

# **A Diary of Undergoing Treatment for Hepatitis C**

**My journey through  
treatment.**

## **Sunday, September 2, 2007**

### ***Before I start treatment***

I am 46, female, was diagnosed with hepatitis C 9 years ago & have probably had it for 24 years. I'm genotype 1a. Biopsies have shown mild disease and I've finally been offered treatment - combination therapy of pegylated interferon & ribavirin.

I start on tuesday 4/9/07 and this will be my record of treatment.

I work full time in mental health services & live with my husband. I want to be able to show anyone thinking of embarking on the treatment what it may be like & what kind of impact it can have on your life. This is what I wanted to know. I struggled to find positive accounts so this is mine - including what is ok and what is not.

I've prepared for my treatment by having a holiday abroad before I start so I won't travel abroad whilst on treatment and getting some other things done. I haven't drunk alcohol since my diagnosis. I have told my boss (a friend) and our staff care section at work about the treatment so they are prepared if I need support or am off sick (though I won't be off if I can help it). Apart from that just my husband & sister & some friends who also have hepatitis C know. I don't want to define myself by my diagnosis so apart from stigma & not wanting to worry people that's why I keep it to myself.

So here goes . . .

## **Wednesday, September 5, 2007**

### *So far so good*

Well I had my first injection at 11am yesterday. I was surprised by how emotional I felt - taking the first step on an unknown & possibly difficult journey I suppose. And I feel like an experiment. Anyway I've been fine. I was very slightly achy & headachy in the evening but then I had rushed round & done loads of housework after I got back from the hospital & possibly still have jetlag. I took a couple of paracetamol about 8 hours after the injection, not because I felt uncomfortable then, but in case it got worse. I slept well & have worked as normal today & felt fine. I had a very slight headache at some points but that may well not be down to the treatment but because we are short staffed & horrendously busy & some of the rooms I work in are so hot, so it's not unusual for me to feel a bit headachy at work sometimes. I've made sure I've been drinking plenty of water & am trying to stick to my resolve to eat healthily.

## **Wednesday, September 5, 2007**

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### *So far so good (continued)*

I don't know if I've just been very lucky with how I've been feeling or if it will change but it's a good start. I have a very busy job, some personal problems & have lots of building work due on the house over the next few months so I'll be attempting to manage that while on treatment.

My viral load in March 2007 was 6ish x 10 to the power of 6, I'm not sure how to write that but it's the highest reading I've had. I don't know yet what the result was for yesterday. My weight is 10.5 stone.

## **Saturday, September 8, 2007**

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### *No change*

I'm still absolutely fine, no side effects at all that I can tell. I've been carrying on my life completely as normal - apart from trying to be healthier!

## **Tuesday, September 18, 2007**

### ***Starting week 3***

Well I've just completed week 2. After the second injection I had lower back pain which I checked with the GP as it tells you to on the medicine leaflets - she's testing me for a kidney infection. If it is just part of the side effects it's not unmanageable pain & wore off after a few days - I eventually took a paracetamol on the third night as it had stopped me sleeping well. Otherwise I've been ok, I've been busy & working full time & managed it all with no problems. I'm about to do my third injection & have felt very tired this afternoon.

My doses are: peginterferon Alfa 2b 0.5ml weekly injection and Ribavirin 200mg capsules - 2 in the morning & 3 at night.

I've been told it gets worse after the first month, I'll just have to take it a day at a time - whatever happens at least I've had 2 weeks that were ok!

## **Wednesday, September 19, 2007**

### **Update**

My kidney test with the GP came back clear. No problems with the third injection so far. I've just had an appointment with the Hepatitis C nurse - I asked her if people were generally worse after the first month, she said she hadn't heard that & that people usually found the first 6 weeks the hardest. She said most people they see don't have a problem with the treatment apart from tiredness which is what I'm finding so far (though I'm not even too tired). My viral load on 4/9/07 was  $3.26 \times 10$  to the power of 6 (3,260,000 units per ml). A negative test is when they can't detect the virus, the lowest reading they've been able to get in a blood test is 15 units per ml. My next viral load test will be in 3 months when they need to see a drop of 2,000,000 in order to deem it worth continuing.

