



THIRTY EIGHT, PREGNANT, AND ON WARFARIN!

Jocelyn is on life long anticoagulants and is expecting her first baby. She has kindly agreed to document the journey through her pregnancy.

In 1978 at 5 weeks old, I had an aortic stenosis heart operation to correct my narrowed aortic heart valve. I've since had annual check ups at the Royal Brompton who in 2012 replaced my heart valve with a metal one. They allowed me to have a metal one as in 2004, I developed an arterial thrombosis and have been on life long warfarin ever since. The Brompton have always said I needed to tell them as

soon as I knew I was pregnant and I'd had various tests to ensure my heart was strong enough to cope. Once I was on warfarin, I always knew I had to know as soon as possible (ideally by 5 weeks) if I was pregnant so I could switch from warfarin to clexane as soon as possible as this is the best anti-coagulation for me and the baby. I knew if I were to get pregnant then it wouldn't be a straightforward one!

Monday 11th January 2016

I'm pregnant!! Everything swings into action! I rang the GP, the warfarin clinic and the Brompton Hospital to book up appointments – little did I know that appointments would take over my life! I was told to come off warfarin and go into my warfarin clinic on the 13th January to change to injecting clexane.

I start off on one injection of clexane of 100mg a day, which isn't great – I'm not a fan of needles but remind myself it will all be worth it. There are lots of deep breaths as I work my way around my stomach with the syringe. It feels a bit strange injecting myself with anti-coagulants and then not checking my INR as I've been using my CoaguChek monitor to self-test for 10 years.

Monday 22nd February 2016

I have an appointment with the cardiologist team at the Royal Brompton Hospital to have an echo and ECG on my heart to see how it looks – so far, so

good! My consultant cardiologist is not happy with the clexane levels which have been prescribed for me and said she will speak to the warfarin clinic to get it changed, as the most important thing is getting the anticoagulation correct. The consultant told me to await her instruction via the warfarin clinic.

Friday 26th February 2016

King's College Fetal Research Unit – first scan!!

I am very nervous about this as I want to make sure everything is okay as I'm a bit of an older mum and I don't want to pass any health conditions on. I am also a bit sick from a bug and then for research reasons, the team fire lots of questions at me. Thankfully the scan went well and so far, all looks good which is a great relief.

7pm – the consultant haematologist rang my house! He'd had instruction from the Brompton to change my anticoagulation and did not want to leave it for the weekend. He told me he had left a prescription



for me in one of the wards at the hospital to collect the next day. I had to change my clexane injections to twice a day at 80mg a time plus 75mg of aspirin – joy, two lots of injections a day!!

Tuesday 1st March 2016

Chelsea and Westminster Hospital. I will be delivering the baby at this hospital as it has a specialist unit for me. I meet the cardiologists from the Brompton with the Obstetrician's from Chelsea and

Westminster there who are the team that will look after me. They tell me that I am in a very high risk category and the most important thing is the anticoagulation. The pregnancy will continue as nature intended but the anticoagulation is vital. The injecting twice a day is starting to hurt as the bruising is getting worse.

Friday 4th March 2016

9am – the first appointment of the day is with the Consultant Obstetrician at the local hospital.

They tell me that they will discharge me from the local hospital as it would get too complicated with Chelsea and Westminster also covering me. The consultant told me that she also injected herself when she was pregnant and that as my stomach gets bigger, then probably someone else would have to inject me, my partner is quite happy to do this! A bit too happy!!

10.15am – I go to the warfarin clinic for a blood test check up.

2pm – I go to Chelsea and Westminster for a scan with them. I took my mum with me as my partner had seen the scan the week before at Kings. Chelsea and Westminster is a mile walk from South Kensington station which is quite tiring but good exercise. I feel much more relaxed for this scan and the baby was waving and kicking!! My mum didn't have scans when she was pregnant so she was excited as this was the first one she'd seen as well.

Get home shattered from the three different appointments!

