to the boat and then go directly to the Marina office and call an ambulance - NOW!

He went smartly off as instructed which left me on my own slipping slowly into shock. Tiggi could sense that there was something wrong and grew increasingly agitated.

I tried to move then immediately thought better of it. What the Fuck just happened????  
Had I been shot??

An eternity passed before Jamie arrived back with two of the marina staff who had a very good grasp of first aid. I still can't thank them enough for their professional actions that morning.

It was at this point I let go and lost any charge I had of the situation happily becoming an unhappy casualty.

So now I'm a man with a badly broken right femur sprawled across the deck of a boat, time seemed to slow down as we waited for the first responder, who arrived carrying a massive medical crash bag.

He asked me all the appropriate questions and assessed his options, I could see the one big question written across his face, "How the hell are we going to get this guy off this boat?" As he was doing so the marina staff John and Dave had the presence of mind to detached the guard rails off my boat to facilitate my expected extraction on a stretcher. At least they had a plan.

As it was a cold winters morning and to avoid hypothermia setting in I was quickly covered with some blankets that Jamie found from below deck.

If the fashion police had been around I would have been arrested on the spot. My new look was completed with a tatty old hat I used when painting the anti-foul paint on the bottom of the boat.

So to add insult to injury in a moment ,I went from Master and Commander and ended up looking like a homeless person lying in a doorway on my own boat. The only thing that was missing were plastic bags sticking out of my shoes and the look would have been complete.

Our band of merry men increased a few minutes later as a second ambulance crew arrived. The conversation quickly focused on how to get me off the boat.

The gang could see I was deteriorating, so talk of getting the lifeboat out to perform the extraction was dropped and swapped for a we can do this conversation. We need to do this now.

The banter level on the dock kept my spirits up, the ambulance team became comedians which definitely helped me through the transition from the boat across the marina and finally into an ambulance proper.

Now to say it was epic getting me off the boat would be in no uncertain terms an understatement.

The small finger pontoon by the side of my boat was never designed to have six or seven rather heavy individuals standing on it at one time, needless to say it started to sink with so much weight being placed upon it when the transfer from the boat to the dock took place.

I do remember clearly chastising my rescue team that the last thing I needed was a bath and that if they dropped me in the water there would be trouble.

Happily the transfer from the boat on a spinal board to a stretcher on the dock went surprisingly smoothly, but once this danger and distraction had passed my brain must have thought oh now its time to switch on the pain.

At this point in the story I will offer my first piece of advice,  
***\*\*take as much pain relief as is offered, don't be shy.***

The ambulance crew were kind enough to give me gas and air to help with the pain, but I think the mixture needed to be looked at as I'm sure I got more air than gas, for the relief it gave.

Its hard to describe how the journey across the wooden slatted dock felt,being bumped up and down as the stretcher was wheeled along the wooden slatted pontoon, bump bump bump, it was tantamount to torture, every jar ground the ends of the broken bone together, I'm not ashamed to say it did make me cry.

I guess I was lucky that the bone didn't poke through the skin and that serious blood loss wasn't added to the list of complications.

Once inside the ambulance it took some considerable time to stabilise the fractured femur which had totally collapsed.

Jamie reminds me that he learnt a few new swear words from outside the ambulance as the crew worked on me ready for transfer to hospital.

Here's me thinking you just got into the ambulance and you just raced off with the blues and two's going at high speed down the road.

To anyone listening at the time I apologise for my colourful language in the marina car park.

### **And so comes the Inconvenience:**

We were only supposed to be in Scotland for the day, Jamie the dog and I. All we had were the clothes we stood in, no washing kit, no towels and no brush for the dog and soon to be no transport.

It wasn't possible or practical for Tiggi to travel with us in the ambulance, so she was left in the capable hands of the marina staff with some food and water and lots of reassurances that everything was going to be ok. But was it?

Jamie had found my car keys and locked the car up and left it in the Marina car park, because of Jamie's age he wasn't insured to drive my car so there it stayed for some considerable time only being recovered by my brother a number of weeks later. Boy was that difficult to organise from my hospital bed and that was just the start of what was to come.

We sped off to Inverclyde Hospital A&E to be met by a team of young doctors who were at first very puzzled by the injury I had sustained, but quickly offered much needed and necessary femoral nerve block pain relief.

The procedure kind of did and didn't work but it was enough to see me off with the fairies and allow me to speak incoherently to God knows who, something I have been teased about ever since.

You should never underestimate powerful hallucinogenic pain relief, it leaves you with at best an incredible feeling of levitation and at worst a massive headache.

The ambulance having done its job, Jamie was now stranded without transport in Inverclyde with no indication as to what would happen to me next. However help might be at hand.

We were fortunate enough to have some close relatives who lived in Glasgow, some 30 miles away, who if available could be called upon for some much needed emergency assistance.

This whole episode was complicated by the time of year falling squarely between Christmas and New Year, so the nightmare began.

With New Year fast approaching Jamie contacted our relatives who by chance had been forced to cancel a family gathering for New Year in the Highlands - Black Isles Ross and Cromarty, their accommodation had suffered a catastrophic heating failure not too dissimilar to what happened to my leg.

Their misfortune was our good fortune.

A concerned cousin Neil arrived at Inverclyde A&E to assess the situation with a look of complete disbelief and a few words of sympathy.

Neil realised there was little he could do at the hospital, so took Jamie back to Largs Marina to recover the dog and sort them both out with a bed for the night in Glasgow, which was a massive weight off my mind.

Cousin Neil and Michelle became our Scottish lifeline providing accommodation and support to us all over the following weeks, absolute stella stars, given that they already a house full from the aborted family gathering; they are the hosts with the most.

Now nicely drugged up and slipping in and out of consciousness there was still one very important thing to do.

Up until this point my wife Jenny was completely unaware of the situation which must have landed like a bombshell when she got to hear from Jamie mid evening, as to what had happened to me during the day.

She must have known that something was wrong because of the number of missed calls from both of our phones.

When Jamie got through the conversation went something like, “Hi mum, dad’s in hospital with a broken leg, but he’s fine” - “It just broke” - “The dog’s with me and I’m staying in Glasgow ,dad says not to worry” - “If you could come up tomorrow that would be good”.

All a very matter of fact delivery, in as few words as possible as only Jamie knows how to do.

Jenny needed this information like the proverbial hole in the head, she was stacked out at work and this could not have come at a worse time, like me we had both been looking forward to spending New Year with friends in Devon as planned.

Driving such a long distance to get to me was also going to be a problem for a number of reasons so Jenny enlisted some emergency help from a good friend Lynn, who in a heartbeat dropped everything to join the circus and head North.

\*\*\*\*\*

\*\*Words of advice on pain relief, take what’s offered, take as much as possible, but drink as much water as you can, little and often , becoming dehydrated only makes you feel worse ,be a happy willing patient, a smile always goes a long way.

## Chapter 2

### PMA - Positive Mental Attitude

I cannot stress enough how having a strong Positive Mental Attitude from the outset has played such an important part in the positive outcome I have experienced so far, thinking things to be right, did and have made a positive difference.

It's see how depressing things could get if you adopt a pessimistic or victim type attitude, not just in the way it affects your own demeanour in a negative way, but in the way others react to you and treat you.

So followed a series of scans and tests and vast quantities of strong opiate painkillers.

The test revealed a collapsed femur and a large tumour which had to have a keyhole surgery biopsy to try to establish its benign or malignant condition. Things are serious and a lot of professional head scratching is set in motion.

Now for the tough part, laying in bed with an open fracture, set in a contraption called a "Thomas Splint" as the waiting begins and a low point began to set in.

