

## The Start

So after years of skillfully batting away the dreaded question, you would rather not be asked, you finally find yourself awaiting your first IVF / ICSI appointment. You realise that one way or another you will finally have the answer to 'that' question. "Do you think you'll ever have kids?" It may help to tell family and friends or you may decide not to. There is no right or wrong way. You will not need anymore stress other than getting through a cycle.

The notes and illustrations I have made are just my experience and are not medically, technical or 'Lancet' worthy. They just helped me process it all. Others will have had different experiences of infertility. I hope there is at least one thing that maybe resonates or informs, if you are currently going through IVF or ICSI. Lots of love to you and yours.

NB: A heart felt thanks to those that never asked us' *that* ' question.



# Information Evening

An information evening is held by Mr DeBono and the Assisted Conception Unit at Halifax. It really is worth attending, there is a lot of information to take onboard before you begin. You can ask questions and chat to others if you wish. They also had a 'patients experience' and this was a huge reality check for me.The couple we heard from, had been through lots of adverse times during their cycles. Looking back, I would tell myself don't get frightened when you read/hear about challenging cycles it does not mean this will definitely happen to you. The lady talking at our information evening ended up in hospital with OHSS, something I'd never heard about. When I had a test for OHSS during one of my cycles I panicked completely and just thought back to all I'd heard about at the information evening.

Read all the information about possible complications so you are prepared what to look out for but then try not to dwell on them. Again easier said than done when your body is full of hormones and your mind full of senarios good and bad.

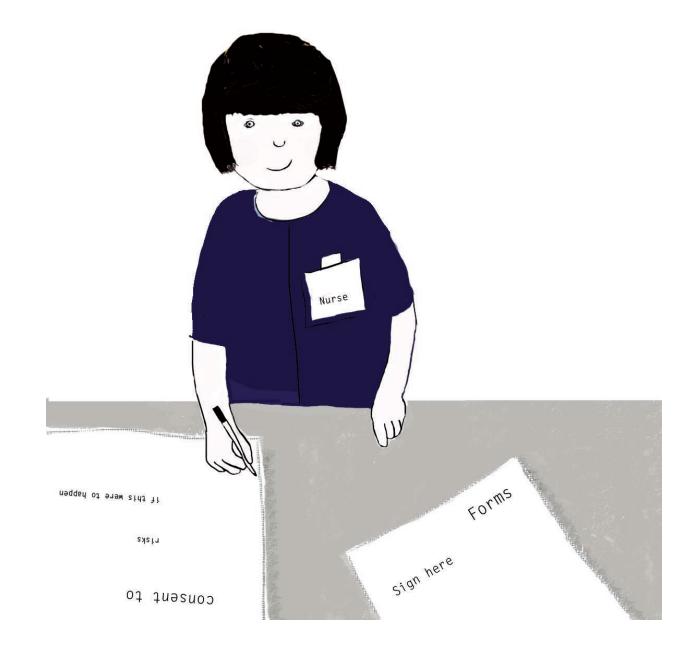
The biggest thing we took away from the evening was Mr DeBono saying IVF and ICSI is the start of a test of your body. It helped seeing other people who were experiencing infertility and knowing we were not the only ones. It maybe useful to revisit your biology knowledge, mine was sadly lacking.



## Official bits

The nursing team will go through all the forms with you and answer any questions before you start any treatments. It is worth discussing all eventualities before hand so you are both clear about what you expect from the process. Think about if you are happy to help medical research or what to do if any circumstances change.

The nursing team and reception staff are very busy and you don't always get to see the same nurse but in our experience they always looked after us. They tried to make the appointments to suit our schedules. The numbers of patients that visit the unit meant there could be a bit of a wait sometimes but an apology was always forthcoming and usually it was beyond their control as the human body does not always react on time, it meant some clinics could be extemely busy.



### Scans

Like everything in IVF/ICSI when you have done the process once everything seems ok but the great unknown can be very daunting. Do they hurt ? (No they don't). Before each scan, empty your bladder whilst you await your turn. You will go into one of the rooms, where a dentist type chair, monitor and medical paraphernalia will greet you. You remove your bottom half clothing and 'resume the position' (get used to this).

You will be scanned regularly throughout your treatment. Scans are the same for a 'Long', 'Short' or 'frozen' protocol. Most days you really don't mind but somedays you really do not want to get your 'bits' out again!