Tuesday 8th March 2016

The warfarin clinic ring me to say that the blood tests from the 4th March were invalid as they were messed up, so I have to have them re-done on the 10th March!

My stomach is really feeling sore, lots of bruising and I still feel nauseous at the time of injection. Is this due to the baby or is it just because I am scared of needles? It will all be worth it!

Jocelyn's diary will appear in two more editions, covering the second three months and the final three months which will include going back onto warfarin after the birth.



THIRTY EIGHT, PREGNANT, AND ON WARFARIN!

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Wednesday 16th March

This time an appointment for me! It was time for my heart echo at the Brompton to check it was still coping okay. The echo took 45 minutes and was very detailed, there were lots of discussions happening which I was trying to understand!

I decided to switch doing my injections from one in the morning on the right hand side and one in the evening on the left to injecting all on one side for a few days and then switch. I hoped this would try and rest my stomach a bit better. I've been using different needles as I went to a different pharmacist which I've found is causing my stomach to bleed a bit more.

Tuesday 22nd March

Two appointments today – thankfully both at Chelsea and Westminster though. First appointment with Miss Patel – obstetrician and two cardiologists from the Brompton (as well as a few observers!). The result of my echo was really good and they are all really happy – the heart is showing the same as it was before I got pregnant and my blood pressure is excellent.

The cardiologists drilled home to be again that the most important thing

is my anti-coagulation and everything else will happen as nature intends but that anti-coagulation is crucial.

I then had a midwife appointment – this was a slight repeat of some of the midwife information I received at Kings when I first went there and so lots of information was taken, but it was all good. The midwife listened to the baby's heartbeat which sounds really fast but apparently that is normal and it's all good and moving around a bit. I felt relieved as I was slightly worried as I can't feel the baby yet and so this made me feel a bit better.

Wednesday 23rd March

Had a really good consultant appointment at the warfarin clinic at my local hospital. Was told that the injection can go into the thigh when the stomach is too big (but it might hurt more due to the nerve endings) and I can also go further around my back if needed. This might help the bruising heal a bit on my stomach. My blood levels are looking great and they are really happy with that and want me to have a further appointment in a couple of months.

Interestingly found out that clexane doesn't affect the placenta and so this is why it is safe for pregnant women to have this rather than

warfarin. I also found out that some women can swap back to warfarin after the first trimester (depending on circumstances) but I never will due to having two conditions that the warfarin is for and I am very high risk.

Monday 11th April

Injection this morning really bled and felt painful all day. The bruising came on really quickly and went blue and purple very fast. I stopped it bleeding but it started again in the shower that evening – I must have done a really bad injection this time!

Tuesday 12th April

Joint cardiac clinic at Chelsea and Westminster again. My heart is still doing really well and they are happy with the way my blood is reacting with the Clexane and aspirin, so far so good on everything! Having another echo on my heart in 2 weeks and then back to this clinic in a month.

Wednesday 13th April

Warfarin clinic check up first thing; the nurses and doctors checked my bruises as so sore, but they are all as expected to be.

Back up to Chelsea and Westminster for another appointment. This time it is a specialist heart scan on the baby



to see if it has inherited my heart condition. I didn't have a lot of sleep the night before due to being anxious on the results from today. Very detailed scan on the baby's heart and so relieved that the baby looks fine for all of its main heart issues – thank goodness!! Was amazing heart scan – showed all the chambers of the heart, just like a mini version of my echo! Rang mum as soon as I came out of the clinic and burst into tears in relief – think its just a relief that this is one of my health conditions that the baby hasn't inherited.

Thursday 14th April

Midwife appointment at the GP – all looking good from their point of view. Told her that the injections were hurting and the bruises were hurting badly as she could see them when examining me.

Have had a few days of really bad pain from the

injections but don't know why - might be exhaustion from the number of appointments I guess. I tried speeding up my injections – I'm quite slow at pushing my needle in so wonder if this is causing more bruising. I am trying to do more of a jab of the needle which will hopefully make things less painful too. Am gritting teeth to try and do this as finding it quite hard.