## Sunday, September 30, 2007

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### Week 4

Well I'm nearly through week 4 and I'm fine. I took a paracetamol after the injection as I had a slight headache. There's nothing much to report really but I'm still going to keep up with the blog as I think people stop writing if everything's fine & keep writing if it's not & that would give a distorted view of the treatment - if you never hear when it's ok. I've had a bit of low mood but I think it's entirely attributable to issues in my life & hasn't got out of hand. I've had the same energy I normally have & have been very busy clearing stuff in the house ready for building work. So far, treatment hasn't really disrupted my life at all. The hardest thing is remembering to take the tablets on time. But some people have to deal with that for the whole of their life, at least this is only for a period for me.

## **Saturday, October 27, 2007**

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### **Week 8**

I'm now in week 8 and all is ok. I had a bug that was going around the weekend before last & was sick & ill in bed for a couple of days & then I went away for the following weekend. I felt very tired & queasy & thought it was the treatment but it has largely gone now so I think it was just the after effects of the bug. I am due to find out if the treatment is working on 21/11/07 when I get the results of my 12 week blood tests. I'm still not really getting any side effects apart from some itchiness & I feel a bit tired but then I was feeling tired before I started.

## **Sunday, November 11, 2007**

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### **Week 10**

Some slight queasiness, tiredness & itchy skin but all manageable, I haven't needed to be off work at all. I have low mood but am dealing with very stressful personal issues which I think are causing it. I'm not sure if being on the treatment is making any additional difference to my mood, I don't really think so.

## **Sunday, November 25, 2007**

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### **Week 12**

I have been diagnosed with a non malignant skin cancer on my nose & tomorrow I'm due find out if I have glaucoma. I'm depressed to a normal degree about these things and will have the cancer cut out in the next week or two, I'm pretty worried about the scarring. My Hep C treatment still isn't causing me any difficulties - I have been away for a long weekend, an 800 mile round trip, driving on my own which I managed with no problems. I will find out this week if the treatment is working.

## Thursday, November 29, 2007

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### Week 13

Well the good news is I've tested negative for the Hep C virus! So I will continue with the treatment, I'm really pleased. I had the skin cancer cut out yesterday & am recovering at home. It's quite a big scar but should be very faint. The doctor will send it away for tests to check it is non malignant. But I have 'normal pressure glaucoma' which I'm completely devastated about. I'm worried sick about what it means for my future if I don't respond to the treatment for it & all my hopes & dreams have been turned upside down. I'm trying to remember how I felt like that when I got my Hep C diagnosis & came to terms with that but this feels different because it involves my eyesight & losing that is the worse thing I can think of. I expect I'll come to terms with it all but I'm not there yet.

## **Sunday, December 9, 2007**

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### *Other thoughts*

I don't think I've mentioned that before starting treatment I took advantage of a flexible working policy & arranged to work longer hours on 4 days per week & start at lunchtime on a wednesday (the day after my weekly injection). I did this in case I felt rough on Wednesdays. However, I have always felt ok & don't really need this arrangement though I'll continue with it during the treatment. My weight seems to have remained the same. I'm pretty itchy now (but you can't beat a good old scratch!) & I have got some E45 cream which is soothing. Still no other particular side effects, I have had loose stools quite often but not to the point of it being a problem. I think positive thinking & visualisation have helped me with the treatment. For example, on the very few occasions I've not felt fantastic or when I would rather not have to stick another needle in myself I think about how the virus is being battered, how if I feel bad the virus must be really suffering & how the injection is going to send stuff in to kill it. It works very well. As far as positive thinking goes, well there are many, many worse things to be dealing with than this treatment & after all it is time limited with a potentially positive life changing outcome.

