Deny, dismiss, dehumanise

MINISTER-PRESIDENT

Mr P. Cluskey
Veurseweg 20
2252 AG VOORSCHOTEN

Binnenhof 19
2513 AA Den Haag
Postbus 20001
2500 EA Den Haag
www.rijksoverheid.nl

T 070 356 44 50

Our reference
4046221

Date 31 January 2019

Dear Mr Cluskey,

Let me begin by expressing my sincere condolences on the death of your wife. I can scarcely imagine what you and Adrienne went through in recent years.

I have great respect for Adrienne's tireless efforts to achieve official acknowledgement and increase transparency in cases of medical errors. I am also terribly sorry that you feel you and your wife did not receive the support to which you were entitled from the organisations involved. I can fully understand your desire to draw attention to this situation.

In your letter to me, you enclosed the letter that you sent to the Ministry of Health, Welfare and Sport. It has been agreed with that ministry that you will receive a detailed response from, or on behalf of, the Minister for Medical Care as soon as possible.

What happened to your wife is indescribably tragic, and I wish that circumstances were otherwise. May you find the strength to cope with this immense loss.

Yours sincerely,

Prime Minister of the Netherlands,

Mark Rutte

Adrienne Cullen

DENY, DISMISS, DEHUMANISE

What happened when I went to hospital

Index

The Scale of the Problem

23% of EU citizens claim to have been directly affected by medical error. Strategies to reduce the rate of adverse events would lead to the prevention each year of more than

- *750,000 harm-inflicting medical errors*
- *3.2 million days of hospitalization*
- *260,000 incidents of permanent disability*
- 95,000 deaths

WHO[1]

In 2003, I became involved in setting up the patient safety programme within the UMC Utrecht. We started from scratch – the Dutch word for patient safety at that time literally did not exist.
Ian Leistikow[2]

"Medical error – the third leading cause of death in the US"
BMJ, 2016[3]

---

[1] A World Health Organization report from Regional Office for Europe.

[2] Ian Leistikow was co-ordinator of UMC Utrecht's patient safety programme from 2003 to 2011. He is now a senior inspector at the Dutch Healthcare Inspectorate. Quote is fromLeistikow, I. (2017) Prevention is better than Cure: Learning from Adverse Events in Healthcare. CRC Press: Boca Raton, Florida.

[3] *British Medical Journal*. (May 2016) A report by Martin Makary and Michael Daniel, Department of Surgery at Johns Hopkins University School of Medicine.

Preface to Adrienne Cullen's book

You are about to read an extraordinary story …

Adrienne Cullen's cancer diagnosis was delayed for two years when a pathology test result went "missing" in 2011 in the hospital where she was being treated, UMC (University Medical Centre) Utrecht. This delay allowed Adrienne's cancer to advance undetected to the stage where it became incurable, meaning that Adrienne would die unnecessarily as a result of that missed diagnosis. This was inescapable. To make matters even worse, if that were possible, her hospital fell severely short in giving her appropriate support after the medical negligence was discovered. For a long time, there was no apology despite the scale of the negligence, and, despite multiple requests to the hospital's board, no investigation into what had caused it.

After a considerable battle, Adrienne and her husband, Peter, received financial compensation that was unprecedented in the Netherlands (though small in comparison with many other EU countries, including Ireland and the UK). However, communication between the hospital and the patient it had harmed was now through their lawyers only. Her doctor tried to maintain contact and ensure there was adequate follow-up care, but he himself was, in effect, also a victim of the hospital's inadequate systems and traumatized by what had happened. He received very little support from his peers. That is perhaps because of the culture in medicine: doctors see themselves as people who provide care, and all too often find it difficult to ask for care and support themselves.

I was, at that time, one of the medical managers in this hospital and belonged to the leadership of the department that Adrienne had trusted to treat her. Only when I met Adrienne and her husband for the first time, 16 months after the discovery of the missed diagnosis, did I realize that we had failed spectacularly to provide the care that was needed by both Adrienne and her doctor when the hospital system failed them both. After 25 years in clinical practice, I finally understood the true meaning of the term 'a just culture' after medical error, and saw first-hand why it is so essential – to both patients and doctors.