Friday 29th April

Had my 20 week scan at Chelsea and Westminster and had the chance to find out the gender of the baby but want to wait for the surprise, no matter how tempting it was!! Had all the tests done and everything looks really good so I'm really happy with that.

Thursday 5th May

Absolutely crazy day!! Had baby's heart scan done at

Kings at 10.30am – was very detailed and thankfully confirmed the same as Chelsea and Westminster the previous week! I then had a regular blood test done for part of Kings research unit. Whilst waiting for my next scan, I noticed that I had bled through the bandage – no idea why but they re-dressed it all. My next appointment was then running very late and when I got into the normal 20 week scan, I had to tell them that they had to be quick as I had to run to Chelsea and Westminster for an appointment there! I had a complete 20 week scan again and had to look away so I couldn't see the gender. Rushed from Kings to Chelsea and Westminster to have my heart echoed to check it is still coping okay and still so far so good! Got home, completely exhausted from my appointments with a massive bruise on my arm from the blood test!

Tuesday 10th May

Had my joint cardiac clinic appointment at Chelsea and Westminster. My consultant from the Brompton saw my bruises from the Clexane and offered me the chance to take warfarin for the second trimester. There would be a slight risk of making the babies blood thin and a very small percentage change of a possible bleed on the brain. Even though I would love to not inject for a few weeks at least, I said no as the baby has got this far

without any of my dodgy health conditions. I'll protect it whilst I can – wow, I sound like a mum!! I wouldn't be able to live with myself if I ended up giving the baby any health conditions. I asked about delivery of the baby and they said they are still deciding how I'll have the baby as there is a high risk either with a c-section or naturally – it will be their decision.

Tuesday 24th May

Received a phonecall from the warfarin clinic to say that my blood test XA results were missing which are the results Chelsea and Westminster are waiting upon so I need to go back in for more blood tests. I'm off work with exhaustion and pain from starting to suffer from pelvic girdle disorder which means all my ribs, back, hips and pelvis bones are hurting. Said I'd go into the hospital the next day for a blood test again.

Wednesday 25th May

Go into the warfarin clinic for a blood test and show the doctor the bruises on my stomach and the lumps which have also started to form. There isn't much room left that isn't bruised so the doctor said that maybe I should have someone else inject me around the back and that if my bruises get much worse, I'm to go back into the clinic.

Friday 3rd June

I've finally released the control and let my partner inject me in the back!! I was very nervous and had to grit my teeth but it wasn't too painful. I've agreed to let him inject me in the back every time he's in and it's time to inject – hopefully this will give my stomach a rest and reduce the bruising on it.

Wednesday 8th June

Another trip to Chelsea and Westminster hospital! This time a 26 week scan to check on the baby's heart again, a bit more closely than last time. It looks good again but they have advised that they scan the baby's heart at 3-4 months old to double check it is all okay. The hospital are certainly being thorough! I had to get the bus to the hospital when I came off the tube as the pain in my bones is now too painful to be able to walk a mile. Hopefully the physio appointments I've booked for this will start to help too.

Tuesday 14th June

Had to drink a bottle of Lucozade on way to hospital an hour before my glucose test – more sugar than I've had for a while! Appointment scheduled with the diabetes nurse at 11am and then consultants at 11.40am. First appointment delayed by half hour so grabbed another nurse and told her and was rushed for a blood test due to the timing for the test with the Lucozade. My heart sounds okay and consultants want the baby scanned 3 more times and my heart echo'd again. My cardiologist consultant also wants the anti-coagulation clinic to give me blood tests every two weeks now to keep a close eye on the thickness of my blood. Going to attend the Chelsea and Westminster delivery clinic in a few weeks but all is looking good so far still.

