The journey through IVF treatment brings many emotions to the surface. Couples who undertake the journey are often taken by surprise by the demands that IVF can make. Success and failure are always possibilities. In this program we hear about Alister's disappointment that is not often talked about but can be a very real part of the IVF journey. In listening to this podcast series please bear in mind that Alister's experience is not universal, it is his story. This podcast is not intended to replace or replicate medical advice.

Transcript

Stopping IVF treatment: a future without children (a man's perspective)

Hi, I'm Alistair; I'm not from Britain although I sound like it. I work mainly as a software engineer, although I do different things

Describe my IVF treatment... it was quite a long time ago and I've mainly blocked it out as a horrible experience.

My memory of it is that we did about five stimulated cycles which were...

It was a hard journey for me, obviously a very hard journey for both of us.

Men don't talk about this stuff unless it's some sort of professional, kind of counselling type of role. In my experience men aren't very good at this sort of thing. Most men have no interest in discussing it. And if they do it's all technical. And also I wasn't aware of being emotionally particularly fraught. I guess I was, I must have been.

It's a very different journey for the man compared to the woman I think. I think it was hard for me to acknowledge what I was going through in a way. When you're the male half of the IVF unit you're in a very feminine world. You're very much, you feel like a spare part. Your role is very limited just a blue room or a lounge as I like to call it. And really driving and making cups of tea so I did a lot of driving and made a lot of cups of tea. And listened patiently a great deal and tried to be supportive, that's your role as the husband really.

As a result it was... It's not as painful for the man. You're less attuned to your desire for a child. I think I was less attuned to my desire for a child although it's always been a thing for me. It was such a big deal at the time and now I can barely remember much about it.

I think the most challenging thing for me about IVF was the lack of control. It was nice to be in an environment of highly skilled specialists doing their best and the whole of the medical apparatus. But knowing that it's a numbers game and there's not much you can do to help, the die has really been cast. I think that was the hardest thing, to not have any control and not be able to fix it. And we're kind of A-type personalities, achieving people. Normally things in my life, if they go wrong I just work harder and things come right. So it was very difficult to be in a situation where it almost
wasn’t up to me. It was in the lap of the gods. (3:19)

It’s difficult I think and I think it’s difficult for men. And also dealing with Anne’s emotions was quite hard although she was less stressed than she had been beforehand. But still a lot of anxiety around it. A lot of uncertainty. Not being able to plan became increasingly difficult. Can’t plan a holiday because we might get pregnant. You can’t change jobs because you might be pregnant. You can’t move house because you might be pregnant, etc, etc...

It’s putting your life on hold for years on end. We met people who put their life on hold for years and years and years and I always thought that was a cautionary tale from my perspective.

I think to be honest I tried not to think about it. There wasn’t anything you could do. The die was even more cast. There was just the wait and try to think about other things. There was no sense worrying about it. And to bring it up was just a huge can of worms. So I just tried to pay it as little mind as possible given the situation.

So at the end of the two weeks when the test was negative and Anne’s cycle came due. It was pretty hard. I’m not that comfortable around massive amounts of female emotion. It was difficult.

But you did have a role though. I knew what I was doing or what I needed to do. It wasn’t unclear. So in a way it was always better to have something particular to do rather than hanging around waiting for news one way or another.

I think we reacted in very gender stereotypical ways. Anne was very emotional, less emotional as she’d been for the preceding period. But she was still very emotional from our perspective. I was rather less so, I was deep into denial which is quite useful when you’re dealing with hard things. I could ignore it quite a lot.

In a funny way I think it was very good for our relationship. I think it had a common enemy and a common project. It felt very much...us against the world. Which I think was.... a good thing.

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You know, it helped us as a couple.

And the difference in our reaction... we talked with a lot of people over the years about this now and our reactions were very typical. Mine was to try to move on a lot and not think about it too much and just get on past the next cycle, and what you need to do. Come on - she’ll be right, positive attitude. Chin up!

Whereas Anne was much more able to experience the emotion for what it was. It was much later that I had the space in my own sort of life to truly acknowledge what I was feeling. Once the clearly defined I get husband role was over I had space to realise I had to deal with my own grief.

It was only then that I realised I had grief to deal with. Knowing in theory I probably was upset. It
was only two or three years after we had finished that I got in touch with it.

