



A portrait of Adrienne Cullen at her home in Voorschoten in the Netherlands.
PHOTOGRAPH: JUDITH JOCKEL

‘I am privileged to still be here to read this book’

Reading Adrienne Cullen's terrifying account of a cervical-cancer misdiagnosis in the Netherlands, campaigner Vicky Phelan finds strong parallels to her own story and those of others behind Ireland's CervicalCheck scandal

Vicky Phelan

Deny, Dismiss, Dehumanise: What Happened When I Went to Hospital
By Adrienne Cullen

Uitgeverij van Brug, 322pp, £19.99

Adrienne Cullen is known to many here in Ireland as another “poor woman” who died as a result of a cervical cancer misdiagnosis. For that reason, her name is often mentioned in the same breath as those of Emma Mhic Mhathúna and Irene Teap, both of whom have died since 2017. Emma and Irene were two of the 221 women affected by the CervicalCheck debacle. What was different about Adrienne was that she was misdiagnosed in another country, the Netherlands. What all three had in common was that they refused to be labelled as victims. In that sense, we were 221+1.

Adrienne discovered she had cervical cancer in June 2013 when a cancer-positive result that had lain “lost” in Utrecht university hospital for two years was suddenly “found”. She rapidly realised that apart from the hospital’s lawyers and some of its gynaecology team, nobody else knew that her cancer diagnosis had gone missing: not the patient safety officer, not

the chief executive, not the board. Not alone that, but it was nobody’s job to offer help to patients damaged by the hospital. International protocols that tell hospital staff how to handle such disasters had never been adopted in the Netherlands.

Six years later, due solely to Adrienne’s fighting spirit, they are now in place. Adrienne was so shocked by what had happened, and by the indifference even afterwards, that she felt compelled – especially as a writer and editor – to set everything down on paper. It is the power of those carefully accumulated facts that I found most shocking. She sums up the attitude of the hospital in what she calls her “three Ds”, which she uses to such effect in the title: Deny, Dismiss, Dehumanise: What Happened When I Went to Hospital. It is chilling that three such words can seem so totally appropriate when used to describe the ethos of a cutting-edge university hospital in an EU country in the 21st century.

Adrienne’s sense of mission did find allies in the hospital whose negligence led to her death last New Year’s Eve. To the embarrassment of the board, her campaign for change was joined by two of her doctors, Prof Arie Franx, divisional head of gynaecology, and Prof Huub van der Vaart, the consultant who never received her missing cancer diagnosis. Franx writes a preface to the book and van der Vaart contributes a poignant afterword. Franx hits the nail on

the head: “Adrienne tells a story that is about much more than human error by doctors. It . . . uncovers the systemic and cultural issues that allow health providers to fail their patients.”

Asked if I would review Adrienne’s book, I immediately said yes. I was honoured. I felt we were kindred spirits. I’d read an article by Adrienne in The Irish Times just days before my own court case exposed the failures in Ireland’s cervical screening programme. However, I had to wait until my case settled before making contact.

Adrienne wrote about the parallels between us: “Like Vicky, my life could have,



Adrienne felt that if hospitals could change the way they responded when patients were harmed, her death might not have been totally in vain

should have, been saved – except we were both let down in the worst possible way by the very people we trusted to keep us safe.” We communicated by email and on Twitter sporadically throughout 2018. I was delighted to see her awarded an honorary doctorate by her alma mater, UCC, just weeks before she passed away.

Personally, what I had not counted on when sitting down with Adrienne’s terrifying book was the huge emotional impact it would have on me. It was very difficult to read about her declining health given that I am eventually going to meet the very same fate. Adrienne’s accounts of her multiple stays in hospital and her descriptions of the pain and suffering each time were extremely upsetting. I had to take breaks from it for days at a time after reading about each hospital admission.

Yet for all that, this is a medical page-turner and I read on. I wanted to honour her memory by writing this review, for one simple reason: I know I am privileged to still be here to read this book.

One of the most disturbing aspects of the story is the way Adrienne was constantly belittled by hospital staff for not being able to speak Dutch. At a time when a patient is at her most vulnerable, it is incredible that professionals could behave with so little humanity. Early on, Adrienne is rushed to hospital by ambulance with urosepsis, a life-threatening condition, and writes: “I

remember trying to explain to the paramedic that I didn’t want to go to hospital because people would give me a hard time for not speaking Dutch.” One of the paramedics put his hand on Adrienne’s shoulder and told her, “I heard what you were saying about people who don’t like that you don’t speak Dutch. I know it happens.” In the teeth of the evidence, however, management always insisted: “It never happens here.”

Also, as someone with first-hand experience of non-disclosure agreements (NDAs), more commonly known as “gagging clauses”, I could fully empathise with Adrienne’s account of how it feels to be terminally ill – and then to be offered money in exchange for silence. While Adrienne rejected four iterations of the same gagging clause, another medical controversy hit the Dutch headlines, placing the clauses in an even more intense spotlight. The health minister considered banning them, saying they had “no place in agreements between hospitals and their patients” and asking anyone who’d been affected to come forward.

Needless to say, Adrienne took up her offer and shone a typically uncompromising light on this despicable practice. No wonder she felt she was in a John Grisham novel.

After Adrienne’s death, her tireless campaigning for an EU-wide ban on NDAs was acknowledged by prime minister Mark Rutte and by the Dutch national broadcaster, NOS. King Willem-Alexander spoke of her “altruism” and “dignity” when he met her widower, Peter Cluskey, in Dublin in June.

The importance of a sincere apology after medical negligence and medical error should never be underestimated. As we know from the CervicalCheck debacle, Dr Gabriel Scally has reiterated time and again that women “would really like someone to say sorry, and someone who means it to say sorry”. Unfortunately, more than a year later, we are still waiting on a sincere apology from someone who truly means it. In Adrienne’s case, both doctors, van der Vaart and Franx, apologised to her, “turning opponents into allies”. The hospital’s chief executive, Prof Margriet Schneider, also apologised in writing – the first such apology ever issued in the Netherlands.

For me, the most striking aspect of this book is the unprecedented alliance between Adrienne and her doctors. Showing that this can be done is Adrienne’s legacy. Stipulated in her legal settlement was that UMC Utrecht would hold an annual lecture on “open disclosure after harm” named after her. Adrienne felt that if hospitals could change the way they responded when patients were harmed, her death might not have been totally in vain. The inaugural Adrienne Cullen Lecture took place on April 13th, 2018, with Adrienne, Franx and van der Vaart all speaking some painful truths. Franx writes that Adrienne was adamant about one thing: “Patients are the co-owners of the healthcare system and the partners of the medical professionals entrusted to run it. Without acknowledging this and acting in a manner which makes that partnership real and meaningful, we will never succeed in improving the services on which countless people . . . depend.”

Adrienne is right. Those are words to live by.

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