Tuesday 21st June

28 week scan at Chelsea and Westminster on the baby. Had a nearly 4 hour round trip for a 20 minute scan so quite exhausting. Baby is looking really good but its head is at 30-31 weeks size so bit bigger than expected!

Tuesday 5th July

Another test for me! This time my heart echo at the Brompton – very detailed and took 45 minutes to do which got a bit uncomfortable after a while. Shot straight from that test to Chelsea and Westminster to attend the Joint Cardiac Clinic appointment which was going to be to discuss potential delivery options! My cardiologist listened to my heart and said she couldn't hear the metal valve "ticking" and I said I hadn't been able to for a bit either – I thought this was a good thing! The cardiologist said that this might be an indication that there was a blood clot on my metal heart valve stopping it from shutting properly and she wanted to review my echo more closely and then run some more tests. Found this pretty upsetting as I didn't feel ill or any different and then my delivery options were put on hold until after I had tests run. Went home shattered!

Wednesday 6th July

Had confirmation from the cardiologist that following reviews of my echo and a chat with her colleagues, that she wanted me to be admitted to the Brompton to run a specialist x-ray and then possibly put a camera echo down my throat! I'm being admitted on Sunday 10th July!

Sunday 10th July

Admitted to the Brompton hospital in the afternoon and had all the usual blood tests, weight etc done. My consultant cardiologist came round in the evening as she was the

consultant on call – so good to see her. She explained that I would be nil by mouth from midnight as might have to have a general anaesthetic the next day. I would have a special x-ray first where they protect the baby but if they wanted a better look, then I would have the camera down my throat under a general anaesthetic. I asked for the possible outcomes so I was prepared:

■ If there is a blood clot, heparin drive for a week to see if it made a difference

■ If no difference, stay in hospital for a number of weeks on a drive and closely monitoring me

■ I asked if it were big, would they remove it and she said that the worse possible outcome would be that she could deliver the baby and then perform open heart surgery to remove it!

Wow, I'm not ready for the baby yet! Not expecting to sleep much tonight then!

Monday 11th July

Woken early for observations but no breakfast or drink! At midday, I got lunch as I hadn't had my x-ray as they had to wait for a blood test first and it was decided that if I need the anaesthetic, then it would happen on Tuesday. Went down for my x-ray and one of my other consultants came into the room with me and reviewed the results there and then and thankfully no blood clot! I went back up to ward, packed my bag and waited to be discharged.)The change in ticking was expected to be the additional blood created for the baby. Although it was very emotional and stressful, so glad to be better safe than sorry and back in my own bed after only one night!

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Wednesday 13th July

2 months now until official due date!! Back again to the local hospital for my INR tests. I also got the nurses to check the bruises and the lumps which are on my tummy from the injections but they all look normal and so pleased this is just part of the process.

Went to Chelsea and Westminster for another baby scan. Both granny's came with me so they could see their future grandchild. Scan went well and the baby is now 4lbs!! Growing fast!

Tuesday 19th July

Appointment at the joint cardiac clinic again at Chelsea and Westminster after being admitted with the possible blood clot on my valve. The cardiologists are happy with everything so far and all the test results but better safe than sorry. The team told me I am one of their most complicated cases with

both my metal heart valve, the warfarin for 2 different reasons and my age so they are still deciding on how I will give birth – don't wait much longer!

Wednesday 27th July

Appointment today with the consultant haematologist at my local hospital. She is happy with how everything is progressing and that Chelsea and Westminster are taking the lead. The consultant confirmed that I am allowed to switch back to warfarin once I've had the baby and that I will be allowed to breast feed whilst on warfarin so that is good news. I will go back for a follow up appointment with the consultant again in October after the baby has arrived.

Friday 5th August

I went to visit the warfarin doctor at the clinic at the local hospital as I have a lot of lumps and bruises

on my tummy again. The doctor checked and said it was an accumulation of bruise upon bruise and suggested that I give injections into the fat part of my thigh to give my tummy a rest. I started to try this that night and found them to be okay but I managed to give myself massive bruises on the inside of my thigh as the needle moved. I did this for a few days so not long but it gave my tummy some less injections which gave it time to heal a bit.