We dealt with the “talking too much issue” by a very strict rule we had called the “11 o’clock Rule”. The “11 o’clock Rule” is a wonderful thing, it is the rule where no-one talks about anything emotional or complicated after 11 o’clock at night. And it sounds a bit strict and arbitrary and stupid but it’s really helpful from the male perspective because otherwise those conversations can drift on all night long. It was annoying that there was a limit to it - a time limit - made it easier for me to actually engage with it and knowing that I was going to be allowed to escape at some point in the near future.

I think that was the single most useful thing we did. And calling it a rule, some arbitrary third party thing. It wasn’t really my fault. It wasn’t me being a prick. This is just a rule, I’m sorry it’s not my fault being a rule it’s nothing I can do about it. And that strangely helped a lot. And that’s probably the most important thing.

And also pretty considerate about respecting my limitations around how much I’m prepared to have dealings within any given 24 hour period.

From a male perspective to try to get some agreed boundaries on conversations about IVF and about how people feel. To encourage your partner to get some third party support like a counsellor, if they seem to need to talk more than you can listen.

I think take care of yourself. Don’t go to baptisms, don’t go to hospitals. Don’t go to one year old birthday parties. Don’t feel you’re being rude to people. And even if you are rude to people they are going to have to cope because this is horrible. Try to do nice things to yourself which is easier said than done.

Go out to dinner or see a movie which isn’t.... or go for a weekend away. Or something that isn’t focussed on IVF. Because it takes up your whole life. So anything that makes it not present to you. Anything which distracts you, that also doesn’t get in your way that you can’t go overseas for extended bit of time, for instance that you might miss a cycle... heaven forbid.

Smallish things. It’s more a question I think of doing nice things, it’s good but much more importantly don’t do the things which are going to hurt.

I didn’t get any support. And I don’t think I really needed it at the time, I wasn’t really particularly upset. We were involved in the art group the support group, which was quite good, quite good to have a peer group. We had all these social events and all the men would not talk about it because there’s nothing to talk about. There’s only one thing you do and you don’t really discuss that. And otherwise you’re just there in this women’s world holding the hand of your partner.

I guess it was nice having the company of people who understood what it was like and it was also nice having people who weren’t going to say, “why don’t you just adopt” or whatever and you could just swap war stories and I think that was the only thing... that was available. Better than counselling for me.

Everyone had stories of people’s awful reactions and useless failures to even attempt to behave considerately. And to be able to swap stories with each other about, to develop the sort of black sense of humour you need to cope with it. And to sort of vie for the person with the most awful response from a friend, sort of thing.

It sounds very negative. It’s such a hard experience. The only way through it is through a deeply black sense of humour. And, I think, that was good to have people too. And jokes which don’t make
any sense outside the context and... sounds horrible to outsiders and because you’re all engaged in the same struggle together and engaged in the same experience. You all had similar stories and similar experiences and similar...annoyances.

It was good to have people who... it was good to talk about it with. And wouldn’t feel judged or angry or upset or guilty.

My work was fairly... I’m a pretty open sort of person so I told my manager. I work in a very team-based environment so I was happy to tell people more than they wanted to know. And then I just told them I had to take time off. I didn’t really ask their permission I just said this is what I needed to do. And they were all fine with it.

It was nice to have a space where I wasn’t wearing my IVF hat. It was nice to have a place where... it’s more comfortable and familiar, achievement-based, success-oriented controllable sort of sphere.

It didn’t really affect my performance. I didn’t get fired. It didn’t affect my performance I don’t think. There was people in the team who had, the parents of very young children. I think their performance was very much affected by the whole being kept up at night by the screaming six month old baby.

Apart from the fact that you have to take a certain amount of time off to not be at things. But... it made work more fun. Not fun. Better because it was a place where you weren’t doing IVF. Somewhere normal and sane and no-one’s crying. Or not usually anyway. A nice calm safe space.

I wasn’t expecting much emotionally from people.

I think the thing I found most annoying with people, firstly people who got pregnant when we were trying. People who didn’t need to tell Anne. I could have strangled them... could have spent days waiting for the right moment to be the bearer of bad news and then it’s my problem. And I’m not the one who’s pregnant. Why is it my job to tell Anne. Let them do it. That’s my first thought - take responsibility for doing it themselves.

I think a lot of people were so traumatised by the whole thing on our behalf that they couldn’t handle it. It was just too much and so they blurted out at the appropriate moment so they’d tell us in groups to avoid the reaction.

The best reaction I had was someone who feigned to be completely callous. Who asked a few interested questions and said yeah, it must be hard for you. And that was the best reaction. A straightforwardness about it. And not to say; why doesn’t he just adopt or what about donor egg or any one of more than a hundred and one half thought through solutions that people desperately want to come up with.

