



DEATH, IGNORANCE AND BIAS

SUE CORRIGAN ON THE APPALLING TREATMENT METED OUT TO THE ELDERLY AND DISABLED IN OUR HOSPITALS

Because of his quadriplegia, businessman and community activist Don Mackay was deeply worried in early 2007 when doctors in his hometown of Port Macquarie in NSW told him he would have to go to a major Sydney teaching hospital to get treatment for a lung problem.

Having lived with quadriplegia for 25 years after breaking his neck in a diving accident, Mr Mackay was very aware of the innate vulnerability and susceptibility of his lungs to any infection. And from past experience in the hospital's Spinal

Care Unit, he trusted neither its infection control nor general care standards. His anxieties proved all too prescient.

Instead of the relatively straightforward procedure the Mackay family were expecting, another, far riskier operation was unexpectedly performed. Following the disastrous failure of this operation – which the family insists should never have been performed on a quadriplegic in the first place – and then a terrible error in which his lungs were suctioned at 10 times the correct rate for 22 hours before

This page, left to right: Don with his family - Alison, Melissa and wife Therese in the back; Don in ICU, before he became infected. Opposite page: Don just before he became ill – Sept 2006



staff realised the mistake, Mr Mackay suffered a respiratory arrest. After almost six weeks of terrible suffering in Intensive Care, Don Mackay died, aged just 56, in May 2007.

Over the past two years, Don's widow Therese has fought relentlessly to call those doctors and nurses she believes directly responsible for her husband's suffering and death to account. So far, however, the most she has received is an apology in writing from a senior hospital executive, admitting it was "clear" that the care provided "let you, Mr Mackay and your family down in a number of ways. We deeply regret this, and apologise for the distress you have experienced".

Mrs Mackay, who is now writing a book about her husband's treatment, is far from mollified. "Doctors operated on Don's lungs without the most basic pre-operative checks", she says. "This would be unacceptable in any circumstance, but for someone with the complex medical problems that result from quadriplegia, it was inexcusable. Don knew that for him, any surgery or anaesthetic was deadly serious. All quadriplegics know the grave dangers of any interference with their lungs. And you'd assume that senior medical specialists in one of Australia's leading teaching hospitals would know that as well – but apparently not."

While official statistics and anecdotal accounts alike demonstrate that doctors cannot always be trusted and that hospitals can be very dangerous places for any patient, there are a number of reasons why people with disabilities are singularly vulnerable to the effects of medical and nursing mistakes, incompetence, ignorance of their often complex medical needs and lax care standards.

With around 10 per cent of all patients grievously harmed or killed by hospital error of one form or another, health safety

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experts like Jeffrey Braithwaite, Professor of Public Health and Community Medicine at the University of NSW, point out that the only really effective safeguard is for patients to be constantly "vigilant" about what doctors and nurses are doing to them.

"Health care is risky and dangerous, even more so these days because of the complexity of care provided", Prof. Braithwaite says. "Patients either need to be their own advocate and watch what's going on very closely, or have people – family, friends or colleagues – look out for them."

But where does that leave patients with a severe physical or intellectual disability that impairs their capacity to monitor what is being done to them, or to relay information to and communicate with health care workers? What if doctors, nurses and allied health professionals have no training or experience in dealing with a particular disability? What if doctors unthinkingly perform an operation or procedure that would be routine for a non-disabled patient, but likely to prove fatal for patients, like Don Mackay, with a disability such as quadriplegia? And, worst of all, what if health care professionals at some level regard the life of a frail, elderly patient or a person with a severe disability as just that little bit less valuable than that of younger, non-disabled patients? →



Alexander Buckwalter



Jo Shepherd

Therese Mackay believes patients with disabilities definitely suffer serious, potentially fatal, forms of discrimination in hospital. Because, by the very nature of their disability, they have higher practical care needs, she says they can be very quickly labelled “nuisance” patients by many nurses – and as a result, “blanked”.

“However loudly Don called for help, there were many nurses who simply pretended they didn’t hear”, she says. “I come from a family with a nursing tradition, and I know what is acceptable. The quadriplegic patient opposite Don knew exactly how to play the game. He carefully kept his needs to a minimum, so as not to be labelled a nuisance and then ignored. Disabled people and their relatives who have experienced hospital care know what I am saying is the truth.

“Another form of discrimination is that even some of the medical staff, who you really would expect to know better, assume that because a patient has a physical disability, they must be intellectually impaired too. Some doctors would talk to Don in a loud, slow voice, or else direct questions meant for him to me, even when he was fully aware and watching. The level of ignorance about disabilities among supposedly highly trained healthcare staff is also inexcusable. Don and I were both amused and bemused at how many Intensive Care nurses would ask him why he couldn’t move his legs.”

Victorian GP and health academic Dr Jane Tracy, herself the mother of an adult son with cerebral palsy, acknowledges that despite recent advances, the standard of medical care given to people with a disability in Australia frequently falls far below that experienced by the general community.

