

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

**Inquiry into the provision of supported accommodation for Victorians with a disability
or mental illness**

Melbourne — 5 November 2008

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Ms S. Stevens, carer.

The CHAIR — Welcome to the hearing, Ms Stevens.

Ms STEVENS — I am Sue Stevens, and I am a primary carer for two of my family members. My sister, my mother and my grandmother have been diagnosed with schizophrenia. My father has a severe head injury and is also physically disabled from a stroke. I am the only well person in my family, and this has been part of my life for about 20 years. I feel some of what I have prepared to say appears almost insignificant compared to some of the stories I have heard today. However, the members of my family have gone through a pretty hard time, and I am sure there are hundreds, if not thousands, of other people in their position and their stories deserve to be heard also.

My sister, Sharon, is 41 years old. She had a nervous breakdown when she was 20. She was diagnosed with schizophrenia at that time. Sharon tells me she has been sick since she was about 8 years old. My parents were not listening. No-one knew what the hell was going on. My mother was not diagnosed at that time. My father was “normal”. My father, Barry, is 65 years old. When he was 40 years of age a drunk driver ran the vehicle in which he was a passenger, off the road, resulting in dad’s first head injury. So my sister was diagnosed and my father had the accident at approximately the same time. My father fell from a bus seven years later, sustained another head injury and had a stroke. He spent about three years in hospital and rehab.

I have hundreds of stories about two people I love. Here are just a few. Barry is now a resident at Hazeldean Nursing Home in Williamstown. My father is the second-youngest resident at Hazeldean. As my father can be a friendly, charming and witty fellow — that is, when you can understand what he is saying — he gets along well with the staff, most residents and the visitors.

Some of the nursing staff have taken a particular shine to Barry, because he is such a charismatic fellow. He is actually one of the few residents who can speak reasonably coherently or speak at all. He shares a room with three other people. Sadly it is a little bit like God’s waiting room, and Dad complains to me that he is just sitting there waiting to die. He has only now just become an old-age pensioner, but I guess he feels quite young in comparison to the people he lives with. My father likes the staff and the food, and he is always very happy for that. He is a shining fellow. He is always optimistic, given what has happened to him. His hobbies are smoking, going out for a cappuccino, the AFL. He follows the “break-your-heart” Bulldogs.

I know this might seem petty, but it is important in comparison to what other people have said. It is about service and the attitudes of staff with regard to supported care at Hazeldean. Due to the severity of my father’s disability, it is a requirement of the nursing home that he is escorted outside by a nurse or a visitor for a cigarette, which is good. That happened after my dad fell out of his wheelchair and did a “header” into the garden. As he tells me, he was lying there for a few hours, but God knows really? He is a bit of a joker and he has a head injury, so he or I, will never know. Anyway he said he was lying there calling out for help for a while and after a while someone actually did come and rescue him. So he is now escorted when he goes out.

My concerns are that there is no awning, no heater and there is no cover outside. Once someone gets a “bug” in these nursing homes, everyone then gets diarrhoea. If someone catches a cold, everyone gets the flu. If people got outside more and maybe got a bit of vitamin D, they might be a little bit happier. If you can provide a little bit of cover for people, it is a simple thing, isn’t it, really?

I actually submitted a suggestion pamphlet, where a number of things were addressed. Outside cover is just one of the things I addressed. The response was that the veranda and the heater would be too expensive and not many people go outside anyway. They might go outside if it was a bit more pleasant. It would be a health benefit for all.

My dad loves the food. I find this a personal insult, to be honest. I cooked for him for at least five years. I cannot imagine why he thinks their food is better than mine. Anyway, about a year ago

Dad was placed on a soft food diet as a part of his personal care plan. This is the result of a nasty choking incident when he went blue in the face and scared the “bejesus” out of everyone who witnessed the event. Because of his stroke he has got vocal cord damage et cetera and he does choke on food quite easily — he can choke on anything, really.

Part of his new personal care plan was that he was always to be in the dining room when he ate, which is great. He was also placed on a soft food diet. A number of times I have found my father in his room alone. When I questioned the staff, they just said, ‘Well, he would be fine, because there was a nurse doing the rounds on that side of the nursing home’. But I wonder? People would actually choke to death without being heard, don’t they?

Anyway, while it was a tough decision to put my dad on a soft food diet, because food is one of the last things that he has, really. It was made quite clear to me he could only have one diet or another — the regular menu or the soft food — although a lot of the soft foods on the regular menu of course he could eat. The staff were not interested in some of my suggestions. I have offered to bring food in, and I offer to help in any situation, whether it be financially, my time or any assistance. It is okay to bring in food myself as long as I take responsibility for him eating the food, which is okay.