Medical error occurs, unfortunately. But Adrienne tells a story that is about much more than human error by doctors. It goes further and uncovers the systemic and cultural issues that allow health providers to fail their patients. Adrienne's perseverance in excavating these complex multi-faceted issues was clear-eyed, quite exceptional, and very courageous. Not many people could have achieved it. In spite of being very ill and a foreigner here in the Netherlands, Adrienne fought for years to get the care she was entitled to, and kept pointing out the many lessons to be learnt from her story, not just by doctors and hospitals, but by patients themselves, by healthcare regulators, and by legislators. She died at Antoni van Leeuwenhoek hospital in Amsterdam on December 31, 2018, but those hard-won lessons live on here in the pages of this book, completed just two days before she passed away.

Adrienne was adamant about one thing in particular, and having been part of her tragic story, I agree with her totally: 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, will we never succeed in improving the services on which countless people – our families, our friends and our fellow citizens – depend every day. In an era when we strive constantly for value and frequently speak about patient-centered healthcare in that context, we need to think again about what we actually mean. As doctors, we must empower patients, use our skills to explain, counsel and recommend, ask what they need, and then listen to them. Adrienne contributes enormously to this notion by telling her own story in such detailed and uncompromising terms. Although she is gone, her words will continue to create a new awareness.

Adrienne has forgiven and, remarkably, sometimes even protected, the doctors who treated her at UMC Utrecht and who subsequently apologized to her. In the following pages she shows huge generosity of spirit, respect for human rights, and belief in her own core values of empathy, compassion and honesty. To quote the 18th century English poet, Alexander Pope, "To err is human, to forgive divine". Perhaps that is the most compelling aspect of Adrienne Cullen's terrible story: her extraordinary capacity for forgiveness and her belief that, in the end, it is forgiveness and not conflict that breaks down barriers and leads to lasting change.

Arie Franx
Utrecht, January 2019

1 | June 2013 … UMC, Utrecht

It is much easier patiently – and tolerantly – to avoid the person you have injured than to approach him as a friend.
You need courage for that.
Ludwig Wittgenstein

I knew something was wrong the moment I saw the doctor arrive. I could tell by the half-smile he gave without true eye-contact, by his tentative body language as each of us stood back to allow the other enter the consulting room first – a hesitancy that had us both colliding idiotically with a pot plant strangely placed right outside the door. I knew this man well, and I knew with certainty what was about to happen next. But when he said "I have bad news", I still flinched and looked away to the other side of the room asking, "How bad is it?"

The answer was that it was very bad. A cone biopsy performed a few weeks previously on my cervix had contained a one-centimetre chunk of an adenocarcinoma. Worse still, the margins weren't clean. That meant that while the biopsy had removed some of the tumour, the rest of it was still inside me. I had cancer, and I had had it for a long time.

Let’s roll back a little to two years earlier, May 2011. I was in the same room. I was with the same doctor, Huub van der Vaart. I knew him quite well as we had been trying to figure out for nearly a year why I had a strange vaginal discharge. Tests had been carried out, but no answers had emerged. So in that consulting room in the gynaecology department of the University Medical Centre in Utrecht in the Netherlands, I was told, gently but insistently, that my vaginal discharge was “idiosyncratic”, that all the tests showed nothing abnormal, nothing worrying. I was told that whatever was causing the discharge, it was not gynaecological in origin. The doctor and the department could do nothing further to help me. And so I went away and tried to learn to live with it. That’s what patients with “idiosyncratic” symptoms do.

But something had been forgotten. Something had been overlooked. Something was sitting in my file unseen by my doctor that day in May 2011 – something that had not been flagged by UMC Utrecht pathologists. That something shouted loud and clear that I had cervical cancer.

A sample of my cervical tissue had been taken a month earlier, on 13 April 2011, while I was under general anaesthetic for cryosurgery, a small, unrelated gynaecological procedure. I didn’t know this tissue sample had been taken and sent to the lab – so I didn’t ask about it when I saw the doctor in May. And because the taking of this sample was secondary to the procedure being done that day, he didn’t remember he had carried out this curettage (scraping of the lining of the cervix) and had sent some of the tissue to the lab. And so he didn’t notice when he received no notification about it from pathology. As a result, the test result that shouted loud and clear that I had cervical cancer remained unheard and unseen. And it stayed that way for two years.

