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Don't make cancer survivors pay twice—the right for them to be "forgotten" should be law everywhere

We need laws that empower cancer survivors to live without the stress of financial toxicity, say Mark Lawler and Françoise Meunier

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An estimated 20 million people in Europe are living after a cancer diagnosis.^{1,2} Improvements in cancer care over the past decade mean that there are now nearly 50% more cancer survivors in Europe than there were in 2010.² In many European countries, however, cancer survivors face substantial barriers that limit their ability to reintegrate into society and live productive lives.³ One of those barriers is financial.

Long term cancer survivors, who have essentially been “cured” of their disease, can still face punishing financial discrimination—including gaining access to mortgages, loans, and health and travel insurance—because of their previous cancer diagnosis.⁴ In many dealings with financial institutions, cancer survivors are required to declare a cancer diagnosis, even if they have lived beyond cancer for many years. Although patients with other non-communicable diseases can also face financial hardships, it is particularly frustrating for people who have been cancer free for many years. This situation must change: those living beyond cancer should not have to shoulder a previous diagnosis as an ongoing financial burden.

During treatment, patients with cancer often experience various forms of financial hardship: accumulating care costs, falling income, or, in some cases, even unemployment.³ Costs that are incurred after treatment—for example, travel to hospitals for follow-up care or rehabilitation with psychological support—may also prove challenging. For long term cancer survivors, this financial toxicity can be compounded by having to declare a previous cancer diagnosis when accessing financial services,⁴ which may compromise their ability to deal with past or future monetary burdens.

Anti-discriminatory laws

Thankfully, countries are tackling this discrimination. In 2016, France became the first country in the world to bring into law a provision for the “right to be forgotten” for people who’ve had cancer.^{5,6} This law meant that a long term cancer survivor—an adult who has been free of cancer for 10 years after diagnosis or a child who has been cancer free for five years post-diagnosis—was no longer required to share medical information with a financial institution about their cancer diagnosis, nor could this information be requested or used by an insurance company. This anti-discriminatory law empowers cancer survivors to live longer and more productive lives without the stress of financial toxicity.

Following France’s lead, five other European countries (Belgium, Luxembourg, the Netherlands, Portugal, and Romania)⁶ have also introduced legislation mandating the right to be forgotten for people who’ve survived cancer. In February 2022, France made its law even more supportive of cancer survivors, reducing the long term survivor definition to five years post-diagnosis.

A further three countries (Cyprus, Italy, and Ireland) are at different stages of adopting the right to be forgotten, through a variety of approaches. In Ireland, a survey by the Irish Cancer Society found that nearly a quarter of those who responded (including those affected by cancer, or who had a partner with a previous cancer diagnosis) indicated that they were unable to get a quote for financial products or services because of their previous cancer diagnosis.⁷ Additionally, almost half of the respondents had experienced difficulties in dealing with insurance companies.⁷ Galvanised by these findings, a campaign led by the Irish Cancer Society, and in which both of us participated, has led to the right to be forgotten being recognised as an issue that will be legislated on by the Cross Party Parliamentary Group on Cancer. Campaigners hope that a bill will be enshrined in law by 2023.

These right to be forgotten laws provide a legal framework that protects cancer survivors from financial discrimination and toxicity.⁸ A study has shown that this legal framework will have a minimal impact on insurers, but it will mean a great deal to patients.⁹ One of us (FM) has led the right to be forgotten initiative within the European Cancer Patient Coalition, which hopes to make this an enduring legal principle. And, encouragingly, the right to be forgotten is prioritised in Europe’s Beating Cancer Plan.⁸ But individual countries and governments must take up the cause too. We need to be much bolder on behalf of the 20 million Europeans who have already experienced considerable medical, psychological, and financial challenges in their survivorship journey. They shouldn’t have to pay twice for their diagnosis. With more and more people surviving cancer, the right to be forgotten must be transposed into law in every country in Europe, putting an end to this discrimination.

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