

## **A Patients Point of View**

Having recently gone through IVF in Calderdale, I realised that amongst the paperwork I received there was nothing describing the treatment from the patient's view. My husband and I recently completed a course of IVF, and this sets out the various steps we went through. This account is obviously limited to the treatment we received, so there is no discussion of, for example, the use of donor sperm or the ICSI treatment. However, I hope that this will give you an idea of what to expect, and help some of you relate to the next few months.

### **Pre-Treatment**

In many ways, I was lucky; my infertility was relatively easy to diagnose. I had an ectopic pregnancy, as a result of which both my fallopian tubes (the tubes linking the ovaries to the uterus) were removed. I therefore cannot comment on the various infertility investigations which many people need to go through before deciding on IVF as the way forward.

Nevertheless, there were still various tests which, even where the cause of our infertility was obvious, had to be carried out on us both before we could commence the IVF programme. These may seem invasive, but the best thing to do is to remember that without these tests the hospital will not be able to determine the best course of treatment for you.

At our first consultation visit, arrangements were made for me to be tested for my hormone levels, and for my husband to provide a sperm sample. Both of these tests are time dependent in different ways. The hormone levels must be checked on days 1 to 3 of your period. This can be slightly difficult if, like me, you start your period on a Friday when you cannot reach the hospital during working hours. The hospital blood testing facility is shut on Saturday and Sunday, but I was assured that a test on the Monday morning would be sufficient.

The sperm sample presents its own set of difficulties, as this must be delivered to the hospital between 8.30am and 9.30am on a set day, and must not be less than one hour old. Fine if your partner lives or works within 30 minutes journey of the hospital, but not so good if, like us, the journey time alone during the rush hour would exceed 1 hour. Your partner may need to be prepared to be creative!

You will then have a further hospital appointment at which the results of these tests are discussed. Unfortunately this next appointment may not be with the same member of the IVF team as the previous one; this is always slightly disconcerting but bear in mind that the team are very busy and this cannot be avoided.

The sperm sample is assessed for many things; not just the number but their movement and the presence of anti-bodies. If anything is low or borderline, your partner will be asked to provide another sample at another date. Remember that a healthy diet (lots of fruit and vegetables, low on alcohol) will help sperm production.

At the follow-up appointment, we needed to decide whether we were prepared to go ahead with the IVF treatment, and if so, when. Even if you are entitled to IVF on the NHS there is a lengthy waiting list (approximately 3 years) and, bearing in mind the fact that the chances of it working decrease with age, you may wish to add your names to the waiting list but also start saving. The cost of IVF treatment at Calderdale compares well with other places around the country; since starting the treatment I have heard many horror stories about people spending £10,000 on one IVF treatment which cost us less than one third of that amount (although the actual cost depends on the amount of drugs you need).

## **Starting the IVF Programme**

Once we had decided that we would start the IVF programme (in our case in early 2006) we received a letter setting out the next steps. The actual date on which you start the treatment is determined by the date of your period, so (unless you are the most regular woman in the world) there is no way of knowing exactly when you will next go to the hospital. From now on, each step feels like a major leap into the unknown.

As instructed, I had started taking folic acid pills; this in itself was a big psychological hurdle as I seemed to be moving from the status of “infertile” to “possibly able to have children with help”.

Your instructions state that, when you start your period, you should contact Mr DeBono’s secretary to arrange an appointment for you and your partner. If you are anything like me, you will spend the whole of that day looking at these instructions with your hand on the phone, not quite daring to call! Eventually I did find the courage to take this first step, and was given an appointment time.

It is important that both you and your partner can attend this appointment, so make sure you know your partner’s availability.

This appointment will be quite lengthy; allow a couple of hours for it as there are numerous matters to be discussed and forms to be signed. Among these forms are various consent forms, where you and your partner will be asked to decide what will happen to any unfertilised eggs, or spare embryos. These forms also require you to state what is to happen if your partner dies during the treatment; this may seem a truly hideous thing to consider at such a time but it is essential in order to ensure that

your treatment could continue (and your partner named as the father) if that is what you would wish.