Back to 2013 again, 3 April, almost two years after the cancer-positive result slipped into my file unseen by everyone, a research student came across it. He saw result indicating suspected adenocarcinoma … but no mention of follow-up. He was puzzled. Why had nothing been done? He brought it to the attention of Van der Vaart.

Let's just imagine for a minute what that feels like. You're a kind doctor. You've always cared for your patients and always treated them with respect. You're hard-working, you're good at your job, and you're dedicated. You're at the top of your field of specialization – in fact, you made professor last year. You're liked and held in high esteem by your colleagues, your students and your patients. You're a good physician. And then you see that your patient – you remember her well – has a two-year-old cancer warning in her file. You ordered that test, you never saw that result, and now some research fellow is standing in front of you. Can you feel the blood draining from your face and the sweat starting to prickle cold around your hairline? Can you feel the urge to sit down quickly because you're afraid your legs are going to stop holding you up? Can you hear the voice saying, "This can't be happening", but knowing it is? What do you do?

Professor Van der Vaart did the right thing. On 3 April, 2013, he phoned me. In my ignorance, I didn't fully grasp what he was telling me and thought it was simply a routine follow-up from the cryosurgery two years earlier. He asked me if I still had the vaginal discharge. Of course I had. He asked to see me at my earliest convenience. I still didn't really get it – not on that day.

Van der Vaart did the next thing right too. A few days after the discovery, he knocked on the door of his line manager, Professor Bart Fauser. He told him what had happened, that a cancer diagnosis had appeared in a patient's file in April 2011 without him ever having seen it or signing off on it and it had only been brought to his attention, almost two years later. Van der Vaart speculated that the transition from paper-based patient files to electronic files that had been taking place at the time might have been responsible. Fauser looked up from his research just long enough to tell him to inform the hospital lawyers. That was the extent of the peer support, counselling and human concern my doctor received from his bosses at UMCU. And it was pretty much on a par with the support, understanding and humanity they showed to me and my devastated husband, Peter.

Better late than never, I underwent various tests to try to put together a picture of what had been happening inside my cervix. The worst fears, shared by Peter, Van der Vaart and myself, turned out to be true. I had a chunky, barrel-shaped adenocarcinoma measuring some 4.7 centimetres long and about three centimetres in diameter. On 13 June 2013, I was diagnosed with cervical cancer.

Strangely, I could come to terms with this. Although it was deadly serious, I was coping, after a fashion. And so was Peter. But what neither of us could come to terms with was the way I was being treated by UMCU. To me, it was central to my treatment that everybody who came into contact with me should know what had happened. They needed to understand why I felt betrayed, terrified, alienated and confused. I had become a hypervigilant patient, watching what was happening to me at every moment, querying every decision. I was traumatized by events, and the fact that I spoke no Dutch was making the alienation unbearable.

But healthcare workers, professional doctors and nurses, would be able to understand this, right? Apparently not. They neither understood nor saw why there was any need to understand. Van der Vaart was no longer in charge of my care. He wasn’t an oncologist, so he had no further role in looking after me. I was almost as devastated by what had happened to him as by what had happened to me, and it was a further distress for me that I had no way of knowing how he was coping. To my mind, he too had become a patient. Paradoxically, although he was the person at the centre of the terrible fiasco that had caused two years to pass before I was given any cancer treatment, he was the only person in the hospital I trusted.

My new doctor, Dr Brouwer, a gynaecological oncologist at UMCU knew what had happened, but didn't see any particular need to address it, beyond an initial acknowledgement that he was aware of it. Nor did he see any need to take it into consideration during my ongoing treatment. Both he and the department's other gynaecological oncologist were adamant that the vaginal discharge I had had when I was sent away from the hospital in 2011 had nothing whatsoever to do with cervical cancer. "It's not a symptom", they declared.