## Injections

So you get a handy purple bag with everything you will need in it. Wipes, syringes, empty needle box and your drugs. Some of the vials of drugs will be kept in the fridge, the nurses will talk through everything you need to do. Do not be afraid to ask as many questions as you need to. I wrote everything down. If you have never done injections before this can definitely be stressful. You will be shown how to and you won't leave before you have the hang of them. Pick a time of day that suits your schedule and then stick to it for the injections. Jabbing quickly worked well for me or you can get your partner to help. You may get bruising on your stomach, this is normal. I have not shown my midriff for years so not a problem for me.

I did the long protocol first, so I started with one injection each day for a couple of weeks. I got bad headaches with the first drug and took paracetamol. I then went back to collect and start the second set of injections. This second drug actually made me feel relaxed or maybe it was because I was not getting the headaches anymore. You will have scans throughout to keep a check on your progress when getting ready for the egg collection. The clinic will keep you informed on all the drugs you will need. Around or after collection you may need to take blood thinners and pessaries.

On the short protocol you will be jabbing for a shorter lenghth of time but you will be doing more from the start. I found these injections very fiddly, mixing and swapping needles. I am naturally clumsy and needed help with the tiny glass vials, there is a knack to opening them, I never managed. On the days that I was fed up with jabbing, I reminded myself I was not poorly and to get on with it. You must remember though to be kind to yourself when you are struggling. I reacted a lot to the short protocol and this backs up what we learnt at the information evening, it is a test of your body and mine had a big reaction to short protocol. Everyone will differ and some people don't get any reaction, so you have to try hard to find your own positives.

On the frozen cycle, I was pleasantly surprised when I went to collect my needles and the nurse gave me the one injection I would need for the 'shutdown' part of this cycle. Then it got better, I would be on tablets for the second part, until the transfer. I was injecting blood thinners and taking pessaries but I was really glad to not be injecting as much as the other protocols.

#### **Endometrial scratch**

After failed cycles, i'd read about and a friend had taken up the endometrial scratch and she now had a baby. It is a procedure that scratches the uterus lining and is meant to improve implantation. Nothing to lose I booked in for the scratch. Now I made the mistake of reading up on peoples experiences of the scratch. A whole bag of opinions and experiences are there to read. People have different pain thresholds and I needed to remember this.

There are medical results of success after the scratch but sadly I was not to be one of those statistics. I had the scratch and embryo glue which still resulted in a fail. Others like my friend had success. So if you want to try, the pain is not pleasant but don't let it put you off. Listen to your own feelings and do not feel guilty if you do not want any more stress, through an already extremely stressful time. On paper and in an ideal world you would become a robot and have all these done with no emotional toil on you but in reality, another procedure may just push you over the edge and not be beneficial to the rest of your treatment. My friend on the other hand is convinced this procedure together with embryo glue was what made the difference on only her second cycle.

Here lies the cruelty of IVF/ICSI, what works for some does not work for others. Everyone is different, and with this knowledge, be kind to yourself and do exactly what you feel comfortable with, don't feel a failure if you opt for some additional treatments and not others. Again funding may also play a part in the decision making.



## Egg Collection

I was very nervous on the day of egg collection and hardly slept the night before. We arrived early in Manchester and from the minute you walk through the door you are looked after. The man escorting us to our room was lovely and smiley and little things like this can make such a difference when you are full of nerves. You are shown into your own room with a toilet (subject to clinic). The doctor will come and talk through what will happen and answer any questions you may have. You will then change into your gown and the nurse will come and take your vitals, weight, blood pressure and check you are ok. You will have had no breakfast or water so take a book to take your mind off thirst and nerves.

Soon enough its your turn and you walk down to the theatre with your dressing gown, slippers and socks. Once in the room you pop yourself up on the table, 'resume the position' (remember you will be expert at this by now) an oxygen mask is placed over your face and by the time all thats done, they give you a little injection and you are fast asleep, no more nerves and the next thing you know you are drowsily coming round, back in your room with a drip in your arm.

#### Egg Collection

Your partner, if male, will have gone to get his sample ready and be waiting for you back in the room. Sedation is so much quicker at coming round from than general anaesthetic, so I was pleasantly suprised how quickly I came around and after a while had a drink and sandwich (subject to clinic).