An internal (vaginal) ultrasound scan will also be carried out on you. This is not painful (slightly less uncomfortable than a smear test) and it may help you overcome any feelings of reluctance if you bear in mind that the IVF team are looking at your ovaries, not you! Scans are carried out by a member of the team. Personally, I found the rotating chair the scariest moment; it felt rather like a fairground roller coaster at first...

The purpose of the scan is to ensure that your ovaries and uterus are at the ideal stage to start the treatment; this appointment is therefore usually about 2 weeks after the first day of your last period, although the exact timing will depend on the length of your cycle.

You will also be invited to attend an IVF open evening, if you have not already done so, and any queries you have about the treatment will be explained to you fully.

In simple terms the treatment has three stages:

the first drugs will, in effect, shut down your own natural hormone production cycle so that the team can control your ovaries and what they are doing

the second drugs encourage your ovaries to produce about 10-12 eggs, instead of the usual one egg per month

the final step, when your eggs are mixed with your partner's sperm and, with luck, two of the resulting embryos are placed in your uterus.

If you do not respond in the right way at any one of these stages the treatment would be stopped and the reasons discussed with you. So, for the next few weeks, I kept ticking off each of these hurdles as I passed them. With each one you feel like you are getting nearer to where you want to be.

This appointment is also the one where, if you are self-funding the treatment, you will need to pay. You can pay for the main treatment on credit card. The cost of the drugs with which you will be provided cannot be put on credit, and you will be sent an invoice for each set of drugs shortly after you receive them.

Whilst at the hospital you will need to collect your first set of drugs (these are not the most expensive drugs; they come later). These drugs are administered on a daily basis, by self injection into the stomach or thigh. You will be provided with an auto-injector, which has a "fire" mechanism to give the actual injection to the required depth (so no need to worry about the needle going too far in or not far enough). This takes a lot of the fear out of the injections. You will be shown exactly how to use it, and sent home with a lovely little purple bag which contains all the equipment you need.

Following the appointment, both you and your partner will be required to have blood tests for HIV, Hepatitis and Syphilis. Again, this may seem like an unnecessary intrusion but if the treatment is successful and you want to store any unused embryos it is important for the hospital to know that these embryos are not contaminated with such infectious diseases. It may help by thinking from the other point of view; you would not want your uninfected embryos to be stored with others that had not been checked in the same way.

## **The Shut Down**

Having left the hospital with my purple bag, I went home and made a calendar for my daily injections. I had been told that it would be better if they were given at a similar time every day, so decided that around 7.30am would be best for me; suitable for weekdays and weekends. I very quickly made the daily injection part of my routine, and found that it only took a couple of minutes to do once I had become accustomed to it.

You will have had an appointment made for you for about 2-3 weeks after the start of your injections, and sometime between the start of your injections and that appointment you should have your period. I had been warned that it might be slightly heavier and more painful than usual, but in the end it was actually lighter – everyone is different I suppose!

The most worrying time was the last few of days before my next appointment, when my period still had not started. You cannot start the next stage of the treatment until this has happened, and the lining of your uterus is thin enough to start the stimulation. Luckily, three days before my appointment, my period did arrive, and by the time I was next in the hospital the lining of my uterus was (just about) thin enough to progress to the next stage.

## **The Stimulation**

At your next appointment you will have another internal ultrasound scan (they will become second nature by the end of the treatment) to check the thickness of the lining of your uterus. If you have had your period and the lining is thin enough you will start the next stage – the stimulation of your ovaries.

This is where the expensive drugs come into play, so if you are self-funding be prepared for a trip to the pharmacy which will lead to a very big bill.

You will be given a date on which to start these injections (usually a day or two after the appointment), and on that date you will also need to change the amount of the first drug (buserelin) that you inject each day. From now on you will therefore be on

two injections per day. You will be provided with a chart for each day's injections, but make sure you are doing them with a clear head to avoid a mix up on the dosage.

If you thought the first set of injections looked like a chemistry set, then wait until you see this lot! These need to be kept in the fridge, and the phial needs to be mixed up before use, so allow yourself plenty of time to do this. I ended up doing the mixing the night before I needed the first injection.

By this stage your thighs or stomach will be starting to feel like a pin cushion; when you are on one injection per day it is easy to use alternate sides but with two a day you might start seeing some bruising, which will fade quite quickly.

