

Venee Burges Hostel 1974

Letter One:

'Please help me. I'm getting more and more depressed every day and I'm taking drugs that don't help. I get worked up easily, so much so I couldn't go through with the operation. There must be something wrong with my mind. I hate myself more and more, for being a CP. Why should I be forced to miss out on so many things in life? Why can't this place provide a hostel where I can live my own life and not be tied down by aging parents or be forced to live in a hostel for kids?

I don't think you fully understand the problems some CP have to face. Look, all I know is that something inside me has changed. I don't know what it is, either environmental factors or just going through a difficult age. All I know is that life for me at the moment is very frustrating and difficult. And above all I suffer from depression most of the time. Please note, I have gone off the Librium. Would an antidepressant drug help?'

Letter Two:

'I hope this letter is better than the last one, and it will give you a better insight into my problem. You may pass this letter on to anyone who wants to know more about the problems a lot of CP have to face today.

I think, unlike some CP, for a year or so I have been able to live an unsheltered life because I had to stay at the hostel when my mother was ill. When through things beyond my control, I started living at home again, I was not prepared to be 'Mum's little boy' any more, more or less secluded from the outside world. However, if a young man who is handicapped to the extent where he has to rely on someone to feed, bath and dress him, namely his aging parents, he becomes more and more agitated because he is forced to miss out on a lot of pleasures in life.

Centre Industries gives me a tremendous feeling of satisfaction by giving me a chance to serve the community. And The Spastic Centre has educated me. But The Spastic Centre and Centre Industries have only fulfilled a part of my life, mainly due to public ignorance by not providing funds in order that accommodation be provided for myself

and others like me. Thus I am forced to live only half the life I should be living.

To face up to the fact that I am handicapped is very difficult. I have learned to live with it; but like everyone else I have 'desires'. A normal person can satisfy them in one way or another, but at the moment I cannot do that altogether, I'm not just speaking in terms of sex and love, although these things play a big part. A lot of the things people take for granted, such as going to various places, even simple things like going shopping or to the local pub.

These things I cannot do because I'm forced to live with my parents, whom I am totally dependent.

I have tried to organise my interests in life without involving them. I should be able to get acquainted with people, seeing that there are so many at Centre Industries, but I can't as everyone is so busy.

I understand when the Adult Hostel Complex is built there will be someone to organise social activities, and I'm hoping these future extensions to the Centre will help to give me so many of the things I've been missing out in life, and like any normal person, I would like to be able to live my life as I see fit.'

AFTER SEVEN YEARS OF STRIVING TO FIND THE MONEY NECESSARY TO PROVIDE A PLACE WHERE THESE VERY HEAVILY HANDICAPPED, INTELLIGENT PEOPLE CAN LIVE THEIR LIVES AS THEY WANT TO – AND AS THEY ARE CLEARLY ENTITLED TO – OUR FIRST ADULT HOSTEL IS AT LAST COMPLETED AND NOW HOUSES FIFTY VERY HAPPY, VERY HANDICAPPED PEOPLE WHO CAN FIND NO OTHER PLACE IN THE COMMUNITY.

OUR JOY AND PRIDE IN THIS PROJECT ARE, HOWEVER, SHARPLY MODIFIED BY THE REALIZATION THAT IT ALL CAME TOO LATE FOR THIS LAD – BRIGHT, INTELLIGENT, INTERESTED IN MUSIC AND BOOKS. HE COULD NOT WAIT ANY LONGER, AND YEARS BEFORE IT WAS OPENED HE DIED – PROBABLY BY HIS OWN HAND.

In 1967, Mrs Audrie McLeod and Mrs Venee Burges were assigned by the Board of The Spastic Centre, the task of reporting on a plan for the living accommodation of the adult cerebral palsied. The Board was conscious of the fact that the facilities in the McLeod House Country Children's Hostel were unsuitable as adult living accommodation because they were geared to the requirements of children only. The delegates visited thirty-three units in the United States, eighteen in the United Kingdom, three in Holland, eight in Denmark, eight in Norway, seven in Sweden and one in Italy. Their conclusion was that many of the things they had seen were applicable to some aspects of our own problems, and that, worldwide, there was no effective accommodation or work for the heavily handicapped adult cerebral palsied.

