

First of all I would like to thank the Greens Party for initiating this Senate enquiry. I believe it is one of the most important enquiries ever to report to the Australian parliament. I would also like to thank the Senate committee for taking the time to read my submission. It is very important that people on the ground floor of any industry are able to give anecdotal stories about their personal experiences. Bureaucrats and lobby groups don't always give the full picture of the industries they represent.

The health industry has a unique series of problems. Without timely and accurate medical treatments, people simply die, or live with chronic disabilities. This makes healthcare a life and death matter, with people's lives dependent on the treatment they receive. The diagnosis of a serious illness is often unexpected and frightening. Most patients seek reassurance and guidance from doctors, rather than asking hard questions about cost and quality of treatments. Information about how treatments for diseases should be carried out, is kept secret among health professionals and hospitals, which puts them in a very powerful position. Best Practice Clinical Guidelines are not available to the general public, with all hospitals claiming their guidelines are copy write.

Information about the practice standards of health professionals is also kept secret from the general public. No website or rating service will reveal which doctor or nurse has been up on disciplinary charges, or which hospital has been placed under formal review for dangerous practices including Coroner's reports. While public hospitals are forced to publish waiting times and infection rates, private hospitals are able to withhold this information, citing 'commercial in confidence' laws. Few health professionals are actually deregistered even when multiple complaints have been made. Yearly renewal of registration does not require any proof of competency to continue practice to be provided.

Healthcare costs are paid for by a wide range of government departments, charities and private companies. On top of that, each individual doctors visit, test or treatment attracts a different fee. And finally, all doctors, hospitals and clinics charge different fees for the same service. Bundled payments for entire medical treatments do not exist in Australia. Information about out of pocket costs for patients is impossible to obtain. Patients simply cannot ring around to get the best quote, when diagnosed with heart disease, or stroke. Most patients only find out the cost of each individual test or doctors consultation when they leave the clinic. Even then, they have to submit the bill they have paid to Medicare and/or a private insurance company, then wait for find out the co payment. It can take weeks for the co payment to be finalised.

Australia's health system is being quietly privatised. Few Australians realise that the majority of many major medical treatments are already privatised. Or that individual private specialists fees range from \$150 to \$600 per visit. Or that private insurance does not cover many of the tests, doctors appointments and hospital stays that medical treatments actually involve. Australians are ending up \$10,000 to \$40,000 out of pocket after paying health insurance all their adult lives.

There is no other industry that withholds vital information in the way the health system does. The consumers rights that are taken for granted in all other areas of commerce, are virtually non existent in healthcare. This is an industry that all major commentators agree, needs substantial reform.

The current Liberal government appears unwilling to listen to the many stories of excessive costs and substandard care coming from both people who have experienced private

healthcare. Even private health insurance in Australia has concerns about this problem. Australia is second only in out of pocket costs to the USA, a completely privatised system. Hopefully, this enquiry will help raise awareness of the extent of this problem.

### My personal story

In 2007 I went to see a private GP in an inner city eastern suburbs area of Melbourne, about a breast lump. She ordered a biopsy, then called me in for an appointment to discuss the results. The pathology test showed cancer. She had already made an appointment for me at a private breast surgeon, the following day. I was grateful for the speed of the referral. The subject of cost was never discussed. The surgeon worked at a clinic [REDACTED]. It was situated [REDACTED] in inner Melbourne.

The breast surgeon did a physical exam then ordered a wide range of pathology tests. There was no up front quote for her fee, I found her costs on the way out, when handed the bill. \$280, full payment demanded upfront by the secretary, Medicare sent me a refund check of a hundred dollars several weeks later. The pathology tests were ordered at a private hospital [REDACTED]. CT with contrast of chest, abdo and pelvis, nuclear med bone scan, liver ultrasound, chest x ray and a large array of bloods. There was no up front quote, I found the costs on the way out, when handed the bill. \$800 out of pocket, full payment demanded. Medicare sent me a refund check of five hundred dollars several weeks later.

At the next appointment the surgeon told me that I needed a mastectomy and removal of lymph nodes. She referred to a private plastic surgeon whom she worked with. Reconstruction was to be done during surgery. No other option was discussed. The plastic surgeon gave full up front quotes, the only person to do so during my entire treatment. The quote was \$3,000 out of pocket.

I saw a breast care nurse briefly after the second surgeon's visit. She gave me a pile of cancer booklets and her business card, saying call me if you have any questions. No discussion of costs was undertaken.

Surgery was booked a week ahead. The day before surgery the private hospital rang to say my private cover wasn't high enough. "Bring \$4,000 cash or fpost (no checks) or surgery cannot go ahead" was the advice from the secretary. Distressed phone calls to and from my private insurance company commenced. It turned out I had an older level of premium and it didn't cover a private doctor in a private hospital, only a private doctor in a public hospital. The surgeon it turned out, did not work in a public hospital, so if I wanted to continue seeing her, I would have to pay the money.