## **Saturday, December 29, 2007**

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### **Week 17**

Well I am now over a third of the way through. I find it motivating to measure my progress so I keep record sheets to break the treatment down into chunks of time which I can 'tick off' when I've completed them. It also helps me ensure I don't miss any doses as I write down when I have taken my medication & the time. I have made sure I'm being consistent with sticking to roughly the same time each day as I read that if you complete all the doses as prescribed for the full duration your chance of a sustained virological response is 63% for genotype 1 & 94% for genotype 2/3. I think I may have missed one dose as I hadn't recorded it which I'm annoyed about. So I have 31 weeks to go. If I was having the 6 month treatment I'd only have 7 weeks to go - that seems like nothing! My message to anyone thinking of trying the treatment is give it a go - I really have found it absolutely fine & you might too. It hasn't disrupted my life & all aspects of it have been entirely manageable.

## **Sunday, February 24, 2008**

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### *Halfway through*

Well I've now completed 6 months. It has been absolutely fine. I have been able to carry on my life completely normally despite this treatment, it is completely different to what I had expected it would be. I think it helps that I'm quite organised so I don't find it hard to stick to routines. Also I'm able to find a positive outlook on most things. I didn't have a huge social life so I don't know how much that would have been affected by the treatment as I tend to go to bed quite early (but also get up very early for work). I do have too much on at the moment - with work on the house, working on my NVQ & excessive demands at work but I'm managing it all. Even though I can do all those things I'm worried about the strain on my health because I feel worn out (as anyone would do) so I am trying to find ways to make things a bit easier.

## **Sunday, March 23, 2008**

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### *Update*

Everything is still ok. I've had some slight twinges in my liver recently which is a bit depressing but my nurse says it doesn't mean my treatment isn't working. I've had builders, plumbers & electricians working on the house & the kitchen is in the middle of being fitted. So there has been lots of upheaval but I've found it no more difficult than anyone else would.

## **Tuesday, April 15, 2008**

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### *Week 33*

I'm quite pleased with myself as I've just done a talk at a conference on hepatitis C - to give the patients' perspective of having the virus & being on treatment. I was very nervous but it actually went very well. The conference was really interesting & it's good to know there are lots of people out there who are committed to helping people with hepatitis C. My treatment is still continuing with no problems. I had what looked like a boil on one of my injection sites - it must have been to do with an injection. I went to the doctor & got some stuff for it & it's ok now. I also had a few days of being very dizzy but it turns out that was an ear infection. I had to take a couple of days off work.

## Saturday, May 10, 2008

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### Week 36

12 weeks left, that doesn't seem long. I've finished my NVQ which is a relief as I can relax a bit more, though I still have quite a few other things to deal with at the moment. We're still doing work on the house so it's still a bit chaotic. I've felt ok, a bit breathless sometimes. And I sometimes get a physical feeling of a build up of pressure in my head. I don't know if that's to do with treatment or the general demands of life & rushing around. I'm going to plan a holiday abroad when I've finished the treatment. I'll wait until then so I don't have to worry about taking the injections & tablets with me & all that that would entail.

## **Wednesday, June 4, 2008**

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### **Week 40**

I had my regular appointment with the nurse today - checked about the breathlessness & occasional rapid heart beats, & a tickly cough. It's apparently normal at this stage of the treatment, I don't need to see my GP & It's not causing me any problems. So it looks like the next 8 weeks should be ok. It seems to have gone so fast. I think the hardest thing has been making sure I take all the tablets & don't miss doses. On reflection setting them out in a dosette box at the beginning of the week might help rather than keeping a chart.

## **Wednesday, July 2, 2008**

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### **Week 44**

I'm feeling a bit stressed as my manager has gone off sick for the next few weeks & I'm going to have to manage everything at work. There is a lot going on at work & I feel tired so I'm worried about being able to care for myself properly. I want the last few weeks of treatment to go well. I'll be finished in 5 weeks.

## **Saturday, July 5, 2008**

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### *Update*

Saturday, July 5, 2008

Thank you anonymous for your encouragement! I've resolved to not try & do everything at work - the world won't fall apart if I don't. I have a few days off next week & had a go at belly dancing last week - the best fun I've had in ages. I also watch old 'Upstairs Downstairs' episodes on Sunday mornings - great for de-stressing!

