

Living with 'carers'

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I am a partial quadriplegic as a result of incomplete fractures of C6 and T3/4 and syringomyelia resulting from the trauma. I have chosen to write about living with carers not only because it is relevant to people such as myself but also because it is becoming increasingly relevant to most of New Zealand's ageing population. At some stage most people will require help from outsiders following a stroke, a fall, an operation, mental or physical illness or ultimately dementia.

In my experience, the more vulnerable your position the greater your chance of neglect. At a friend's (double amputee – high amputation both legs) funeral earlier this week I recalled that we first met 11 years ago (prior to my accident) when I wrote a feature article on him. Subsequently I wrote follow-up articles on the work he was doing to ease the way for people in wheelchairs. We became good friends and, after my accident, discussed the difficulties associated with pain, carers, loneliness, and lack of mobility. After I came back from Burwood Spinal Unit those interviews paved the way for me to accept my own predicament.

His enthusiasm and involvement in the community gave me something to aspire to. The work he had done with the local council and others to make public places more accessible made my life fuller and easier than his had been. We both required 'carers' to function, but to my mind he was one of the best, though unpaid, carers I have had the privilege of knowing. I go on to paint a fairly bleak picture of the 'carer' front in rural areas but I am airing these concerns because I believe that there is something that can be done about it.

In the last 20 years a lot of spin has been put on the names of numerous government departments, public services and public and private institutions. Go past a 'smoke-free' school and you can bet your bottom dollar that some kids are smoking in the bushes, or a teacher is walking the pavement nearby to have a quick puff. Go past hospitals that are unable to deal quickly with anyone but the seriously ill and you'll see signs proclaiming 'health care' not 'care of the sick'. Nearby you'll find rest homes filled with people

well along their inevitable path to death. But the sign outside is likely to read 'life care'. New Zealanders, out of work and with little cash, report to 'Work and Income' not departments for the 'unemployed and broke'. Such misnomers distort the public perception of reality.

Unfortunately, members of a group of the lowest paid, most poorly trained people in the country, doing one of the most difficult and important jobs one human being can do for another have been named 'carers'. Many are 'not carers' and for good reason.

A significant number of these people are sent by WINZ to the ill and disabled via agencies contracted to ACC, health boards and private individuals without adequate preparation.

Some agencies originally specialised in 'household management' (cleaning and cooking) but, as private demand and public money for personal care increased, they morphed into organisations offering 'quasi' nursing services (assisting the sick, immobilised, elderly, dying and paralysed with

problems ranging from incontinence, dementia and pressure sores, to bathing and showers). Despite their \$10.35 base rate (as at 2 February 2007) and poor training, many house cleaners are required to shift their heads from dirty ovens to dirty bottoms and do double duty as the person doing your housework, to carer, transferring you from your bed to your shower or wheelchair, doing passive exercises and washing out your catheter bags. To enable them to make the transition from one job to the other some have been given training (or have

paid for it themselves) to gain first aid certificates (although, in reality, these have often expired). Others have gained a carer's certificate (about one in six where I live). A minority of these are paid between \$11 and \$13 per hour – the majority get less.

Many agency workers failed to keep jobs elsewhere but, as governments moved to have people cared for at home rather than in institutions, a growing number of infirm required help from a diminishing pool of labour. As more of these jobs opened up the number of unemployed went down and, despite compulsory police checks, many proved unsuitable for unsupervised work in people's homes, let alone caring for the vulnerable and the sick. For every well meaning, kind, 'carer' you will find four or five maladjusted, discontented 'don't carers', who are obliged to engage in this work when they do not want to do it. Initially they take on housework and cleaning but as demand and rosters alter they move into the field of personal care for which they are paid a pittance.

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That said, a good carer is worth his, or more usually her, weight in gold. If you find one or two hang onto them for dear life, but they probably won't stay too long because they'll have the drive and intelligence to find jobs that pay at least \$15 an hour for much cleaner and easier work. Those in this category who do stay on and work all hours of the day and night are to be admired because they worry about the people they care for despite having poor employment conditions and difficult patients (read clients). They tend to be overworked, overtired and lucky to take home \$350 a week.