The effect of these drugs is now to stimulate your ovaries to produce lots of eggs. You will need to be monitored (by internal ultrasound scan) to check that your body is reacting appropriately to the drug dosage. If your ovaries produce too many eggs you can suffer from the over-stimulation, of which more later.

From now on, you will have quite frequent hospital visits. They are usually early in the morning, but if you are working make sure your employer is happy with you arriving at 9.30am on odd occasions for the next 10 to 14 days. You may have your next scan after 5 days of injections (especially if there is a risk of over-stimulation), but most women will have their next scan after a week of injections.

At these scans you will be able to see the egg follicles growing in your ovaries; they will be measured on each visit, and the aim is to continue with the daily injections until the biggest follicles are about 17mm across. In order not to miss this you will have more and more frequent visits (if necessary at the weekend) until the team are happy with the number and size of follicles. This will usually be after about 10-14 days of the second set of injections.

This was both an exciting and worrying time; I could actually see the progress my body was making but I then worried about whether the follicles were growing too quickly or not quickly enough. It was difficult to put the frequent hospital trips out of my mind for the remainder of the time in between but you do need to try to keep a sense of perspective.

You may get slightly sore ovaries during this phase, as they are doing far more work than they usually would on a monthly basis, and some women feel rather bloated during this time. Finally, though, you should be ready for the egg collection.

## **The Egg Collection**

Once your follicles are of a sufficient size you will be given a date for your egg collection (this may be in Leeds or Manchester). Your partner (obviously!) also

needs to attend that appointment, so both of you will need time away from work. The difficulty is the fact that no one will know until a day or two before exactly what the date for collection will be, so if you are both working you will need to arrange for some flexible time off.

Immediately prior to the collection, you will stop your usual injections, but you must then give yourself the final injection. I called this injection the “detonation”; it tells your body to prime your eggs to ensure that they are ready for collection, and needs to be given exactly 36 hours before the time of your egg collection appointment.

The exact time for this injection will be notified to you by the staff at Leeds or Manchester when they tell you your appointment time. If, like me, you have a 2pm appointment for egg collection that means that your final injection must be at 2am the previous day! You must not miss this injection time, so set lots of alarms if need be. Unlike the other injections this cannot be given using the auto-injector, so it might help if you have your partner on hand to assist you.

The following 36 hours are rather strange; there are none of the usual daily injections (which have become so much part of your life) and nothing to do other than try not to worry about this looming appointment for the egg collection.

My collection was in Manchester, so both my partner and I turned up about an hour early full of nerves. We were taken to a private room, where I prepared as if for an operation. Whilst the egg collection is going on, your partner will be left to his own devices to provide the sperm sample.

The egg collection is not usually carried out under general anaesthetic, but under sedation. I wasn't quite sure how awake I would be but it is like being in a very deep sleep; apparently you might speak to the medical staff but you cannot remember saying anything, as though you are dreaming and talking in your sleep. The advantage of sedation is that you recover from it far faster than from a general anaesthetic, so I was fully awake quite soon after the collection.

We were then left together in the hospital room whilst I recovered from the sedation, and after a while an embryologist came to see us to report on how many eggs had been collected, and whether the sperm sample was suitable. We were then free to leave whenever we wished, although you must not drive after the sedation – make sure your partner has the car keys!

After the collection you will have some bleeding, which should not be too heavy and will stop within the next couple of days.

I was given an appointment for the transfer back of any fertilised embryos in two days time. For the rest of that day I was too weary to worry particularly, but the clinic in Manchester had promised to call me the following day to report on the fertilisation progress. This was an anxious time; we had gone through so much to get to the egg collection yet you have no control over how many will now fertilise.

Luckily, I had a relatively good fertilisation rate (not all eggs will fertilise, but this is a fact of nature) so the embryo transfer would go ahead the following day.

There is no need for your partner to attend the embryo transfer, other than to offer moral support. You are not sedated for the transfer, as it is not painful (in many ways it is similar to a smear test). You do, however, need to have a half-full bladder, which is an interesting thing to try to assess!

