

Diary of a HBO User

Enough is Enough I have decided. I don't know how much more I can cope. The pain is beyond description. I am struggling to get out of bed. – What is the point? After waking up – if I managed to get some sleep, I have to wait till the dizziness has gone, the funny head has returned to normal, I can see colour and no grey swaying images. I hit and rub my legs to wake them up from the dead - strange how something can be so dead and numb, yet at the same time the pain can be so bad.

You slowly move your body to the edge of the bed, and think “Here we go again”. You slowly put that dreaded first foot on the floor, the sharp needles spear up in through your foot up to the knees. Then up to your hips. Sharp pain shots through you. The other foot reaches the floor and again the pins and needles shear up taking your breath away. As you struggle to get up the feeling of broken glass under your feet gets sharper and sharper as your full weight presses down on your feet. You slowly take deep breaths, that start to become louder and faster to cope with the soaring pain in each step you take. You are all hunched up, in pain thinking is it all worth it? You see the kids wake up and see their wonderful faces and think YES it is, I love them so much. But how much can I or body take?

You struggle with every step as you cling on to the banister to go down stairs. The legs don't move, the muscles are hard and tight, they won't allow you to bend them at all. The foot won't flex to allow to take a step. You wobbly and pray you don't fall. You can't grip with your right hand, so you have to use your left hand and balance yourself over the banister as you descend down the now dangerous staircase.

You struggle take 5 steps at a time, you sound like a heavy breather, as each step takes your breath away. The hallway seems to stretch; it looks longer than before; it takes forever to get to the kitchen. You have made it. You slowly fill the kettle with a small amount of water – just enough for that important cuppa. You reach to take a pill, your lifeline to survival - only they don't work – you wonder why you bother. How many types drugs does it take to give you a better life?

They say nothing more can be done. You have had it all, “Sorry you have to live with it”. If I was an animal, they would be in Prison for Cruelty to Animals; yet it is OK for me to suffer; me a human being who also has feelings and needs. I just want to be pain free, to be able to move better than I can now! – ***Is that too much to ask for!***

I know what I need. I know what I want... I want a better life. I want to be able to walk to the local shop, which takes Hubby just 5 mins to walk to. For me it takes 20 mins to walk the 150 yards if it is that far. It is only 9 houses up from us. How can you carry a shopping bag with just a paper, tin of cat food and a loaf of bread, when you use the same hand for the walking stick? (because the pain and because there is no strength to carry it in the other hand). I don't want to have to worry about any little bladder accidents along the way. Or will I collapse? will my legs give way? Can I make it without looking like a

drunk? or will it take me longer? and I will black out? Can I cross the road quick enough before another car comes? I know I have a time limit before I start to get that noise in my ears; my head goes light; I start to sway; my vision goes all blurred.

I know enough to realise why this is happening to me. I spend hours looking for information, trying experiments, reading research papers. I also know common sense. Why people get cramp/spasms, why people get pins and needles, and numbness, why hands and feet get cold. Oxygen has to be the key ingredient!

I know my body has to be lacking in oxygen to get some of these key symptoms of RSD. I tell people try HBO, there are so many people who have tried it and improved so much. Some are back at work, people who haven't walk for years are now walking. I have met so many people who are far worse than me. In the last two weeks I have heard of members who have died, this is not unusual. This time of year (winter) you hear of people having complications from the RSD that riddles our body, lowering our immune system, making us vulnerable. The ages vary from children to adults. I have a very dear friend who has spent the last couple of months in and out of hospital. They don't think she is going to make it. I pray so hard that she does, but I know only a miracle will save Wonder Woman!

I know last winter I was so ill. I am scared that I will be just as bad this year. Don't even know how I will survive the normal day-to-day living. The Cold gets so bad. I feel myself freezing up. The doubled-over double quilt and the electric blanket, along with several jumpers, heating and fire on doesn't warm me up. I leave painful marks on people if I touch them. My freezing body burns them.

I must do something to try and make my life better. Do what I want, **TAKE CONTROL...**

So today I decided I am going to try HBO. I have nothing to lose and perhaps everything to gain. I went to my local MS Centre. I was made so welcome by Judy, the Centre Manager, and Paul the Chairman. They were great. We talked in depth, and we decided that after I get permission from my G.P. I could start on Monday. I would do a crash course, diving once a day for 3 weeks. The first week I will go to the depth of 16 ½ ft, the second week I would go down to 24ft, and my third and finally week I would go to 33 ft. Once I had completed my course. I could go back once a week for a top up, or have extra dives if I wanted them.

