



Embargoed: 00.01 hrs CET, Wednesday 7 November 2018

Campaigners call for stronger rights to work for people living with breast cancer. Governments challenged over disconnect between cancer care costs and patient outcomes

Brussels, Belgium: Campaigners are calling on EU parliamentarians to make it easier for people with advanced breast cancer to return to work and to support them properly with flexible working arrangements.

At an event at the European Union Parliament today (Wednesday) hosted by MEP Lieve Wierinck, members of the Advanced Breast Cancer (ABC) Global Alliance highlighted to policy-makers that the financial burden of breast cancer includes not only the direct cost of treatments, but also the indirect cost from loss of productivity when people living with advanced diseases, who are able and willing to continue working, are unable to because of a lack of understanding about their disease or direct or indirect discrimination.

Chair of the ABC Global Alliance, Dr Fatima Cardoso, of the Champalimaud Clinical Centre in Lisbon (Portugal), said: “Most people with breast cancer are in the most economically productive years of their lives: their 40s, 50s and 60s. Not being able to work is bad for them, not only financially, but also emotionally and psychologically, and it is also bad for society. There are many studies now that show the indirect costs of cancer because of lack of productivity are actually bigger than the direct costs. If these people can continue to work and be productive, it will be much better for society as a whole.”

Breast cancer is the most frequently diagnosed cancer worldwide, affecting mainly women but some men too. Over two million new cases of breast cancer will be diagnosed in 2018 and nearly 630,000 people will die from it, almost all from advanced or metastatic disease – cancer that has spread to other parts of the body. Around **6.8 million people** are either breast cancer survivors or currently living with advanced disease, many of whom are capable of, and want to, work [1].

“Making it difficult or impossible for these people to continue working is resulting in a colossal loss in economic productivity to society,” said Dr Cardoso.

Ms Barbara Wilson, who heads the social enterprise Working with Cancer in the UK, which helps people affected by cancer return to work, told the meeting: “Even for people who are living with the long-term side effects of their treatment, it’s perfectly possible for them to continue to work if there are proper strategies in place to support them. This is **not** about making people return to work, but if someone wants to return, it can, in most cases be managed successfully.



“In order to achieve this, employers need to understand cancer, they need to communicate effectively with employees affected by cancer, and they need to implement flexible working policies during and after treatment, including providing individualised support for those that need it in the form of one-to-one coaching. Too often employers assume either that you should not work and encourage you to leave, or they think that a few weeks after treatment, you’ll be fine and then wonder why you are not ‘back to normal’ as quickly as expected. Neither of these assumptions is helpful; even terminally ill people can sometimes work, nearly up to the time they die, depending on their cancer and the type of work they do.”

Ms Wilson and Ms Karen Benn, deputy CEO of Europa Donna [2], called for all employers to ensure they have training to improve their understanding of cancer and how they communicate with their employees, and they should also have policies that support flexible working. In addition, governments across Europe and, indeed, worldwide, should put in place legislation to make it unlawful for employers to discriminate against people with cancer.

“At the moment some countries have such legislation, while many others don’t,” said Ms Wilson. “Workplace adjustments often cost tiny amounts compared with the cost of losing a good employee and the cost of recruiting new people.”

Ms Benn said: ““It is vital that people living with advanced breast cancer are not discriminated against in the workplace and policy needs to reflect this.”

Professor Richard Sullivan, a surgeon and global cancer policy expert at the Institute of Cancer Policy, King’s Health Partners Comprehensive Cancer Centre, King’s College London (UK), said not only were there costs to patients, employers and society through loss of productivity when people living with breast cancer found it difficult or impossible to work, but also because of the way cancer treatment and care is managed and funded. He challenged national governments to address the current disconnection between the costs of cancer care and patient outcomes.

“This is a really serious problem.” he told the meeting. “We have data that show that the cost of cancer care versus the outcomes for individual patients are completely unconnected. You have countries in Europe that are spending huge amounts on clinical care but are seeing virtually no improvement in outcomes. For instance, Greece is spending a substantial amount on breast cancer treatment – €34,500 per new case per year – but has seen only minimal improvement in breast cancer outcomes, whereas other countries have a reduction in the number of deaths of around 20-30%. This all comes down to the governance of cancer care; most countries are just not doing this properly and are paying a lot of money for rubbish care.”



He said this was a complex problem that had difficult and uncomfortable solutions. “A lot of countries across Europe are losing the battle in delivering affordable, equitable, high quality care. Governments need to have ruthless pricing and reimbursement control through a transparent mechanism that relates cost to patient outcomes, and that also relates to what is happening in the real world, not just in super centres of clinical excellence. In addition, there needs to be proper governance of clinical care and pathways, so that all patients receive the correct care at the right stage on their cancer journey.

