

# Campaigners call for stronger rights to work for people living with breast cancer

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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.

"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, 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.

Provided by European School of Oncology

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