The plight of carers is one thing, but the plight of those they care for is just as serious. When you have been ill for any length of time, and are cared for at home, your family will be unable to cope unsupported for long. A minimum of three and up to nine strangers will come into your home each month if you require seven-day care. The chance of them all getting on with you and your spouse is negligible. One will prove adequate, one a gem, and the others a liability.

This is a barren outlook but it comes from personal experience. I required care for 23 to 24 hours a day for nearly two years and over 10 hours per day for the last four years.

In Burwood, where I stayed between March and October 2001, I learned a lot about who cares for patients and who does not. Although I'll always be in debt to the Director and others who treated me well and taught me to gain a degree of independence, some 'carers' made life miserable. Generally the best care came from doctors (with one notable exception) and physiotherapists, trainee nurses (who paid course fees to be trained there, but received no income for their work), paramedics and nurses. There was disharmony among the professionals. Fully trained nurses regularly fought amongst themselves – they even had an expression for it: 'horizontal violence', meaning being rough on others working in the same pro-

fession. Doctors were also divided but more discrete with their opinions (read: robust debate, protection of their position in the hierarchy and, in some instances, just stubborn refusal to work as part of a team).

Nurses often aligned themselves with one faction or another and some who disagreed with judgement calls from particular doctors over-rode their decisions. This fragmentation in a multi-disciplinary environment was not beneficial to patients. A culture that had grown up over years, if not decades, was demonstrated in one phrase reiterated ad infinitum: *'When you come to Burwood you leave your dignity at the door.'* It didn't have to be that way. I did not want to be seen half naked on my bed, or later in my toilet chair, in full view of those in the corridor, including rehabilitating patients (female patients were in the minority), their extended families, whanau, staff and many visitors (since then en suite wet areas have been added to some rooms).

During the months that I was confined to bed and further immobilised by weights screwed into my skull (to keep my spine straight) my greatest fear was of fire. That was until an overseas porter (carer) came on the scene. On several nights I'd feel a presence at the end of my bed. On one occasion I said, *'Who's there?'* and an American drawl came back, *'Your biggest nightmare.'* I was too afraid to make a formal complaint but some other staff shared my concerns about this guy. However, he was still there when I returned months later. One nurse 'carer', who held my head while the weights were taken off, let my head slip and when I said she had hurt me she scathingly replied that she had been doing the job for years, was senior and I had better be careful about whom I criticised. It was written in my notes that I was a 'bit tearful' that day. Urology wasn't fun either. There was nothing more distasteful than having intermittent catheterisation taught in front of a middle-aged

untrained woman who snickered *'when I get home my husband just doesn't believe what we do in here.'*

Another unpleasant memory involves being slapped by a nurse when I suffered psychosis after a steroid (dexamethasone) was administered during spinal surgery leaving me mad as a hatter for a week. As she slapped me she said, *'We'll have no more of your misbehaving madam.'* I have no idea what I did or said that was wrong. I may have been unhinged but I believe I remember every mad thought that went through my head and all the comments made by staff who thought I was oblivious. I was very afraid of staying mad. The experience was worse than the accident that left me paralysed. In Burwood I was afraid that complaints would lead to retribution and that has remained the case ever since I have lived back in the community and accounts for a lack of formal complaints. An angry carer, or one who doesn't like you, is a scary thing when you have limited movement and live alone.

On my return from Burwood, unable to move any part of my body from the chest down, having diarrhoea eight or more times (day and night), incontinent and unable to use a toilet, I required around the clock care. The agency contracted to ACC provided nine carers to look after me in shifts throughout the week. They decided I should meet six of them, all at the same time, shortly after I came home. It was an incredible hurdle to meet one or two strangers, let alone a crowd. A co-ordinator was sent to my bedside to ask me how I wanted to arrange their hours and what needed doing on each shift for my two children and me. I got to Tuesday and then, sweating and nauseous said *'I just can't do this.'* She stood up, dropped the roster sheet on the bed and stalked out. That particular co-ordinator has not visited since.