The practical advice here I would give is to \*\*take a pragmatic attitude towards the information you are given.

Don't expect the doctors to know exactly what is wrong immediately, they have to do tests, they have to gather information, which will lead to more test, which takes time, more time than you can imagine.

Top tip \*\*Be patient and don't get agitated with lack of information.

It's important that you and others don't get all wound up through what you might think is the lack of information.

At this point dealing with early stages of frustration by being patient and emptying your mind will help keep your stress levels down.

Top tips for the diagnosis phase of treatment and hospitalisation:

Even though its early day's in hospital the first few come as a shock, they are noisy busy places with lots going on day and night. It takes time to get into a routine, but the thing I noticed the most was the noise, a good nights sleep is almost impossible in hospital.

\*\*Take Ear Plugs or better still Headphones and a Radio at the very least into hospital with you.

I found that being on strong pain killers seriously affected my attention span, so reading a book or magazine was hard work, listening to a radio or music was relaxing and easy to do.

**\*\*Strong painkillers have unpleasant side effects, especially the delicate subject of constipation and wind.**

I can't tell you how quickly you have to park or let go any dignity you might have when you get onto a hospital ward. The only consolation is that everyone else is in the same boat.

Farting uncontrollably was at first very embarrassing , but as soon as you realised that you were not alone with the affliction, school boy toilet humour soon kicks in and it becomes very funny.

The worst part about constipation is that at sometime or other what you have eaten has to come out.

Now that's either going to be in the form of a barbed wire encrusted hand-grenade, the size of what for me, felt like a bowling ball, or if you have been taking Lactulose, Senokot or better still Volcano strength Laxido, either way it is very uncomfortable and hurts like hell on exit.

Ask for Lactulose and Senokot soon as you hit the ward, if you don't become condition motion regular , ask for the Magic Orange Powder Laxido, the Mount Etna of chronic constipation treatments, drink lots of water little and often, this of course I found out too late.

By this time I had been in Inverclyde hospital a week and celebrated New Year with a nip of Malt Whiskey, smuggled into the ward by one of my fellow inmates.

Boy did I meet some interesting people, I think Inverclyde prides itself on having all the Scottish speed speaking champions all in the same place, this mixed with the heaviest of Scottish accents made me think I was in a foreign country.

It was clearly the birth place of Rab C Nesbitt, I couldn't understand a spoken word.

Here's another top tip **\*\*“nod and smile nod and smile”** give yourself time to understand and decrypt what the hell was being said.

I would have to say at this stage of my journey I was off my head on painkillers having sent the most bizarre text messages and held disjointed phone conversations with friends and family, I cannot say to this day I remember any of it at all.

Jenny and Lynn in the first few days of this epic flitted back and forth offering comfort and support slowly being sucked into an unwelcome repetitive cycle with little or no idea of an outcome.

The Inverclyde medical team by now went into Thunderbird mode to get to the bottom of what happened to me. So I was scanned to within an inch of my life.

From the CT, MRI, X-Ray, Bone Scan and biopsy, it was clear I had a tumour , so was promptly transferred to a specialist tumour bone unit in Glasgow Royal Infirmary, and the care of Mr Mahindra, a first class bone man with a reserved disposition and a very dry sense of humour.

My entourage Jenny & Lynn ,followed and navigated the labyrinth that is Glasgow Royal Infirmary each day.

The food in hospital didn't leave much to the imagination, so each day I got a treat from the local M&S - a life saver.

Again I count myself a lucky boy that in the face of adversity we have such good friends who were able to offer such fantastic support, most of which was at short notice.

It was decided by my care team that after having had this open fracture for ten days, the best course of action because they had run out of options, was to plate and fill what was left of the femur, in an attempt to repair it as best as possible, and await the outcome of the pathology regrading the tumour.

What everyone failed to mention was just how long that was going to take, again a massive test of resolve on the old positive mental attitude PMA, but also a test on everyone's else patience, remembering this all happened over the Christmas and New Year holiday.

Into January now and I was starting to develop a routine on the ward where I met some fantastic people, some for a short period and others for a much longer period.

Stuart was the first of my new Scottish friends, he had been mashed up in a motorcycle accident in France in the summer of 2014 and had been transferred to Glasgow Royal in an attempt to save his right leg.

This man was a total inspiration and the one thing he taught me was that being negative or even having a negative thought in hospital was not going to help you get better. He was an optimist's optimist and a great guy to have on the ward.

Stuart wore an exoskeleton, a metal framework of pins and steel holding his leg together, the most surreal and macabre sight you could wish to see, even with my own situation post operative, I was sporting an over engineered neoprene leg splint that made me look like the Elephant man, in comparison he made me feel inadequate and lucky at the same time.

I think its important when faced with a long term stay in hospital that you develop a friendly rapport with all the staff and patients on your ward, being jovial and good humoured and engaging others helped me tremendously in stopping me becoming institutionalised, introverted and depressed.

I suppose what I'm trying to say is that having a laugh matters, or as the Irish would say "Good Craic".

Now one of the unwelcome side effects of painkillers I mentioned earlier was personal wind. It is possible with practice to save and control your outburst, saving them for visiting time can be very funny, at others' expense and embarrassment.

My other good friend in the bed opposite "Kneebo Nigel" also helped make time on the ward bearable with his Wit and Repartee, and timely outburst of the windy trumpet involuntary.

As it turned out we spent more time than we both liked on the ward, but as a result formed a shared experience bond only we will know.

Nigel has become a good friend and we keep in touch regularly to make sure we are both doing well, I guess a kind of self help. We continue to laugh and joke about our recovery and will do for many years to come.

As time marched on and the treatment phase of my journey was starting to become my recovery phase, this is where you want to start thinking about going home and what that might entail in regards to practical adjustments.

Now at this point all I had was a broken leg with complications, I was soon to be mobile on crutches, but as all the posters on all the walls of all the hospital wards said "Avoid Falling Over"

The nursing staff pointed out it was to save them having to process the accident form paperwork, and save me both the embarrassment and more pain.

The point of the poster was to emphasise how careful you need to be to get yourself to a point where you can actually go home.

Going home brings two new people into your hospital life, a Physio-terrorist, and an Occupational therapist.

The PT ,physiotherapist will get you walking up and down stairs, which is harder than it looks without making a fool of yourself.

The OT will get your mind spinning thinking about the adaptations you will need at home, we certainly over thought this phase and went out on a buying spree ,some of which proved wholly unnecessary.

Top tip\*\* here is wait till you get home and see what you actually need and act accordingly.

In my case getting hold of a wheelchair, a commode , litter picker, and a door ramp were all I immediately needed. A plastic pee bottle did save me getting up in the night to hobble to the toilet, it came in handy for the first few weeks at home, no shame in that for me.

I mentioned in the blog earlier that doctors don't always have the snap answer and lying in Glasgow Royal Infirmary with an open fracture was not the best situation to be in.

To stabilise the fracture I was strapped into a Thomas Splint, as far as I could see it was a Victorian torture chamber tool, weight were attached to the end of the splint in effort to stop bone grinding.

The dilemma for the consultant treating me was that he had no idea whether or not the tumour was malignant or benign. Either way I had a ruptured blood filled tumour invading my whole blood stream, a thought best put to the back of my mind.

Results from a bone biopsy and blood test were slow in coming back.

Again at this point in the proceedings learning the value of patience is a lesson well learnt.

In the end my consultant Mr Mahindra took the brave decision to attempt to repair the damage and fix the femur as best he could with what turned out to be an impressive array of titanium plates ,screws and bone mash filler.