People have to be prepared... if they want to have any sort of relationship with someone doing IVF they have to be prepare to wear the cost of that. They’ve got to be... If you get pregnant or something on IVF. Or if you just want to have a conversation with someone on IVF especially woman, they’re upset. If you don’t... If you can’t cope with that then you’re not... there’s no relationship there.

If you just try to avoid any negative feelings... you have to yeah. The way to support people is to accept that they’re completely traumatised and upset and angry and to just bear with that. And not to rush to solutions.
Well I can’t be sure to have said to have made that decision really. It’s a very women’s world, the men have a supporting role and I think that’s true of finishing treatment as much as being in treatment.

For me I guess having said that, there was a bit of a trigger which was when we looked for a second opinion about the treatment and the doctor started talking about donor sperm and donor eggs and surrogates. And I thought, this really isn’t for me. It turns out this is my boundary. It’s not everyone’s boundary.

It’s that... sense that it wasn’t going to work. I had a way of explaining to people which is hospitals only had one thing to treat for people’s legs. If there’s anything wrong with your legs they put it in a plaster cast. If the leg’s broken that’s good and it heals it. If it’s got a cut it’s no good at all. That was my experience of IVF, they could do one thing. And if your problem happened to be relevant to that one thing it would work. And if you had something that wasn’t touched by it then you may as well not bother. Whatever our problem is it wasn’t being affected by the things IVF could do. It seemed less and less likely to succeed.

So I was pretty ready to give it a rest when Anne suggested we weren’t going back, I was very relieved.

But I think for most couples... for us... not most couples the lead for that came from the female half.

Initially when we stopped it was wonderful. .....to the hospital and drink again. ...make plans ....two weeks ahead. We went to Vietnam for a month. It was great. It was really good to get away and to have our life back, it was fantastic.

And that went on for a while. But after about two years I went away for a weekend I was really upset.... and couldn’t figure out what I was so miserable about until I was driving back and thought to myself; I bet that’s got something to do with IVF I thought to myself.

That took about two or three years I think before I really had the space I think to be able to be upset. Because the first sort of.... initially finished ....such relief and then...and you’re still kind of helper, coper, strong crying shoulder kind of mode. And so it takes a while to wear off and by the time Anne was back standing on her own two feet again in tears on a weekly basis because it had got sort of calmer. It was only then that I could sort allow myself.... the space to acknowledge how upset I was.

There’s only enough room in a relationship for a certain amount of emotion. And for six or seven years Anne had all the emotion and of course she was more tearful than men there wasn’t space for me to have the emotion.

So.... when I did get counselling and try to find. Because of the uselessness of my old friendships about this sort of thing I think. Or at least my male friendships it wasn’t something I could discuss easily with people.

And it’s very hard..... to people... sort of failure, which it feels like. And it's a kind of a death really. The death of your.... putative children you sacrifice so much for. Of a future you and it takes a while to even begin to realise that’s happened and longer to come to terms with.... grief around. I would talk about it like that. And that’s what it feels like.

It’s like losing an arm...something. A permanent state of affairs which you now need to adjust to. It takes a while for the reality to sink in.
I try not to think about what I miss about not being a father. It’s part of my coping mechanism is just to not think about it. So I know that’s not very helpful.

Since we finished IVF I have dropped.... part time in my engineering software kind of hat. And I’m studying. And as Anne has said we’re running a small faith community that takes up quite a lot of time.

For me it’s very important to... find some other role to nurturing in my life. To find some other way of being sort of.... low key dad for people. There’s lots of people who need that sort of masculine energy and support. And I guess I’ve just been locating them and doing that. It’s been kind of... how I can... play a positive kind of role in a pastoral sort of way.

And that’s help me a lot. We... I mean... As I said before, it’s more like losing an arm than other things because it’s a permanent loss. You’ll never be better. You never get to be just OK like you were before.

So you can become a deeper emotionally richer kind of person as a result of going through something like this. If you choose to. Some people seem to get very stuck. I’ve met people who’ve been ten, fifteen, twenty years grief stricken and never moved on. I think it’s possible to do so if you take concrete steps.

I think our life’s been very different because of the freedom of not having children has given us. It’s not freedom I’ve wanted but. Given... it’s good to make positive meaningful use of... so hence not working all that much.

And in our post IVF community we talk a lot about travel and people like sports cars and all that kind of things. And they’re all fine as well. But for me it’s been about finding some positive kind of generative way of spending my time so that I have that kind of part of me which wants to look after people gets expressed. And I’m not tied up... in my own self... so much.