We envisaged a hostel aimed at accommodating fifty workers already employed at Centre Industries, whose parents, for a variety of reasons, were unable to care for their children at home. In planning for the living accommodation of the adult cerebral palsied, it was necessary to consider two important factors: satisfying the needs of the people who were to live with us, and providing a training medium to prepare as many as possible to achieve independent living in the general community.

In a letter to the Director General, Department of Social Services in June 1972, we wrote:

'We have recently submitted to your Sydney Office an application for subsidy, under the Sheltered Employment Assistance Act, for a Hostel to accommodate forty-nine severely handicapped cerebral palsied persons who are employed at Centre Industries and who, because of the severity of their handicaps, will probably remain in this hostel accommodation throughout their working lives. It would be impossible for them to obtain outside accommodation with the level of personal service they would require.

In spite of the fact that these people are so heavily handicapped, because they are young and energetic, they do not believe that the facilities available in this hostel should be geared to the kind of sedentary life, which may be more suited to the elderly inmates or a nursing home.

Most of them will be in motorised wheelchairs, therefore the hostel must be designed for wheelchair access, not only to rooms, but to cupboards, washroom vanity tables and showers. In addition, wheelchair footpaths must be provided to enable them to take themselves to and from work, without the need for engaging outside assistance. These people also require independent access to other sporting and social amenities, provided elsewhere in the complex.

To provide an efficient design, it is necessary to provide new standards of space, plumbing, circulation and social activities within the hostel . . .'

In the past, due to the fact that most of the adults living with us were invalid pensioners, the weekly charge had been extremely small. Now that these people were being trained in employment at Centre Industries and their earnings were increasing, we needed to adopt a more realistic attitude, making our weekly charges more in line with those applicable in the community generally. Unless we did so, we would find that our adults would always have a false conception of living costs. It was our duty and responsibility to teach them to budget their money, firstly for the essentials of living and secondly, for expenditure on those things which would give them a more comfortable and happier way of life.

The hostel design is similar to a motel, with four six-bed dormitories and thirty single bedrooms. The single rooms have connecting toilets and bathrooms for every two rooms, and that applies to the dormitories too. The minimum size of a one-bed bedroom is approximately fifteen square metres, in order to provide the bed with alternative access. In special circumstances we need access to both sides of the bed. From later experience we have found this minimum too small for long-term occupancy, having in mind the wheelchair space and the accumulation of the occupant's separate personal pursuits. We would prefer twenty-one square metres. Other furniture comprises a bedside table, dressing table or desk, chair and wardrobe, and the space permits turning of a wheelchair.

A bathroom entered direct from the bedroom is a more desirable arrangement than a bathroom accessible from common corridor. This can best be planned by locating a bathroom between two bedrooms, the occupants of which having sole use of this bathroom. The advantages of this arrangement are, in the first place, as assistance is generally required from hostel staff in bathing and toileting, more privacy is obtained, less space is required for wheelchairs, less travel from bedroom to bathroom, and it expands the personal living area of a person beyond one room. The minimum size of a bathroom containing a toilet, shower and basin is approximately 50 per cent smaller than that required for the bedrooms.

The provision of outdoor recreation areas is most important. Access to these areas is planned at several points in the hostel, to restrict travel from bedrooms to a minimum. These areas can be developed with screen walls, gardens, barbecues, into smaller sections which provide for group or individual enjoyment.

The Spastic Centre's first adult hostel for the cerebral palsied, the Venee Burges Hostel, was opened by the Honourable L. J. Waddy, O.B.E., D.F.C., M.L.A., Minister for Health, supported by Mr R. Dowell, Director of Social Security, and Sir Vernon Treatt, K.B.E., M.M., Q.C.

