

POSITIVELY WOMEN

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This month's guest editor Bea is a well-known face at PW, having worked in various roles until she had to resign due to ill health this year. Here she guides us through her various ups and downs of working positively.

Eighteen months into my asylum application, I was granted a work permit. Filled with excitement I embarked on finding employment. Little did I know that having permission to work was not the only prerequisite to getting a job.

My first application was for two positions, Day Care Centre Manager and Day Care Assistant. I had all the qualifications for the management post having worked in Uganda as a manager in Family Planning.

I was offered the assistant post, which felt like taking a step down the ladder. Nonetheless, it was a positive step and I was happy to be getting into work.

The offer was subject to suitable references and permission to work in UK and was withdrawn because my Home Office papers stated that I was 'a person liable to be detained'. What a blow! The disappointment, frustration and confusion that followed I cannot begin to describe.

The double standards of being given a 'work permit' that didn't guarantee getting into employment, was such a mockery. I was rejected because I didn't have permanent residence in the UK. This was 1992, it was not until 2000 – 8 years later – that I was granted Indefinite Leave to Remain. I was diagnosed HIV Positive in 1992.

Looking for alternatives I joined Brixton Refugee Training & Employment Centre but soon found the pressure unbearable. As a result my health deteriorated and I was forced to give up studying.

Close to breakdown point, I contacted the National AIDS helpline and was referred to AIDS Care & Education Project (ACE). I met other positive people, including one African woman who introduced me to The Landmark, where I discovered PW and from that point my life turned round.

The irony is that through my diagnosis I rediscovered myself and reclaimed my profession. My first contact with PW was in 1994 as a service user. Since then PW has been where a lot of my personal and professional growth has taken place – working in different roles, meeting different people and forming different relationships.

Starting as a sessional worker in 1994, I soon joined the Direct Services Team on a full time basis. Promotion followed in 1996 seeing me back into management. As Senior Direct Services Co-ordinator, I had the challenge of supporting the team of HIV positive women offering peer support. Though hard work, it was an amazing experience.

My HIV positive journey brought an opportunity of meeting incredible women. Women broken by the horrible diagnosis and fighting their way back to survival, for some with renewed passion and zest for life.

In September 2000 I was again promoted but the challenges of working full time with a chronic illness coupled with bringing up four young children and looking after my mother were huge.

I was asked several times, 'how do you manage?' I always viewed my work as therapeutic, focusing on others' problems has been one of my coping mechanisms. Recently I have questioned myself whether it wasn't some form of denial.

I started HIV treatment in 2001, soon after my last baby, to boost my immune system but unfortunately suffered severe side effects which were something I had been totally unprepared for. Six months of fatigue, rashes, diarrhoea, vomiting and many other

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symptoms compounded the already bad situation frustrating me even further.

I had started my medication to get better but instead was left feeling worse than when I started. Normally a strong person, used to waking up early, I found myself with very low energy levels and suffering constant nausea forcing me to delay my return to work from maternity leave – after a new promotion this left me feeling I had totally failed the organisation.

Since my diagnosis in 1992, it has been my belief that I would die of an AIDS related illness. Last year that view changed when I was involved in a fatal car accident with all my four children in the car! My car collided with a motorcyclist who sadly died on the scene. A part of me died that day and my life will never be the same. I am still traumatised by the incident and have gone through a period of depression when I did not know who I was.

For the first time I faced HIV in a different light. I was constantly unwell and the stress brought my immune system to its lowest. To start feeling unwell after a long period of 'good health' was like going through a second diagnosis, not even the experiences of my work could have prepared me for this.

What has helped me is counselling, hospital support, support from family and friends and especially one magical friend. Sometimes I resented it but slowly I started finding myself again. I did not know how low I had fallen. I still see a counsellor, a psychiatrist and still take anti depressants. These things always happen in the movies or to other people it's never to you...or so I thought.

With HIV ring fenced money gone and the era of Primary Care Trusts, support for people in work by Social Services is hardly there, helping neither employee nor employer. HIV positive people in work have to deal with terrible side effects and health uncertainties but the support system is failing them.

Employers likewise are finding it harder to sustain HIV friendly policies, because of lack of funding. The future looks grim, with positive people having to make hard decisions as there is no inbetween.

Stress is the worst thing to an already compromised immune system. I feel that had I been supported more by Social Services soon after the accident, my recovery, especially physical, would have been faster.

Life is always about making decisions. The hardest I ever had to make was to leave PW. My health was on the table. I felt I was letting down the organisation as I had been unable to work for six months, the children and I were still in therapy, death was hanging over my head and a court case was looming. The job was the easier option to let go. I wish to thank everybody at PW for the support during the hard times. I couldn't have made it alone.

Having suffered a terrible trauma from the accident the last thing I needed was what I have gone through with the benefits system. It's a degrading shift from work to benefits. I have been able to regain my sanity through help from the advocacy team at the UK Coalition of People Living with HIV and AIDS (UKC). I am still waiting for incapacity benefit.

I will return to work in the future, this has been a reality check for me. Never to take life for granted the second time round and to know that as a positive mother of four, I have to work hard and secure my children's future within the shortest time possible as I don't know what disaster is lying round the corner – for me there is no life insurance.

During my most productive years I was unable to obtain a mortgage because of unstable immigration status, HIV and insurance issues. Now there are ways around these things and I find myself unemployed due to ill health. I'd like to believe the worst is over. The fighter in me is beginning to resurface – time will tell. **PW**



BY **BEA**