Three weeks and counting: the countdown to my return to work

In exactly three weeks' time, towards the end of April, I am going back to work. It will be one day off eighteen months since I was last in the office. I clearly remember the parting conversation with a couple of colleagues about how I was off to see the breast consultant for my biopsy results that evening. I hadn't been worried about the biopsy, after all I was only 42 and I ticked all the boxes for minimising any risk of developing cancer. Plus, nothing had shown up on the mammogram that was taken the previous week: the biopsy was of a tiny little lump in my left armpit. But, as I was preparing to leave the office, I began to feel a bit apprehensive: a feeling with which I am now more than familiar because I did (albeit unexpectedly) receive a cancer diagnosis that evening and over the past eighteen months a general feeling of apprehension has hung over me as I have been scanned, tested, prodded, poked and treated for breast cancer.

Coincidentally, I wasn't due to work the week following the evening of my breast consultant appointment because it was half term and I had booked some time off work to spend with the children (who were, at the time, aged 9 and 11). We had planned the cinema, swimming, bike rides, play dates and days out. What actually ensued were medical appointments, MRIs, a CT PET scan, a thyroid scan, blood tests plus lots of nerves, no sleep, zero appetite and a fast track appointment for surgery to remove the cancer-laden lymph nodes (the lack of breast lump itself is a whole other story).

I called my departmental manager within a day or so of my diagnosis because, although I wasn't due in the office, I needed to let him know about the imminent surgery date and everything that was going on. I was lucky, he was incredibly supportive and understanding. He told me to 'down tools': I wasn't to think about work, just focus on the surgery and treatment. So, I did that. Other than to inform a few colleagues that I wouldn't be around for a while and to do some handovers, I 'downed tools'. I switched off my laptop and my work phone. I focused on the surgery and treatment (which consisted of chemotherapy for 6 months, radiotherapy every day for three weeks, a Herceptin injection every three weeks for one year and a daily hormone therapy tablet which I am due to take for 5 to 10 years). I didn't think about work other than to naively think that I would soon return.

A naïve expectation to return to work soon after treatment ended

In my naivety I expected that I would have surgery, get chemo out of the way, go through radiotherapy, take a month to recuperate and then, whilst still having my three-weekly Herceptin injections and daily hormone therapy tablet, I would jump back onto life's little treadmill and pick up where I left off, including going back to work. I mean, some people can carry on working through their chemo and radiotherapy, the least I could do would be to return after an indulgent month of recuperation once the 'big ticket' treatment ended. I could imagine that chemo and radiotherapy would be hard work, but surely a little Herceptin injection every three weeks wouldn't cause too many problems, let alone an innocent looking little white hormone therapy tablet. Well, with the end of radiotherapy marking the end of the 'big ticket' treatment in mid July 2017, according to my plan I should have been back at work by September last year. However, it has taken until now to feel ready to even tentatively place one foot back onto life's little treadmill. So much for that one month of recuperation. Eight months more like. And they haven't been an easy eight months.

Cancer treatment is tough in many ways

Breast cancer treatment itself is physically tough and many side effects from the treatment remain even once treatment is over. Chemo literally floored me and I have slowly been putting the pieces back together since. A number of side effects lingered around for a while after chemo finished, such as the intense fatigue, the aches and pains and the chemo brain. Add in the general fatigue caused by radiotherapy and Herceptin, together with some intense menopausal symptoms brought on by the not-so-innocent little white daily tamoxifen tablet, and it has been an undeniable struggle. These lingering side effects are slowly improving, but I am still not at my pre-cancer physical state: I have to take life at a slower pace, I feel physically older and I feel generally more fragile: that the slightest thing will set me back.

On top of all the physical ailments, breast cancer treatment is mentally challenging thanks to something called 'chemo-brain'. This is a by-product of chemo which causes a general mental fogginess – difficulty remembering things, trouble concentrating, forgetting names and words for things and general absent-mindedness. Again, chemo-brain often doesn't disappear when treatment ends. For a long while after the end of treatment I still suffered from chemo-brain-absentmindedness, I couldn't multi-task like used to, I got overwhelmed easily and I was really rather forgetful. Things are improving, but at a much slower process than I had expected (and hoped).