I am feeling positive, but I don't want to get my hopes up. I am always let down. But at least this can't do me any harm. No chemicals, no needles, just oxygen. No Doctors! I cannot wait. I feel so excited. I decided to keep a type of diary of how I get on, including a list of the problems I now face. It will be interesting to see if any of them subside...

Legs, Hips and Lower Back/ Stomach/ Hand & Arm:

- Pins and needles
- Numbness

- Dead and Heavy Feeling
- Freezing
- Burning
- Muscle Spasms
- Shakes – tremor
- Weak and jelly like
- Sensitive to draught, movement e.g. in a car on a train
- Occasionally touch
- Colour change: skin tone, purple, blue and off white

Various different types of pain:

- Shooting
- stabbing
- burning
- aching
- twisting

Joints

HIP Joint area: very painful, noticeable changes – dips in

Joints :Stiff, as if they have seized up, not very moveable. i.e. bend

My right hip has now changed shape (instead of curving out, it curves inwards and is very noticeable)

Ability and Mobility:

I have days where I have severe problems walking around the house.

At night my legs go so dead I have problems moving them. I have to hit them “to bring life back” and lift them with my hands.

The reason why:

Legs either:

- Go dead and cannot move very well
- Feet drag
- Go all weak and cannot support myself
- Pain all over
- Can manage 10-15 paces on a good day, bad day this can be 3-5
- Legs feel as if they are clamping together.
- Have pins and needles feeling in hips, bladder area.
- Daytime not so bad, night-time worst. I cannot decide if I need to go to the toilet or not.

Head

After being on my feet (stood/walking) for more than 30 mins:

- Heavy feet
- Dry Mouth – lips stick to teeth
- Hearing: noise is muffled
- Vision: Colour goes grey
- light headedness and dizzy

Weak all over - Feels as if I am swaying - Heart feels as if it beating faster - Feels as if I am going to slip away on to the floor.

Normal Bad head Day:

Dizziness & Light head

Feel things are getting worse. Medication does not seem to be working. Have even tried some Medication (Lidoderm – Lidocaine patch 5%) which I got from the USA. I have been known to take up to 30 tablets a day just to survive.

So, I'll start my... HBO Diary

Week One –16 1/2ft

Day 1

Not sure what to expect today. I feel rather nervous which is stupid considering what I have already been through, and this my choice. I decided that *I* wanted to do it, not the Doctors.

Back - wow, what can I say? I met a few other people who I would be joining in the chamber. They were really sweet. I got in my seat, and had my mask fitted. The door was closed and there was a loud hissing noise, we had started to descend. My ears were popping like mad. It was a strange sensation as they only normally pop like that when you are in a plane. It was really weird not having that stomach-doing-somersaults feeling, or the force pushing you back in your seat. When we got to the required depth of 16 ½ ft we put on our masks and relaxed for an hour. I read my book - it was the first time I had felt relaxed for a long time. As I didn't know what to expect, I was surprised to see the lady opposite me take her mask off and have a drink. The hours past quickly, which really surprised me; Paul came over the intercom and said he was bring us up. We took off our masks and I expected to have to re-pop my ears, but I didn't. There was another hiss, the temperature went chilly,

I wrapped a blanket around me, and it seemed so quick to get back up to normal air pressure. The door opened and I slipped off my shoes covers and had a coffee. Did I feel any different? ...the strange things is YES I did. I couldn't put my finger on it, but something was definitely different.

On the drive home, I felt alive, but tired. When I breathed in it felt like my lungs were expanding fully; it was an odd sensation as I don't have problems with my lungs. But I was so tired. When I got home I went to sleep, still not knowing why I felt different.

Day 2

What a night! I woke up after my first full night's sleep since I don't know when - years it must be! How could the oxygen taken at a certain pressure give me a good night's sleep? Don't know and don't care, but it was the best night's sleep for years. Can't wait for my next one today.

As I drove there I felt excited, and happy. I don't really know why. I don't want to get my hopes up, but something does feel different!

Today I went down with another couple. Lots of people go and have a dive one day a week. The centre is so friendly, I feel so relaxed and wanted - and that they care for me. I went into the chamber and as I looked around it made me think of a space rocket; the little round windows, and the hissing noise of the pressure being drawn out as we dived down to 16½ ft. I was totally relaxed, and got stuck into my book (half way though and I only started it yesterday).

When the session was over I came out and had a coffee and a Mars bar... all of a sudden I felt hungry, something I don't normally feel. I couldn't stop yawning. But that strange feeling I had continued. As I drove home I felt as if I was sat next to a fire, I could feel myself warming up as if I was glowing. My face felt as if people could see it glowing in the distance; it felt that warm. It was a pleasant feeling. My lungs still felt as if they were being used to their full capacity.