The embryologist will then come and tell you how many eggs were collected and fill you in on what happens next. The nurses will then want to check you have managed the loo once your drip has finished and you can go home and rest.

Different protocols can have very different results in the egg collection procedure and the 'short' protocol was more challanging for me than the 'long' protocol but this is because I responded very well to the drugs and collected a lot of eggs. I had some bleeding immediately after collection. The doctor came and promptly gave me an internal examination. The nurse who was on duty asked the doctor to hang on and she would get him some lubricant to make it more comfortable for me, the doctor said i didn't need it. The nurse gave me an apologetic smile over the doctors head who had already started checking. I apreciated the nurses thought for me as i'd been very uncomfortable before egg collection and everything was tender.

Again its the little things that can make the difference. Once he was satisfied it was just due to the ammount of eggs they had collected and not a problem I was given a pain killer and told to rest for a while and then I was fine to go home. Weary and bloated we made our way home.

#### Embryo transfer

On the day of your embryo transfer you head back to your clinic. The timing of your transfer will depend upon the quality of your embryo/s. Try and time a full bladder to the time of your appointment. This can be tricky if appointments are over running ! I spent my first transfer concentrating on my very full bladder.

Before the transfer you remove your 'downstairs' clothing and pop on some 'gardening' type shoes and a towel for modesty, for the very short walk to the room where friendly faces are waiting for you. Pop yourself on the chair whilst the doctor and embryologist come and have a chat about whats going to happen. If you have the embryoscope (payment required), it shows the embryos on screen which are about to be transfered. Once they are ready a speculum is inserted, getting you ready for the catheter to be fitted, which then guides the embryo/s in to place. The nurse will guide the catheter for the doctor with an external scan on your belly with cold gel (this really helps the bladder!). The embryologist then brings in the embryo/s and the transfer takes place. The very moment the transfer happens it is captured on screen, which is amazing. Once its done off you pop into the changing room and straight to the loo. This loo visit probably lasts for as long as the actual procedure! The embryos will not fall out but your brain seems to want to think they will as you wee.

The nurse will then tell you the do's and don'ts. No hot water bottles allowed now. I was weary but relieved and thankfull that we had got to this stage. We headed home and on with the blood thinners and pessaries. Again my experience for embryo transfer was fine, I know others can have challenges at this stage of IVF/ICSI.

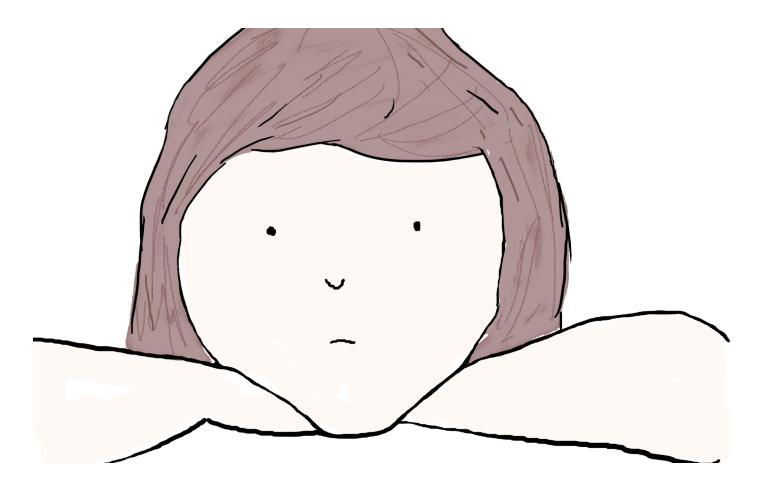
Now onto the two week wait.....

#### The Two Week Wait (Sooooo Slooow)

If you are lucky enough to get to the 'two week wait', do not underestimate this part of the process, occupy your brain. Now is the long wait. Two weeks until the pregnancy test. Fill your time othewise you slowly find your thoughts second by second going through every possible senario, which after years of waiting you have already had all these thoughts milling through your mind everyday, they go into hyperdrive. 'What if we never have a baby?' to 'be realistic what are the odds', to 'maybe this time'.

On the long protocol I first dipped on the day the clinic rang to say no more embryos had lasted, so none to freeze. If it didn't work this time, off you went again from the start. This was the hardest part of the process pyschologically, because you are trying to prepare yourself for positive or negative news. After waiting two weeks, they take some bloods (subject to clinic) and send it for testing. You then ring back at lunch time to be told the result.