I made the mistake of asking what the bone filler was actually made from, ground up femoral heads which are collected from other patients who have hip replacement surgery, I was told, gulp! yuck.

The ground up femoral heads act as a filler, they reckon they used about ten inside me on this particular job ,which means I became officially Scottish, Scottish ,Scottish, Scottish - you get the joke, with a wide choice of Highland Clan to choose from.

So part one of the surgery was complete leaving me with an impressive line of very neat stitches the whole length of the outside of my upper right leg. The surgery wasn't without its moments,I lost a lot of blood in the procedure having to have five additional units of blood during surgery and post-operatively.

Without wishing to appear alarmist we all normally wander around with eight or so units of blood, so clearly this was going some.

With massive doses of antibiotics to avoid infection risk, I recovered reasonably quickly - now looking back at some of the pictures however I must admit I did look like Casper the Ghost's older brother, lucky again I guess.

This luck was as it turned out a little short lived feeling. Even though a great job had been done repairing the femur, we still didn't know the results of the histology and haematology surrounding the cause of the pathological fracture, big words for we didn't have a clue.

At least I was well enough to be discharged from Glasgow and sent home to recover with my out-patient care transferred to the Oswestry , Robert Jone and Agnes Hunt Orthopaedic Hospital.

My short lived rehabilitation involved the use of crutches and a wheelchair, crutches are the most frustrating piece of kit ever invented, of course you don't find that out until you come to rely on a pair, and its worse when you have been an active individual.

Not being able to pick a cup of tea or move any distance with a plate because your hands are full of stick, is a killer.

### **Tips so far:**

- Your family and friends will suffer the sarcoma as much as you will, I found that by texting a news update regularly on my situation as well as my thoughts helped break the ice in any communications I had, I didn't want people to feel sorry for me because that was depressing, as much as I needed to have a positive mental attitude towards my situation so did my family and friends. Laying out an overview of what had happened and explaining to my friends how I would like to be treated meant I had no awkward conversations throughout pretty much all the ordeal to date.

- Employ a positive mental attitude or pretend to, implying PMA will help stop you becoming depressed or morose about your situation, easier said than done but give it a go.
- If you're superstitious and have a boat don't change its name.
- If you break your leg try to stay as calm as possible, don't let others around you lose their heads, instruct the person nearest to you to call for help, get them to make you as comfortable as possible without moving you too much before help arrives, and keep talking to help stay conscious.
- Emergency pain relief, take as much as you can when it's offered.
- PMA - Positive Mental Attitude, I cannot stress enough how having PMA plays such an important part in the positive outcome I have experienced, even though I had no idea what was wrong. Letting dark thoughts into your mind in this situation only leads to fear anxiety worry and depression, all of which are not going to make you better, focusing on the attributes that are going to make you better - do exactly that.
- Now the waiting begins, the practical advice here I would give is to take a pragmatic attitude towards the information you are given. In early stage diagnosis the doctors know as much as you do, they gather information and are hesitant to tell you what they think so that if things change they don't end up mis-informing you, so be patient you will only ever get drip fed information to share at this stage.
- Take ear plugs, headphones and a radio at the very least into hospital with you, because of the painkillers you can't concentrate, hospital wards are very noisy day and night, ear plugs, headphones and a radio will provide entertainment but will also help you get off to sleep.
- Strong painkillers have unpleasant side effects, especially the delicate subject of constipation, drink vast amounts of water to keep hydrated but also to combat constipation from the painkillers, it's a big deal if you're not told when you get onto the ward.
- Ask for Senokot and Lactulose as soon as you hit the ward, if you don't become regular ask for the Magic Orange Powder Laxido, the Mount Etna of chronic constipation treatments, better prevention.
- My best advice is to drink as much water as possible, at least three of the jugs of water provided a day, far more than you would normally drink at home and take any laxative medication offered to avoid the hurt, get into a routine of sipping a bit of water at a time often works best, then you don't end up feeling bloated.
- Here's another top tip when in unfamiliar surroundings where the local dialect is difficult to understand "nod and smile nod and smile" give yourself time to take in and understand what the hell they mean by what they are saying.
- I think its important when faced with a long term stay in hospital that you develop a friendly rapport with all the staff and patients on your ward, being jovial and good humoured and engaging others, helped me tremendously in stopping me becoming institutionalised and introverted. I suppose what I'm trying to say is that having a laugh matters, or as the Irish would say "Good Craic".

## Chapter 3

### The Waiting Continues

To recap, we have a broken leg that has been repaired and after a long ambulance transfer I'm now back home in Cheshire, but the circumstances surrounding the cause of the break are still unclear as to why. The unspoken spectre of cancer is about to be voiced.

"Is it or isn't" it malignant?.

Samples of the bone blood and gunk were sent off to a number of pathology laboratories across the UK, all but one of which came back with a contradictory result, as you can imagine this left us all with a frustrating dilemma, who was right and who was wrong?

Fortunately a sample had also been sent off to America - (my first feeling special moment) - to the Mayo Clinic in Boston USA, the world leader in bone medicine, which confirmed our worst fear that it was in fact a malignant bad boy I had to deal with.

At this point in my story I owe a big thank you to the the Oswestry Agnus Hunt Pathology Lab (thank you Les) for questioning the other UK path lab results. An outstanding and brave spot.

Fortunately it appears to be standard practice, that once your care is transferred from one health authority to another you get re-tested under the new regime so that everyone is working with the latest scans, pathology and histology.

I can't say that I wasn't disappointed in the final results that the American tests came up with, but because it had taken so long to confirm, I had had plenty of time to prepare one way or the other.

The confirmation of the malignant diagnosis meant fast track Chemotherapy to see if the growth of the tumour could be contained, suddenly now I was a Cancer patient, strangely something I possibly naively had not even considered.

Life suddenly picked up pace, from the long term malaise of waiting and waiting and waiting now it was action stations and all hands on deck.

Within a couple of days I'm walking through the doors of the famous Christie Hospital in Manchester and introduced to yet another medical team, everything is spelt out in very black and white terms, some consent forms are signed and we get on with it.

Treatment then, first up is a "Hickman Line" a catheter device inserted into my chest that allowed the delivery of the Chemotherapy drugs directly into a central vein.

The young lady who put this frightening device in was a star, something in my mind that made me think it was going to be like open heart surgery, but without an aesthetic, she made the procedure totally painless. This is nothing to worry about if you find yourself in need of the same.

Now I've got two tubes sticking out of my chest which felt surreal, they were about to become the most important part of my life for the next few months for the suffering they were going to save me.

A few days later and I am admitted for the first round of treatment which involved a Tuesday to Friday stay in hospital.

You get handed a massive amount of useful and not so useful literature when you are fast tracked into the Chemotherapy system, we are talking a door stop's worth for every door in the house.

I made a conscious decision to trust my doctors and only read my Osteo MAP Regime Treatment Plan, which I had been handed on day one. Sorry to all the people who put that other bump together, but it was just too much to read.

Others might think that silly, but I tell you just by focusing on one plan which is five pages long with the energy I had left was more than enough to do.

### **The Moment I had been waiting for:**

I settled into my bed which was going to be home for the next four days, and later that first evening I was hooked up to an orange bag of "Iron Brew", a toxic concoction called "Cisplatin" and its brother "Doxorubicin" both designed to kill all in their path.

I was shocked and surprised to learn the origins of Chemotherapy came from Mustard Gas deployed in the trenches from the First World War.

This was the easy bit, you just lay back and watch the drug slowly be pumped into the "Hickman Line" and allow the Chemotherapy to invade every corner of your body.

I had been waiting for this moment for a long long time, I began laughing to myself, tears started to stream down my cheeks ,but not for the reasons you might immediately think.