Tuesday 9th August

Had another specialist heart echo on the baby. The heart looks good but there might be possible fluid on the baby's kidney – booked into have a urology scan on the 25th August. Next went down the corridor to the Joint Cardiac Clinic – there were 9 people in the room today, bit cosy! My cardiac professor is impressed that I've got this far and I have been asked to return

in a week to see if I can give birth naturally but the jury is still out on the final decision.

Tuesday 16th August

Next appointment at the joint cardiac clinic – feel like I'm always here but the care I'm getting is brilliant. The consultants are more than happy with my heart, my blood pressure and how my INR is looking. I was examined and told I was 1cm dilated and the baby was engaged already!! Wow, crikey wasn't expecting that! The plan is that I will have the baby on the 25th August so I have cancelled the urology scan. I've been asked to attend the cardiac clinic on the 23rd August with my suitcase and then be admitted. I will then be taken off clexane for 24 hours and then induce me on the 25th August. I will only be allowed to be in labour for about 12 hours due to being taken off the blood thinning drugs and my clotting will be

monitored during labour. I will also only be allowed to push for 30-45 minutes due to my heart condition. The plan is to give me an epidural immediately so I can have a c-section if needed so all bases are covered.

I'd best start packing my bags then!

Saturday 20th August

4.30am - my waters have broken!! Whoops this wasn't in the plan from the hospital. Quickly ring Chelsea and Westminster, finish packing my bag and we drive to hospital. Thankfully the traffic at that time of the morning is very light and we make it there in an hour and we arrive at 6am.

I was sent to triage and met a consultant who checked when I last took clexane – 7pm the night before. As I'd done this, I was told I wasn't allowed to have an epidural and that I was only allowed 12 hours from my waters breaking to deliver the baby – no pressure!

I went through the labour stages really quickly and ended up in the delivery room fairly fast which was really good to try and complete delivery in 12 hours. I had a midwife and my partner in the room for the majority of the time and sometimes there were lots of people in there checking my heart, blood, baby's heart etc. At one point, they couldn't hear the baby's heartbeat but it was all okay.



As I wasn't allowed an epidural, I had gas and air and in line with my health conditions, I was also allowed a pain relief drug called Remifentanyl which gave me a hit of pain relief every few minutes – it was great!

The labour started getting close to 12 hours and it suddenly started getting really busy in the room. I was told that I would have to go into the operating theatre to be prepped for a c-section in case I couldn't deliver the baby naturally. The consultant told me that I had one last chance with forceps and then that would be it as it was going on too long and I couldn't be off the blood thinning drugs much longer. The pressure was on but I felt really calm as all the team were so amazing and making sure I knew what was happening. We had our

green hats and gowns put on and were wheeled into theatre with the needle in my arm ready for the general anaesthetic.

The obstetrician used the forceps and thankfully the baby came out – I did it! 12 hours and 15 minutes, thank goodness! I had a son. He was 24 days early for his official due date but he was fine.

I went to the High Dependency Unit and was told I was staying there for 2 nights so they could monitor my heart and my INR. I was injected with clexane and was wired up to the ECG machine. I went to the bathroom at one point in the evening and got a wheelchair back to my bed. I then passed out and woke up on the bed wondering why I was in hospital!! Thankfully it was only due to lack of food

and drink and everything else was good. Even though I was on clexane, I lost barely any blood during labour so the team were really happy with the overall outcome.

Sunday 21st August

The majority of the delivery team - consultant, midwife, and anaesthetist came to visit me and said that both I and the baby were doing really well. We sneaked a few visitors in even though we weren't really supposed to on HDU and we decided to name the baby Noah.

