

Let us be prepared

Bebe Loff

Public debate is required if families are required to fill the gap left by hospitals which now only "care" for the illness and not the patient

I told myself I would write this article as I was dragging my 8-year-old's drip behind her at 3:30 am when she decided it was time to go for a walk in the semi-lit hallway of a paediatric teaching hospital. My daughter has severe autism, intellectual disability and suffers from epilepsy. Although I am probably a little better informed than most, given my experience in the field of bioethics and health law, I am a lay person. Thus, my description of events will be in terms that are perhaps not medically accurate, and from my own perspective. Having discussed my experience in a non-statistically-rigorous fashion, as a lay person does, with several others who have recently been hospital inpatients or whose relatives have been inpatients, I find that my impressions are uniformly shared. My discourse should not be interpreted as a criticism of the staff of the hospital, whom I found to be as accommodating as conditions allowed. I would also like to make it clear that my concerns should not be dismissed as a commentary on the nursing aspects of my daughter's hospital admission. They are intended as a critique of the direction of the way hospital services are generally delivered, and this — as is well understood — is the result of many contributing factors.

Before her hospital admission my daughter had had a urinary tract infection that had been treated with various antibiotics. Nonetheless, she kept vomiting up anything that passed her lips as well as having occasional bouts of diarrhoea. Her temperature remained very high. Her eyes were sunken, and she was pale and weak.

It was fortunate that one of my daughter's therapists decided to accompany me to the emergency department. She stayed with me from 11 am until 3 pm. Had she not done so, I don't know how I could have gone to the toilet or obtained anything to eat. My daughter cannot communicate readily, does not understand the concept of hospital, and would have been distraught at being left in an unfamiliar environment with unfamiliar faces, and at dealing with the shock of having an intravenous line inserted. It is not possible to explain these things to her. Fortunately, humane staff in the emergency department permitted me to use a hospital phone to call my husband, otherwise this would have been an impossibility. (Even if I had one, mobile phones cannot be used, and a public phone was some distance away.)

I was provided with a plastic bag in case my daughter vomited. When she did, I did not know where to dispose of the bag. I imagined that I should not put it in an ordinary rubbish bin. I wandered out of my daughter's cubicle and asked a nurse, who directed me to a bin for infectious waste. Later in the day, a Red Cross volunteer provided me with a cup of tea and a sandwich. Having spent most of the day in the emergency department, and

being intermittently assisted by helpful and polite medical, nursing and administrative staff, my daughter was admitted to the general medical ward.

My daughter could not move herself from the trolley to the bed so nurses did this and then departed. The job of straightening the bed was left to me. I was then given most useful advice from the mother of an infant in the next bed who had been in the hospital for some time. She told me that there was a toilet for parents, but if the queue was too long, the nurses sometimes let you use the toilet for the children. As I shortly discovered, the parents' toilet was nauseating. The bin in the toilet seemed not to have been emptied for some time and was overflowing. No one told me there was a shower. It became clear, although no one mentioned this, that the tasks of toileting and cleaning my child, as well as making her bed and eventually feeding her, were reserved for me.

I was asked to collect all of my daughter's urine and a specimen of her faeces. Again, for a host of reasons, I had thought that this was a nursing task. I did not feel confident about doing this and this was not because it was distasteful, although I must admit I wasn't thrilled about it. It was more because I was not familiar with where things were kept, and how to get my daughter to urinate into the container that was placed in the toilet. It also took me some time to realise that collecting the urine was not now for the purposes of testing but just to see how much she was passing. I was therefore also unsure of what to do if the faeces contaminated the urine.

It is well known that hospitals are not places that are conducive to sleep unless you are so unwell that staying conscious is the challenge. Consequently my daughter was able to sleep for most of the night, but I was not. An older nurse helped me set up a single "sofa bed" for myself. By morning I had a headache, was coughing and sneezing (not related to the hospital stay) and was exhausted. A lovely nurse popped in to provide advice about parking fees, the family resources centre, use of the internet and the room on the floor available to parents. While my daughter was asleep, I chanced using the accidentally discovered shower, hoping she would not wake in the meantime, and found it to be in a similar state to the toilet.

During the morning, the paediatric consultant ordered an ultrasound of my daughter's renal system and appendix. This eventuated by about 4 pm. While waiting in the x-ray department, my daughter was sitting on my lap when she had an episode of diarrhoea. Luckily her 20-year-old sister was present so I was able to find someone to give me a towel to try to clean my daughter and myself. My daughter was provided with a surgical gown. My jeans were not the best.

Fortunately, the ultrasound was normal. At around 5 pm, a charming doctor payed us a visit and said we could either stay another night or leave. I asked her what she would do in our position. She advised that the intravenous fluids had probably provided my daughter with some stability and she was more likely to begin eating at home than in hospital. That being the case, my

Epidemiology and Preventive Medicine, Monash University, Melbourne, VIC.

Bebe Loff, PhD, Head, Human Rights and Bioethics.

Reprints will not be available from the author. Correspondence: Dr Bebe Loff, Epidemiology and Preventive Medicine, Monash University, The Alfred, Commercial Road, Melbourne, VIC 3004.

Bebe.Loff@Med.monash.edu.au

response was that the hospital would have to put me in chains to keep us there.

My daughter is now fine. I am left wondering why it has come to be, amid the continual structural reforms, that health professionals have time to attend to equipment and defined clinical tasks, and not to people. Indeed the most "care" I received was from the Pink Lady who volunteers her services one day a week. The time devoted by health professionals to personally tending to my daughter would have amounted to a matter of minutes.

Parents come into a hospital already worn down by worry. They are tired. They do not expect that the responsibility for care will be left to them. I have discovered that my experience is not confined to paediatric hospitals, nor indeed to the public hospital system. One woman told me that she paid professional carers to look after her mother day and night while in a private hospital. Another said she had been so shocked at the lack of personal care that she and her sister stayed on to look after their mother. In another instance, a woman in her 80s described having to make her own bed with an intravenous line in tow, and being regularly left sitting in the shower unable to move after major surgery. Is this a failing of our health care institutions, or just what we should come to expect?

While I have no wish to be inflammatory, some of the problems I have mentioned are clearly matters that should return to the

province of hospital staff. Basic issues of cleanliness on the ward cannot be a responsibility of patients or their relatives. Failing to attend to an elderly patient left sitting in a shower is frankly disrespectful. Insofar as my daughter has special needs, I felt some additional care was taken in the mechanics of her treatment. By this, I mean three nurses were on hand when she was injected with gentamycin, and a specialist was called when a young doctor failed to insert the intravenous line after several attempts. The woman taking meal orders did try to be flexible in getting the kitchen to produce food to meet my daughter's idiosyncratic tastes. Otherwise, there seemed to be no cognisance of the fact that some effort needed to be made to engage her and gain her confidence. Nor was there any recognition of the difficulty I faced in leaving her side for short periods. In regard to some of the other issues, such as the extent to which families are expected to look after their loved ones in hospital and to which inpatients are required to fend for themselves, there is clearly need for public debate. Changes of this magnitude should not be introduced by stealth or attrition. If we are moving towards a system in which care from families is routinely required, then this ought to be made clear. At least then we may be better prepared.

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