

Amy's Story

After I found out I was pregnant, I initially had some light spotting, so I went to A&E and was referred for a scan one week later at my hospital's Early Pregnancy Unit (this was at around 7 weeks). At the scan they initially couldn't see what they were expecting to see at this stage of a pregnancy. They also checked my HCG level which was much higher than what they were expecting. At this point they suspected a molar pregnancy.

Around half a week later I had a second scan with a specialist doctor, who also suspected a molar pregnancy and I was swiftly booked into surgery for an SMM (surgical management of a miscarriage). Around 3 weeks later, once they had tested the 'product', it was confirmed that I'd had a complete molar pregnancy, and I was referred to Charing Cross to be monitored in case it became persistent GTD.

When I was diagnosed I had a real mixture of emotions - confused (we'd never heard of this before), upset but probably most of all, scared. I almost completely forgot this had all started with a pregnancy. It had gone from something so exciting, to an absolute nightmare - I just wanted to wake up and get back to my normal life. I don't think I could ever fully put into words how utterly devastating it is to think you're pregnant, only to find out actually you're not pregnant but may have cancer (which of course, I did indeed go on to have in my case). It was all really heartbreaking and scary.

Once I had been diagnosed with persistent GTD and put on treatment, it felt as though my whole world had been turned on its head - I was signed off from work, I wasn't allowed to exercise (a huge part of my life as a part-time fitness instructor alongside my day job), and I didn't always have it in me to see many people. My life had become a series of hospital appointments and blood tests (the one positive being I managed to fully overcome my fear of blood tests....!!). I just wanted to be better.

I was treated with Methotrexate - single agent chemotherapy. I mostly felt tired and sick during treatment weeks, and my eyes would get pretty sore - even post treatment for a few weeks my eyes would start to sting and water heavily.

I was (and continue to be) very lucky, I had the most wonderful support. I found it really tough explaining exactly what had happened at the start, so my husband and Mum did a lot of the explaining to people for me which was a huge help, so people would understand why I wasn't my 'usual self'. It's also a really complicated thing to explain as nobody has ever heard of it, so I was very grateful I didn't have to keep recounting it.

I don't think I could have got through it if it weren't for my husband, family and close friends just being there and listening. It was a shock and upsetting for them too (particularly for my husband, he'd experienced the loss too), but I got nothing but love, kindness and support. They were my absolute strength when I felt as though I had none.

A very select few people distanced themselves from me, I assume because they didn't and continue to not know what to say, and in some cases find it easier to not acknowledge, but truthfully, I'm very lucky in the support I do have.

The team at Charing Cross were wonderful. I remember being absolutely terrified being told that I had to pack a bag for a week and come to Charing Cross to start treatment. But honestly as soon as I met the specialist nurse, I felt as though a weight had been lifted. They all knew exactly what they were talking about and explained everything so clearly. I felt horrendous in myself, was bleeding, had the worst headaches and I knew I was 100% in the place I needed to be to get better.

As an outpatient, they were also very quick to respond to any emails or give me a call. Right through to what will hopefully be my final appointment there (as lovely as they all are!), they have shown me enormous compassion and also hope for the future. At the end of my final appointment, Prof Seckl said to me "now go and have a lovely life", I could have burst into tears. They are an exceptional team, and I have every faith in their knowledge and expertise in my ongoing follow up.

It's been such a whirlwind, it's kind of hard to believe it actually happened. I'm much more comfortable talking about it now and like to consider it more of a 'blip'. I'm experiencing more sadness around the pregnancy loss these days, and do have fear around the future, whether this will happen again. I also definitely have a lot more health anxiety these days, which I try my best to manage.

The experience is not something that will ever fully leave me, and it's certainly changed me and my outlook on life. But I am intent on moving on as best I can, and starting to enjoy my life to the absolute full, throwing my energy into the things that really do matter most to me.

I heard about CTRT in conversation with Prof Seckl at my post treatment appointment and having experienced a molar pregnancy and GTD, I know what a hideous nightmare of a rollercoaster it is, and the team at Charing Cross are truly incredible. I wouldn't be here if it weren't for their life-saving care. So, I would be honoured to help raise funds, particularly if some women requiring more intensive treatment could be saved from some of the nasty side effects of the more toxic treatments.

My incredible husband, brother-in-law, brother, and their amazing team took part in Tough Mudder recently and raised just over £400! And my husband and I are soon planning a 24-hour cycle (committing to it now it's in writing - I'm sure he will thank me for that!). So watch this space...!