

**Presentation for the RAINBOW VISIONS HUNTER
AGEING FORUM**

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Finding a pathway through the maze of health and aged care bureaucracy

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This is a transcript of a talk given by Sandy at the Rainbow Visions Community Forum on Ageing held in Newcastle on Saturday, 17 July 2004

Late last year, my partner of 17 years suffered a series of strokes and heart attacks, most of them after being admitted to John Hunter Hospital – but that's not a criticism of the hospital.

We had both been in previous long-term lesbian relationships, in which we were "**under cover**" for various reasons. When we found each other, we were determined that this time we would be **out**, so have spent many years treading on toes, causing great consternation to neighbours, colleagues and general community, because little old ladies are not supposed to even know what a lesbian is, let alone declaim we are.

So when Elin collapsed at home, the ambos were the first to have to deal with our relationship, starting with the many paintings and photos of naked women decorating our walls. They coped pretty well, better in fact than the staff in Emergency, who stubbornly decided we were "friends". Once we started the admitting procedure, they had to accept that I was more than her friend, we were life partners, I am her next of kin, and we have granted power of attorney to each other. So we eventually won that first round. I can't emphasise enough how important power of attorney is, especially for people in same-sex relationships, and how critical it is to have that legal document. They can't ignore it or you when you have that power.

The next few weeks were terrifying, hopefully more so for me, as Elin was unconscious, resolving after some weeks into unknowing and unaware. No muscle control, unable to swallow, speak or even hear, and her legs contracted in foetal position. She did tell me many months later that she was really pissed off that everyone ignored her when she asked or answered questions during those weeks – unfortunately, she wasn't vocalizing.

During this period, the various specialists treating Elin held many conferences with us (Elin has 4 children from a previous relationship), and I was repeatedly asked how aggressive their intervention was to be. I have no medical background at all, and due to my rather non-functioning state at that time I had absolutely no idea which process or behaviour I was being asked to decide on. About 2 months later Elin was transferred to an interim care unit at Newcastle hospital because her condition had improved remarkably, and I was asked that question again. This time I pinned the

geriatrician down – to discover that their usual practice for someone as damaged as she, is to discontinue feeding. Well, thanks to my naivety, that didn't happen.

Hats off to hospital social workers who steer grieving, ignorant partners through the steps from hospital to care. Those who work in the health or aged care sectors will understand the logic, but I'm sure most of us outside find it incomprehensible. Making a decision on "the next step" is very difficult when you're not even sure what the last one was – and bureaucrats often have a very high level of "assumed knowledge" for partners or next-of-kin.

During these same 2 months, the Aged Care Assessment Team, ACAT, was brought into our lives when Elin's recovery seemed to be as good as it was going to get, but that would preclude her coming home. Legs irrevocably contracted in an almost-foetal position, a clot occupying most of the base of her heart and severe heart damage or disease: investigation is not an option. It's astonishing how heavy a tiny body can be when it has no muscle control, so it takes 2 trained people to turn her every two hours. We don't have a choice, even though she breaks my heart every few weeks asking when she's coming home, because she keeps forgetting she can't.

The ACAT process is fairly painless – it's trying to fathom your way through the requirements of the various Commonwealth departments that causes the real problems.

The 15 page application form for respite or aged care ("supported by the Department of Health and Ageing" – no Department actually claims ownership!) must be submitted to every care facility you choose as a possible home for your partner. A heterosexual spouse or de facto, or a dependent child, or a carer, or a close relation, doesn't have to include the value of the family home in the asset declaration, which determines the amount each resident is charged. But there is no descriptor for us on any Commonwealth Government form.

Department of Health and Ageing doesn't assess your assets, that's CentreLink's responsibility. But their assessment is not binding on Health and Ageing. I was lucky enough to find a CentreLink financial adviser who understands the hidden possibilities in the questions, and who provided some interesting interpretations and definitions. Hopefully, she got it right, because we're still awaiting their assessment on whether we'll be liable for an additional penalty payment of around \$100 per week if Elin's asset total is too high. Being joint owners of our home rather than tenants-in-common does give us some additional security.

Searching for the right aged care place is soul-destroying. Of course they're going to show you the best side, but you feel such a traitor, and how on earth do you know what to look for anyway? And once you've decided where to apply, you can't leave the phone for fear of missing a place offer. The pressure is on big time, because refusing an offer is not allowable – area health commissions have the power to transfer patients from a hospital to an aged care facility anywhere in their area if the offer of a place is turned down. I'm fairly confident that Elin is in a happy, caring residence, but you never feel quite sure. During the inspection/application period I continued to be up-front and **out** about our relationship - they had to understand who we are or it wasn't

a right place. The staff where Elin is seems to be supportive, caring, and totally accepting, and the director allocated Elin a single room, so we have some privacy.

I used to be a control freak – well, we both were actually, so we had an interesting relationship. Now I've learned to live by the day when she's having good times, or by the hour when delusions are frightening her. And even though she hasn't been able to fully re-establish emotion pathways after the stroke trauma, physical contact like holding hands is extremely important, and she gives a good cuddle with a little assistance.

I've heard there are some gay accommodation and care facilities already existing in America, but I don't believe our communities in Australia are large or affluent enough to go down that path yet. A book recently published in America by an aged care worker had some frightening statistics, the author calculating he could allocate only 17½ minutes per day per resident because of short staffing. Perhaps that's why the gay communities in the US have started to create their own specific facilities. I don't think Australian homes have become as desperate as that yet.

Around 20 years ago, some friends of ours, four lesbian couples, purchased a small block of flats in Sydney, but that venture failed when couples broke up and individuals wanted to opt out. About the same time a Sydney lesbian coalition attempted to establish a housing cooperative for residential units plus an aged care facility as the second stage. It failed due to a lack of financial backing from individuals and, predictably, total lack of interest from the Government.

In a recent ABC Radio programme, a few callers discussed the benefits of friends buying adjoining town-houses to ensure easily accessible support in crisis, some even going so far as to have the units identically keyed. That latter successful venture doesn't, of course, address the specific theme of ageing in **our** communities. There is obviously massive scope to improve all types of services in our communities, but I'm certainly not qualified to offer that sort of direction.

Maybe gaining recognition by the Australian government would be a good starting point?