I arrived at the hospital late and agitated, after going to the bank. I had to borrow the money from my boyfriend. I was frightened about going out of my depth financially.

The surgery went well. The result was only grade 1 cancer. The surgeon said I was lucky. At the next surgeon's visit, she said there had been a meeting with other doctors and it was decided I needed chemotherapy. I was referred to a private oncologist [REDACTED]. His fee structure was similar, no upfront quote, \$150 out of pocket, Medicare refunded a check for \$80 a week later. When I asked about the side effects of chemotherapy, the oncologist scribbled on a piece of paper a few side effects, hair loss, nausea, mouth ulcers. There was no discussion about costs, or education about how to manage side effects.

I tried to get an upfront quote, but was bounced from the clinic to the hospital and back again by secretaries and nurses. Finally I was told \$370 for chemotherapy and \$750 on an overnight stay out of pocket. Cash up front, no checks. When the bills arrived they had to be sent to my private health insurance, and it took months to recover some money.

I walked into the chemo day room to find a woman with long, straight, blonde hair, most were bald, one sat directly front of me crying. There was only one nurse who was very busy. The crying woman was left unattended. I waited for half an hour before the nurse came over to introduce herself. Several cancer council brochures on chemotherapy were flipped on my lap, a cannula was inserted and the drugs were begun. I was instantly very ill. My best friend who came with me, demanded the nurse gave me something for the nausea. Only then did she come over. I had no idea about the side effects that hit me, which were frightening. Afterwards, dizzy and ill, I was taken to a small private room in the hospital, and left alone.

I had been told I would be monitored overnight and cared for. Instead I was ignored, despite ringing the nurse constantly and asking for assistance. No doctor was called to review me. I was only given one very basic anti nausea drug and one small dose of valium. In the morning the doctors walked in to review the patients. I told them how sick I had been and how I had been left with no assistance. They dismissed my concerns and sent me home with a few days worth of anti nausea drugs.

I remained nauseous for days. At the urging of my best friend I rang the private clinic asking for assistance. The oncologist did not return my call. His nurse rang back to say a script for a basic anti nausea drug had been faxed to my local chemist. Her advice was 'this was chemo, get used to it'. By the end of the week I was still ill and had not eaten. I went to see the GP for help, \$75 out of pocket, \$35 returned into my bank account within 24 hours. The GP rang Canberra to get an authority for a script of anti nausea drugs specifically designed for chemotherapy. It was \$32 out of pocket for four tablets. I went through one tablet a day. The rest of my treatment involved constant trips to the GP for more scripts for chemotherapy specific anti nausea drugs. At times I wondered why I was paying a private specialist so much money, only to end up in a GP's office.

There were no health assessments each time I saw the oncologist. No one reweighed me, despite my losing 15% of my body weight, going from size 12 to size 8 and complaining continuously about not being able to eat. The chemotherapy nurse did not take any vital signs, did not ask me about my health or ask if I had any concerns. I became angry about the lack of interest in my health, despite the large amount of money I was paying for private treatment. On the last treatment I started talking to other patients. They also experienced being left ill and unattended in hospital after the first treatment, despite paying to be 'monitored'. I asked the nurse for an explanation. She admitted that patients were often left unwell overnight, without medications to alleviate their symptoms. "The doctors don't write any medications on the drug charts for us to give patients" she explained, before rushing away.

After chemotherapy was over, my health remained poor. I was dizzy and fell heavily several times and broke ribs. A front tooth decayed and required extensive dental treatment \$3,500 out of pocket. I tried to find nutritional supplements from the chemist but nothing put weight back on. I began to experience menopausal symptoms without knowing why. I spent hours on the internet looking up forums and overseas cancer sites. Chronically ill, without any education or support, I became depressed.

My best friend, who had accompanied me to all the chemotherapy sessions, was very unhappy about my private treatment. She had worked as a nurse in public cancer wards and couldn't believe how different my private cancer treatment had been, to the high standard of care public patients, who paid nothing out of pocket received. She had repeatedly suggested I move to a public hospital to continue my treatment.

I rang the breast care nurse to complain. She quickly brushed me off saying everyone reacted differently to chemotherapy, and sent me a brochure about 'moving on after cancer treatment'. I transferred to another oncologist [REDACTED], a woman who wrote me a script for the drug tamoxifen. There was no discussion of side effects. It made me severely ill and I couldn't continue on it. There was no discussion of side effects or how to manage them. Each visit was \$160 out of pocket, Medicare refunded \$80 a week later.