Before the transfer you will again be given a report on how many of the embryos have continued to develop and divide into two cells. Don't be disappointed if this number is less than the number that initially fertilised; not all fertilised eggs continue their development and this is entirely natural. Remember that you only actually need one to get pregnant.

If there are more than 2 embryos the embryologist will select the best two for transfer. Any spare embryos which are of sufficient quality to cope with the freezing and thawing process will then be frozen for your use at a later date should you choose. The rather odd part was when I was shown the embryos on a screen (and given a photograph to keep) before they were transferred back. After the transfer I was allowed to rest for as long as I wished before leaving the hospital.

There is a temptation at this stage not to stand up / go to the toilet etc. in case the embryos fall out, but I was assured that this would not happen. Basically, all you can do is take it easy for the next few days and keep your fingers crossed.

## **The Two Week Wait**

After such a flurry of hospital activity the next two weeks are a real no man's land, with no injections or hospital visits. The only medication you will need to give yourself is a progesterone pessary each night for the next two weeks, to help ensure that your hormone levels are sufficient.

You want to give the embryos the best chance possible, so I acted as I would if I was pregnant (I cut out all alcohol, for example, stayed away from smoky places and ate only the foods which are allowed for pregnant women) but also had to stay realistic about the actual chances of being pregnant.

You will have been given a date for a hospital pregnancy test, which is usually a little under two weeks after the embryo transfer (my transfer was on a Friday, and the test the following Tuesday, so 11 days later). This is a blood test, so far more sensitive than the over the counter pregnancy tests. There is therefore no point in trying to cheat by doing a self test earlier as it will not detect anything.

I was told that the embryos would implant themselves in my uterus (if they were going to at all) about 3 days after the transfer. I therefore spent the whole of that day completely pre-occupied by what might be going on inside me and trying desperately to feel some sign of implantation! Some women do experience a slight amount of bleeding on implantation, but don't worry if you don't have any bleeding then; that doesn't mean it hasn't worked.

I tried to focus on the positives at this stage; even if these embryos didn't implant the fact that I had got to this stage meant my body had responded appropriately to the various drugs. If you have had some embryos put in the freezer that will help to reassure you that, even if this attempt does not work, the frozen embryos are there for the next attempt.

## **The Pregnancy Test and Beyond**

On the day of the blood test, you need to visit the hospital in the morning to give a blood sample, and then call back in the early afternoon for the results. Make sure you plan something to keep yourself occupied for the rest of the morning. Going shopping is not the best idea; you do not want to be faced with the dilemma of whether you buy ordinary clothes when you might need maternity clothes soon. Even food shopping can be problematical – are soft cheese and pâté on the menu or not?

When it came to the time to call of course I found that the phone was engaged; keep trying and keep calm!

Oddly, even when I was told that the result was positive I couldn't relax, as it was obviously such an early stage of the pregnancy. When you do an IVF programme you find out you are pregnant when you are only about four weeks pregnant, whereas most women would not suspect they were pregnant until 5-plus weeks or later. There are still all the usual risks of miscarriage at this stage, so I thought it was important not to let myself get carried away yet.

You will have another appointment in a fortnight for an internal scan. By this time (when you will be 6 weeks pregnant) you will be able to see the embryo. Be warned – it will not look anything like a baby! However, for me, this was when my pregnancy started to become real. I was also feeling some of the common pregnancy symptoms such as sore breasts and I could finally start to relax. Having had the ectopic pregnancy one of my concerns was whether this one was in the right place and being able to see something clearly in the uterus was hugely reassuring.

This is also the scan where you will find out whether you are expecting one, or two. Remember that, as two embryos are usually transferred, there is a much higher possibility of twins with IVF.

If all goes well you will only have one more visit to the IVF team, for a final scan at 8 weeks. At this scan the embryo looks a bit like a prawn (!) but you can see a heart beat and that in itself will reassure you enormously.

From then on, you are let out into the usual ante-natal system, but one final word of warning – don't expect to be the happy-go-lucky first time mother that your friends may have been. You have gone through a lot to get here, and are therefore more acutely aware of each of the potential problems that can arise in a pregnancy. I did not even start to relax until I had had my 20 week scan.

**Good luck, and best wishes for all of you.**