My tumour was too big to be removed by robotic surgery – UMCU's preferred method for dealing with early cervical cancers. So the protocol dictated radiotherapy with adjuvant chemotherapy. I was asked if I'd take part in a Europe-wide clinical trial in which half the patients with my stage of the disease underwent surgery after their radiotherapy and chemo. I wanted to know which was better – to have surgery afterwards or not, or indeed if conventional surgery on its own would be better, or surgery and then radio-chemo. I was told it didn't work that way. I had to choose whether to go on the clinical trial or not and then it was the luck of the draw whether I'd be in the surgery group or not after my radio-chemo, and if I wasn't, they wouldn't operate. I didn't want to be experimented on. I wanted to know which was the best option for me and to have that option made available. Peter agreed with me. The doctors apparently didn't see it that way. The conversation went nowhere. I asked for something to help me sleep as I hadn't slept since I was first given the diagnosis the previous week. I was asked why I couldn't sleep. I thought the reason was obvious.

At the MRI suite, I joined the queue with all the other patients. I was reprimanded for not alerting them in advance that it was difficult to insert a cannula in my veins. I had apparently delayed their morning's schedule because they needed to call an anaesthetist to insert a cannula for the contrast dye. Stupidly, I apologized and said I'd remember to tell them in future. No one there knew or cared that UMCU had made a serious error that would ultimately cost me my life. I was just another patient getting in the way of an otherwise smooth-running system.

In the operating theatre, where I had to have a gynaecological examination under anaesthetic, a well-meaning staff member asked me why I was there. I told her I had cervical cancer. She replied, "Never mind. I'm sure they have caught it very early". I burst into uncontrollable tears. I wanted to scream, "No! This hospital lost my cancer diagnosis for two years and there's a good chance I'm going to die!" But I said nothing. The woman had intended to be kind. I just cried and cried and no one had any idea why. No one knew I was a victim of medical negligence at their hospital. The anaesthetist didn't know either. "Think of something nice", he encouraged. That made me cry even more. He didn't have time for this unreasonable display of emotion, so he just knocked me out anyway. Where was my doctor during all this? Who was there to support this totally traumatized patient? No one. The fact that I was the victim of medical negligence at UMCU wasn't known. No one told any of the staff who were looking after me in the theatre, post-operatively or in the wards what had happened. So they must have decided it wasn't relevant.

When I came around from the anaesthetic, I was still crying. I was very distressed and shivering uncontrollably. The nurse looking after me kept saying, "Stop shivering. I can't get proper readings because you keep shivering". So she didn't know anything either. She was just looking after an emotional foreign patient who was causing a fuss for some reason.

I remembered TV ads about MacMillan Nurses who specialized in supporting cancer patients, so we asked in UMCU about an equivalent service here in the Netherlands. We were told there was nothing like that here. So we asked for a psychologist in the hospital who specialized in looking after patients who had just had a cancer diagnosis. Again, we were told, "No, there are no cancer-specialist psychologists in the hospital and we are unaware of any such speciality anywhere in the country."

We were puzzled, hurt and disbelieving that there was no specialist help on offer for me. Why was UMCU not stepping in to help? Everyone was treating me as though nothing unusual had happened, and I needed to just get on with it and stop making a fuss. We asked about making a complaint. We were given a brochure in Dutch about the hospital complaints procedure and a form to fill in. For us, the situation had gone way beyond filling in a complaints form.

We discovered later, much later, that apart from Fauser, the hospital lawyers and a few members of the gynaecology team, no one in the hospital knew that they had lost my cancer diagnosis, not the patient safety officer, not the hospital board and not the CEO, Professor Jan Kimpen – and it was nobody's job to offer help to patients damaged by hospital errors and medical negligence. "Second harm" was a concept they had apparently never heard of. UMCU had no policies for dealing with the consequences that medical errors and negligence have for patients and their families. The hospital had no "sentinel events" policy that included any form of specialized care for patients, for their families or for the physicians involved. Apart from Van der Vaart, who was devastated, no one at the hospital apologized to me. It never occurred to them that this would be the appropriate thing to do. There wasn't even enough common decency or compassion at UMCU to realize that they should have been actively helping us, not looking at my tears with incomprehension and tight-lipped disapproval.