Monday 22nd August

I got moved from HDU and thankfully ended up in my own room with an ensuite bathroom and the nurses said that my partner could stay each night too on a mattress on the floor. I felt so lucky that I had my own room especially as I knew I was going to be in hospital for a week. My cardiologist came to visit and said that all was looking good and the paediatric consultants checked Noah's heart and so far so good! I was moved down to just one clexane injection a day – feels really weird not injecting a big bump anymore.

Tuesday 23rd August

I started to take warfarin and be bridged across from the clexane. Can't wait to not have to inject myself any longer – the end is in sight!



My consultant confirmed that if my INR is back in range, as I am a self tester, he would let me go home by the end of the week so I could monitor myself in the comfort of my own home – fingers crossed!

Thursday 25th August

Noah woke looking like a banana – developed bad jaundice. Within 10 minutes he was seen by the paediatric consultant, put under the jaundice lights and checked with blood tests. I felt really weird today as I was getting better and looking to go home but then Noah got ill and we could have to stay in longer and I started to get “cabin fever” as I was just stuck in the room all the time. My consultant sent me out of the hospital for a walk which I found I was really nervous about. Never thought I'd feel like this as I usually feel in control with my medical conditions and felt like I wasn't. Managed to go for a bit of a walk though and came back to have blood tests and then I was only given warfarin – no more clexane injections - hurrah! That made me feel better. A pharmacist came to speak to me about my INR but once she spoke to

me, she ended up mainly asking my opinion on my warfarin and my INR levels as she realised that I had been in control of it for so many years so that was nice.

Friday 26th August

My INR was taken and I was within range and was officially discharged as long as I self monitored regularly when I got home. We just needed Noah to be discharged from his jaundice now. We were convinced Noah was going to be able to go home that night but sadly when he had blood tests, he wasn't allowed to go home and they wanted him to be re-checked tomorrow morning. We were both so disappointed but better safe than sorry to make sure we are both well enough to go home.

Saturday 27th August

First thing Noah was given a blood test to check his jaundice levels. The result was that it hadn't got any better but it hadn't got any worse. The consultant came to see us and said we could take him home as long as we fed him every 3 hours and make sure we go to the doctors if he doesn't get better in a few days. After one week, we were going home! We were so excited putting Noah in the car and driving home to start our new life.

Sunday 28th August

I self tested my blood and everything is looking completely back on track. Was getting used to being home with a baby but suddenly became ill after eating. I was boiling hot, dripping in sweat and couldn't keep any food in. I rang the maternity care unit at Chelsea and Westminster who didn't want me to come back into the hospital having just got home and told me to drink water, starve myself and try and get some sleep and ring them in the night if I still felt ill. Thankfully Noah was able to be fed

from a bottle so I was able to sleep in the spare room and my partner was able to do the night feeds.

Monday 29th August

Had a day of chilling out with a visit from the midwife. Was bank holiday Monday so am unable to ring the warfarin clinic so I decide to self test my blood as I know that any illness can affect my INR. Even though I am feeling really ill, I've managed to both express milk and breast feed Noah which I have been told I am able to do even though I am back on warfarin as it won't affect him.

I ended up with a sickness virus getting on for nearly a month so my self testing was invaluable as I was able to keep an eye on my INR and feed back to the warfarin clinic and adjust my dose. If I didn't have my machine, I would have had to go to the hospital for blood tests which I didn't relish with a new born baby and feeling ill. The upside to my sickness was a great weight loss though! I had a follow up appointment with the consultant at the warfarin clinic who was happy with how my INR was and was pleased that everything went so smoothly during labour. I also had a follow up appointment with the cardiologist and obstetricians at Chelsea and Westminster who said that my pregnancy and labour had gone better than they expected, they were really pleased with how my heart and blood dealt with everything and advised that I should wait a year before I start trying for another baby!! Don't think I'll be rushing to go through that again any quicker!

Despite everything with so many hospital appointments, scans, a heart scare and what seemed like an endless amount of injections, I would go through it all again tomorrow and Noah is a dream come true.