

# A tale of a few hospitals

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"I would like to think that the patients in my hospital are treated in the same way that I would like my mother to be treated."  
... More CEOs than can be named

I am currently in the unhappy position of suffering a life threatening illness that involves outpatient attendances, inpatient care and other services provided by four Australian public hospitals. Three of the hospitals are tertiary referral centres, hospitals that provide the top end of care for patients in my predicament. Two of the hospitals are located in regional Australia.

I hope that this article will serve as a stimulant to all health professionals to undertake a reality check on whether the services they provide are patient focussed, consumer- and family- friendly in nature. My experiences in these four hospitals so far have been dramatically different, yet very little effort and little or no funding would be required to fix the hospitals where the service has been less than ideal.

## Patients need real respect and compassion

Patients' needs are very simple. They wish to be treated with respect, dignity and compassion – this is presumably the reason that many hospitals include those words in their service charter or mission statement. If the patient can be cured as well, this is an added bonus.

In one hospital that has provided care for me during this difficult time, the respect and dignity were stripped away within moments of my first appointment when the pathology technician abused me for not bringing patient labels from the outpatient clinic to the laboratory so that blood collections could be correctly labelled. I did not know that the clinic staff should have given me the labels; but it caused no end of grief as I felt absolutely threatened by the technician as he became increasingly angry while drawing blood. As I composed myself after this ordeal while awaiting the next set of tests, an engineer peered in behind closed curtains, while I was, umm, undressed.

On another occasion in a busy treatment area, I was asked from the other side of the room whether I had had my chlamydia test. Many patients and staff heard the question and were interested in the response. When I refused to answer across the room another patient commented that I would become used to everyone knowing my business. On more than one occasion I have had my history taken in a busy waiting room and it was only when I balked at answering some of the more detailed and personal questions that the history taking was halted.

I have had a health professional who was at most half my age and who does not know me call me 'dear' and 'love'.

When standing at an outpatient reception desk, I have been able to read on a computer screen the list of patients for the coming week. The list included the patients' personal details, their diagnosis and referring doctor. Interestingly, I knew one of the patients and had not known prior to reading her details on the computer screen that she was ill. This raises the question as to who has access to my records.

I have been insulted by laboratory staff who have clearly been uncomfortable with my questioning the outcome of test results. For someone in my position, test results are an important indicator to me of the progress of my disease and ultimately my longevity. I have been abused for walking into a laboratory, even though I was instructed to enter by the receptionist. I was told by the technician that I should have reported to the receptionist. When I advised that I had in fact done this, the technician told me that the receptionist did not realise I was a patient. What does a patient look like? I did identify myself and state the name of the person with whom I had the appointment. I do not work at any of these hospitals and did not wear a hospital identity tag.

## **Good and bad experiences in emergency and outpatients**

However, there have been many positive experiences. The first was being treated competently by junior and senior staff of a public hospital emergency department, in a prompt, compassionate and caring manner. This restored my faith in the system: there is no doubt that if a patient is really ill, the best place to be is a public hospital emergency department.

I visited an outpatient department recently and was greeted by a smiling receptionist. Halleluia! I was invited to take a seat in the waiting room. My next thrill was that there were in fact empty seats in the waiting room, because this particular outpatient department operates on a staggered booking system. (Another outpatient department that I visit regularly has all patients arriving at the same time, and I have often arrived at this hospital at 8 am after a three or four hour drive and not been seen until mid to late afternoon.)

The thrills abounded in the 'good' outpatient department, as I noticed tea and coffee making facilities available. In the other place, on many occasions after my long drive I have not even had a glass of water for another few hours for fear of missing my place in the queue. I once arrived at the clinic at 8 am, and was not seen by the specialist until after 3 pm. I remember commenting at the time that I did not even have any lipstick on, which the specialist thought was hilarious. My point, however, was that I could not leave the waiting area during the entire time.

There is no place in this day and age for a 'one appointment' outpatient system. It is relatively easy to calculate how many patients can be seen in an hour. Patients do not mind waiting a little time. They do mind waiting a long time in crowded waiting rooms with histories being taken around them. They do not mind if things go wrong when there is clearly an effort being made to ensure that the patient is the centre of attention. They do mind if the patient is coming a bad last, and gossip about the social life of the health professional seems to take priority over seeing the patient promptly and in a dignified, respectful and compassionate manner. Patients who are gravely ill do object to their consultations being continually interrupted. It is impossible to follow a conversation or a thread if three or four other patients are being dealt with at the same time.

Tea and coffee making machines, cold water and even fruit juice are not expensive. Those hospitals that are strapped for cash could charge patients. But hospitals that are providing services to rural, regional and remote patients really should ensure some basic comfort, so that the patient is not being made sicker by the interaction with the hospital.

Parking is a particularly difficult issue for any hospital, but on behalf of disabled people let me say that there are not enough disabled parking spaces around hospitals. Disabled people ought to be able to park near a hospital, and if this is at the expense of able bodied people then so be it. Patients from rural and regional settings also have difficulties. Generally they will need to drive considerable distances, and very often have no relatives who can assist in taking them to appointments. The special needs of these groups of patients should be better understood (asking them would be a good start) – solutions would probably be neither costly nor difficult.