Above all, a diagnosis of cancer is a pretty huge thing to come to terms with, process and move on from. Often, the realisation of having cancer doesn't hit until the treatment ends: during the treatment period all energy and attention is focused on getting through the treatment. Once that comes to an end, the realisation of what you have just been through can hit you head on. For me, the combination of dealing with this huge shock and my completely upside down hormones meant that once treatment ended I had to deal with the emotional debris of the diagnosis: I was no longer a level-headed person but one whose moods swung up and down like a yoyo, my anxiety levels were often pretty high, I was constantly fearful about the possibility of recurrence and about the spread of cancer and I often felt unable to cope. Again, there has been some improvement, but from chatting to other cancer survivors, I think I need to be prepared for some of this anxiety and some of these fears to stay with me.

A desperate desire to return to normal

Whilst going through treatment, most cancer patients, myself included, are desperate to get back to 'normal'. We want to get the whole cancer thing over and done with so that we can resume 'normal service'. Get our old lives back, forget the horror of a cancer diagnosis and the harsh treatment. But often, it isn't possible to return to normal. Thanks to the lingering side effects from treatment, the physical changes and the emotional and mental issues, some people never go back to their pre-cancer selves, whilst others find it takes much longer than they had anticipated to get back. And even then, it isn't quite the same but more of a 'new normal': perhaps similar to the pre-cancer normal but with some changes.

One of the ways in which we can find our old pre-cancer selves is through work. Work is usually away from the home where cancer may have infiltrated itself. Work is what we were before we had cancer in our lives. Work is nothing to do with hospitals, scans, medical appointments and doctors. Work is somewhere away from the sofa or bed where we spend our waking moments struggling through chemo side effects and worrying about everything that cancer brings with it. Some people are able to work through their treatment, whilst others (like me) have to take time off.

For those of us who have had a break due to cancer, the thought of returning to work is doubleedged: on the one hand, we are desperate to have our old nothing-to-do-with-cancer lives back, but on the other hand we are dealing with all sorts of physical, emotional and mental issues associated with our cancer treatment.

The physical, emotional and mental issues which may be hindering a return to work

We all take for granted how we each function on a mental level. We know our mental capacity and limits: we know what we are capable of and, as we travel through life, we live within these personal limits. So, when our capabilities are altered (by, for example, chemo-brain) we start to question our limits, mistrust ourselves and wonder how we will cope with stepping back into aspects of our precancer life. Before cancer, I was a very organised, level headed multi-tasker: nowadays I try to be organised but I am always forgetting things, underestimating timings and having to do everything at a much slower pace. I have, over the past few months, gradually adapted to these limitations at home, but I am due to return to a job that I was doing when I was a better functioning, more capable pre-cancer me. How can I possibly do the same job post-cancer, and do it productively?

And how am I going to cope with the physical demands of returning to work? OK, so I have an office based job which means that I sit at a desk most of the day, but my day will involve taking the children to school, getting a train into London, walking to the office, doing a day's work (which, given my mental limitations as described above, I am expecting to be exhausting), getting the train home, collecting the children from after school clubs and then doing the evening routine of dinner, homework supervision and so on. How will I possibly have the energy and stamina to do all that? And if I am doing this on a daily basis, I can see myself returning to the unsustainable pre-cancer lifestyle of a multi-tasking, plate-spinning, juggling life of a working mother. One where life is a rush of mothering, working, commuting, house-wifely duties with very little me-time. And if there is one thing that I have learnt over the past eighteen months, it is that 'you cannot pour from an empty cup'. And there is no way that I want to go back to that crazy busy lifestyle again. I need to get a better balance between work, home and me.

There is an important balance to be met: returning to work to help resume some sort of normality, but also only being able to return when we are physically, emotionally and mentally strong enough to do so.

"When are you going to return to work?"