Van der Vaart asked a particularly kind and able nurse, Claire, to look after me when I was at the hospital – and without her kindness, Peter and I would have been in a very bad place. But Van der Vaart and Claire were the only ones helping us. It wasn't enough. We spoke to Van der Vaart twice in the days after the cancer diagnosis to see if we could learn more about what had happened. He told us again that he believed that somehow the transition to electronic patient files had caused the test results to slip into my file without him seeing them. But this was only speculation on his part. He had no answer as to why the pathologist had not contacted him directly by phone to notify him that his patient had a suspected cancer, especially since the finding was so much at odds with the procedure being performed by him in theatre that day. It was an unexpected finding that he would have expected the pathologist to have flagged. But that didn't happen. And no one from hospital management was stepping forward to explain. We were so sure that an investigation was being carried out that we didn't even question it. We were waiting for those investigating the errors to talk to us.

Each time we went to UMCU, we expected someone to find us and say, "We heard what happened to you at our hospital and we'd just like to say how sorry we are and to assure you that we are doing everything in our power to find out what went wrong". We also expected them to say, "We realize that getting a cancer diagnosis in these circumstances is doubly traumatic for you both. What we can do to make this easier? We want you to know we are here for you". But no one said any of those things. In fact, UMCU had absolutely nothing whatsoever to say to a patient who now had a potentially terminal cancer as a result of their negligence.

So we went to a lawyer, and there we found compassion. She asked UMCU's legal department to report the incident to the Dutch health inspectorate (IGZ).[4] They declined on the grounds that whatever had happened had occurred two years ago, so in their opinion, it was too long ago for the inspectorate to be interested in it. And anyway, the specific circumstances of what

---

[4] IGZ stands for Inspectie voor de Gezondheidszorg. Since 2017, it has become known as the Inspectie voor de Gezondheidszorg en Jeugd (IGJ).

happened to me would not be repeated because they did things differently now. So UMCU's lawyers told no one. We were also assured that there had been no similar incidents involving other patients as UMCU moved from paper-based files to electronic files.

Our lawyer encouraged us to ask for a second opinion – fast.

2 | July 2013 … AMC, Amsterdam

There should be no discrimination against languages people speak, skin colour, or religion.
Malala Yousefzai

Dr Ko van der Velden at the Academic Medical Centre (AMC) in Amsterdam was a breath of fresh air. This unpretentious man disarmed me with his common-sense kindness and insight. And he had read my file. That might sound obvious, but I have discovered over the past five years, in almost every hospital I have visited, no one reads the patient's file. No one knows the patient's history. It was clear to me after talking to Dr Van der Velden for five minutes that he was "my man". Whatever it took, this was the doctor I wanted to be sitting across from as I went on the cancer journey. He spent the first ten minutes of our meeting recounting my own story to me in English tinged with an Australian accent. He had worked in Sydney for a while in the 1990s during his training and some of the Aussie tones had stuck. Listening to him tell my story to me was both shocking (because it externalized the harsh facts) and reassuring (because it was a comfort to see that someone understood the catastrophe that had befallen me). Not given to commenting on the mistakes of others, he nevertheless found the details of my story hard to fathom. On the matter of my vaginal discharge, which UMC Utrecht had been adamant was “not a symptom of cervical cancer”, Van der Velden merely observed, “Oh, I think it is. Don’t you?” And he was correct. Staining tests carried out on the tumour later revealed that my adenocarcinoma was mucinous, and a vaginal discharge such as I had was indeed a symptom. But I’m getting ahead of myself a bit here.

After what had happened to me in Utrecht, it was going to be very unlikely that I would ever again trust another doctor or another hospital. In fact, it seemed to me then – and I still believe this – to be a dereliction of my duty to myself ever again to place my fate blindly in the hands of others. But I couldn’t treat myself. I needed the help of doctors, nurses and hospitals. So in so far as I was ever going to trust another doctor again, I decided to trust Van der Velden. That afternoon, I asked him if he would agree to take me as a patient, and by close of business I had informed UMCU that I would not be back. Within days, I was booked in for a gynaecological examination under anaesthetic. Afterwards Van der Velden told me that he and the radiologist who performed the examination with him had reached a different conclusion from UMCU about my cancer staging, and so about my treatment options.

