

“Everyone Needs To know About This”



Stewart and Robyn – People First Southern Office Trainees – June 2009

I have hole in heart and all my life my breathing has been a bit slow. In the middle of May 2009, my breathing became more difficult. So, after being in hospital for a week or two, I am now living in an Old Persons' Rest Home Hospital.

I want to tell you about my experience so I can help myself and to help all young people my age who find themselves in a Rest Home Hospital.

I now live in a Rest Home Hospital in Christchurch. The old people who live here are not my age. Many of them here are very sick. It is really hard to live here with all these elderly people. It doesn't really suit me well.

When I was living at Hohepa, Canterbury I liked it there. I lived almost independently. I had the life of an adult. I lived with people my own age. We had fun. I could help people with their problems. I am good at communicating with people my age. I like to help other people. I talk at conferences and help run advocacy training with people like myself.

When I lived with my flatmates we could support one another to cook and clean and things like that. We understood each other very well. I am missing all my friends and also missing my flatmates as well. I liked going shopping and doing my jobs as well as I could. I can do things on my own easily as long as I go at my own pace.

Let me tell you what it is like to live in a Rest Home Hospital.

My room is very small. I can't get around in it. I like having my own bathroom, but I have to put my wheelchair in there when I am not using it. I only need my wheelchair to walk long distances, so it is a pain.

When visitors come there is only room for me to sit on the armchair at the end of my bed and then they sit on another chair on the other side. Our knees touch. Otherwise I have to see visitors sitting in my bed. I can only see one visitor or maybe two small ones (!) at a time.

When I lived in my flat there was heaps of room. We could go to the kitchen and make coffee and sit in the lounge. My flatmates could join in if they knew my visitors.

My family has bought me a laptop because there is no room for a computer desk in my room. But to use my laptop I have to move everything off the bedside table and find somewhere to put it. If I have my door open I can't get to my cupboard to get my clothes and things. There is no room for any more things.

My honey comes to visit me but he can't get into bed with me or cuddle me that easily on the bed. It's not a comfy one. It is a hospital bed that goes up and down at both ends.

When we lived in the same house, we could spend a lot of time in our bedrooms together. Now, my boyfriend can't stay the night, but I might see if he can sleep on the armchair some times. I think the staff would be shocked if they found him there in the morning!

Watching TV in my room is all I can do in the evening. There is no one to talk to except the staff. They are busy. I phone people a lot. I feel I have to stay in my room. There are lounges but no one goes in there from the hospital at night. The lights are off. There is nowhere to make a drink.

At night everyone is in bed by the 6pm news. They are very sick. They don't move or want to talk. They are asleep in their rooms with the TV on loud after tea. Everything goes quiet. All the time you hear people coughing, using buzzers and lots of TVs very loud on different channels. Sometimes people shout out. It's annoying. I find it hard to hear my TV. I like to have my door open. I need fresh air.

Some of my things have gone missing – my hairbrush, my iPod, my wireless connection for my laptop. Even though my room is small - things keep hiding.

There's nothing much to do at the weekends.

Why would I want to go sit with old people who don't talk or are sick or grumpy? I'd rather just lie in my room and watch TV.

I do go to 'Happy Hour' on Tuesday and Thursday afternoons because Kevin makes it fun. I like having a drink of lemonade and I listen to the entertainment, but no one wants to talk very much. I don't think they can hear me well with the music.

I used to help cooking with my flatmates and going shopping. We used to choose what we wanted to eat. Now my meals are given to me cooked. I don't know what I am going to eat at any meal. Sometimes the food is cold when I get it.

I used to do my own washing. Now my family pick it up and do it so it doesn't get lost.

The staff are very nice but they are always changing. I get different ones every day and I never know who I am going to get. When I lived in my flat I had two staff, one in the week and one at weekends. They came in the afternoon to guide us with our cooking, house meetings and shopping. They knew us.

The nurses talk to me but they are busy. They can't stop for long. I like the nurses but not the residents!

Only some of my friends can visit - the ones who can get the bus or get a lift.

I don't take any medication. I have to have a bit of oxygen when I feel dizzy. This doesn't happen very often. This is why I am in a hospital. The specialist said that when I get out of bed in the

morning, that is the time I could get dizzy the most. But I have to have staff around all the time. Yet, I can go out when I want! So I don't get it! Why am I still here?

I do not want to be in this Rest Home Hospital for all my life.

This is not right for young people. I find it so hard to talk about this place because I cannot believe that I am allowed to be here!

With my work at people First, I have learned all about having my own choices. My choices are not being heard. Living in a Rest Home Hospital is so wrong for me!

My family and friends have been looking for somewhere else for me to live but they can't find anything. Sometimes they think they have found somewhere, then it turns out that I can't go there.

My dream for myself is:

Choice 1

I would like to go back to where I lived, I love my flatmates. I know how it all is there and my boyfriend also lives there. It was my home

Choice 2

I would like to live with my boyfriend in our own house. I would like my boyfriend to leave where he is living to get support somewhere else to live with me.

Choice 3

I want to be sharing a house with other people my own age.

I don't want to live back with my family - although I love them.
Because the most important thing is that I am living as an
independent adult. Because I am!