Not from fright or the thought of what the Chemo might be doing, no this was the first time in nearly five months I felt I was actually fighting back, and that little bastard tumour that had been causing all this grief was finally getting what it deserved, a good kicking from my new "Iron Brew" friend Chemo-man.

I really felt as though I had started to wrestle back some control of my situation and my life ,the fight back was on and I told myself I am going to win.

The atmosphere on the side ward I was in, was very different to that which I had experienced in Glasgow, it wasn't the staff, it was the patients, unsurprisingly there was a palpable tension on the ward, everyone was very guarded, almost barricaded in their own personal space. That in itself made Christie different.

Uncharacteristically I joined them, headphones on I began to waste time waiting for the treatment to do its job hunting down my unwelcome house pest.

The staff at the Christie are fantastic , they do the best dark humour you can wish to come across, the hospital itself is an over run meat factory, with packed corridors of sick bewildered people, a sight that really you need to be prepared for, which I admit even now I wasn't.

Again we are back to PMA Positive Mental Attitude, I was fortunate that I met someone who had had cancer some time ago and saw first hand what having a negative mental attitude did to his condition.

All I needed in a dark moment when I felt my spirit drop its guard, was to remind myself that I was not going to be that negative person.

Here again in a new hospital environment you learn how to wait, cancer treatment is a never ending round of blood test after blood test, The "Hickman Line" was a God send, a must have Chemo fashion accessory.

It was like a badge of honour hiding under my shirt, it had to be taken care of, although it was a great device, it was a potential source of infection, so I guarded its sterile integrity jealously.

Having blood tests becomes a boring routine. The blood room in the Christie is amazing, bish-boff-biff you are done in a flash, on a normal day they take and process over 300 blood samples, its like the cheese counter at Sainsbury's, take a ticket and wait your turn.

Having a Kindle or iPad with downloaded or recorded books or programs is what you need, the WiFi network at Christie is flaky, so a radio is even better as it's more reliable. Anything to form a distraction to kill time will become your best friend.

My Cancer treatment involved a round of a few day's stay in hospital to administer the Chemotherapy in controlled conditions ,a release home, a short recovery at home and then back to hospital for more of the same. Welcome to my routine and my new life.

Without boring everyone, once you are in the program basically you start to experience the compound effect of the drugs, I kid you not the first week you wonder what all the fuss is about, no nausea , no feeling sick, you think you are the luckiest person in the world and that if it stays like this you have the Big C beaten in no time.

Round two is a different matter, the feeling of being nauseous , weak and sick is overpowering, the good news is there are drugs to help combat the seasick feeling and nausea.

The treatment plan listed Ondansetron,Dexamethasone and Metoclopramide, the Metoclopramide literally KO'd me, by far my best night's sleep ever,the other two did their jobs to varying degrees but I guess everyone is going to be different and will experience a different result.

The top tip I have here is to ask the nursing staff about anti-nausea drugs before you start feeling sick, ask to take them as soon as you can in the treatment cycle, getting on top of the sick feeling is important, playing a game of catch up I found miserable, four days of unnecessary suffering.

I found the more responsibility you take in asking questions and understanding what is happening to you, the better the outcome you could expect. Fewer things got missed on the treatment plan, as no one is perfect.

For example as with painkillers the Chemotherapy causes severe de-hydration, so drink little and often, your mouth and throat will also take a battering, I got oral thrush, severe cold sores and tooth ache, which was difficult to get on top of and again made me feel miserable for over ten days, all of which was avoidable.

On the subject of the tooth ache, thank you to Andy "McTooth" McCrae for the emergency appointment, and the tooth extraction, a top bloke and not a half bad dentist.

For the oral thrush, a tablet a day over the course of the whole cancer treatment "Fluconazole" did the trick, the cold sores took two and half weeks to sort out with "Zovirax" and the sore mouth was sorted with the help of "Difflam" mouthwash, toothache was sorted with standard "Paracetamol".

Getting this lot of health issues on top of the Chemotherapy was my first real low point in the whole process, I knew there was no magic wand here and that it was going to take weeks to sort out. So it was a question of knuckling down and simply getting on with it, thank God for Radio Two.

In time the white furry secretion in my mouth, my friend oral thrush, started to disappear, the "Zovirax" started to do its job and the cold sores also started to dry up and get better.

Now here is a little known fact about "Difflam", for some reason it's a really bright green in colour, looks more like antifreeze. I don't know why, but I made the assumption that it was a mouthwash to be used after a meal, to be used after brushing my teeth to improve my mouth hygiene.

In fact "Difflam" is designed to anaesthetise your mouth and throat prior to eating food to enable you to swallow your food. It's really easy to start feeling sorry for yourself when your mouth and throat are a mess.

The ward pharmacist commented that everybody seemed to make that mistake, to think it was mouth wash, even the ward staff.

Bizarrely, time at the Christie Hospital turned out to be quite a precious time.

My condition had become clear to my medical team, that to be as sure as possible to ensure the success of the Cancer treatment further surgery was going to have to be considered.

This was a polite way of saying "To be sure here Paul you are going to have to make the unpalatable decision to have your leg chopped off completely". For a small number in my medical team it was already a foregone conclusion that the leg would have to come off.

Having now taken two Chemotherapy treatments we reached a balance point where we would now have to stop the Chemotherapy in order to be fit enough to survive such major surgery.

I can only say you know when you know; you build up a mental picture of what physical reserves you have, and it became clear to me that if I continued to take any more Chemotherapy treatment I was not going to be in any shape to survive surgery.

Hindsight is a wonderful thing, I have since recognised it's only in these difficult decision moments that you really feel truly alive, that such a monumental decision will really change your life for ever.

What tipped the balance for me was a severe case of lower limb vasculitis. The visual manifestation that the Chemotherapy was doing its job well, possibly too well and it was now time to stop.

The vasculitis itself presented as a very painful and visible rash on the whole of my right leg up to the knee, which blistered and bled. I can't imagine what it was doing to the rest of my body inside, with the bits I couldn't see, all my vital internal organs.

Fortunately the two weeks which it took to recover from the vasculitis ahead of surgery was just enough time for me to prepare physically and mentally for the right leg amputation.

So for now I said goodbye to the Christie Hospital and hello again to the Robert Jones Agnes Hunt Orthopaedic Hospital in Oswestry.

There could not have been a greater contrast in the atmosphere of these two great institutions. Christie was a very manic environment which at times appeared to be swamped by its own success. Its corridors filled with resignation and hope but not in equal measure.

Oswestry as a polar opposite in comparison was a scene of calm and serenity, with what appeared to be almost a laid-back environment. This was a most welcome feeling, given the fact I was about to lose the whole of my right leg.

As you can imagine this whole process generated a mountain of paperwork, appointments, test results, more appointments, more pre surgery assessment tests.

Somehow at short notice my consultant managed to book a prosthetic consultation at the Ability Centre University of South Manchester Medical School, with Prof Kulkarni.

I must admit I wasn't quite sure what to expect from this consultation because it included conversations with a counselling practitioner, also based in the Ability Centre Facility in Wythenshawe South Manchester.

Being sceptical of any benefit, I had managed to convince myself that I was already a strong enough person and would not require any counselling, but I was persuaded by my wife Jenny that I should sit on my pride and take any help and advice that was offered. I could then choose to act or not upon the advice given.

Annoyingly as always, she was right.

As Jamie had been in the thick of the action earlier in the year when the leg actually broke, I asked him if he would like to accompany me to see what the professor and the counsellor had to say, Jamie reluctantly agreed, and off we went.

