Cancer Health™

Lost Focus

At times I feel like I'm flapping around in a panic, not really knowing what to do, wasting time worrying and not really achieving anything!

June 20, 2019 By Amanda Hayes

So this is a bit if a distorted post. I should have posted it weeks ago but my focus at the moment is very off. I've kind of titled sections as it comes so I'm sorry if it doesn't flow very well but that's the way my brain seems to be working of late! The first part was written back in April and the last bit was completed a few days ago. It's the longest post I've mulled over to date! I just couldn't seem to find my chosen topic so pretty much used it all. I don't normally write like this but I guess its the easiest way to show you the jumbled mess I have to deal with sometimes.

Anyway, apologies in the delay. There has been a lot going on… cancer and non-cancer!

The forgotten — 30.4.19

There is something I've discovered during all this cancer crap that I never really considered but it has always been there beneath the surface of it all.

There is this fear of being forgotten.

Cancer invades every aspect of your life that there is no doubt about it, it changes you. The friends you have either have to be very understanding and have compassion to these changes… which to be fair everyone is at the beginning! Or they find that this new life of yours is too much and you find they'll distance themselves from you. They become quiet and it all just slowly drops off.

You try so hard to be the person you used to be but there gets to a point where it is exhausting. You're never going to be that person again and you just have to accept it.

It's a whole new world, this side of cancer. You look well. You look normal. Your hospital appointments become few and far between and it almost becomes a new norm; out of sight, out of mind.

I'm well enough to re-join society but not sick enough to be part of this cancer community I have been for the past two and a half years.

I'm extremely thankful to be in the position to re-join society but there's this whole new set of barriers that I never realised existed before.

For nearly 2 years I’ve been claiming benefits. Not anything substantial. As I moved back with my parents it’s just enough for daily living. Over time, you go through stringent measures to make sure you’re still eligible for what they pay you. Sick notes from doctors, the surrender of all bank accounts so they can review your accounts to make sure you’re not hiding anything, and face to face meetings where they ask you numerous questions about a normal day in your life, analyse all current medication. Everything about it is incredibly invasive. You feel like you’re being judged when in reality none of this has been by choice.

I don’t dispute any of their measures… it’s a system I have to comply with.

Unfortunately, my latest assessment meant that one of my benefits were cut. I don’t dispute this either. However, it has just made putting my life back on track harder. As it has meant over a 50% drop in what I was getting. It’s fine, it will (hopefully) only be temporary. At least until I get my beauty bus up and running but it’s hard to keep positive about it when you know that the reason it has been cut is because someone previously (or currently) is abusing it. Claiming it when they shouldn’t.

I am happy to work. And I am! I’m back working a few days each week. It is no where near enough to make up for what I’ve lost but it’s a start. Fatigue is the major halt to me increasing my hours.

I’ve discovered something that I never really thought much about before. A lot of products on the beauty market use quotes like “fights fatigue!” and I hate it. They equate fatigue with tired. Fatigue is nothing in comparison to tiredness. Tiredness can be fixed with a nap. Fatigue is a lot stronger. It can last for several days and I find it effects my whole body and mind. It can also pop up for no reason!

Anyway, back to my latest dilemma, the loss of my latest benefit occurred because I’m pretty sure it’s impossible to claim benefits for fatigue. Hence why I don’t dispute their latest decision. It sounds ridiculous even to me! There’s just this massive gap that I fall in that I never realised existed before all of this and I find it kind of unfair.

The work I am managing to do all helps with building my stamina and strength back up. But it is why I came to the decision of doing the Beauty Bus. Working for myself will be a lot easier to navigate. I can work the hours that suit me and if I find I have harder days then I can schedule days off to recover.

The other side of cancer

You may find it strange and hard to understand when I tell you that I actually find life harder this side of my diagnosis then when I was in active treatment. It seems you get to a point where peoples tolerance to your new way of life gets a bit much. I find myself extremely lucky in the fact that my side effects after treatment are fairly minimal. There was talk at one point that if the treatment I was first put on didn’t work I would have had a full bladder and bowel removal along with a full hysterectomy.

As life-changing cancer has been to me it could have been a hell of a lot worse and I definitely think it would have severely impacted my mental health. So although my current side effects from it all have been minimal they are still there, pretty much daily. Just because these side effects aren’t often spoken of does not mean they aren’t there. I’m pretty sure people look at me now and think there is nothing wrong, and I shouldn’t have anything wrong with me any more. I don’t think I will ever be able to put across clearly to anyone how drastically my body has changed because of cancer and its treatment but that’s ok.

I’m ok with my new way of life. I actually think I’m a lot more confident in myself than I ever was before. I feel a lot happier in life. Hard to see, you may think, but I’ve said it before, I’m a half glass full kind of girl.

The Titles — 17.05.19

A lot of titles come after a cancer diagnosis. Some of them are obvious, and others can creep up on you without you realising them.