When I got home, I felt sleepy, yet as if I had lots of energy. Really weird feeling. But I had a snooze on the sofa. Judy had warned me that some people either feel really tired after a crash course of dives or feel the opposite as if they were on a high. I was both, my brain was buzzing, but I couldn't stop yawning.

Day 3

Another sleepful night. Two nights of NO waking up, no bladder accidents, no having to wake hubby up to get me to the bathroom. No nothing! I even didn't have the dizziness I get when I sit up in bed. I didn't even have to move my legs physically with my hands to move them or to knock them to wake up. Something is definitely happening to my body! And I feel great!

Poor Nigel (hubby) he has had two lousy night's sleep. Bless him. He said because I have slept so deeply and have not moved a muscle, he has had a bad night. He couldn't sleep well as he had to keep checking me to see if I was still breathing. He is so used to me rubbing and hitting my legs or disturbing him at night that he was not used to the no-noise-and-no-movement-at-all.

I really can't wait till my next dive today!

I feel so alive. This thing is working. I feel so positive. I feel as my face is hot, glowing. I am walking around with a big grin on my face as if I have won the lottery. It certainly feels like it. My limbs are still very cold, in fact they are like ice. But I have a feeling they will start to thaw.

Day 4

I can get used to this! Another night free from waking up. And Nigel said he had slept a bit better. Just can't get used to me not moving or moaning about the pain! Perhaps we should get a water bed – he would have movement then... lol

I popped in to Mum's before I went for my dive... she actually said I looked different! That's a compliment from my Mum. The only time she says anything normally is when she tells me I look a mess, and asks if I am not well today. Walking is easier; something really does feel different. And my pins and needles aren't so sharp today; even the numbness does not feel so bad. The painful dead heavy feeling I have in my legs is different. I feel as if my body is a radiator and that I am still glowing! Judy told me about the children who used the chamber last year. Outside of the chamber they could hardly move, but whilst in the chamber their Mums used to go in and give them physiotherapy - they could move even more. So today whilst in the Chamber I shall be doing some exercises; who knows? It may even help more by pumping the blood and oxygen around my body quicker.

Day 5

This is fantastic; another night of blissful sleep. No pins and needles, no numbness, no dizziness, I even got out of bed in a smooth movement. No moving so far, then stopping and moving a bit more. It was one flowing movement! It is amazing! And still another night of no accidents. I thought there would be, especially as I am now having a deep sleep!

I really do feel different. I feel like a new person - a spring chicken. Something is happening to me and I am loving every minute of it. I am most certainly glowing, my face is warm. Perhaps they should use me as a beacon! I was even told today that I don't look haggard and drawn! Boy I feel wonderful. This is really the start of something great. I have never had so many changes in any treatment before!

Apart from the fact they have never worked, all those chemicals I have put in my body over the years and the torture I have endured just to get some pain relief. But now, something so simple as oxygen is working. My theory is right!

Week Two – 24ft

Day 6

This is amazing. I wondered how I would feel after having a weekend away from HBO. Would I go back to what I was like before I started? NO I haven't. The pins and needles were a touch stronger than they were on Friday, but I have missed two days.

Can't wait to see what I am like after the end of week 2! And guess what – I actually went out on Sunday Night, and I wore heels for the first time in nearly 2 years! OK the heels were only 2 inches high, but I have been living in trainers and flat shoes for so long because I could not wear them! And the noise at the disco we went to would normally drive me mad. The sound vibrations hurt me and cause so much pain, but guess what – it didn't and we were sat in the front near the speakers (we went out with friends and that is where they sat). This is a first. I don't like the vibrations when the TV's on loud, or the music from the children. Even when they are play-fighting and making a noise it hurts me - the noise goes through me... but not this time! It is wonderful.

I must look a right sight sat in the chamber, with my mask on doing all these exercises! I bet I look funny. Who cares? I don't.

Day 7

Boy do I feel great! Another great night and pain is really reducing. It is amazing. Especially when you think I did a lot over the weekend. I still can't believe I actually wore heels! Is my life becoming normal again?

The drive to and from the centre is so much easier. I don't feel all the bumps in the road. The pain is definitely reducing, and so are all the other symptoms. And I am definitely a radiator. My limbs are still cold, but they are not like ice. The deep bone pain is really getting easier. It is not as painful as it was!

Day 8

I am really getting used to sleeping through the night and so is hubby. It is wonderful. I feel human again. No sleepless nights, no crying in pain, I am so happy. I wonder how long it will last? I don't care!, I am enjoying it while I have it.

Day 9

Pain is really reduced. I am not imagining it. I have really cut back on medication - and I am weaning myself off them. I am definitely getting warmer limbs. There is no doubt about it. Not only I can feel it, but also so can Nigel. I don't leave a cold burn on his skin when I touch him. He used to say when I touched him he would hurt for a long time after because I was so cold.