The meeting with Prof Kilkarni to say the least was jaw-droppingly frank and gruesome, he gave me a short physical examination then proceeded to explain exactly what was going to happen during the surgery, using a pelvis and leg joint skeleton, to explain exactly how I would be left physically.

Phantom post operative pain from the surgery was touched upon and the sort of things I could experience and expect. I was immediately prescribed “Progabilin” to help deal with those phantom side effects pre-operatively to build up a buffer against the expected phantom ahead of surgery.

The professor was at pains to point out how rare a condition “Hip Disarticulation” was, and he reassured me that surgery, in my case, was the best option for long term survival.

He gave me some very good sound advice, he said

**“Make sure you are clear that you make the distinction between feeling and pain”.**

**“Feeling from the phantom limb, the notion that it is still there, but of course it's not there and the pain you are bound to feel from the actual amputation wound site itself”.**

Having had my leg for 57 years it was obviously going to take my brain some considerable time to stop sending signals to the phantom limb that isn't there. Progabilin twice a day was the ticket.

Leaving the Ability Centre left me feeling a little numb, the reality of the surgery I faced in just a few days time had been laid bare, there was only one thing to do, so I asked Jamie if he would like to try out a new burger restaurant “Five Guys” at the Trafford Centre in Manchester so we could take stock of what we had just been told.

This turned out to be a rather pleasant afternoon after all, the numbness of my situation surprisingly subsided quite quickly and we got on with life, it was almost a trance like moment.

Involving Jamie in that meeting was important to me, I wanted him to see how matter of fact things were going to be, but I also wanted him to be able to comfortably answer questions about where I stood (no pun intended) when asked by his friends.

Being comfortable talking about my condition dealt with the White Elephant in the room (Cancer) and put people more at ease.

### **Surgery Time Again:**

Preparing myself for life changing surgery that weekend even now brings a lump into my throat, the weekend itself was a quite muted affair, after all what do you say to a man who is about to lose his leg, well if you're any of my friends you joke about it.

Single handedly I became responsible for a nationwide shortage of blow up parrots and peg-legs, as my friends raced to buy inappropriate props for the following week post operatively. I liked the optimism.

It wasn't until the Sunday afternoon that I sat down in my office to write my “**what if**” letter to both Jenny and Jamie, **the ;- if you are reading this letter it's because it all went very wrong.**

I really didn't want to put pen to paper, eventually I did, keeping it short with what happily turned out to be un-necessary anguish as I made it through the operation and am recording such now.

The practical stuff in the letter contained all my bank account details, insurance policy documents, my will, all this to avoid probate problems if it all went Pete Tong Wrong, especially with the bank accounts, I enclosed signed dated blank cheques for each account so that if in the event it did go wrong, access to money was not going to be an immediate worry.

Only when you are faced with the prospect of impending doom, do you suddenly realise these practical matters should have been sorted out any way, a top tip would be in any event to have your affairs in good order.

So now comes the big day, In fact the day before the big day.

I arrive at Oswestry RJAH Hospital saying my goodbyes to Jenny, and settle in to my room for what has proved to be the most restless nights sleep of my life so far.

For such a big event in my life things are moving fast when really I wanted them to be slowing down. The following morning I'm dressed in a surgical gown ready for theatre.

I found myself sitting on the side of my bed looking at my right leg laid bare, with a marker pen in hand and thought that the moment needed to be recorded for posterity, but what to say. This was a big deal so I wrote on my right thigh “**Parting is such Sweet Sorrow**” which seemed the only appropriate thing to do.

I hoped my surgeon would appreciate the sentiment.

The day before the operation I had one wobble moment, because I became really concerned and choked up as to what would happen to the spent leg once the operation had been successfully or unsuccessfully completed.

I wanted to believe that some good would come from the loss.

My salvation was to meet a wonderful lady from the Oswestry Pathology Research Department, who assured me that good use would be made from my loss, for others to benefit.

This is what I needed to hear and it proved to be a tremendous comfort and relief ahead of the operation, which made me feel so much better.

It was again a weird feeling, I felt I was grieving the loss of my leg almost without realising, only natural I guess.

Now the scene is set for pre-operative anaesthetics and the comedy routine of introducing me to epidural anaesthesia.

The “**Gas Men**” as I called my anaesthetists had their own little anti-room just outside the operating theatre.

I was no stranger to the procedure because of my previous surgeries in Glasgow. We had the normal banter of “Bet I can count to ten before,” the next thing I know I am waking up in HDU - High Dependence Unit feeling thirsty minus my right leg - how did that happen?? I ask you just like that.

It’s difficult to begin to describe what a weird feeling losing a leg is like, not least the fact I felt so well immediately after the surgery, post operatively I was in no pain at all, mind you the painkillers I was an am still on might have had something to do with that.

I can only thank the whole team who took part in the operation for a job very well done, I understand the operating theatre was packed because of the rarity of the conditions. It could have been standing room only, I bet there is a video somewhere. And to all the team in the High Dependency Unit for looking after me so well post operatively.

So we are now back on Ludlow Ward, home for a week or so and the reality of the surgery slams home, as I lay in my bed there’s no going back I thought ,I am officially disabled. Or am I?

Post Operatively, now I had time to think, a dangerous time ,I didn't want to start falling into a tail spin over the situation, I needed to get a grip, no time to panic.

Now was the time I needed to give myself a good talking to, it was going to be all too easy to fall into a slump or depression and become an invalid, that was the last thing I needed, I needed an injection of fun and positivity to counter this first dark hour. Something to keep my spirits up.

Looking around my room the hospital had provided a very novel notice wipe board unlike any other I had seen on my recent hospital travels.

For my benefit the name of the duty nurses looking after me, headed the board, as well as some other information for their benefit, like my name, allergies, likes and dislikes.

At the bottom of the notice board was a heading “How do you like to be addressed?” I needed cheering up so for bedevilment I scrawled “Your Highness”

Now to the credit of the nursing staff they all played along with my request and soon I was King Paul of Ludlow Ward, addressed as, “Your Highness”

This was an amusement for a couple of days and set in train an opportunity to have a different name each day.

Anatomically I needed to recognise my loss. Hip Disarticulation leaves one’s gonads asymmetrically challenged lets say, you will need to picture that in your mind for a moment - so the obvious name became “Wan Hung Lo” and the following day “Wan Hung Hi”

Cliff, Van Dangle, Shirley ,Shirley Not and Wanda, all had a day on the wall ,keeping both myself and the staff quietly amused.

Visitors and friends alike all brought gifts to amuse as well, all playing an important part keeping up my morale.

From blow up parrots, miniature orange traffic cones, to stop people sitting on my bed where my Right leg would have been as well as other tacky paraphernalia (Thank you Lynn and Claire)

The single right-handed shoe for my phantom leg which was not my size, was particularly cruel (Thank you Gordon) even a Mankini Swimsuit which I did try on, but it was too much of a distressing look to parade about on the ward for the Nursing staff, and they had seen some sights.

Needless to say the jokes became infectious and at this point in time life became something like a racing car and time passed very quickly, right through to post operative discharge.

To say I managed to create a high in my demeanour, caused my physiotherapist a bit of a problem, in that I don't think he had met someone who just wanted to get on with things in quite such a positive and speedy manner so soon after surgery.

I'm sure I left Gez with a lasting impression, not least because he soon became the owner of one lightly used Mankini Swimsuit for his troubles.

Because this was my second recovery back onto crutches in the same year ,there was nothing new here for me, so all the balance test, stairs and general transferring from bed to chair, toilet and so on came back very easily.

It was at this point I had resigned myself and acknowledged that Crutches and a Wheelchair would always now be a part of my life and my recovery for ever.