By now I was out of pocket \$10,000 in medical bills, had been off work for six months and had sold my house to pay my bills. Money was an overwhelming concern.

Still very weak, I went back to work as a nurse. The public hospital nurses were very warm, helpful and welcoming. They gave me advice about managing my constant health problems. One day I shared lunch with a public oncology nurse. I mentioned my concerns about my chemotherapy treatment, particularly my severe weight loss being ignored. She didn't understand. "We have to reweigh all the chemo patients as soon as they come into clinic. Otherwise they can't have the treatment. It's compulsory. So how could they possibly give you chemotherapy without reweighing you?"

The public nurse explained that the dosing of chemotherapy was based on a height to weight ratio. If the patient changed their weight by more than 10% then their chemotherapy dose was usually changed. I was shocked, but also realised there was a connection between my severe illness, inability to recover and an incorrect dose of chemotherapy, the most toxic of all medications.

I went on to ask her about standard management of breast cancer patients. Before lymph nodes are removed, a dye procedure is done to check if there is actually any spread of cancer. This saves healthy lymph nodes being unnecessarily removed. Full body and bone scans before any surgery for early breast cancer are unheard of. Normally a biopsy confirms cancer, then it is removed in surgery. Further testing is only based on clinical proof that cancer may have spread around the body.

Before anyone has chemotherapy in the public system, they have education about the drugs, their side effects and how to manage them. Patients are always reweighed and given a health assessment before each chemotherapy session. I couldn't believe how different my treatment had been. I asked the public nurses I worked with, about private hospitals. There were scathing. "People pay a fortune for private medical treatment" they said, "without realising how low the clinical standards often are". Private doctors tended to be older, out of date with current practice. Private nurses were frequently untrained, and had to manage far higher nurse to patient ratios than in the public system. Private hospitals were only concerned about making money and cutting costs.

I went back to the private clinic for one last time, to get some answers. "Who is in charge of chemotherapy here" I asked one of the nurses. "No one" she replied, startled, "the doctors all just see their own patients. "Who is in charge of this clinic? Aren't they part of [REDACTED]?" I asked. "No, the clinic is a private company [REDACTED]" she replied. "I've paid out thousands of dollars in out of pocket fees and all I have received is treatment that falls way below public hospital standards". "That's not my problem". She replied. I walked out, then wrote to the surgeon telling her I would file a complaint about my excessive cost and sub standard treatments. I then wrote to the GP asking her never to refer anyone to this clinic again.

I began to investigate. As a nurse, I knew I was in a unique position. I contacted two public oncology nurse unit managers, working in large public hospitals. I explained my experiences and asked for an explanation. They both gave similar explanations.

'Private doctors are a law unto themselves. They refuse to educate their patients, they want to maintain total control over patients treatment in an old fashion manner. They refuse to work in a team environment. Private hospitals are completely financially dependent on the patients private health insurance payments. Hospitals know that if the doctors aren't happy, they will just take their patients somewhere else, and they will lose out financially.'

Both nurse managers had tried to work in the private sector and had left, frustrated by private doctors blocking reform and a lack of support for nursing roles.

I discovered my private oncologist also worked in a public cancer hospital [REDACTED]. I did some casual shifts there, to see what the standards were in his public practice. I was shocked. The public hospital used an oncology-specific computer system for patient care, including drug charts. Chemotherapy could not even be charted unless the patients current weight was entered. I spoke to the hospital pharmacist. She would not even release chemotherapy to the ward unless the patients current weight was entered. I had paid thousands of dollars for a doctor to have far lower standards of care, than he gave his public patients, who paid nothing. Meanwhile, he travelled [REDACTED] between his public and private practice, to deliver completely different standards of care to his patients.

I then went to see an oncologist in a large public hospital. "Why on earth did you have chemotherapy for grade one cancer" was one of the first questions I was asked. The oncologist showed me a website that gave a estimate of risk reduction of death from cancer by chemotherapy. It was for my age and stage of disease... 2%.

"I see a lot of private patients" said the public breast care nurse. "They end up in the public system broke, lacking in education and health supports. Some have been unable to complete their treatments due to excessive costs. People think the private system is better because they pay for it. But it doesn't work that way." My out of pocket costs for half an hour with an oncologist and an hour with a qualified and supportive nurse? Nothing.

I filled a written complaint with the Victorian Health Department. It took them nearly a year to review my case. I finally received a brief letter from them saying that the problems I experienced at the private hospital had been resolved, but thanking me for my efforts. Several weeks later the private hospital rang me, asking for an informal chat to check everything was OK. I agreed, then the secretary let me know the private doctors would all be attending the meeting.