It appears that the rules are either broken by staff or strictly adhered to, depending on how much time it will save the staff. I appreciate that people in those positions are underpaid. I understand that Hazeldean is closing down. I understand that the possible closure will reduce staff morale. I did not choose to be my father’s daughter, nor my mother’s daughter, nor my grandmother’s granddaughter, nor my sister’s sister and everybody’s carer.

If you take a job in one of these organisations, you choose to take the job, so when the staff want to complain to me about all of these things, about my father, think about the steps I have walked and think about my people, my family, before you start complaining to me. I am sure you have all felt that, carers. Our people have done it harder, and I have done it reasonably hard too.

Watching or listening to the “break-your-heart-Bulldogs”: is a part of my dad’s care plan. I do not think this is an unreasonable request. Every Saturday during the footy season I go into Hazeldean or I ring them up and say, ‘Hey, the footy is on’. They do not have Foxtel, so if it is on the TV I tell them when it is on. Hazeldean is in the western suburbs, and most people in there are Western Bulldogs supporters. I know that is not a big issue. As a Marketing lecturer I offered the management a fundraising plan and assistance to get Foxtel installed. On a number of occasions I have gone to the nursing home and there is not a TV on or the AFL on. The radio is not even on.

It is not just my dad I am concerned about; it is simple stuff. My dad has a head injury. He probably does not remember; he does not even know where they, the Bulldogs, finished on the ladder. He keeps asking me whether the footy is still on. Is that really the point? I only want the footy on; I only want a radio on. A lot of people there enjoy it. It is just the tiny little things that add to all the frustrations. As I said before, I know this is not big stuff, but it is still important to me and it is important for him. He has to get a few laughs somewhere, and it is not just him I am concerned about. Some of the staff are fantastic. I do not want to complain about the whole facility.

Once I paid a visit to dad and he had wet his pants. My dad is in a wheelchair. He is 100 kilos. He is a big guy. It must be humiliating. I asked the nurses to change him, and they seemed annoyed. They actually debated it for about 10 minutes. I was disgusted. I felt quite emotional, and after it was all resolved I started crying, and then I felt angry. They debated that it was not his turn to get his nappy changed. They were upset about it because the job required a lifting facility to lift this 100 kilo man out of his chair. I know he is heavy; he used to collapse at home, and it was up to my sister and myself to pick him up. I know it is hard. At least they have a lifting facility. ‘The man is sitting there in a wet nappy and he wants to get it changed. Can you just change him, please?’. I noticed several staff members were gathering together with their meals; I guess it was mealtime. ‘I

can't be bothered. I can't be bothered. I'm not paid enough. I don't care. I've got enough going on in my own life' — that is what I hear, without actually hearing it from the staff.

Occasionally when I approach the staff they almost seem to get annoyed with me. I know I am outspoken; I have to be. 'Be bothered. He's my dad'. I did not choose this for my father. My sister and I took care of him for a long time, beyond our physical and mental capabilities. My father was adamant that he was okay while enduring his last years at home and would get angry and abusive if we ever mentioned that he needed more help. My sister has a severe mental illness, and you are familiar with that. She threatened suicide during my father's last days at home. That was when I made the decision, in the end, to put my dad into care, because the decision seemed to be between my sister's life and my father's.

How can we make nursing homes more livable? How do we encourage employees and nurses to adhere to care plans? I am not the enemy. I do not want to be treated as such. I do not think they think that, but sometimes I feel that because I am a bit more outspoken and because I want to be involved, I feel like I am noticed by the nurses in a negative way. I do not know. Sometimes I just feel a bit awkward. That will not stop me.

Just a quick paragraph about my sister. My sister Sharon has also lived in supported accommodation. When she has not lived there she has lived with my father or my mother, or occasionally with me. She tells me she had a great support counsellor which made a difference. There are not many of these support counsellors around. Unfortunately she suffered mental and sexual abuse in the accommodation facilities. When we went to complain no-one really cared. We went to the police. The police ignored us.

The CHAIR — I am conscious of the time. Could you please conclude?

Ms STEVENS — Yes. This is the last sentence. She cannot remember when she left the accommodation. It was difficult for her to deal with the residents. They were often more mentally sick and usually more negative than she was. Naturally the sicker she gets the more her health deteriorates. Thank you.

The CHAIR — Thank you very much.

Witness withdrew.