Searching the internet and Ebay became a regular routine to find out what kind of kit was available and what kind of outcomes others had found most effective post operatively.

[www.disabledgear.com](http://www.disabledgear.com) hit the buy secondhand button. This kind of research became very therapeutic because it offered me hope of regaining a great deal of my former life and more. I dared to dream even of a possible prosthetic.

The wound site was now healing well and I was getting used to looking at the "Cornish Pastie" shape piece of flesh poking out where my right leg used to be. Strangely though I could still feel it, only it was a sensation and for the most part uncontrollable log-like dull weighted feeling.

When I moved it moved, when I sat up in bed, it would poke through the middle of the bed and touch the floor, it was a feeling not pain just as Prof Kilkarni had said, right down to a tee.

I was taking strong opiate pain killers for the surgery which I have to say worked really well, as I felt no pain whatsoever much to the relief of the specialist pain nurses, the Phantom Leg was altogether a different matter with a mind of its own.

Progabilin for Phantom pain is great.

### **Tips:**

- In diagnosis getting more than one opinion is a good idea and could save your life.  
\*\*\*\*\*Read this bit twice
- PMA, Positive Mental Attitude, if you are diagnosed with Cancer your battle starts the moment you hear the words, "it's cancerous," in that split second you will win or lose the mental battle you are about to start, by you talking to yourself and getting your head straight as in how you are going to deal with what you have been told in a practical pragmatic way is key to a positive outcome. Miss this opportunity and you will be sorry.
- Get a Hickman Line they are great, saves having loads of needles stuck in your arm when drugs or bloods need to be taken.
- Christie WiFi network unreliable, take a radio as a backup.
- Feeling Sick and Nauseous - ask about Anti-Nausea treatments before you have the sick feeling, ask to take them as soon as you can in the treatment cycle.
- Progabilin for Phantom pain is great.

## Chapter 4

### Phantom Pain and Pain of Death

Once it became clear I was going to need an amputation there was vague talk of this phenomenon called Phantom Pain.

To combat or to help alleviate this pain/feeling I was prescribed a drug called “Pregabalin” which is fine and I’m sure it works to a degree, however I found these words of advice from Prof Kilkarni pre-operatively most useful and enlightening.

*“Make sure you are clear that you make the distinction between feeling and pain”*

to reinforce the point he said it again slowly.

*“Make sure you are clear that you make the distinction between feeling and pain”*

These words of advice have stopped me asking for stronger and stronger painkillers which would not have worked against the feeling or sensation phantom pain inflicts.

I have accepted that I’m going to experience phantom feelings for the rest of my life on a “go with the flow” philosophy, in the same way I have also accepted the “Tinnitus” and a 50% hearing loss , as well as sensitive streaming eyes caused by the chemotherapy side effects, all of which I’m sure will have been documented in my fine door stop bundles of booklet after booklet of information which I hadn’t taken the time to read.

Now it might sound like I’m a bit of a wreck but back to my optimistic outlook on life ,and once you park this lot in your mind, you can get on with your life.

Now it’s sounding like we are home and dry in this little story, but to make doubly sure those little Cancer stragglers are ejected from the party, it’s sensible to continue with the Chemotherapy, so yes you guessed it, back to the Christie Hospital in Manchester to continue the Chemotherapy regime, hopefully to a satisfactory conclusion.

Feeling resigned to the situation I organise my life back into the routine of hospital visits, and the inevitable battering of my immune system. Jenny and Jamie are clocking up the visiting hours and miles which are also frustratingly routine.

Back to the “Iron Brew” party and the intravenous hookup for at least another three rounds of treatment.

Time had marched and in the blink of an eye we were in late August 2015.

By chance on the August Bank Holiday weekend I had an appointment on the Bank Holiday Friday morning ,to assess the healing progress of the amputation site back at Oswestry Orthopaedic Hospital.

There had been a couple of minor complications in surgery but for all intents and purposes it appeared things were going well.

Oh how appearances can be deceptive. The night before the hospital visit I experienced small spike in my temperature. Nothing I was unduly concerned about, you could say I felt a little rough.

During my routine examination it was noted that I was feeling unwell and thankfully one of the nursing staff suggested a blood test just to rule out any infection risk.

Taking that blood test saved my life.

My wonderful staff nurse returned with an ashen look on her face, she could not believe the results of the test and immediately sprang into action.

The combination of surgery and Chemotherapy has severely affected my immune systems ability to fight infection and I was in fact in the early stages of contracting a severe sepsis infection, which if not treated within hours would likely have proved fatal.

I can only describe what happened in those few hours to my health as being not too dissimilar to falling off a cliff without a parachute.

The nursing staff around me, who I knew quite well because of my previous stay in Oswestry, were clearly panicked when they realised the situation I was in, not least Jenny who maybe I forgot to mention is a doctor in General Practice and was only too aware of the seriousness of the situation.

Panic stations started setting in when it became clear Oswestry Hospital were unable to admit me because they could not provide the necessary infection control medical care and more importantly at that time a bed to cope with my situation. I needed an urgent transfer.

It's a Bank Holiday weekend, Oswestry was a No. Christie first choice was a No. Countess of Chester Hospital was a No. It now turned into a hunt a hospital bed in Cheshire, so I could be treated.

An anxious five hours saw a rapid deterioration in my health as the sepsis infection set in, I was fortunate and eventually a bed was found in Leighton Hospital just outside Crewe. A thirty five minute torturous fast ambulance ride away.

A high-speed sprint in an ambulance found me in the Leighton Hospital Admissions Suite, then finally onto a ward where high dose antibiotics were administered over a 15 day period. For a time it was touch go with the "Grim Reaper", the fact of which I have to say I was blissfully unaware at that time.

Sepsis normally causes organ failure which often results in amputation, losing the one leg I considered bearable, but to have additional amputations as a result of the sepsis, on top of elective surgery would have been too much, but hey I'm a lucky chap.

So fifteen days of isolation nursing and daily checks on my white blood cell counts, was definitely a challenge of character, in the end it all came good, and soon I was back home with my family and the dog. What an uplifting experience that is, getting out of the hospital environment and back in the comfort of your own home..

After the little sepsis moment we all concluded that to continue Chemotherapy would have a negative effect on my health, it would just allow the sepsis a foot back in the door, so

instead of trying to kill me with more Chemotherapy we thought we would all have a go at making me better instead.

So now the recovery phase starts proper and I can begin to start to regain control of my life.

Tips: Accept you are going to lose some battles, if you do that then they won't set off end of the world thoughts:

Tinnitus, Hearing Loss, Phantom Pain, Streaming Eyes, are nothing. Not even worth thinking or complaining about. I'm alive and that's what matters!!

## Chapter 5

### Bureaucracy and Recovery

There was a stellar moment in the consulting room at the Christie Hospital when we had just finished the short conversation with my cancer consultant Dr Lehey, when he said to my surprise, "That's it your done ,my work here is finished, you're as well as I dare make you, there is no benefit to giving you any more Chemotherapy".

I looked at Jenny and she looked at me, she must have seen and felt the sense of relief on my face, it wasn't the news either of us had expected quite the contrary, I was prepared and expecting more of the same "Iron Brew" Chemotherapy treatment for the next few months.

There was a pause after the news, I guess a moment for what had been said to sink in, I could see the doctor revving up for living with cancer conversation.

I really didn't need to hear any more, the explanations about what the future might hold, reoccurrence and how careful I would have to be, my selective hearing kicked in and I said "well thank you, I don't think we need to go into any more detail" "I get the picture this is the time when you say see you again in 3 months time," he said yes and that thank God that was that.