Throughout treatment, and especially since the big-ticket treatment ended, I have regularly been asked by friends, "So when are you going back to work?" "Are you going back to work?" "What are you going to do about work?" And, whenever faced with a question along these lines, I would panic: my palms would sweat, I felt the heat rise on my face and I would feel my heart beat that little bit faster. Work! How could I possibly cope with work if I couldn't cope with being me. I had very little room in my brain for anything other than cancer. Being a wife and mother just about fit in there, but there was certainly no room for anything else.

So, for the past eight months since radiotherapy ended and whilst I have been going through my Herceptin treatment, I have taken life one day at a time, not planning things in advance and just getting through the weeks. Around a month ago my husband wanted to talk to me about our plans for the year: could we afford a holiday in August, should we take a trip to over Easter, what other expenses might come up over the year. And as we discussed the year ahead, I realised that my recovery had reached a point where I was ready to go back to work. I wanted to go back to work. It was time to go back to work. Yes, I still had some of the side effects lingering around, but I was feeling less tired, my aches and pains had calmed down a lot, the emotional rollercoaster had started to level out and I felt ready for the next step of my recovery: trying to step back into precancer professional me.

Top tips if you are going through cancer treatment and thinking about work

So, as I sit here writing this with three weeks until I step back into the office as 'professional me' rather than 'cancer me', I would like to share my top tips for someone going through cancer treatment and who is feeling apprehensive about returning to work.

- Keep in touch with work while you go through your treatment so that it doesn't feel like work exists in another life or other universe. You don't need to keep up to date with everything that is going on, but it might help you to not feel completely cut off if you have a regular call with your manager, HR or a colleague. Feeling cut off from work during your treatment could make it harder to take steps to return.
- 2. If you can (and I realise that not all employers are as supportive as mine, and that some people do not have an option about taking a leave of absence for various reasons) make sure you are in a good place, physically and emotionally, before returning to work but also remember that it might take longer than you expect to get there.

- 3. As you get closer to the return date it might help calm any return-to-work nerves if you pop in for a couple of short visits, discuss a phased return and raise the issue of a change to your working hours if that is something you are thinking about.
- 4. Get in touch with <u>Working With Cancer</u>. There are so many ways in which they can help you prepare for returning to work.

And if you are an employer, manager or colleague take note...

And, employers, managers and colleagues, please take note and provide support, understanding and patience for your employee or colleague who is returning to work after having been through cancer treatment. Being off work and having treatment for cancer is not just a question of finishing treatment and picking up where we left off. The physical, emotional and mental issues associated with a diagnosis and treatment do not end when treatment ends. For many, these issues persist long after treatment ends. I count myself as one of the lucky ones - I am ready to return to work eight months after the end of radiotherapy (and three weeks after the last Herceptin injection): a lot of people need much longer to get to a physical, emotional and mental state when they can return to work (if they can get to that place at all). Here are some things to think about if your employee or colleague is off work due to cancer and is due to return soon:

- 1. He/she may look 'normal' on the outside but that doesn't mean that they feel 'normal' on the inside.
- 2. There is likely to be some apprehension and anxiety about returning to work and being able to do the job to the same level as pre-cancer.
- 3. There may be some side effects with which they are still suffering which may impact on their ability to do their job, such as; fatigue, chemo-brain, aches and pains, hot flushes, anxiety and stress.
- 4. These lingering side effects may not only affect them at work: but their day to day life might be a struggle which in turn can impact their productivity at work.

And off I go...

So, with mixed feelings of excitement, relief, expectation, anticipation and apprehension, let's see how it goes in three weeks' time.

BIO

Sara is the founder of <u>www.tickingoffbreastcancer.com</u>, a website dedicated to helping people through their breast cancer treatment from diagnosis to living life to the full once treatment ends. Aged 42 when she was diagnosed with breast cancer, Sara decided to set up the website to help support those who do not know which way to turn for help after receiving a breast cancer diagnosis; those who are overwhelmed by the online support for breast cancer; those who may be scared to go online for fear of what they might find; and those just looking for a comfortable, safe, easy to navigate online resource. The website provides practical advice for each step of the way, together with many links and signposts to other online resources. Follow her on <u>FaceBook</u>, <u>Twitter</u> and <u>Instagram</u>.