The new plan was to operate to remove the tumour. This would entail a Wertheim Okabayashi radical hysterectomy. Anyone interested in the gory details, feel free to Google it, but all you really need to know was that the cervix, the uterus, lots of lymph nodes and as much of the surrounding tissue as the surgeons dared to take would be removed. One of the big downsides was that it was hard to perform this operation without damaging at least some of the nerves to the bladder. I might wake up from the surgery not able to empty my bladder normally, and whether this would be permanent or temporary, only time would tell. But the major advantage was that I had about a 50/50 chance of needing no further treatment – so no radiotherapy and no chemo.

I was admitted to the gynaecology ward of AMC on 22 July 2013 for surgery the following day. The nurse who admitted me was very "curious" that I was living and working in the Netherlands and didn't speak Dutch. "But you are planning to learn, right? If you're living here, you should speak Dutch", she admonished. "The law says you must." Idiotically, I tried to justify myself. My explanations about working for an international company where English was the common language sounded lame, as did excuses that a long daily commute and working 40-hours-a-week in a dynamic new job while trying to deal with an undiagnosed cancer left little energy for anything except sleep. But I was getting nowhere. This nurse made it clear that trying to live in the Netherlands without speaking Dutch was, in her opinion, bad-mannered and impractical. She told me that I could get a better job if I spoke Dutch, that staff were not allowed to treat patients in any language except Dutch, and that it was not fair to expect staff to have the same empathy with patients who didn't speak their language. I felt very unwelcome, but tried my best not to let this nurse upset me. Curiously, I don't think she had any idea that she was being unkind. She thought she was helping me by setting me straight. She knew what was best for me. I fought back the tears and waited for someone else to come on shift.

The surgery went well. The tumour was gone, as were my uterus, cervix and 36 lymph nodes. It was too soon yet to tell if my bladder was still functioning.

The day after surgery, I started to feel itchy all over and very unwell. Sensitivity to one of the painkillers was suspected, and I was wheeled back to post-operative recovery to have the offending drug stopped. They gave me OxyContin instead. That made matters worse. For the next 12 hours, I was on the scariest of “bad trips” – hallucinations, feelings of dread and terror, heart racing, dry mouth, inability to sleep or even remotely relax. Luke was the nurse on shift that night. He explained to me what was happening. He told me how long it was likely to last. He held my hand. Somehow, knowing what was happening and that it would end by the following morning made it more manageable. I could bear it, even though some of the hallucinations were overwhelming, repulsive and very dark.

I had been aware that I was sensitive to the benzodiazepine family of drugs (tranquilizers such as diazepam and temazepam) after suffering an extreme paradoxical reaction to midazolam a few years earlier. Now it was starting to look as though I was sensitive to some painkillers too. Luke checked on me regularly to make sure I was alright and to reassure me it would eventually stop. I started to tell him what had happened to me in UMCU. Actually, I had assumed he already knew. I thought everyone knew. I was still a “hospital innocent” at that stage and believed that important information about patients was communicated from department to department with the patient’s file and from shift to shift. I thought it was in some obvious place in my file – the first thing anyone looking at it would see. But even in my OxyContin-induced horror, I realized that Luke knew nothing of my background. Neither he nor any of the staff looking after me had any idea that my cancer was as advanced as it was because of serious medical negligence at another hospital.

Over the years, Peter and I have told many people in several hospitals about my medical background and the proven negligence at UMCU. In every instance, the person we told has agreed that it is vital for nurses and doctors to have this information in order to understand fully how best to care for me. But in every instance, the only way they have ever found out was if Peter or I told them. On that night, Luke listened patiently and with full understanding of the impact this must have had on me as a patient. He is a good nurse and a good listener, but it is not easy to tell my story to strangers.

As promised, the OxyContin worked its way out of my system shortly after sunrise and I started to doze. Nurses came and went. I was cleaned up and, feeling more comfortable, I started to relax.

Mid-morning, the door to my room opened and a woman came in. She started speaking to me. I caught that her name was Anoeska (the same name as one of my friends) and that she was a physiotherapist. I held out my hand to her and said, "I'm Adrienne, and I'm very sorry, Anoeska, but I don't speak Dutch". She drew back from me, put her hands on her hips and shouted at me, "Why don't you speak Dutch? You *live* in the Netherlands!"

I asked her to stop shouting at me and said I couldn't believe that she had just said that to a patient in a hospital bed. She shouted back that she wasn't shouting at me. I put my head in my hands and asked her to leave.