Day 10

What can I say? Things are just getting better and better.

Week Three - 24 and 33 ft

Day 13

I did some painting this weekend! OK it was only one door with some gloss paint, but I can't remember when I could hold a paintbrush. Yes it took me a long time - well long for a non-RSDer, but it felt so good! I am so chuffed. I can't explain so I feel. I really am happy. My cheesy grin has not moved. I even did the ironing, without sitting down or stopping. That is an achievement. It normally takes me hours to do some ironing. In fact

when I did the ironing, I left the ironing board up as it took me so long to do it and I had to rest and have a break after each item. I could not stand for so long or handle the clothes and iron. My life is certainly changing! I am walking without using my walking stick! Before I started I could manage 10–15 steps on a good day, without having to stop and rest because the pain was so bad, or because I would go all wobbly. On bad days this was 3-5 steps. I have not had the blackout feeling since I started. I wonder if this has made my BP go back to normal? I know it was very low before.

Day 14

I bent down and touched my toes today! I can't remember when the last time I could touch my toes!

My hands, feet, legs are now just chilly. *It is GRRREAT!*

I have not got any pins and needles to speak of. I haven't lost my balance, my legs have not collapsed on me, I have not had any spasms, cramp or numbness for days. And as for pain, it is bearable! I really think HBO is fantastic! Everyone should try it!

Day 15

I am so happy. I cannot explain how I feel. It is amazing. Pain is really reduced. I am sleeping, and feel great! I have this grin on my face – just like the Cheshire cat. And I am still walking with out the walking stick! I haven't walked far but I have not had any of the problems I normally have... AND it has been very cold!

Day 16

Today was the moment of truth. It was the day of the Lincoln Christmas Market. My son James had the day off school because of Teacher training. I haven't been in town for a while and he wanted to go around the Market up at the Cathedral (See NOTE¹). The last time I went there was 4 years ago, and I couldn't stand it, the pain was so bad - and I only had RSD in my arms back then.

Off we go; we parked the car in the only free spot, and walked around the shops at first. I always have a route mapped out where the toilets are, so I have got somewhere to go in a hurry, and also places where I can sit down. I have to have my route planned, because if I am stood up for more than 30- 35 mins I black out. The problems I have trying to live a normal life – go shopping etc. are very hard to cope with. But guess what? I had no feeling of blacking out, no feeling of collapsing, no nothing!

We caught the bus up to the market, and as I expected it was packed. And it was only 10:30 in the morning! We walked around and in the evening went on the Big Dipper. (*Never again.. lol*) I didn't get any pain, but I remember why I didn't like them! After we walked around the Castle and Cathedral, we decided we have had enough. It's time to go back home. This is the best part, I - well we, walked back to town down Steep Street, that very steep and cobbled street that runs from Castle Square down to the Shopping Centre on the High Street. The last time I did that was 10 years ago when I was

¹ For those who don't know it, Lincoln Cathedral and Castle are at the tope of a very steep hill!

RSD-free young and fit. I still had to hold on to the rail way back then, stopping every so often. But this time I didn't stop, didn't hold onto the rail. I walked down grinning at all the passers-by as they struggled with the climb and descent. It was a wonderful feeling. I just could not believe what I have achieved. I wondered whether I would be paid back big time for over doing it. These last 3 weeks have totally changed my life!

But who cares? – I did it J

Day 18

Boy did I overdo it! I ache like I have never ached before! But it isn't RSD pain; it is pain from muscles that have not been used for such a long time. It sounds silly, but I am pleased with the pain; It just shows that my muscles are working! I am not a write-off any more. The Doctors are so wrong! They said things like I will never get better – Well, just look at me. My limbs are getting warmer, pain is dramatically reduced, I am doing things that I could only dream about 3 ½ weeks ago. They will be shocked when I go to London next. Written me off – I'll just love proving them wrong!

What I didn't notice was that my period was due. Why didn't I notice? – Over a week before I am due I am normally in so much pain. My RSD becomes much worse. In fact normally two weeks out of the month, I am in so much pain, I just do not know what to do with myself. I always know when I am ovulating because the pain starts, and does not finish till I am on my period. But this time, I never noticed! It was wonderful! And I have had no bladder accidents either. I feel like new women. And it is

GRRRREAT!!!!!!!

I am starting a weekly diving session next week. I shall keep you posted on how I get on, and whether or not my symptoms return. I feel positive for the first time in 6 years. Who knows I may re-train and eventually go back to work J wouldn't that be great. ***I can't wait to see My Doctors down in London!***