Depression

Anxiety

PTSD

Panic attacks

All of the above I will tell you I’ve never had. And that will be a lie. Why do I lie to you? Because, yes, at some point I’ve probably experienced it but it’s hard to admit. Not because I am ashamed, far from it. I’m sure at some point most people have experienced at least one of those from the list. However, a lot of these terms get thrown around. There are varying grades to all of them. Just because I’ve had days of parts of them doesn’t mean I can’t handle it. Its all part and process of it all. I deal with it, I talk about it, I move on.

It’s common to experience these things after a cancer diagnosis but I know it will be short lived. I’ve found this last year hard. There has been a lot of processing of what’s happened. A lot of the time, when you’re in treatment, you get told things that will happen and you take it on board and file it away to the back of your mind. There is a lot that goes on and you just focus on the now and not all the shit that is falling apart around you. Well I know I did, anyway.

I get my results Monday from my latest CT scan. I always end up on a massive downer on the lead up to the results, I feel like I’m constantly balancing on a knife-edge. I’m so close to everything around me falling apart again. There is nothing anyone can do to help me. It’s hard knowing I’m having to do this by myself again. I know I should be grateful for where I am now. Life could have been so much worse, so much harder.

The truth is it doesn’t matter what the results are. Everyone is waiting for me to tell them that the “good” news continues. And the usual good wishes and cheers will follow suit once I tell them (if it goes that way) but it's never good news to me. It's postponed news. I don't ever want to get bad news again. The bad news; being that it returns. But at least with the bad news, I know where I stand.

Back on the other side… maybe — 12.6.19

So this is the now. As I said at the start, the above was all written out a few weeks ago. Reading back on it I feel like I spoke too soon!! It doesn't flow as nicely as some of my other posts as I wrote parts of it at various stages. This has been the longest working post I've ever done. I've found it hard to focus on projects of late… at times I feel like I'm flapping around in a panic not really knowing what to do, wasting time worrying and not really achieving anything!

So my latest CT scan results came in and it wasn't the best of news. There's shadowing on my right lung which looks like new scarring but because the cancer can be so aggressive, my oncologist has requested for me to have a PET scan. This isn't usually thrown about. I have only ever had 2 PET scans before, one just before my diagnosis and then again when it went to the lungs. It's used to determine if the cancer has spread anywhere else.

You would think with this news I'd be on a massive downer but I'm not. It's like I've said before, I know where I stand when I'm in active treatment. I feel good in myself so I know I'm not on the edge of death, I actually feel the best I've been in a long time! I am probably in a better position to handle treatment then I've ever been. So I'm just going to use this time to prepare myself for the worst. Get my fitness up, keep my weight steady, I'll do everything I can to make sure I'm in a good position. Mentally and physically. It probably all sounds a bit like denial if I read back on this post in a few months but oh well, denial worked really well for me before!

I think by now I've seen all sides of cancer and its diagnosis. This time round I can be a bit clearer on what I'd like. I'm not bumbling around in a minefield I have no idea how to navigate.

If I have to go on chemo then I'd like to keep my hair this time. I'm in love with my pink curls! You may think I'm being a bit narcissistic but I don't care! I deserve to keep my hair if I want! I worry about how my hands and feet will cope with chemo if it goes that far… There is still have numbness in my feet from the last lot of chemo I was on and my last chemo was 19 months ago!

There's a lot they can do these days to prevent further problems and you may well think I'm worrying over something that may well never happen but I'll tell you this: you can't tell me not to worry or advise me on what I should do unless you have been in this position… even then I may just challenge you — not everyone has their shit together. It really varies day to day on how I feel. I feel sorry for my close ones because they're the ones who are really navigating a minefield with my mood. Some comments can go over my head and other really sit and niggle. Nothing is ever said maliciously but that's the way of a cancer life! Some days you're up and some days you're down. It's a real mental torture.

Today — 20.6.19

So finally, for a true update of today. I'm finding the menial tasks of life hard. I'm still waiting on a date for my PET scan… They can call you up last minute to arrange a date. That I find incredibly annoying. I was told when I got my No Evidence of Disease, over 12 months ago, to go get on with my life. SO that is what I did. But now that I'm on the brink of returning to the full-on cancer life they expect you to drop everything and take whatever appointment is free. That all fine and well when you're in treatment and you basically have no life outside of the hospital but it's not realistic. I have a life now. I kind of resent that they think I'll just jump and take whatever appointment they can give.

I'm kind of in this angry stage at the moment. I'm pissed that I've been left waiting. Again. I'm pissed that I may have to go back on to treatment, I'm pissed that I have to wait 6 fucking weeks for the next available PET scan, I'm pissed that 2 months will have gone between the not sure scan and a clearer scan. And finally, I'm pissed that I am having it fake at life all again in the mean time. I am generally pissed about everything.

But hey, exactly a month on Saturday, I will find out my fate… So I've just got to wait… And fake it.

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