“Some of this is a system problem because we have mixed models of private and public sectors, each gaming each other. Some of it is due to clinical failure and corruption. In other areas it’s because the system hasn’t put in place proper pricing mechanisms. But all we’re seeing at the moment is greater amounts of money being paid for fewer returns in terms of better, more equitable outcomes.”

At present, the EU Parliament is looking at proposals for a new directive on [work-life balance](#), which will include provision for leave from work for people caring for children or seriously ill relatives. ABC Global Alliance members are asking them to look at the working rights of cancer patients as well.

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Notes to editors:

[1] Current national estimates of cancer incidence, mortality, and prevalence, available from the WHO International Agency for Research on Cancer (IARC) ‘Cancer Today’ website (<http://gco.iarc.fr/>).

[2] The Advanced Breast Cancer Global Alliance is an initiative of the [European School of Oncology](#) and has members from around the world, including many in Europe who are represented by [Europa Donna](#) – the non-profit, independent European Breast Cancer Coalition – and in the USA by the [MBC Alliance](#). It aims to encourage the worldwide breast cancer community, policy-makers and the public to unite and work towards common, achievable goals in order to change the future for patients with ABC for whom, at present, no cure exists.

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“I was determined to keep working”: Lisa Mann’s story

“The Lisa who has come into my office today, will not be the same Lisa who leaves today.” These were the words of the breast cancer consultant to Lisa Mann when he told her she had been diagnosed with breast cancer. “He was right; cancer changes your life and I had no idea to what extent.”

Lisa was just 27 when she was diagnosed with stage III, HER2 positive breast cancer in 2007. There was no history of breast cancer in her family and she did not have mutations in the BRCA 1 / 2 genes, which can increase the risk of developing the disease.



“I didn’t notice any lump in particular, but my left breast just didn’t feel right, it felt lumpy. My GP thought it was probably just my hormones, but I asked a consultant, who was treating me for hyperprolactinaemia*, in case it was a side effect of the medication. He referred me to a breast consultant who wasn’t too worried either, but sent me for a biopsy. This was on a Friday. On Monday I was told I had breast cancer. It was a bit of a shock. I hadn’t been worried about it up to then as they had all been so blasé because of my age. It was all a bit of a whirlwind after that. I started chemotherapy on the Friday of the same week.”

Lisa, 38, lives in London, where she has a busy career as a senior strategy consultant for a large, international marketing agency. When she was first diagnosed with breast cancer she was working in marketing for an airline.

“I was determined to keep working,” she said. “I tried to work all the way through my treatments. I pretty much managed to do that through the chemotherapy and surgery, but radiotherapy was every day for five days a week for five weeks, so that was a bit more difficult and I had to dip in and out of work then.

“It was good to keep working. I love my job and I don’t want to be sitting at home thinking about my cancer. I’ve worked hard to get where I am and I had career ambitions. Work isn’t everything, but it’s really important and it’s part of who I am. I enjoy the social side of work too.”

Lisa had five months of chemotherapy, during which it was discovered that the cancer had spread to her sternum. In April 2008 she had a nipple-sparing mastectomy and breast reconstruction, and this was followed by a form of targeted radiotherapy called tomotherapy. She was also prescribed trastuzumab (Herceptin), tamoxifen and zoledronic acid. Her treatment was a success and a biopsy showed the cancer had been cleared from her sternum.

Since then Lisa has had a rollercoaster ride with the breast cancer returning in 2012, for which she had two rounds of chemotherapy and then, after changing consultants, was prescribed what was, at that time, a relatively new drug, T-DM1, that had been shown to be effective for patients whose cancer had progressed after treatment with trastuzumab. Lisa has had annual PET scans ever since her cancer diagnosis, and in 2015 a scan detected a small tumour in her brain. This was treated successfully with Cyberknife[®], a robotic radiation delivery system that delivers radiotherapy with pinpoint accuracy to kill the tumour.

However, Lisa started to have seizures and at the beginning of 2017, a scan showed the brain tumour had returned. She was due to have surgery in July to remove the tumour, but the day before her surgery she suffered a seizure caused by the tumour rubbing on the membrane around her brain, which led to a bleed in her brain. She was rushed to hospital and had emergency surgery but was left paralysed down her left side.

“Up to then I had managed to keep working, and I had been told this latest surgery would just be five days in hospital and a couple of weeks to recover. Actually, I was in hospital for two months, and I was really ill for the rest of the year as I kept getting sepsis and was in and out of hospital. The movement in my arm came back fairly quickly with intensive physiotherapy and determination in hospital, but my left leg has taken longer.”

Lisa had to move back into her parents’ house so they could look after her while she recovered. She returned to her own home in January 2018, but required carers to come in daily to help her; she has regular physiotherapy to rebuild her muscles and improve her walking.

