Ismena Clout
UK patient with advanced breast cancer

Two and a half years ago I was diagnosed with secondary breast cancer, advanced breast cancer, metastatic breast cancer, there’s even debate over the name of it.

The cancer had returned in my lungs, liver and bones, so there were three organs affected. Don’t get me wrong, I’m very happy to still be here two and a half years later and actually in pretty good shape.

But it is hard, every single day.

I’ve never been fortunate enough to have a family, so I very much focus myself on work because it defines who I am. I enjoy it, I enjoy having an impact on society. It has changed the way I work though and it did take me about a year and a half to accept that I could no longer work full time. And I now have my own consultancy company and do work for lots of different people.

I’m very open about my disease, I’ve told everybody. I’ve actually told the whole world pretty much, by publishing blogs. So everyone’s very forgiving and very nice, but the other side is you also don’t want to be seen as a charity case.

I know I’ve got one, two, three, four, five, ten years maybe because of the amount of organs involved and the aggressiveness of the cancer when it does come back. And sometimes you think about the cure, or you know living longer term than that. That’s quite a terrifying thought in some ways because in my head I’ve thought well I’m never going to retire, and all of that so... because I am at the moment trying to squeeze a whole lifetime into the next few years, and you kind of think, well what if I do end up having a 30 year career ahead of me? Oh, where will I end up going? Rather than my current theory of doing everything now.

I was stable again, actually put me into about a four, five week depression because it’s great news, and I know it’s great news, and I’m really excited by it, but in my head you have to go, okay I can start to think a bit more long term again. I can start to plan again, I can start to think more about doing some work. I should get some of my mental capacity back. So yay that’s great, and... but the other side is it takes a lot of energy to do that. But also you know that you’re going to open your world up again a bit more.

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here & now
Lots of people go on about hope and fighting and I do have hope but it’s a different type of hope. I think I’m too far gone for any sort of miracle to happen, but I hope that people behind me who get caught earlier, can have much better prognosis than me. But that doesn’t mean a little part of me still sits there going, maybe I can get 20, 25, 30 years. You just don’t know.

One of the interesting things of being diagnosed is it has completely changed my prospects and my dreams for my work. I think you have to kind of take your original ambitions, kind of put them to one side, but you create new ambitions. I’ve been doing lots of work to raise awareness in the community and to the outside community. And I find it really important to use what’s happening to me and use my story for the best, because I know there’s lots of men and women out there going through a similar thing, and they don’t feel they can talk about it. And I hope that me talking about my story helps them, helps the people around them to understand what it’s like. And, I get great pleasure about making the most out of what’s happening.

I’m still a very ambitious person and I think one of the challenges is my body’s not keeping up with my ambition.

I don’t like to think of fighting the disease but just getting out of bed and getting dressed and showering, and then going out into the world and operating in a healthy world is a fight in itself. And it’s draining, it’s very draining. It’s a fight and I don’t want to stop because it’s, it’s important to kind of keep going and not just shut myself away at home and close the blinds and ignore the world. It’s important to keep engaging with the world, engaging with people outside, keep pushing myself.

Ismena of old, used to be, used to be quite a fighter, go getter, energetic, always up and around and doing things. And it’s hard to watch who I am now. And having to need to rest for a day because I was at a conference the day before, having to turn down walks in the country or dinner with friends because you just need to rest.

You can’t afford to run yourself down, you can’t afford to weaken your immune system to catch colds. It’s another reason to stay off the tube. Whenever anyone coughs I physically recoil away from them. It’s like no don’t make me ill. People who sneeze, they’re the worst. But it works; I haven’t really had a cold for the last two and a half years. I think I’ve had one cold in two and a half years, so there you go, good hygiene and avoiding people who are sick does work.

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