As Education Director of the Centre for Developmental Disability Health Victoria, based at Monash University, Dr Tracy devotes her working life to improving health professionals’ awareness, knowledge and skills in treating people with disabilities of neurological origin such as

cerebral palsy, autism and learning difficulties. But she says that while curriculum changes for trainee doctors and other healthcare workers, which she herself has played a key role in introducing, are gradually improving the care of people with disabilities, there is still a way to go.

“People with developmental disabilities are 50 times more likely to die before the age of 50, and up to five times more likely to have a mental illness compared to the general community”, she says.

“While these statistics are of course partly due to the nature of particular disabilities, it is also the case that many medical problems in such patients go undiagnosed or under-treated. Chronic complex medical conditions, combined with communication and cognitive problems, mean many people with developmental disabilities often find it difficult to have their symptoms recognised or treated. And as a result, they simply aren’t getting the care they need.”

Although unable to comment on any individual cases, Dr Tracy said one disturbing story put to her by Link typified how communication breakdowns and lack of co-ordination between different sections of the health care system can cause horrendous problems for patients with disabilities.

In January 2008, Jo, a 30-year-old South Australian woman with cerebral palsy who works part-time but who cannot walk and has difficulty speaking, began to experience intense pain in her right hip. Twelve months later, her hip joint, plus 10cm of femur, or leg bone, were removed, but because of the fragility of her bones, a hip replacement was not possible. After two weeks in hospital, Jo was sent home – without any essential follow-up rehabilitation or modifications to her wheelchair to ensure her torso remained upright.

As a result, Jo’s right femur kept sliding into her ribs, causing her severe pain. Her family say this was reported to the orthopaedic surgeon and GP several times, but Jo was simply prescribed morphine patches and told she had no

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choice but to live with the pain. Eventually, after strong complaints from Jo’s family, she was sent to a rehabilitation hospital, where she spent four weeks in traction, and where her wheelchair was finally modified to keep her torso upright.

Sydney resident Maree Buckwalter, whose 23-year-old son Alexander has severe epilepsy and an intellectual disability, says she is convinced healthcare workers treat patients with an intellectual disability with far less attention and respect than would otherwise be the case.

“As a parent, it is your responsibility to learn all you possibly can about a disabled child’s health needs and problems, because you are almost certainly going to have fight every step of the way for appropriate care and treatment”, Mrs Buckwalter says.

She recounts that at 17, her son had what appeared to be a stroke on his way home from school, leaving the entire left side of his body paralysed. But she says that when she called Alexander’s neurologist, he said it was almost certainly a transitory problem and advised her just to put him to bed and wait 24 hours.

Early next morning, with her son’s condition unchanged, Mrs Buckwalter called an ambulance, but says she and Alexander were then made to wait for a nightmarish 13 hours in Accident & Emergency before he was admitted to a ward at 2am. In the morning, a neurologist confirmed Alexander had had a stroke. She says even then, however, she and her husband were left entirely alone to work with Alexander and teach him how to walk again. When, after six weeks, her son was discharged, she says she was left without any help or assistance to hire a wheelchair for him.

“Doctors, nurses and other hospital staff just seem to be so overworked these days, they appear to have lost all humanity”, an angry Mrs Buckwalter says today. “So many doctors and nurses are also from non-English speaking backgrounds, which often makes communication even

more difficult and error-prone. I cannot imagine how people with intellectual disabilities or speech problems, who have no family or friends available to sit constantly by their side, watching out for what is being done – or not done – to them and explaining their needs, how they must fare in hospital. Their extreme vulnerability to neglect and mistreatment is very upsetting to contemplate.”

As numerous anecdotal accounts suggest, aged people are also at greater risk than the community as a whole of suffering poor standards of care. A friend whose 71-year-old mother died of breast cancer told me recently that when he requested his mother’s medical notes from her GP, he was horrified to see the referral to a cancer specialist had been marked ‘non-urgent’.

“I’m convinced that assessment was made not on medical grounds, but solely because of my mother’s age”, he says. “And, as events proved, even if that assessment was made on medical grounds – it was wrong.”

In another disturbing case brought to Link’s attention, an elderly NSW woman who spoke only Italian and was dying of leukemia was dropped by nurses when being transferred from her nursing home bed to a wheelchair. An X-ray revealed a broken leg – but the lady was not told and later that day, when her family called to take her out, staff entirely failed to mention this fact to them too. With the fracture left untreated, the family only found out many days later why the woman was in such pain.

Dr Tracy says improved education and training for all health care workers on the particular needs of people with disabilities and the aged are key to raising health care services and outcomes.

“Up until 10 years or so ago, there was little if any specific teaching or training for doctors and nurses on disability issues”, she says. “The attitudes doctors and other healthcare workers have to people with developmental disabilities are also vital, and attitudes are influenced by knowledge.

“Of course, we can’t give medical undergraduates detailed training in every type of disability, but we don’t need to. We just need to give them a good general framework for understanding developmental disability, and the needs of and challenges for people with such a disability.

“Another extremely important development was the introduction in July 2007 of Medicare rebates to enable GPs to provide regular, thorough health checks and screening for people with developmental disabilities, thereby encouraging pro-active health care.

“We have come a very long way in the past 20 years in services for people with developmental disabilities, but there is still a long way to go before the disparities in care standards and outcomes are removed altogether.”