When I walked into the hospital meeting, the private doctors were all sitting around a table. "Can we tape this interview" was the first thing one of the doctors said to me. I refused, saying this was an informal meeting called by the hospital to see how I was going. I went on to raise my issues about the excessive and undisclosed costs I had been forced to pay, and sub standard care I had received. I pointed out that I would have received far higher quality treatment for free, if I had gone public for my treatment. |

[REDACTED]

I also mentioned the case of a woman I had developed a friendship with, who had previously attended this clinic. She had also spent thousands of dollars in out of pocket costs, for treatment that fell well below best practice standards. In her case, this meant being given nine months of continuous chemotherapy, with no second medical, opinion being sought, despite the fact that that her cancer was not responding to the treatment. This was on top of a previous six months of chemotherapy several years previously. I had by now learnt that there were lifetime limits on the accumulative dosage of this particular drug, due to a proven link to heart failure. I also raised the case of a woman whose daughter had been given chemotherapy at this private clinic without first being told it causes infertility. She subsequently found out she could not bare children. Referring childless younger people to IVF prior to cancer treatment was standard practice in public hospitals and recommended practice by all major oncology groups.

My concerns were all completely dismissed. When they were satisfied I was not taking legal action, the private doctors got up on mass, and walked out of the meeting.

I joined several cancer support groups. Substandard and overpriced cancer treatment in private hospitals was well know about among cancer survivors, but never raised publicly by any organisation. Finally I found a sympathetic group in Cancer Voices. [REDACTED]

I began to read media reports about excessive out of pocket costs for substandard medical care. The subject was even raised by the CEO of Private Hospitals Australia, the body that represents Australia's private health insurers. Dr Armitage had commissioned a report into private hospitals that had "unacceptably high infection rates." He questioned health insurers "backing up truckloads of gold to pay for ratshit outcomes". The report was apparently buried by lawyers acting for private doctors and private hospitals. No member of the public can even read a draft of the report.

I asked a senior health bureaucrat why the health department was not investigating overpriced and substandard private hospitals. He advised me that attempts to access information about patient care and out of pocket costs in private hospitals resulted in aggressive lobbying from medical, business and political groups, to shut down any investigations. A national cancer group executive told me the same story.

I read academic reports about public and private hospitals having completely differently reporting for hospital infection rates and hospital errors. I looked up the My Hospitals website and found information on private hospital infection rates was withheld, citing 'commercial in confidence' laws.

I read articles in every major news outlet in Australia, about private patients ending up \$10,000 to \$40,000 out of pocket, despite years of paying private health insurance premiums. I read highly regarded health advisors, talking about the difficulties of controlling costs in private healthcare, due to lack of transparency of pricing and the power of certain health lobby groups to manipulate costs. And finally I read about the billion dollar cost of tax payers subsidising private health insurance premiums.

Finally, I read a series of articles in the New York Times about American patients being bankrupt by over servicing, price fixing and lack of accountability in private hospitals. One article was titled 'The \$1,000 toothbrush'. That was how much one American private hospital was charging patients. An Obama led review of private healthcare in the USA had led to a report revealing that across the country hospitals were charging up to ten times more for the same procedure, with no increased benefit to the patient. Basically, private healthcare in the USA was just a matter of open profit making, and governments, patients and insurers had no bargaining power to drive prices down.

In conclusion, this enquiry into out of pocket health costs cannot avoid the broader issues in a privatised health system. An discussion of costs inevitably leads to the lack of consumer power in healthcare. Patients have no pricing power what so ever. The 'free market' simply does not apply to private healthcare. All power and control is in the hands of private doctors, private hospitals and private clinics. If anything, private healthcare resembles a cartel, run by powerful and politically savvy business groups.

The ability of some private doctors to over service and overcharge for essential services is bad enough. However the ongoing tolerance of poor clinical standards in some private hospitals is just appalling. Some of the stories that patients and health professionals have reported at website [www.wikihospitals.co.uk](http://www.wikihospitals.co.uk). Some private hospitals resemble nursing homes, in their employment of unskilled staff, working with unacceptably high nurse to patient ratios.

Like police corruption or pedophilia in the Catholic Church, the problems in the health system are deeply entrenched. Which is sad, because there are many hard working health professionals who just want to care for sick people, and make them well again, or at least keep them comfortable. Good healthcare doesn't require excessive full body scans, extreme medical treatments for low grades of cancer and thousands of dollars in out of pocket costs. It just requires the minimal tests and treatments, at the lowest possible cost, for

Due to the financial, political and legal power of the health industry, reform seems unlikely. Neither of the major political parties seem prepared to ask hard questions about privatised healthcare. I personally believe that a Royal Commission into both the costs and the clinical standards of Australian healthcare, as well as the shift to privatisation is the only way that reform will ever be achieved.

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