The opening of this building, named in honour of Mrs Venee Burges, a dedicated voluntary worker since the inception of The Spastic Centre, marked a further phase in plans to help spastics from birth to their final retirement. Over the years they will have received treatment and therapy, special schooling, on the job training and, above all, will have known social contact and the dignity of working alongside and using the same machines as able bodied people.

Mrs Burges paid tribute to the late Mrs Florence Deaton, who had worked with her for twenty-nine years as a volunteer, and to Mrs M. Joule, who was responsible for the attractive drapes already installed.

In the course of his speech, Mr Waddy said, "This is the first of four buildings planned for orphaned spastics and those whose parents are too old or too ill to look after them. This single-storey brick and tile hostel houses fifty-seven young adults working

in nearby Centre Industries, the rehabilitation division of The Spastic Centre of New South Wales. They are part of the workforce of 271 spastics, who share a normal working environment with a further 500 able bodied people. Each unit has been designed to meet the individual needs of the occupants, with wide doorways and special shower and toilet fittings for those confined to wheelchairs. Great attention has been paid to details such as extra light switches and special shower and cistern fittings to enable easy operation for the most heavily handicapped. Those who can do so, walk, others wheel themselves or travel in electric wheelchairs along wide cement paths and ramps to their place of work in Centre Industries. Medical and therapeutic services are close at hand in Centre Industries during the day, when those requiring treatment have their regular appointments."

Sir Vernon Treatt, President of the Appeal Committee, said, "The Spastic Centre has now become a national institution, recognised by its activities and contributions to human happiness. Milestones achieved since the 1945 inception of The Spastic Centre are: 1947 – voluntary weekend labour built first part of Spastic Centre at Mosman. A school and therapy block. 1950 – two more floors added and the building extended at Mosman, using voluntary labour; 1954 – the inception of the Miss Australia Quest by the Australian Cerebral Palsy Association. 1957 – completion of the Country Children's hostel at Allambie Heights, built by voluntary labour; 1961 – Centre Industries established. Using Sunday voluntary labour, 350 workers erected 1200 square metres in one day. 1966 – the Baby Training and Management Clinic began. 1967 – Newcastle Treatment and Training Unit opened. 1969 – major extensions to Centre Industries complete. 1971 – further extensions to Centre Industries. The Action Appeal was launched under the Chairmanship of Sir Vernon Treatt. 1972 – the Allambie Medical Treatment Centre and School complete. And now, 1974 – Venee Burges Adult Hostel opened."

Voluntary help and the determination of parents to help their heavily handicapped children, the foundation on which The Spastic Centre has been built, today remains the main factor in its continued development. The Spastic Centre believes that the men, women and children in its care have the right to live a normal life in a normal environment, and the Venee Burges Hostel has helped to achieve this aim. It is a happy place, people with disabilities, relaxed workers, who know that because of the generosity of people in general, they can look forward to the future as productive members of society.

Mr R. Dowell, Director of the Department of Social Security, said the hostel represents the very successful participation between voluntary organisation and State and Federal Governments. In 1967, a subsidy of 2:1 on employment for people in sheltered workshops came into effect. The number of those employed in Centre Industries was: 1967 – 64; 1973 – 223.

The Social Security Department contributed to the Hostel the maximum subsidy, at that time consisting of \$5,200 per person, at a building cost of approximately \$11,000 per room, which The Spastic Centre assumed.

On that day, I made the following points to the assembled guests:

'This hostel, beautiful as it is, is no Country Club for spastics. It is a serious experiment in independent living for the heavily physically handicapped, and if it has cost twice as much per person as the Commonwealth now allows, it is still inadequate as to space and facilities for its purpose.

Twenty years ago we built the Country Children's Hostel. In those twenty years we have learned a great deal about cerebral palsy. Then we planned it to supplement a highly specialised orthopaedic hospital, which we proposed to establish in the fourth wing. Now we know that orthopaedic surgery has only a small, if important place in our treatment schedules.

But the Country Children's Hostel is out of date, and we will have to substantially rebuild it to enable it to serve its proper function.

In 1961, we started Centre Industries as a model for something better than mere sheltered workshops. With the aid of the Department of Social Security, we have established that the quality of the rehabilitation work at Centre Industries clearly shows that the most heavily handicapped can compete with able bodied workers in highly technical fields in industry.

