

# “Permission to speak”: a carer’s experience

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**BILL, MY LIFE PARTNER** of 40 years, was diagnosed with cardiomyopathy in 2003 when he was 60. The latter is a quite common severe heart disease, usually of people older than Bill. Coronary heart disease saturates publicity about heart disease, making other heart disease invisible. Coronary heart disease tends to be a disease of coronary arteries but Bill’s arteries are very good. Cardiomyopathy is a disease of the heart muscle. The damage has led to heart failure, the inability of the heart to pump sufficient blood to supply his body’s needs. In heart failure or reduced function, the heart is unable to pump as effectively, with symptoms such as shortness of breath, tiredness and fluid retention.<sup>1</sup> Cases are sometimes treated with a heart transplant.

I retired in 2003, and ten months later became Bill’s informal carer when he suffered a stroke as the result of a heart procedure to replace, with a defibrillator, his 1999 pacemaker, which was malfunctioning. His heart was defined in the profoundly-to-moderately impaired category. His ejection fraction (pumping capacity) was 25% compared with the healthy heart at between 50%–80%. During the heart procedure, difficulties arose removing the old pacemaker and a clot around the old pacemaker leads escaped. Four days later he suffered a stroke.

I have chosen to write about two aspects of the carer experience where the structure of medicine and the related professions compound the difficulties with managing chronic disease. From at least the 1890s, carers and relatives have been regarded as a nuisance to medicine, and in my view this persists. I have been constantly excluded from hospital environments and become an illegitimate and shadowy figure, yet I am central to Bill’s chances of extending his life.

When it suits powerful members of the “health team”, I can be wheeled back in at discharge to take almost complete responsibility, after five minutes training, for his medications and all other hospital functions.

## Seen but not heard

I was forcefully inducted into “my place” as “seen and not heard” when Bill was transferred to the stroke ward of a different hospital following the clot debacle. At that time, he was in the most acute phase of aphasia, with difficulty comprehending and speaking. Speech damage is in a switching area and the wrong words emerge. Like most people, Bill is a split asserter: assertive about some things and not others. He would sometimes tell me important symptoms and not the doctors, nurses or therapists. He continually told me he had a pain in his right stroke foot and showed me it was shooting out. I initially approached a physiotherapist with Bill’s concerns; she said since the information had come from me and not Bill it would not be acted upon. It took me three weeks to be allowed to communicate this information to the “health team”, which I finally did through a responsive nurse, and he was given Panadol. Whenever I tried to offer useful information I was repulsed. The doctor gave the distinct impression he was doing a battery of tests, including a foot x-ray which I had to pay for, to prove I was wrong. After Bill left the hospital eight weeks later, it was diagnosed as an electrical impulse caused by scarring in the brain from his stroke and is still troublesome.

Bill was fortunate to be accepted for six months more rehabilitation at another facility. However, in my view, the poor level of his cardiac function was never communicated adequately to the treatment staff. In time I became concerned at the intensity of the physical exercise program for a

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person with profound-to-moderate heart failure. When Bill started to have new and worse heart failure symptoms at home I approached the physiotherapist with my concerns but was told that the program could only be modified through medical advice. It became clear they were treating his disease as coronary heart disease not cardiomyopathy. I contacted our general practitioner, two cardiologists and our stroke physician and they intervened with letters to the rehabilitation facility. Unfortunately, in the meantime, a physiotherapist had Bill running!!! at the gym and walking at a fast pace to our local shopping centre where he was so ill he couldn't get back without a myriad of rests.

We later met, by accident, a human movement expert linked to a heart transplant team. He said that this exercise regime could have led to a serious incident — inappropriate aerobic exercise is a pathway to death for this disease. He did tell us that appropriate exercise had been reported in the human movement journals to be associated with recovery. The trick has been to find suitable exercise. Exercise machines have resulted in Bill going to bed for a week. So far we have had more success with yoga and tai chi. Further to Bill's attendance at classes, the tai chi teacher was prepared to come to the house for private sessions for a moderate fee. As a result, Bill has been able to lift his stroke arm above his head, and only he and one other man in his stroke group have accomplished this.

During another admissions process I experienced again my thoroughly discounted status as a carer. The nurse at the emergency department made it clear that she wasn't going to listen to anything I had to say; she was only going to speak to Bill and read the referral letter. This made me feel like a private in the army waiting for "permission to speak" from my authoritarian superior officer, and made me defensive about being in the hospital at all.

These examples illustrate the ambiguous status I felt as a carer in the medical process. There is a "hard bar" or professional barrier which you are not allowed to cross. I did not expect this level of exclusion which is at its most pervasive in the

stroke ward and not quite as total in the heart ward. It exhausts the carer pushing against the barrier, makes difficult advocating for the person and limits, even prevents the communication of important information to make sure he/she is alright.