## Communication issues

The biggest thrill I have had over this difficult time was the recent experience of being given all the available information, including the bad news, in a frank and comprehensive way. I know that many health care professionals have difficulty in delivering bad news and sometimes early on in the development of my illness I have relied entirely on the internet for information. The need for respect, dignity and compassion as key components of good patient care also applies to delivering the good and bad news. In my case, different professionals delivered the news in a variety of ways – some delivered it comprehensively, yet others uttered platitudes and expected me to draw my own conclusions. I have had a health professional tell me that this is a 'serious illness' when I needed to know whether it was potentially fatal - clearly I was supposed to draw a whole heap of conclusions from those words. I could perhaps understand a reluctance to deliver both sides of the equation if there was no interest shown by the patient. However, I have been clear in my desire to have all the information about the disease and likely outcomes.

In one hospital, the specialists have their doors open during consultations, and numerous clinic staff wander in and out of the room while the consultation is occurring. My experience in this hospital is that because of the disruptions to the person delivering the care, it is near impossible to give any useful information to patients who are hanging on every word uttered. Yet in another hospital, both good and bad news were delivered without the professional having to leave the room, or without other clinic staff interrupting. Open door or closed door during important consultations? My advice is clearly a closed door approach so that no one interrupts.

Over the years as a senior health service manager, I have been hell bent on ensuring that hospitals are able to minimise the difference in outcomes across hospitals and I have therefore been extremely active in benchmarking initiatives. My focus has been that patients should expect a similar outcome with the same symptoms or illness, irrespective of the hospital that they visit. However, I did not ever envisage that some health care providers would assume that all patients were the same. While their illness and eventual outcome might be similar within disease groups, as individuals within a social setting of family and friends they are all quite different. My dealings with some health professionals during this awful time have led me to the conclusion that there are too many people who believe that the health system is designed for a standard patient who does not deviate from the 'norm'.

I have been given some stupid advice, including a suggestion to catch a train with all the accoutrements of my disability - clearly ridiculous when I live in regional Australia and some of the equipment that will keep me alive requires electricity and is extremely heavy. When I travel to any city hospital, I am keen to have my family with me, given the death sentence that I am facing. One health professional told me that I could be accommodated at the hospital, but it was bad luck about my husband and child. I would have to share with another patient, despite the fact that the machine that keeps me alive at night is extremely noisy and would keep the other patient awake (as well as me). The offer was not really worth making.

A series of appointments with various health professionals is compulsory for the illness that I have, and a sequence of follow-up general sessions in a group setting with other patients is organised – not simply offered – after this series of appointments. This assumes a level of idiocy amongst patients that is breathtaking in the extreme. I am sure that some patients would appreciate such sessions, but equally others would be offended that their last precious months on this earth are taken up with finding a car park and being treated like an idiot about something fairly basic about living and dying. Some patients reluctantly comply with the requirements, fearing lack of appropriate care and treatment if they refuse to participate. Such sessions really need to be subjected to the evidence-based rigour of other health care services to ensure that the benefits (including cost to the health care provider and the patient) far outweigh the drawbacks. Different methods of delivery could also be considered, such as the use of videotape so that the patient is not kept away from home and family unnecessarily.

It would have been useful, however, to receive precise information about the different types of equipment required, financial suggestions and options for accommodation while undergoing treatment, but such suggestions were not readily available. Part of the problem, of course, relates to the fact that Australia is divided

into jurisdictions that operate a whole range of services differently. If ever there was an incentive for the health system to break down its barriers – including those built up by the Commonwealth, State/Territory, public/private and veterans' affairs systems – then the management of chronic or acute life threatening illness is surely a convincing need.

My final comment relates to continuity of care and importance of the general practitioner. It has only been my stubbornness that has ensured that my GP has been kept informed of the important issues relating to my care and likely prognosis. I pity the patients who are not as stubborn and assertive as me, or who just have no idea how this all works. However, my own experience was not without effort. When I contacted my GP for a consultation to deal with the initial but overwhelming symptoms, I was told cheerily by the reception staff that I could be seen on Thursday fortnight. I then scoured the yellow pages for another practice nearby, and stumbled across my current GP who is now my life saver. I am sure such efforts are no news to people in rural, regional and remote Australia.

## Conclusion

It is obvious to me that the key issue in providing patient care in a dignified, respectful and compassionate way is the hospital's culture. The leadership shown at unit and hospital level is critical in influencing staff to care for their patients. I have had plenty of time sitting around waiting rooms to notice the differences!

Many friends and colleagues who know me would say that I am a fairly assertive person and that I generally have no problem in conveying a point of view. However, given the severity of this illness it has been difficult for me to complain. At each unsatisfactory appointment, I am treading a fine line between being grateful for being kept alive, or being disgusted at the way I am being kept alive.

Is the care you and your staff provide to patients of a standard that would satisfy you if it really was your mother in the bed?