We will have to convince our legislators that the quality of rehabilitation done on the most seriously disabled counts as much as the numbers of more lightly handicapped pushed through the pipeline.

We quarrel with the legislation that equates a hostel for children or a hostel for active young adults with nursing home requirements, or with regulations for the conduct of private, profit-making nursing homes. Rigid regulations framed for another purpose are inappropriate to our work. We are dealing here with young people who want to live their own lives in their own way, and I complain that those regulations now applying are not in the best interests of these young adults.

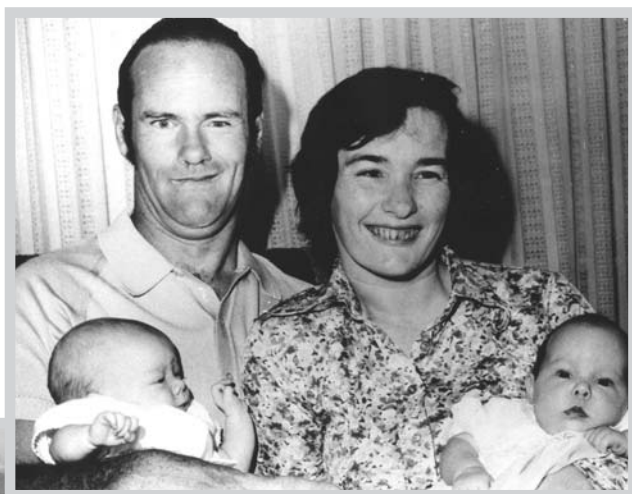
The Country Children's Hostel and the Venee Burges Adult Hostel are places of long term residence for heavily

handicapped cerebral palsied children and adults. They are energetic young people who have their lives ahead of them, and their interests are the same as those of any normal person of the same age group. They are not sick, they are well. They do not want to occupy a bed in the daytime, they want to go about their affairs as best they can on their own feet, on crutches or sticks, or in a wheelchair. But they are heavily handicapped, requiring physical assistance in feeding, drinking, toileting, bathing, dressing and undressing and administration of medication. These requirements of services have been, and must continue to be, at the background of the Venee Burges Hostel. The real objective of the place is the lifestyle of the CP person, and the services must not impede that objective.'

THE FIRST TWO WEEKS AS SEEN THROUGH THE EYES OF JENNY McLEOD:

I entered Venee Burges Hostel on my first afternoon in my electric wheelchair, and I was at home almost immediately. There was a very happy and warm atmosphere about the place. After unpacking and having a cup of tea with my parents and some friends, I saw my parents off at the entrance. Then back to the duty room because it was time for my pills. At this time I delivered all my medication to the Sister in the duty room. However, she did have some trouble in understanding what pills I took and the times I took them. Fortunately Dr Blight was present, and when my medication had been disposed of she asked if I preferred a bath in the morning or at night. I said the mornings were better, but I would fit in with the staff situation. I had a long talk with her about this, because she was trying to please me, and I was trying to please her and the staff. Dr Blight stressed that she wanted to make it a 'home away from home', with everything to suit us, like breakfast in bed, baths when we wanted them, and so on. She was really being very kind and helpful.

By this time it was our 'happy hour' as Colin named it, which is a drink with everyone just before dinner. Everybody was so happy. It was wonderful to see Bill and Carmella sitting talking at the table, and Bill helping Carmella with her food just as a matter of course. There was an air of excitement and complete happiness. There were some wonderful people helping us, not only the nursing staff from our previous hostel, and I think that for the first meal this was a great help, as they knew us so well. Before dinner Ingrid helped sort through the drawers in my bedroom. I sat at her table with the other young people. To make it even more enjoyable, the people who



To Mr and Mrs John Morgan – twins.



The completed hostel is surrounded by two miles of virgin bush and has a commanding view of the City.

helped us with our food sat with us and ate their dinner. This meant a lot to us all, because it was more relaxed and more like home. This, I feel, is very important because it creates a social atmosphere where we have to talk, as well as having to eat our meal, with the least possible mess.

