

## Interview with Jo Churchill MP – 9 March 2016

*“It’s really important employers understand that when they are dealing with somebody they are dealing with the person, not the Cancer”*

**BW: I understand you had two diagnoses of cancer – would you be prepared to tell me about them?**

**JC:** Yes, my first one was when I was 31. I wanted another baby, I had a two-year-old and a one-year-old and I was taking a drug at the time for a hyperactive thyroid which wasn’t very baby-friendly. My doctor suggested a partial thyroidectomy but during the surgery they found a tumour and so five days later they had to do a radical thyroidectomy.

The person I will always remember from that time was a nurse, similar sort of age to me who had also had thyroid cancer and we spoke about the different pathways and what might or might not happen. One night when I was finding it hard to sleep, she just sat and chatted to me for about four hours. That was probably the most special piece of treatment I had: sometimes it’s not the pills or the potions or the treatment, it’s human contact that really makes a difference.

Then, in my mid-forties, I was diagnosed with breast cancer. I found a lump which wasn’t actually cancerous. I was referred very quickly and within two weeks I had had a triple assessment – really impressive. Unfortunately, it was cancer. The treatment went well but at my one year check they found pre-cancerous cells on the other side. It felt a bit like being on a snakes and ladders board.

The hardest thing the second time and the third, really, was telling my children who by that stage were 17, 16 and the twins were 13. At that age they are more cognisant of what you are going through and I was a lot more aware of the fact that this time it was a female cancer and I had four daughters. So, the impact was greater from that point of view. It’s obviously had a knock on effect because my cancer was oestrogen receptive so my girls have issues in and around any sort of family planning that they may want to take on. We have to be pretty careful but that’s the journey of life.

**BW: Were you working at the time and if so how did you manage your work and your cancer?**

**JC:** I worked and I made a positive choice to work when I felt able to. It was basically one of those situations where I just let my body guide me. At both points when I was diagnosed I was running my own company. I chose mostly to try to work every day. Occasionally, I would have treatment and I would just feel too tired, but I was able to work around that.

My friends and family were marvellous. A support network came from nowhere. And I’ve always tried to do the same for others. You know it’s not a big deal to take a cake or a shepherd’s pie around to somebody, when you know their life’s just a little bit complicated for some reason.

**BW: Did you consider not returning to work – was it an option for you?**

**JC:** No, not returning to work really wasn’t an option for me. The first time I was diagnosed I had critical illness insurance cover but afterwards I found it virtually impossible to get cover. We had four children, a mortgage and bills to pay. So, no, it wasn’t an option for me not to work, and working gave me a sense of purpose. It normalises you when you feel very medicalised.

**BW: What worked well and what worked less well?**

**JC:** What worked well in managing my work and cancer was the fact that I had supportive people around me. That was a huge plus and it was also a huge plus for me to be working.

What was tricky was that my husband found the second diagnosis much tougher to deal with. I think he felt lucky after the first was successfully treated. When the third set of tumours was found he really did begin to feel 'This isn't fair...! Why not somebody else?' I think sometimes it's much harder for loved ones. You, as a patient, are fighting something; they, as the people who love you, have no ability to fight it for you. There is also an expectation in this country that a man is big and strong and will respond in the same way he responds to everything, with strength and determination and humour. It inevitably puts pressure on your relationship. The first time I had cancer it was part of my body but then it was part of my womanhood, and that brings a different set of challenges.

In the end I asked whether there was any CBT or something like it that I could try. I only needed a couple of sessions. Some other things had happened in our lives at the same time. One of my children had the opportunity to go to boarding school. I felt I had lost part of my family and felt disempowered from the decision making. When I unpicked it, it wasn't the illness that was to blame but the fact that the illness had undermined my ability to control things and make decisions.

**BW: What did you learn about yourself and others?**

**JC:** What I realised was that I have some amazing friends, just unbelievable friends, and both times I learnt that, actually, this is life. It's luck...! It might be bad luck this time but it's luck. Doctors talk about breastfeeding, not being overweight, not drinking heavily, all these things might prevent cancer. I haven't really ever smoked in my life, I'd breastfed four kids, I'd always kept myself reasonably fit, I wasn't overweight.

Also some of the most fantastic people were ones in the medical profession - just for their compassion and their ability to unpack things for you.

**BW: It is interesting though because what I do and a number of other people do increasingly is that we are forming a kind of community of people who provide CBT coaching for people with cancer. It's a really useful way of supporting people at a very difficult time in their lives and sometimes in my experience, with one or two sessions an individual, can absolutely transform their thinking about themselves and their lives.**

**JC:** Absolutely! You are not loading people who love you with additional questions that you might have, for example, 'what happens if next time I go and get some results, they are really rough and it isn't going to be a positive journey?'. You do think about things like that - I would find myself thinking about what I might pop in a letter to my girls if I wasn't going to be fortunate enough to see them grow up, get married, see them have children of their own. ...

As I began to feel better, I wanted to put my efforts into helping others. When I'd had thyroid cancer the first time, I joined a group of women who raised money for a Macmillan nurse. The second time I joined Breakthrough, the breast cancer charity, that's now become Breast Cancer Now. I guess that's partly why I ended up in Parliament 6 years later!

I would like to see the government doing more. I think, there is a role out there for facilitators to advise employers, particularly small employers, and employees on when and whether it's okay for someone with cancer to work if they wish to, to discuss the risks and whether it might be making things worse or better if they come back to work.