If you have a positive result, excellent, all that hard work is probably momentarily forgotten for the joy of hearing the happy news. If however it is a negative result you stop all drugs and thats it, 'full on' to 'nothing'. Some people get a chemical pregnancy which entails continued treatment. Words of wisdom for a negative result when doing IVF or ICSI would be extra kind to yourself and your partner, at least you are trying.



#### A checklist of things you really don't want to hear whilst doing IVF / ICSI

When you are going through infertility you will be used to comments made by those already blessed with kids and will have learnt to count to ten or paint a smile on your face. On a good day you make allowances. Being in the minority, thats just how the world works but when you are pumping your body full of drugs and the stakes are high for finally getting your chance at maybe joining the rest of the world in having kids, you can forgive yourself for not wanting to hear the unhelpful comments. Here's a few I've learnt to count to ten at over the years. Im sure you will have more to add to the list.

'When are you going to have kids then ?'

'You better get on with it you are not getting any younger'.

'You are lucky not to have kids'.

You are lucky you have time to....'insert' one or all of the list of activities....read, go to the cinema, have a bath, sleep. (believe us we'd swap in a heart beat any of the above for a baby).'

'I don't have time to do that'. (feels as though insinuating 'my life has less meaning than yours').'

"Thats what kids do, you'll find out one day." (as if you are clueless about kids).'

'Just relax it will happen'.

'I had a friend, who's sisters, cats, neice had IVF and it worked for her, so don't stress.'

'We had to try for 3 months before we had 'insert' childs name'.

During a cycle these comments are so hard to bat away like you have done over the years. Most infertile, childless couples will have witnessed friends and relatives at first hand in their journey through parenthood and the absolute exhausting time it is. Infertility is a different type of weariness.



#### Are my thoughts normal ?....

The more cycles I went through I felt more and more isolated even after years of feeling separate from the masses of parents out there. Your circle of friends are on with child number two or three. During a cycle the physical side of things can be tough but psychologically it really is a roller coaster. You are embarking each time on what could be the start of your chance at a family. Some people may find speaking to a counsellor helps and this is avaliable through your clinic. I wanted to chat to people in a more informal manner, away from the place I was receiving treatment.

For me personally, forums were also a minefield full of people who shared every graphic detail of their treatments. This can put you off and also make you feel as though you are yet again a failure because you don't know every medical detail or research paper or acronym connected to IVF and ICSI. For others forums are a godsend and can just give them the feeling of not being alone and help move the feelings they are having along enough to function for the rest of the day. As I say forums were not for me, after one of the advisors suggested my being stressed would not have helped the implantation and this could be why I failed cycles. To say this didnt help my mood that day would be an understatement.

So after a couple of failed cycles I felt utterly rubbish. I just wanted to find people who were going through it so I could chat and ask if my feelings were normal.

I tried accupuncture to try and relax for my next cycle and found Caitlin Allen in Leeds. You have a short chat before each session and these chats were perfect at just releasing some of the built up pressure, it was a great support. I used medicash which gives you a large percentage of the cost back. Caitlin and Rachel recommended a website in Leeds for possible infertility support. The tone of the website was finally what I had been trying to find. I typed out an email a couple of times then deleted it as my confidence came and went. Finally I pressed send and a lovely email came back from Natasha who runs the site. She told me about a meeting coming up where I could come along, it would be in a little cafe, hired specifically for this meeting and I could chat about infertility or just go and listen. BINGO just what I had been looking for. I was nervous on the way but once there I was so relieved. To finally hear people chatting about similar experiences, thoughts and feelings it was such a relief, I felt NORMAL after a very very long time. www.irisfertility.co.uk.The drive home I felt lighter, I really wish I had found this support from the beginning, I really do think it would have reduced my stress through some of my cycles.

Through IVF and ICSI some will have success and others will never have their own child. Having the luxury of hindsight I would say to myself, go with the flow the days you feel sad, weary, stressed and bitter and hope for the next day to be positive and hopefull. Be proud that you tried and even if it doesn't work out at least you gave it a go. Try to ignore people with an uniformed view on IVF and ICSI and don't read any 'gossipy', layperson, 'health expert's' article and definitely not the readers 'comments' !!

Love to all who are on the IVF/ICSI roller coaster, you are stronger than you think, but it definitely tests your limits.



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