After dinner I went to my room, turned on my light, closed my three doors and sat, thinking – this is all mine. Everything in this room is going to be mine. This sounds a bit selfish – what I really meant was that this may be my room for the rest of my life. Then I got all my night gear out and waited until someone came to put me to bed. I was going to do a lot of waiting over these first few weeks, so I decided not to watch the clock, but just take my time and not worry, which I did. Finally I got into bed, fairly late for me, and I experienced another 'first' ... the smell and the feel of new bed linen.

The next thing I knew, the door opened, the light went on, and a big 'Mumma' type of Sister came in – I found out later she is Spanish – and introduced herself, saying "You are down for a bath; where is it?" I pointed to the shower and she went over. "No bath here pet, will you have a shower?" I told her that I couldn't sit in a showerchair and I had to have a bath. However, she did not understand my speech, and asked me again if I would try the chair. By this time, I was thoroughly awake. She went to the door, saying she would have to get the male aide to help me into the chair. I spent the next few minutes pulling down my nightie and wondering how I could get out of the situation. When the Sister returned with the showerchair and the male attendant I said, "Sister, I do not have a chance of sitting in that chair." The male aide, who I recognised, asked if I would prefer a bath, and I said, "Yes." Then he said, "I think it may be better if you waited, Sister, until the other girls come on at six o'clock to bath Jenny." So I breathed a sigh of relief, and eventually at six another Sister from the nurses club came and bathed and dressed me, which took about forty minutes because she did not know me; then she put me into my wheelchair.

I had been woken at 5.45, so by breakfast time I was still a bit 'under the weather'. I got Sister to leave my bag on my little chair, and after cleaning my teeth she left me. I found my makeup in my drawer and put half of it on, but couldn't get the rest of it out of my bag, so I left it. Then I did a few other things, like washing a glass and putting it in my cupboard, turned off my light and went out. Gee, that was a lovely feeling! Then to breakfast – appetising bacon and eggs. But my pills were not right, so that I wasted time whilst getting them.

At breakfast, someone had spilt coffee all over Ingrid's blouse, so I told her that I would help her remove it. Ingrid had the next bedroom to mine – she is a severely handicapped athetoid. So after getting my pills, I went up to Ingrid's room and we both struggled to remove her blouse, with me trying to undo five little buttons and Ingrid holding the blouse down. After about half an hour, I managed to get two buttons undone, which was enough for Ingrid to get the blouse over her head. It was a struggle, but we made it, and then she put a jumper on. There was not the staff available, so we just had to do it ourselves, and it felt good! I stayed with Ingrid until she got her jumper on, then I went and had a talk with Mr Fisher and Peter about things like meals and their times, staff positions, where they would come from, outings, and so on. We did this every morning in these first two weeks.

Venee Burges Hostel is about two hundred metres from Centre Industries, and we approached it along a wheelchair pathway through the gardens and gum trees. It was a beautiful drive in an electric wheelchair when the sun was shining, with the multi-coloured flowers and the magpies singing their morning welcome.

We were located at the edge of one hundred hectares of bushland, so there was no shortage of bird life. The vociferous kookaburra outside my door, the grey and pink cockatoo and the yellow-legged plover on the lawn, the flight of clamorous lorikeets in the wattle trees, and the distant calls of crows and currawongs. I had never seen so many birds.

The second night it was raining. It was lovely to arrive into a warm place and make my way to my room, to be stripped of my wet weather gear, have some lipstick put on, and off to the lounge room where everyone was gathering for our 'happy hour'. The dinner was very nice, and it was relaxing to have the people who were helping us sit down to have their meal with us. This meant an awful lot to me and to the others, because it was the type of thing that you would enjoy in your own home. I'm all for this, even though it presents big staff training problems.