As an employee, if you've never been through the journey, it must be really hard to go back and say 'well, I'd like you to pay me - I am not bringing a sick note in, then also some days I may not pitch in.' If one in two of us are going to get cancer as the research indicates then we need to be a little more flexible. Interestingly, small firms are often very much better than large ones at finding solutions

because they work very closely with people. It was actually something I was working on, which I had termed 'moral proximity'. When you are working closely with people, you understand their lives, they are not a number.

Of course, you can't be prescriptive. Cancer treatments are very different and everyone is unique. Large companies have to be relatively standardised and prescriptive in what they do so it's really important they understand that when they are dealing with somebody they are dealing with the person, not *the Cancer*. People tend to frame you as 'that woman with cancer' (*whispering*). But I'm still me! It's always been part of my life but it's never been something I have advertently spoken about. I carried on running a business, I entered local politics, and then national politics; it's part of who I am! I am not going to hide it, but it's not the defining part of who I am either!

**BW: Were there any surprises for you or for others?**

**JC:** I think some of the surprises are that you are not 'ill-ill' and it's like that comedian who says 'Are you out or are you out-out'? People ask "Are you ill?" as in "are you ill and getting better or are you ill-ill?" It's a very hard thing for people to cope with particularly if you look well and take care to look your best!

There is also a problem for the generation above us because for them and for my parents' generation cancer did, to a large degree, mean you were going to die. So when you say "oh, I have cancer", those people tend to say "oh, she's got cancer..." (*whispering*). Why do you have to whisper?! You wouldn't say 'she's got a cold' (*whispering*), but the C word does have those connotations.

So, I think there is work to do and that's why I am pleased that I am now talking to Macmillan about survivorship and care because, actually, I do think it is part of that educational journey. Yes, for some people it's not so good, they don't get the 'all clear' but for a woman with secondary's a couple of decades ago that would have been a really short journey and now you can live well for many years, you can still work, you can still engage. You might choose a different life; you might choose to become an artist or a potter or to do something that you always wanted to do. If you have a set of choices and your finances and your family circumstances allow, maybe you can do that. This is about us as individuals, not a homogenous group of cancer patients.

**BW: If you were diagnosed now, would you do anything differently?**

**JC:** That's a hard one! If it was full blown, it would be time number three. When does your luck run out? It would depend on the cancer, it would depend on the diagnosis, it would depend on all manner of things.

I work, or I certainly did before I came to this place. I'd worked really hard trying to keep myself healthy. The lifestyle in the House is challenging, I really think it's quite an important thing that you do occasionally 'treat' yourself. If my husband were listening to this, he would be killing himself laughing because he thinks I don't treat myself very well at all. I work, I love to work, also I read, and I travel. I go and see people and I try to understand and learn more about other people's perspectives. So, I am treating myself in a way by doing the job that I do.

**BW: What would you say to people trying to juggle work and cancer now?**

**JC:** I'd say, don't be too hard on yourself! Do what feels right for you! If you are forcing yourself to work when it doesn't feel right, you won't be working well and if your body is telling you not to work that will be a challenge for your recovery. Just listen to yourself and the people around you and, let's be frank, if you didn't like your work before you got cancer, chances are you ain't gonna to like it now! So, sometimes cancer can be cathartic and provides a chance to re-evaluate life.

The big challenge of course is for individuals who have very little economic resource. That's where Macmillan does such a good job with crisis payments and so on.

**BW: What would be your advice to employers, fellow MPs and to the government?**

**JC:** I think they should look more closely at the 'facilitator' option I mentioned earlier. I am glad to see we are giving mental health and physical health parity because most of the research indicates that there is some element of mental health challenge when you are going through any major disease, diabetes or Parkinson's or Alzheimer's or heart disease – or cancer. Let's be clear cancer is really tough... it's a tough gig! When you can laugh and cry for the right reasons again, then you begin to get a handle back on normality.

I would also try to give some assistance to employers. Some people have very physical components to their cancer, and there is a lot of work to be done with employers so they understand that the person they are recruiting on Monday will really be worth hiring. Often we make better employees, with increased loyalty and at times a better work ethic. Most cancer survivors tend to take quite good care of themselves when they come out the other side of treatment and it's not a degenerative disease. So, actually, as an employer you're probably on to a safer bet!

So it's about getting the government just to be aware that sometimes employers need to be encouraged to do the right thing.

**BW: Is there adequate protection in place for people that want to work after cancer and if not what further support should be provided?**

**JC:** That's quite a challenging one because it's about the individual. I would like to see a 'nudge-type' approach for the provision we put in place and an enabling approach. Very often people don't respond well when you force them to do something, whereas, if you offer them options, you may well find that they get to where you need them to be of their own volition. Sometimes the individual is also frightened that maybe they can't take full time work on, so we should make more use of rehabilitation programmes for cancer returners. And now I'm interviewing you - do the CIPD and other agencies do work in this area?

**BW: They have published a number of articles about this but very often it's the line manager who makes the real difference as to whether someone returns successfully to work, not the HR advisor.**

**BW: Finally, if you could give one bit of advice to people managing work and cancer what would it be?**

**JC:** It would be that if you want to work after a diagnosis of cancer you must engage with your employer. In the end the onus is on you to be as open as possible in order for them to be as responsive as possible. That leads me to a wider issue which is that we as individuals have a broader responsibility to do all we can to manage our health and wellbeing. Two thirds of people in this country are obese, one third of people in this country drink too much and 20% of people smoke too much. That has to change so we can all live healthier lives.