### **Picking up the pieces**

I also found that caring for a relative with a chronic illness was made more difficult by the insular and closed nature of medicine itself and the related therapy and skill areas. As a participant, this decentralisation of expertise was breathtaking. It actually falls to the individual who is chronically ill and/or the carer to coordinate the expertise to manage chronic disease. While GPs can play a vital role in coordination, at one level the body is reduced to blood test figures on a piece of paper and reporting the results to other doctors. This narrows the scope to coordinate the needs of people living with chronic illness whose body needs are broad-based. Chronic illness is lived on a daily and weekly basis through a series of problems which develop because the disease causes bodily weakness and impairment. Once parts of the body are seriously compromised, ongoing extra problems can relate to the way the person tries to go on, for example, using the wrong muscles or toes that are too small to take the strain and so walking becomes even more difficult and acute pain results. The expertise to handle these problems comes from lower status professionals like podiatrists and chiropractors who may not even be acknowledged as having necessary expertise. This includes our masseur, a physiotherapist from Bosnia, bristling with skills and knowledge but forced to drive buses because he is not allowed to practise in Australia. In real terms, crises occur regularly, and the carer (or the person themselves), if they have the resources, obtains assistance where they can to extricate the ill person from immobility and pain.

Learning to manage excess fluid has been vital for us. The fluid comes mainly from the heart's inability to excrete salt and water via the kidneys

so the retained fluid settles in the legs. In addition, the weak stroke limbs build up fluid of their own because muscle activity is essential to moving blood and fluid. We were fortunate to find a clear explanation of heart failure in an American book by a medical journalist, Castleman.<sup>2</sup> From this we came to understand the disease, the symptoms from the congestion such as shortness of breath and coughing, the retention of fluid and the need for diuretics, fluid and salt restriction, sipping water and using ice-cubes. Once I came to know more, I could ask the specialist and the GP more relevant questions.

Pharmacists have been helpful, one giving us information on the Cardiomyopathy Society. Surprisingly, the pharmacists at a patient support service for one of the heart drugs provided a genuine space to learn about the disease and discussed my concerns about the advisability of extra diuretics. This happened at times when I needed immediate answers as they encouraged patients and carers to ring. We would have terrible days where Bill's legs would look like bridge pylons; his body would be cold and shaking. I would put him to bed at 6 pm. The pharmacists were much more open and supportive than the specialists, and gave information such as because Bill had been a veteran athlete, his system was used to low blood pressure and lower doses of the heart drugs would still work. They gave me the knowledge to ask the specialists to increase the amount of diuretic. At the next consultation, however, one of our specialists forbade me to ever discuss the diuretics with him again because he said he was just there to check the machine in Bill's chest.

Over time, I have arranged with our main specialist to email him occasionally during crisis periods. Like our GP, this specialist listens and is flexible. Our GP is thorough and she has exceptional emotional labour skills, unusual in doctors. She has always been supportive and said from the beginning that she was learning and that we were all in it together. It has taken us 2.5 years to finally come to grips with the fluid so we can manage it on a daily basis.

Part of that journey has come from times in hospital when I watched a specialist reduce the heart failure using fluid restriction. I copied this at home. There is a heart specialist frequently on duty in the heart ward. He has always helped us. One can only admire his sense of duty, and there is no doubt the heart specialists we encounter work long hours and are conscientious. They never mention death and are always positive, trying new strategies. This helps with fighting a disease like this.

We met this specialist on duty again when a replacement GP ordered me to take Bill to hospital for renal failure, itself due to poor cardiac function. I demanded this GP at least contact our main specialist and consult him about this. I had only gone to check Bill's blood pressure because we were going on holidays. (That was to be the first of three breaks I had to cancel because of recurring health crises, and I limped through exhausted until the end of last year). Bill's kidney figures were serious. But I heard a doctor say that kidney specialists were a law unto themselves in Adelaide and refused to visit that hospital. Our main specialist adjusted medications until the kidney and blood pressure figures stabilised. The other specialist mentioned above was prepared to say that there were no easy answers to the fluid problems. This is an accurate and realistic summation of dealing with heart failure. Through trial and error we now know that when Bill exercises we can control the fluid by limiting Bill to 1.5 litres of fluids. We painstakingly measure every drop of fluid; less than 1.5 litres causes problems for his kidneys; any over accumulates in a few days into "bridge-pylon" legs.

The management of Bill's oedema is an example of how the insularity, the reluctance to share and receive information across boundaries,<sup>3</sup> caused difficulties dealing with this chronic illness. I had learned from previous personal experience that oedema has to be treated carefully. Cuts and scratches on the compromised limbs had to be attended to immediately with antiseptic cream, and daily moisturising and exercise to prevent infection or ulceration in the swollen limbs. There was an ever-present danger that a limb could

become infected and so swollen it would be near impossible for experts to reduce the limb to a reasonable size. Such an event would be the last straw for Bill in a fraught illness journey.