"Do you want pelvic physiotherapy or not?" she demanded.

"Just leave me alone."

"Whatever you want", she said as she flounced out the door. She wrote in the ward's day book that the patient had "refused treatment". But, of course, she didn't say why.

Some time later, a kind nurse, Anna, came in to see how I was. She didn't say anything about my morning visitor, so I told her that a very unpleasant woman had been in earlier. A physiotherapist.

"She shouted at me because I can't speak Dutch", I told Anna.

"I heard", she replied.

I thought she meant she had heard her shouting at me, but all she meant was that she had heard that the physiotherapist had been turned away by me and that I had refused treatment. No one had asked her why. And to this day, although I have told numerous people at AMC what Anoeska did and said, no one has ever approached her to ask her what she was thinking of shouting at a vulnerable, post-op patient about not speaking Dutch. Most people prefer to believe it never happened.

The reason, it transpired, that a physiotherapist had come to see me was that I needed to learn a new technique for emptying my bladder, in case the surgery had damaged the nerves to my bladder too much. If I didn't succeed in mastering the physiotherapy technique, or if there was too much nerve damage, I would have to learn how to self-catheterize and would have to do so five or six times a day for the rest of my life. Visions of trying to insert catheters while balancing precariously in smelly, cramped public toilets flashed across my mind, as did hiding catheters in my locker at work and figuring out how to get them to the toilets without causing curiosity. Learning this physiotherapy technique was going to be important to my quality of life from now on.

A few days later, Anoeska's physiotherapist colleague, a woman around my own age whose name I mercifully can't remember, came to show me how it was done. Anna promised she would stay with me throughout and assured me that this lady had no problem with English speakers as some member of her family was married to someone from England. The physiotherapist arrived and immediately started speaking Dutch and continued for some long sentences. I didn't understand any of it. After half a minute or so, I apologized and told her that I really didn't understand Dutch. She smiled and said, "I know, but I like to start every session with a few words of Dutch, just so we all remember what country we're in".

Anna was very embarrassed and didn't know where to look. I had a choice. I could take exception to this nasty little speech and ask the woman to leave (furtively concealed catheters, smelly public toilets, disposing of bags of my own urine all danced across my mind again), or I could submit and let her have this petty and mean-spirited power over me. So I laughed as though

I too thought this was a good-humoured observation and the appropriate way to deal with a foreign patient's lack of Dutch. I still haven't forgiven myself for doing so.

This "treatment" for not speaking Dutch continued intermittently for the rest of my stay. The kind nurses, the majority, were always caring, careful and concerned for me, but two or three others continued to bring up the language issue every time they were on shift. Sometimes, it was just some pursed lips when I responded to something with a polite, "I'm sorry, I don't understand". Other times, it was disapproval disguised as well-meaning advice, and with one nurse, it was disbelief that I couldn't understand what was being said to me, so the sentences were repeated, still in Dutch, but louder. The only person on the ward who really couldn't speak English was the most compassionate and most patient person. With gestures, smiles, humanity and patience, we communicated just fine.

But as time and the hour always run through even the roughest days, I was discharged back into the real world. I tried to forget the unkindness and focus on the fact that I had a doctor I liked, that the majority of the nurses had been kind, that this hospital had not lost any of my test results, and that soon I could get back to my husband, my home, my cat and the job I loved.

DENY, DISMISS, DEHUMANISE –
What happened when I went to hospital

ISBN13: 978-90-6523-223-6
Also available as e-book (PDF) with ISBN13: 978-90-6523-273-1
NUR: 402,860,870,897

1st edition, April 2019

Editing: Helen Burke, Eleanor McNicholas
Graphic design: Eugenie van Dam van Isselt
Cover design: TenU – Den Haag
Cover photo: © Sudok1 | Dreamstime.com

More information
🌐 www.uitgeverijvanbrug.nl
ⓕ www.facebook.com/uitgeverijvanbrug
🐦 @vanbrugboeken
☎ +31(0)653950054

Adrienne has described her experiences in this book as accurately as possible. Many of the names used have been altered for privacy reasons. The names of a small number of people have not been changed, because they can be revoked at any time in connection with their (then) position.