## **Wednesday, July 17, 2008**

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### *Week 46*

Things are much the same. I'm not itchy but am a bit tired so I take it easy & rest when I need to. I've had quite a few twinges in my liver over the last week or so which is disappointing. I know that doesn't necessarily mean it's the virus but I would feel more hopeful of success if that wasn't happening in the last weeks. I've planned a couple of trips away for when the treatment ends. I wonder if I will feel more energetic when it's finished. I'm not sure what normal is really.

## Friday, August 8, 2008

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### *Finished*

I finished the treatment on Monday (4/8/08) & had my blood test on Tuesday. I will get the results in a couple of weeks to tell me if I am clear of the virus at present - I have chosen to receive them in the post. Apparently any side effects will take about a month to stop. I feel a bit flat really. I suppose it's the wait for the results but also because of feeling that there is now nothing else I can do myself. While I was on treatment at least there was something I was actively doing about getting rid of the virus. If I am clear of the virus I go back in 6 months to see if I am still clear. If I am, I'm considered cured, though there is a 1% chance it could return. I think I'd be paranoid enough to go to the GP for another test some time after that. Anyway, at the moment I just have to wait for the results in 2 weeks. I will post the outcome here.

## Monday, August 18, 2008

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### *Results*

Well I got my letter today, I'm clear of the virus at present. I am pleased obviously but feel worried about sustaining it. I think my positive feelings about reaching this milestone are dampened by feeling so worried about my eyesight problem. Also I have some difficult personal problems & stresses at present. I think I also feel a sense of disbelief that I might be one of the people who clears it. I have a blood test in November (not sure what for) & then the final virus test in February. So I just have to be patient. Anyway, what I can say is that my experience of the treatment has been absolutely fine. All aspects of it have been manageable & I've continued to lead a normal life. Based on my experience I'd encourage anyone to give it a go. There seems to be plenty of support for if it feels tough & also you're not on an unstoppable roller coaster if it is unbearable. And you're checked at several stages so you won't be going through it if it doesn't show signs of working. Good luck to anyone out there about to start treatment. I'll post on the blog every so often & respond to any questions people may have posted to me.

## **Sunday, September 28, 2008**

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### ***Life after treatment***

Thankyou C. I do have a holiday booked for November which will be nice. I have enquired with my nurse about if it will be safe to drink a glass of wine, I'd really like to be able to. My hair is still thin & scraggy but is beginning to grow back. My eyebrows were affected by the treatment & grew in strange directions - I thought it was just age but as they are now going back to normal it must have been the treatment! I saw the dentist recently & he said my gums were still sensitive after the treatment, apparently it can be hard on them, & he suggested using a soft toothbrush for a few months. So if you're on treatment don't scrub your teeth madly! I've been eating like a horse (not that I didn't have a good appetite anyway but now I'm ravenous) & so, disappointingly, have been putting on weight. Generally I feel pretty much the same as I did while on the treatment (maybe slightly less tired?) & before the treatment which is to say I feel normal & not ill in any way.

## **Saturday, December 13, 2008**

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### *Update*

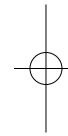
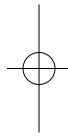
There's nothing much to report really, I feel OK. My hair is growing back. I know someone who is having a tough time on the treatment at present, emotionally & physically. It really does seem the experience is different for everybody. I think the best approach is to hope for the best but prepare for the worst.

## **Sunday, February 22, 2009**

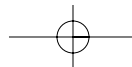
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### *Final result*

I found out a few days ago that I am still clear of the virus at my final 6 month check up. I don't think the news has actually sunk in yet. There is a less than 1% chance of it returning. I may go back to my GP in a year & ask for a PCR test to be sure it really is gone. I feel very lucky. I hope other people who try the treatment are successful in clearing the virus. I am gradually beginning to feel 'normal' again.



The Liver Unit at St James's University Hospital, Leeds, would like to thank the author for allowing her blog site to be reproduced into this booklet. The author developed her blog site with the intention of sharing her experience to support others.





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