Three days before the admission for renal failure Bill had an ultrasound for a suspected deep vein thrombosis (DVT) in the enlarged stroke leg. This had been a “fishing expedition” from yet another physician consulted over an infected, swollen and painful scrotum and dermatitis (now permanent) from chlorine, picked up during eight months of exercises at a heated pool. The ultrasound operator had to push hard through the excess fluid, and as a result Bill’s leg doubled in size and became bright red from bruising, aggravated by the effects of the anticoagulant warfarin. No DVT had been detected, yet in the emergency department, three days later, the doctor wanted to order another ultrasound for a DVT on the stroke leg. I had to practically stand guard over his leg to prevent a full blown oedema episode through a second unnecessary ultrasound.

Oedema expertise in Adelaide comes from one of the foremost researchers in the world, but unfortunately for us this researcher is not a medical doctor but instead comes from a lower status part of the health care “team”; a professor originally from nursing attached to an oncology unit. Most of our doctors seemed curiously ignorant and unconcerned about oedema in the compromised limbs, and as a result the treatment is discounted and is not covered by Medicare or private health funds. It is so marginalised it took me a year to get an appointment for Bill, who was finally diagnosed with venous oedema and directed to exercises to activate the lymph system. We were also given the crucial advice to keep antibiotics in the freezer to deal with infections from tears and scratches.

## **Lessons from my experience**

In September of last year, we were jubilant to learn that Bill’s ejection fraction had risen over the preceding 12 months from 25% to 36%. However, as I write he is again very ill and breathless

following an adverse drug reaction and is back in the heart ward. Yet another break has been cancelled. We do not know what the future will bring.

It needs to be said that many other health-related people have helped us during this very hard journey. During stroke rehabilitation, a social worker was wonderful to both Bill and me, acknowledging me thoroughly as a carer and helping me personally. Occupational therapists were also approachable and accepting of carers. The speech therapists grasped Bill’s tragedy as an academic, losing his life-long superior facility with words. Many went the extra mile to help him. Eight months after the stroke, with my support and that of friends in Brisbane, pale as alabaster, he successfully launched his book,<sup>4</sup> finished one week before his stroke, to a committed group of Aboriginal people and friends at the Museum of Brisbane. A related group of Aboriginal people honoured him the following year, for preserving their heritage and helping them find their families.

From this experience, what would I recommend? It would really help me if there were Heart Failure Centres in Adelaide as there are in Melbourne. Most of all, access to a cardiac nurse would take the agony out of trying to decide whether to battle on with the heart failure symptoms or go to emergency. Eventually, special centres (at an intermediate level compared with hospitals) for people living with chronic illness could be staffed by salaried professionals representing a wide range of skills. There should be an obligation on doctors, particularly in stroke wards, to speak to the carer at the beginning, so she/he doesn’t have to spend days trying to find them. Stroke facilities in particular could update themselves on the growing literature on carers and start including them. A sizeable minority of health care professionals could stop pointedly excluding informal carers. Talking directly to the person with the illness is important, especially if they have a disability, but such an action should not be used to treat the carer with disrespect. There is a way, practised well by our main specialist, our GP and the oedema expert

described earlier, of addressing the person with the illness and also including the carer. I would like to have some standing as a carer in hospitals. At emergency, you could be asked, "Are you the carer or the main person responsible for this person's care?" and then be treated respectfully. When I say to Bill's nurse "Perhaps it's not a good idea to put that drip in his stroke arm" I'd like to be listened to instead of being discounted or treated warily until the thinned blood starts pouring out of the wound. Hospitals could begin making carers visible by putting the word, "carer" on some of their signs, even the signs that say "Staff only. Patients and Visitors go to the cafe". It would provide some recognition if the sign said "Patients, Carers and Visitors go to the cafe". There might be a carers' space with instant hot water to make a hot drink.

While we found particular individuals in the health care system to be personally admirable, long-held beliefs and system boundaries made it difficult for even them to adequately support my role as a carer for a person with serious chronic illness. Family carers are a fragile and declining resource for the health system.<sup>5</sup> The politics of exclusion and marginalisation practised by some members of health teams is unjust and disrespectful. It is also a waste of precious resources including tacit skills and knowledge about the management of the condition. In reality, informal carers are an important part of "the A team",\*

helping extend life and in some cases even restoring a person's health, and should be recognised as such.

## Acknowledgements

\*I would like to thank Barbara Buttfield for the idea of "the A team". As a valuable friend, she has contacted me on a weekly or fortnightly basis, as has my sister, Gwenyth. They have provided crucial emotional support which has helped me sustain my role. Ian Buttfield has been there for us too.

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(Received 25/02/07, revised 27/02/07, accepted 8/03/07) □