

# HOW RED TAPE ALMOST KILLED ME

**Deborah Sims** recounts how she had to beat red tape to beat cancer.

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**T**o be told you are suffering from terminal cancer is a traumatic experience in itself. Discovering that life-saving medicine is beyond your reach because of government red tape is devastating. Yet this is the reality facing so many cancer patients in

Australia, and I am one of them.

In August last year I moved to London in the hope of getting on a clinical trial that would potentially cure my leukaemia. This was the only way to guarantee access to a new drug producing remarkable results with little or no side effects.

And in a cruel case of irony, the drug was created in Melbourne.

Venetoclax has been described as a 'miracle treatment' and a 'magic bullet' for certain types of blood cancer. I can vouch for that. But it has come at a huge personal cost thanks to

Australian red tape, and if it weren't for the fact that I have a British passport, I wouldn't be here at all.

It was just before Christmas in 2011 that I was diagnosed with Chronic Lymphocytic Leukaemia (CLL), an incurable form of blood cancer that would kill me in about five years' time. My little daughter was sitting on my lap as the news was broken to me. I hugged her and thought: 'But she's only two'. I was 38.

CLL is rare in someone my age. Almost 80 per cent of all new cases are in people over the age of 60, and



the average patient is a 72-year-old man. It occurs more frequently in men than women, and very few are under the age of 40. The diagnosis came totally out of the blue. I mourned myself for two weeks and went into my shell.

I was in ‘watch and wait’ mode, so I launched my own in-depth research into CLL while continuing to work full-time. I’m a journalist and I needed information. I joined forums, subscribed to medical journals and was referred to a number of specialists for second opinions.

This included paying for a genetic test that is not the standard of care in early diagnosis. I wanted to know how bad my markers were, and I found out mine was the type of CLL you don’t want. It’s an insidious and clever cancer that relentlessly crowds the bone marrow and lymphatic system, becoming resistant to treatment. By October 2012, I was really sick and very tired. I couldn’t schedule afternoon meetings at work. In January 2013, I started chemotherapy.

Chemo is the standard treatment when patients become sick enough, and sometimes that’s enough to gain a long remission. I had no side effects apart from a sudden feeling of wellness.

Three months later I returned to ‘watch and wait’, with three-monthly bone marrow biopsies, but at six months it was clear the disease was slowly progressing. Most patients who relapse after chemotherapy as quickly as I did have less than two years to live.

My specialist talked about me getting ready to undergo a bone marrow transplant. I have a perfect match in my younger sister, so I knew it was a definite option. But the more you know about such transplants, the less you want one, and I’m always doing risk assessments to give myself the best chance of being here to care for my children.

By my next appointment, in December 2014, I was starting to feel sick again. Symptoms included bulging lymph nodes (so very unattractive), night sweats, weight loss and recurring infections – this is a cancer of the immune system after all. Pneumonia is the biggest killer. A transplant was earmarked for early 2015 and I had my hair cut short in preparation.

Before the transplant was scheduled I dipped into my superannuation fund in April 2015 to attend a patient conference in the US on CLL clinical trials. While there I had a consultation with Professor Thomas Kipps, an international expert on this type of cancer. ‘You should not have a transplant,’ he said. ‘We are on the verge of a cure. We just have to work out what the best drug is. You need something to buy yourself time.’

➤ **ULTIMATELY, I’M WAITING FOR A DRUG THAT IS ALREADY REGULATED IN ONE OF THE LARGEST ECONOMIES IN THE WORLD TO BE REREGULATED HERE.**

The next day by sheer chance, one of the guest speakers, Dr John Gribben from the UK, sat next to me. As we struck up a conversation, he told me about a clinical trial in London that he believed would be the best possible treatment for me at this stage. It was trialling Venetoclax, developed in Melbourne. The irony wasn’t lost on either of us.

I returned from America thinking it would be ridiculous to travel 17 thousand kilometres to get a drug that came from my home town. But that’s when I came face to face with the reality confronting many cancer patients in Australia—



■ The author with Tony Abbott

the life or death battle through a complex maze of red tape.

This isn’t about risk aversion or rules that are in place for good reasons, such as restricting access to new medicines that are still under investigation. I’m talking about a needless burden of regulations blocking innovation and keeping Australia two years behind countries like Britain and the US. Cancer patients have to deal with layers of bureaucracy, not just at the federal level, but within each state. Hospitals and research centres are not immune, with unique rules at each facility and a frustrating clipboard mentality.

This confusing and complicated barrier forces people to go to great lengths to gain access to life-saving medicines, from fundraising to media campaigns to going overseas to join clinical trials. Some have to sell all of their assets. For many ill Australians, if they fail to beat bureaucracy, they die—killed in effect, not by cancer, but by toxic red tape. It’s a nightmarish absurdity worthy of Kafka.

Kafka’s book *The Castle* contains the scenario. A man tries again and again to overcome bureaucracy



■ St Bartholomew's Hospital, London

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blocking his entry to the Castle, and therefore his salvation. The inevitable outcome is that he dies before being granted access. It's a fate familiar to families of cancer patients.

The only chance I had of gaining access to Venetoclax in Australia was through a randomised trial. That meant a 50-50 shot at getting either the new drug or chemotherapy. I'd already had chemo so I couldn't take that gamble. I asked one of my Melbourne specialists what he would do if he were me and he answered: 'I'd get on a plane to London.'

It knocked me that the best treatment was on the other side of the world, but I used my super again to go to the UK, even though there was no guarantee I'd get on the trial. I had to be sick enough to qualify and well enough to tolerate phase one protocols. I also had to find a job in London (where I'd previously lived for 10 years) and get a National Health Service number before gaining a referral to St Bartholomew's Hospital, known affectionately to Londoners as Barts. And, of course, there was a lot of paperwork.

There were only 40 places in the world for this trial—two at Barts and none in Australia—which was very frustrating. According to my risk assessment, this could buy me a long remission and possibly a cure. I went back to work at the BBC as a freelance reporter, started writing a blog and waited. When I heard the news that I was accepted for treatment I was so excited, it felt like I'd won the lottery. Altogether, I was away from Australia for seven months.

The good news though was that I suffered no side effects and a CT scan in February showed I was in partial remission. Since my return to Melbourne my blood work has got better and better. Now I'm back to working and going out, with my life ahead of me again. In April I got the fantastic news that I was in complete remission and in the very near future I'm hoping to have no detectable disease (molecular remission).

I'm loath to come off the drug, but because I can't have Venetoclax dispensed in Australia, I have had to travel to London every three weeks. It's part of a treatment odyssey that has cost me \$500,000 in lost income, flights, accommodation and living expenses—so far. And all this is so

I can receive an Australian-created drug that is available to me in Britain, but not here, and has been approved in America, but not here. This cruel absurdity puts life-saving drugs out of reach and must be dealt with. Ultimately, I'm waiting for a drug that is already regulated in one of the largest economies in the world to be reregulated here.

The Australian Government has made a commitment to ensure new medicines are made available. Last month it confirmed plans to overhaul the rigorous regulatory approach and fast track the process to slash the waiting time for patients. Reform can't come soon enough.

Australia must cut the tangle of red tape impeding breakthrough treatments and clinical trials by introducing a new national framework. For even though we have a global reputation for great research scientists and specialists, the burden of regulations makes us less competitive for clinical trial investment compared to other regions, such as Asia.

The medical system here must get up to speed and adapt to the rapidly evolving world of anti-cancer therapy. If I didn't have dual nationality, I wouldn't be alive. 