Among those first nine carers a couple stayed with me for at least two years and one until the present day, six years later, so I've been fortunate.

But in between I've had at least 20 others (here and in other centres). Some have stolen drugs, one dropped me, an 18-year-old had to lie down because she *'felt giddy from steam off the dishes'*. Several suggested my accident was 'all for the best', 'meant to be' or 'if I'd been better in past lives I wouldn't be in a chair today'. One 'carer' (in this case a trained nurse), after experiencing difficulty putting my pants and shoes on, asked me why I didn't have my legs amputated as they were just a nuisance. If all the bits that didn't work on me were chopped off or out I might as well put my one good arm, head and big mouth into a vase on the mantle piece.

Unfortunately, because so many carers (not all) come from a sector of the community that struggles financially and in many other ways, they bring their troubles with them. Although it's against (routinely ignored) Agency Rules, the longer they know you the more you talk about their personal lives, share in their troubles and, by default, over the years the more exhausting and depressing your own life becomes. Five underpaid, sad, stressed carers a week don't make life all hee hee ha ha. And the worst thing you can do as 'the cared for one' is have a down day yourself. It's almost taken as a personal affront. My experiences are not one off; I've talked with many others in similar positions around the country and they too have stories of being left without a drink for 17

hours because 'carers' have failed to turn up, having had money stolen by carers they thought were mates and so on. One paraplegic, who returned to Burwood because he was unable to get adequate care outside, told me he had been robbed three times. My best friend from Burwood days had

a substantial amount of money taken from near her bed while she slept.

At retirement homes/hospitals where I have had relatives it is an uphill battle to get them three showers a week, even when they are incontinent. 'Carers' patiently explain that, as they get older, 'clients' don't perspire so much, their skin and hair are not so oily, and so two showers a week is standard. If you fight you can get them three.

When their bladders don't work they are wrapped in undignified square paper and plastic naps, when perfectly decent disposable incontinence pants are available. In one home no nappy changes were made between midnight and seven in the morning. At night there was often only one registered nurse on per shift, a nurse aid and a small number of 'carers' who often didn't (this for more than 70 residents spread over three wings). If residents 'have issues' and get angry a few times in a row, they are likely to be 'reassessed' and low doses of anti-psychotic drugs such as haloperidol prescribed because they work as anti-anxiety agents. But in some cases they have highly unpleasant side effects on the recipients – mouths so dry they can barely talk, dreadful dreams and mental changes that make them feel

hopeless and appear more demented than they are. I asked one geriatrician if, in his experience, these drugs actually did the patients any good and was told *'well, no, but it makes them more manageable'*. I'm not talking about crazy, violent, old people here, but the frail, frustrated, confused resi-

dents who occasionally want to retaliate against perceived indignities. They don't expect to pay upwards of \$700 a week to be treated like this. To me the worst nursing homes are run by indifferent carers for chain operators wanting to maximise shareholder gains. There appears to be as many checks and balances on the welfare of their inhabitants as in the country's mental hospitals in the 1950s and 60s.

Many people enjoy their rest homes until they become inarticulate, incontinent and vulnerable.

But the weaker you get, the more care you need, and the way things are, the unhappier you are likely to become.

I have an associate who worked as a team leader in a call centre recovering debts from people who owed fines. She earned over \$100,000 per annum with bonuses for achieving targets. I have another who works for a bank selling services and debt for the same kind of pay. I am not arguing about their levels of remuneration but rather how it compares to that of 'carers' who are supposed to look after the physical and emotional wellbeing of our mothers, fathers, disabled children and so on. They are lucky to earn \$12,000 a year. Care of vulnerable human beings should rate above debt collection and money management on our scale of priorities. Looking after people in their homes or in institutions should be a high status job, well remunerated in return for good patient care by properly trained people who have empathy for those they work with. This can only be achieved by lobbying government for standardised qualifications, increased remuneration, and thorough unscheduled audits of our community's carers and their umbrella organisations.

Competing interests

None declared.

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