In the space of a couple on minutes in my mind I had most of my life back just like that. I can only describe the sense of elation and relief as the burden of treatment was removed, I felt ACE.

Shortly after being given this great news and sharing it with our friends and family came the harsher reality of dealing with recovery.

When I was in hospital I had this massive institutional support network, healthcare professionals and nurses around me 24/7. The moment I was discharged that support evaporated, so there was little or nothing.

The one thing I immediately found surprising was just how expensive life becomes when someone hangs a disabled sign around your neck.

Getting yourself back into mainstream society as a productive Tax paying individual is tougher than it sounds, and if your not driven I can easily see how depression and mental ill health can be triggered, then compounding all the physical challenges that you might have to deal with day to day.

So without rambling on too much these are some of the additional challenges I am facing or have faced to date.

## **Access and Mobility.**

### **Access**

Before the operation I knew I was going to spend the best part of the summer of 2015 recovering or being treated with Chemotherapy, so time to make some alterations and adaptations to the house.

I'm lucky, I live in a large family house, the back of the house already had a modest decking area, from which the garden dropped away steeply onto a large lawned area.

To make my recovery more bearable, I had the forethought to significantly extend this decking to make the whole area wheelchair friendly, and to give me a outdoor recovery space to enjoy what was left of the glorious 2015 summer.

My Sister in Law is a sculptor and has a great eye for garden design , with a bit of encouragement, and a bottle of red wine, we went for the infinity deck design with a super-size me element.

Everyone said "Don't you think thats a bit too big" the answer was "Yes it is" but with what I had just been through I didn't care.

A red wine fuelled idea quickly turned into reality with just one phone call - enter Digger Dylan.

A mini-digger and 10 day's hard graft, which I kind of supervised in what I would describe as the "ill watch", the bit of the Chemotherapy treatment people don't want to talk about, let alone experience, saw me be sick in-between Digger Dylan and Chippie Darron doing all the hard work, and me suffering the side effects of the treatment rounds.

That's Chemotherapy for you, your hair falls out and a sick bucket becomes your new best friend.

It is amazing what you can achieve once you get past the let's just do it phase of your decision making.

This one super structure has been the best investment I have ever made, an outside space to entertain and relax and recover.

The rest of the property has steps at both the front and backdoor, I was musing over days and nights on eBay, as to the type of access ramps to buy ,and cursing the fact that an Occupational Heath Assessment Visit was proving impossible to organise, so it was a case of taking matters into my own hands.

How people in more unfortunate financial circumstance manage I don't know.

By pure happenstance some friends from Northampton called in to say hello, and would you believe it, had two sets of aluminium ramps at home which they insisted we use, and delivered a couple of weeks later, it is as though they were made to measure and fitted the property perfectly.

I wasn't sure if after the operation I was going to be confined to the ground floor of our house, which was entirely possible, my hospital crutches were bloody uncomfortable to use for any period of time, getting up and downstairs repeatedly wasn't a happy thought and put a massive strain on the top of my shoulders.

A stairlift would be possible, but at huge cost, another Occupational Therapy Assessment yet to be had - you will see the bureaucratic recurrences as we go on.

Access then; I was fortunate and was sorted for now with two ramps and a pair of crutches to get up and down stairs. Not ideal but nothing I couldn't cope with.

## **Mobility**

I was keen to get back behind the wheel of my car as soon as possible. Foresight again played a part before my amputation, a little bit of internet research pointed to either a foot control car conversion or a hand control car conversion, which to go for?

A trip to Geoff Goslings in Stockport with my existing car to see what was possible, was on the cards and was executed just a week before the operation.

We talked about the possibility of applying for a car from the governments Motability Scheme, and to convert my existing car which had 60000 miles on it.

Don't feel too sorry for me I have a Mercedes 350 R Class, very comfortable, very big and packed with all the toys, the question was am I going to have to give this up for something else less comfortable.

Happily not, for the sum of £550 the job could be done, hand controls no problem, that was something really to look to forward after the operation, the loss of my car would have been very psychologically damaging.

Being self employed I was also keen to explore what help there was to assist me in getting back to work once I was clear of the operation - a little optimistic I know, as it could have gone a bit 'Pete Tong-Wrong' and these enquires would have been academic as I would have been dead.

Nevertheless I had the most helpful and informative conversation with a lady at the Department for Work and Pensions about the funds available to get you back to work.

The Access to Work fund is available to assist employers to adapt a workplace to allow you to continue back in employment, and the assessment is unbelievable simple in my experience. And the fund considerable.

Now at this point I need to break down what happened in real time but then explain what I did wrong and would change second time round.

## **So a bit of Back Story first.**

I had plenty of time to experience life on both crutches and a wheelchair whilst recovering the first time from the original broken leg from December 2014 when the femur snapped, and the subsequent plating and bone grafting to recovery in June 2015, before the actual amputation on the 14th July 2015; almost in the blink of an eye I became disabled.

Explaining disabled discrimination is difficult, I guess it's something better felt rather than spoken, but would say if you are able-bodied you can try this out and see what I mean for yourself.

The first time I tried my first wheelchair out, my Baxi BREEZEY BASIC , a smart black little number with solid grey tyres, a deep velour pile washable seat cushion also in matching black, big brakes and silver coloured push rims, it looked the dog bollocks.

What Car Wheelchair Magazine if there was such a magazine would have given it 5\* Star ,but you know what, it didn't matter, as I pushed my way around Cheshire Oaks Designer Outlet Village in Ellsmere Port, wearing a pair of tight goatskin driving gloves, to get extra grip on my rims and avoid getting any unpleasant shit on my hands, I might as well have had Harry Potter's cloak of invisibility on.

This has been a seminal moment when I first experienced disability discrimination.

I guess because you are at the general population's crotch height, people seem to immediately ignore you and consciously or un-consciously avoid you, shop staff ignore you, it's as though you have just become an inconvenience.

This lack of height made for a shitty shopping experience, which was thoroughly depressing.

Bizarrely almost in slow motion I passed other wheelchair users, there was a nod of sympathetic acknowledgement or maybe resignation of kindred brother or sisterhood as we passed each other.

Body language is powerful communication, I'm sure it wasn't a recognition or envy of my wheels, smart as a Baxi BREEZEY BASIC is, but of our low down bum vertically challenged situation.

Similarly when I repeated my shopping experiment on crutches it left me with a similar comparable but dulled feeling an experience of social rejection.

In my quest to get back to work in sales at least, if I was going to survive and be successful again, what both experiences of social rejection in a wheelchair and on crutches taught me, was that I had to be able to stand up to become socially visible and taken seriously - no question about it.

My goal was going to have to be to get a prosthetic leg, and this was going to be my end game ,I needed to think smart about my access to work request ,I was in a rush and didn't think things through as well as I might.

I decided I needed a manual wheelchair that would go all terrain, in an effort to keep me fit.

A conversation I had with Prof Kilcarnie my pre-operative prosthetic consultant, brought home the scale of my prosthetic problem.

As an illustration of the difficulty I faced, he pointed out that he had over 30,000 amputee patients, only 19 had a similar condition or worse than me, and that only 3 used a prosthetic leg for any period of time.

He called the standard prosthesis he used “The Beast”, on account of its weight. He pointed out that to even consider a new leg physical fitness was the key as each step would take 200% more effort than an able bodied person.

If fitness was going to be key here, I scoured the market and found a self-propelled lever driven wheelchair, “The Mountain Trike” that by pure chance was build locally ,within a few miles of my home address.

My thought was not to go for an electric powered chair because of the decrease in fitness it would likely cause. Fitness levels would ensure success with a prosthetic and success in my future business life, so I have a lot riding on this.

