## Back to Work in post-treatment 'Limbo'

It is now a year since my diagnosis of oesophageal cancer was confirmed. I've now emerged from 10 months of treatment and I am dipping my toe – tentatively – back into the world of work. I've learned a lot about the importance of work to people living with cancer and other serious illnesses, the lack of priority given to work by some clinicians, and the vital role played by employers and colleagues in supporting the 'vocational rehabilitation' journey. I'll touch on each of these issues briefly in what follows and will go into more detail in subsequent blogs in the weeks and months to come.

Of course, every cancer diagnosis is shocking and disorienting. My diagnosis happened only days after the sad loss of a very close friend and colleague, <u>Dr Penny Tamkin</u>, whose positivity and good humour after being told her liver cancer was inoperable was a huge inspiration to everyone who knew her. For me, it meant that the best tribute I could pay to my great friend was to approach my own treatment with the same positivity. Easier said than done, of course.

Let's get the clinical stuff out of the way first. I spent a few weeks in the summer of 2018 experiencing difficulty swallowing. My father had been diagnosed with oesophageal cancer in his early seventies, so I was alerted early on to go to see my GP. After a couple of endoscopic investigations, a <u>laparoscopy</u>, a CT scan and a <u>PET scan</u> I was eventually found to have an adenocarcinoma at the bottom end of my oesophagus. Luckily, no metastasis was detected. I was subsequently given four infusions of <u>FLOT chemotherapy</u>, at two-week intervals, before Christmas and my CT scan in January showed that I had 'stable disease' and would benefit from an <u>lvor Lewis</u> oesophagectomy operation which I then had in February 2019. This was intrusive and uncomfortable but went well though the histology showed that, despite only one lymph node being involved, I had a <u>resection margin</u> of R1 (by an infuriating 0.2mm). I was advised that, if I could bear it, another round of FLOT chemotherapy followed by 25 sessions of radiotherapy would be a sound 'belt and braces' way of attempting to extinguish any remaining cancer cells.

Reading these few sentences back, I realise that I've condensed 10 months of uncertainty, anxiety, discomfort and fatigue into a short paragraph. This is not to make light of the treatment which I and many others have to go through. It's tough and taxing on the willpower of the patient and the nerves of family members and friends whose support – together with my employer and colleagues – has in my case been incredible. Just to update the story, my recent clinical review meeting confirmed that 'there is no evidence of any remaining cancer'. Fans of semantic hair-splitting will note that this is <u>not</u> the same as 'there is no cancer'. It's still really good news, however, and a testimony to the brilliant NHS & MacMillan staff who have treated me with such professionalism and compassion. I'm told that if the cancer stays away for two years, my prognosis improves appreciably. In the meantime, I have to get on with a life punctuated with CT scans and nervous waits for the results.

I've started a phased return to work. As I do 'research' in my job (ironically, focused on the health of the working age population), I'm not exposed to physically demanding tasks and can function pretty well with a laptop, a 'phone and with travelling to the occasional face-to-face meeting and presenting at conferences and workshops. My <u>employer</u> has been supportive but not pushy and has allowed me to make the running on where, how and when I work. I realise, of course, that this is by no means everyone's experience. Indeed, just before Christmas last year, I <u>published an article</u>

highlighting the challenges being faced by too many cancer survivors whose path back to work is not as smooth as mine has been.

Having just started my role as an Ambassador for Working With Cancer, I'm struck by fact that far too many working age people who are living with cancer or who have survived cancer are struggling to get back to work in a way that helps rather than hinders their recovery and their adjustment to their new 'reality'. For me, the background anxiety of not knowing if my cancer will return has been compounded by the uncertainty over whether I can still perform well in my job. This is a difficult 'limbo' period because my treatment is over, I look pretty well (if a bit slimmer – no bad thing) on the outside and I'm expected to pick up the threads of both work and life pretty much where I left off. Having been only infrequently connected to work for several months exacerbates the feeling that I have been a burden to my brilliant colleagues during my absence and that I'll have to do something eye-catching and spectacular in the near future to convince them that I'm still an asset to the organisation rather than a liability. To be clear, nobody else has even remotely made me feel this way. The pressure, guilt and anxiety I feel has been entirely self-generated, and so it's down to me to rationalise it away.

I'm by no means alone in experiencing this 'limbo' and it's not something that is easily explained to others unless you are going through it yourself. This is where my new friends at Working With Cancer provide such vital support, either through advice directly to employers or individual coaching support for people navigating their way back to work. I think that an increasing number of employers are realising that they can do much more than what is required by law to help cancer survivors back into work because the moral duty they have to do so is even more pressing than their legal duty. Finally, I'd like to see more done to help clinicians to prioritise return to work for those patients who want or need it as a 'clinical outcome' of treatment and care. Too often doctors and nurses forget to ask about a patient's work and the role it plays in our lives. Even though getting the right treatment is always the priority, helping patients to plan ahead for their return to work can also be a vital part of recovery.

I hope to be contributing regular blogs to the Working With Cancer website and supporting the work of the team in other ways too. In the meantime, please contact <u>Barbara Wilson</u> or any of her colleagues if you think they can help you in any way.

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