Neither her employers nor her bank have made life particularly easy for Lisa. Her employers have been sympathetic but had little idea how to support her and gave her little guidance. Her bank, where she has had an account since she was 15 and with whom she has her mortgage, “were not interested in helping me one bit”. Lisa has been on half-pay for more than a year now and is struggling financially, but the bank is currently refusing to agree to a mortgage holiday.

“This has been so stressful for me and for my family,” said Lisa. “I wanted to work, but it was also a necessity so that I could pay my mortgage and live. I’m struggling financially: my outgoings are more than my income. I’ve had to borrow money from my parents. After my brain surgery I sold my car because I couldn’t drive, but because of my mobility problems I can’t use public transport, so I have to use Ubers whenever I go out to medical appointments, physiotherapy, the gym and so on. I am a really strong person, but it’s very stressful to deal with all this. To be worrying about money is an added stress on top of living with breast cancer and when I’m learning to walk again.

“In terms of managing my work, I knew I needed help, but didn’t know where to get it. Eventually I was put in contact with Barbara Wilson through a charity called Shine Cancer Support. Barbara knew what I was entitled to, so that I could advise my HR department about how they could help me.”

With Barbara's help, Lisa realised that she didn't need to rush straight back into work full time, and could have a phased return and flexible working practices that included working from home.

"Barbara helped me manage what I did with work so that I didn't kill myself working," concluded Lisa.

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Notes to editors:

** Hyperprolactinaemia is a condition in which there are abnormally high levels of a peptide hormone called prolactin in the blood.*

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Founding member of Europa Donna Cyprus puts her experience of breast cancer to good use

Evi Papadopoulou was 33 years old with a four-year-old daughter and a six-month-old son when she discovered a lump in her breast while having a shower; it was then confirmed as early stage breast cancer. She lives and works in Cyprus.



“In 1985 in Cyprus breast cancer was virtually not spoken of, cancer care was primitive and patients were referred to centres abroad. Having an oncologist friend practising in London was a life saver and we immediately flew to London for all the necessary tests and treatment, including radiotherapy.

Two years later I had a relapse and a mastectomy and breast reconstruction.

Five years later I had another relapse, and more radiotherapy and chemotherapy. The cancer has returned on several occasions and I have had surgery in Germany. For the last 12 years I have been treated at a modern cancer centre in Nicosia in Cyprus. During the past six years I have had bone metastases, and also, recently in the liver. At the moment I am being treated with chemotherapy.”

Evi is now aged 67, her children are married and she has two grandchildren. She has worked for her family juice and drinks business in Cyprus for more than 40 years as a board member and marketing director, having obtained a BSc in Economics at Brunel University, UK.

“I had already built a team with which I could communicate and although I needed some time away from work for treatment and recovery, I never stopped working even when I was abroad or in therapy. My mind needed to be kept busy. My parents looked after my family because I knew I could not have given them enough attention without their help. Apart from the physical weakness and the psychological upheaval that one goes through, I could not have managed by myself. At the time there was no supporting services or any patient groups.”

For 18 years, Evi has been a founding member of the Cyprus branch of Europa Donna – one of the 47 country members of the European Breast Cancer Coalition, which works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. She is president of Europa Donna for a year ending in December 2018 and has been a board member for five years.-She was co-chair at the ABC4 conference in Lisbon in November 2017 and was co-chair of the 2018 European Breast Cancer Conference, held in Barcelona, Spain, in March 2018.

“It is a compelling feeling to share and use my experience to help others once I had been through this experience. I had the opportunity to learn from many sources, I had good training, many

opportunities for education and advocacy, and I feel I must put it to good use. The results give me greater impetus to do more. Going through chemotherapy for the nth time in my position is not easy. But I keep a big smile, trying to give courage to others first and to diminish the effects of the therapy. There is a role to play here too, as in other parts of our lives!”

Evi believes that being able to continue working is of huge importance to women after a diagnosis of breast cancer.

“Our work defines us, we have our title, our role and our space. We have stability, a social status and we create friendships with colleagues at work. When we are out of work we lose this stability and our sense of self within this corporate environment. We lose our sense of belonging and our sense of responsibility and of working on useful and important matters. Keeping all of this while on treatment and afterwards means that a good part of your world is kept stable.

“It is important for a patient to stay visible, sociable and to keep a normal daily life, staying interested in things other than yourself. This gives a sense of continuity, it sets short and longer term goals. Self-image and self-confidence are important ingredients in retaining self-esteem through a period when the world around you is changing.”

Evi knows that breast cancer patients in many countries face significant challenges, both in accessing the best treatment and also supportive care. “Depending on which country you live in and its particular health system, the financial burden can have a serious impact on your finances. You might have to be taking care of the costs of treatment, as well as other costs such as help at home, travel and childcare, while also losing income. Europa Donna is working to improve conditions for breast cancer patients across Europe.”

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