So back to my shopping list for the Department of Work and Pensions - DWP

1. Mobility and the car; Hand Control Conversion
2. All Terrain Wheelchair - for fitness

Not such a big list then but remember I had only been officially a super-crip for a couple of months, what did I know.

It turns out that if you are prepared to contribute yourself 2/7ths of the cost of your access to work kit personally , the application is viewed more favourably for fast track approval.

The thought being you work 5 days, so get to use the kit at the weekends, then up to a certain amount of £ pounds spent, a verbal authorisation followed by a letter of agreement, allows you or your employer to purchase the kit and be reimbursed on the provision of an invoice.

So the conversation's going really well and my case manager asks how heavy the chair is, 25Kg I say, will you be able to lift it back in the car? light bulb moment, hadn't even given it a thought , 'you will need a hoist then won't you'

like being lead by the nose, I happily said yes, you know what she was right, pump that chair around for a couple of hours and no way Jose would that go back in the car - so much for thinking about being macho.

I'm happy I've got all I need to cover all my work needs, so I order the kit post operatively and wait to physically recover sufficiently to make use of the car and my cool all terrain chair.

In the meantime there is a dawning realisation I'm gong to need another chair, my God thats three!!!

Why? I hear you ask.

Well the all terrain is too big and dirty to come into the house, that makes sense, my original chair my BREEZEY basic was for my office upstairs in the house, an open plan office it was ideal to save me bashing around on crutches.

Downstairs was a problem. When I brought the BREEZY down from my office it was a nightmare, although a folding chair it wasn't something I could manage to get downstairs on my own.

I was a hostage to muscle availability to move between floors, besides the leg rest damaged all the kitchen furniture as I crashed it into cupboard doors and cabinets.

A proper active chair is something you can turn on a sixpence - so back to my friend eBay and the good old internet.

By this time I had recognised crutches and a wheelchair were always going to be a part of my situation for the rest of my life, and that to try to get the best I could right now ,would only make my life that little bit better, so time to invest.

The crutches were an easy purchase, the best I could find are called Sidestix, Canadian carbon fibre, all singing all dancing, what I call and I hope the taxman agrees a legitimate business expense and at over £500 the pair some will say an eye watering business expense, I have them now and they make a big difference, I wouldn't now be without them.

Trawling eBay looking for a deal on an active chair, I set myself a budget of £1000, which as I mentioned earlier in the post, becoming disabled is expensive.

All the hours of research on the internet I had been doing into a prosthetic legs pointed to a brand and market leader called Ottobock, and to my surprise up popped an Ottobock chair in my favourite colour orange and black.

The brand sold me on the chair, I made an offer which was accepted, miraculously it fitted really well and at £850 with something that for all intent and purpose was brand new - showroom price £2700 a billy bargain.

Here I was lucky, what I should have done was get a Wheelchair assessment , I could so easily have got the wrong kind of chair and wasted all that money.

Time marches on and more reality strikes home.

Three chairs Hallinan now realises that having spent sometime in his new chair attending some business exhibitions some form of electrical assistance is definitely needed, it's all well and good thinking you are super fit, but pushing a wheelchair over carpet even just a short distance is absolutely knacker.

A lesson learned ,don't be too quick out of the starting gate with a list of your needs , your needs change, I now need electrification, the unfortunate bureaucratic situation I find myself in is that I cannot apply for an extension to my original Access to Work application so soon after my original request.

I now have to have a Wheelchair Needs Sssessment to confirm my state of need. The wait for assessment currently runs at 22 weeks in the Crewe and Cheshire area, ridiculous I know, just goes to show how many wheelchair boy racers are out there if there is such a long wait.

If I'm lucky I will get my dream solution a MaxPower SmartDrive MX2 , we shall see, my twenty two weeks are up this week, fingers crossed. You can make your own mind up about the bureaucratic wait.

You will be pleased to know before finishing this little tale the application has been successful and I am now fully tooled up.

More on mobility and getting your application off for you Blue Badge, it takes four weeks to come through, a simple form , lots of silly question, can you walk twenty paces unaided - no -why- I only have one leg and fall over , that kind of thing.

A blue badge has made me very popular this christmas with the girls, as I can get them closer to the shops and no parking fees.

Bladder Control ? apply to the same office as the blue badge for a "Radar Key", this allows you to access locked public toilets often in shopping centres saves you getting caught short.

I must admit I wasn't prepared for the best test the PIP, Personal Independence Payment Assessment, an assessment of need.

I had hoped I would qualify on the points based system for me to acquire enough points to be able to get on the Motability Scheme

You soon realise however that you have to be totally incapacitated, as in squashed to death by a big truck, to get enough points to qualify, so the people who might benefit most will be excluded. I failed by two points, its a massive document which ends with a Home Visit Assessment.

I had to laugh because the assessor walked in through the door and said this is going to be quick, even so, I'm sorry to tell you hip disarticulations don't cut it.

I'm Gutted, No Mobility Scheme for Me.

Having failed the Mobility test I needed a distraction, I woke up the following morning and decided I needed to answer a question I had been avoiding, "Could I still snow ski?"

Before my operation I had been an accomplished Skier and Snowboarder, Snowboarding was out but Skiing - doable?

My body wasn't in the best shape to find out but giving myself the hope that with some effort I could ski again would be a massive morale booster.

Another inspirational phone call later and I'm booked for a one hour lesson on real snow at the Chill Factor-e in Manchester,

I was that ugly duckling on the nursery slope, in no time at all the hour was over, not pretty not elegant, more raw and hurt, but the little slipping and sliding I did manage to do told me it was possible, talk about back to the floor again , it's going to be hard but I know I will make it back.

There's lots more stuff yet to check out, Disability Railcard for one, I even got into the cinema for free with a fee paying friend, companions and carers often get in free or at a seriously reduced rate. I have yet to check out sporting venues and concerts and see how well or badly I'm treated - let's be optimistic.

Jenny my wife had supported me every hop of the way so far and pointed out in November that we want hadn't had any kind of a holiday or break from the intense year that had been 2015, so we made a last minute holiday cottage booking in Devon of all places.

I can only say it was a great break but Devon is hilly as hell and not wheelchair friendly, Norfolk would have been a better choice, I guess there is always next year.

Taking that break gave us a little quiet time to reflect how lucky we had been, yes it had been a struggle but one worth fighting for.

My year comes to a close and not soon enough, a great family Christmas brings closure to a traumatic year.

## Lessons Learned

The things that will not be missed, the time wasted travelling to and from hospital, the wear & tear on all our cars, finding a parking spot, getting a parking ticket (don't get me started), the long nights alone, the sleepless nights and the worry.

What will be missed, all the fantastic people we met only for a short time along the way, we might miss them but they will never be forgotten.

I think we all deserved a pat on the back, I'm trying hard not to make too much of this life changing event.

I surprised myself at a friend's 30th wedding anniversary celebration recently, put self confidence aside and got up on the dance floor. I have no idea what I looked like, with crutches a flailing, I managed not to care, it felt great, a new normal, if that guy could do it on People's Strictly Come Dancing, then hey.

Here's to the new normals everyday and a new credo:

**“The only person for stopping Me from doing anything is Me!”**

Two people who although they don't know it inspire me and make me feel humble, are two UK War Veterans Rick Clements and Ben Parkinson. The challenges I face are but a pin prick in comparison, their stories are amazing beyond belief.

My story so far is of an optimistic bystander who needs to understand the difference between a challenge and an opportunity.

The challenges will be doing things I did before a little differently, the opportunities are mastering things I haven't done before with new friends, what could possibly go wrong this time?

To be continued...