Just after dinner, I was asked by Sister if I would like a nice leisurely bath that night, because they would not have the necessary staff in the morning. So after some talking around the subject I said I would have my bath at night,

until there was more staff in the mornings. By 7.30 that night there was no one around, so I decided to go to my room and get things ready for my bath. I had tried to pull my bedspread off, but couldn't. I got things out of my drawers, put my hairnet and showercap on, and tried to open my bottle of face cream, but couldn't do that. So I called on Brian, a neighbour, and got him to loosen the top, then I was right, only the cream went everywhere. I cleaned up most of it. Then I waited a long time for my bath. Eventually I got into bed.

I had trouble getting the right pills for quite a while – I guess it was because they were new staff not used to giving one individual so many tablets. So, I just told them what I needed and eventually I gained their trust. By the second week, they generally had the medication right. Another nice thing was that with my bedtime pills the Sister would come in while I was having my bath, and either stay or leave them with me. That meant that I didn't have to wait up for them.

Nothing was a problem to them. If I needed some other medication they would go and get it without any fuss or complaint. They were all wonderful and still are.

In that first week, we were very badly off for staff, both morning and night, so you didn't know who was coming in your door next. There were rumours in the early days of that first week that the staff from the Children's Hostel were not permitted to come down to assist. Gradually, one or two did come down, as well as some staff from Centre Industries. So, although we were late for work, we had a lot of fun, because you had to tell each person what you wanted, over and over again. As I said, time didn't mean much at that stage. You were woken up at different times, so you just had to take your time at breakfast because you didn't have anyone to help you, as most of the staff were dressing other CP. I went back to my room after breakfast to have my wash, clean my teeth and put on makeup, then Peter, Mr Fisher and I had a talk, so I came up to work at about 9.00. Most of the other girls went back to their rooms for different reasons, the same when we arrived down at night.

There were two English women who worked in the evenings in McLeod House who had put in transfers as soon as Venee Burges House was started, but were turned down because the Matron wanted totally new staff. The third evening they arrived at the hostel and I knew they had plans to stay, so I thought I had better do some training. I got one of them to help with my dinner, knowing that anything I said would be repeated to the other one. I told her that we liked them to sit down with us while helping us with our meal. I told her about this as I was having my sweets, which she liked, so she went straight to the other woman and told her. I told her about us setting a time for our baths and showers, but I did this all in a slow subtle way, and she accepted it. So I did this with most of the new staff. Whether I did the right thing, I do not know. I thought if I told these things it would create a better understanding of what we wanted them to do.

By the weekend I was tired and looking forward to a little sleep in. As I drifted off on the Friday night, I was thinking about this. However, the next thing I heard was a male voice, shouting, and each door opening. At the top of his voice he was saying, "Get up! Breakfast is on in half an hour." He was waking all the wing up, especially the boys. This was at 6.00 am, so everyone was up in arms. I could hear Colin telling him off for going into Bev's room and waking her. He opened my door, and I just pulled the bedclothes over my head and pretended to be asleep, hoping he wouldn't come any further, and he didn't. He just closed my door and I tried to go back to sleep, but it was impossible because he was still going to each door and shouting, "Get up! Get up!" So I just waited for someone to come to dress me, which was about 7.00. Gee, I was mad! When Sister came in I asked her, very nicely, what was the idea. She missed the point of my complaint and said he may not have known whether my room contained a boy. I complained about the noise and she smoothed it over. I was to find out, quite a long time afterwards, that he was the son of one of the female aides, and she wouldn't come near me for a long time. I don't think Sister went to him then, but the same thing was to happen the next morning.

Breakfast over, I grabbed Margaret McColl and went to my room and had a quick wash and put my makeup on, as my father was coming to take me to the hairdresser at 9.30. Then Margaret changed my sheets, mainly because I wanted to take them home to be washed. We just made it. I went to the hairdresser and then went home until the late afternoon. When I got back everyone was very angry, because a Sister had done so many wrong things to five of the girls. It was like stepping into a hornet's nest. I cannot remember exactly what had happened, however, the things she had done were pretty terrible, like telling Ingrid she was only allowed to speak to her mother for one minute on the telephone. When the minute was up, she dragged Ingrid away from the phone! Other things were just as terrible, so we talked about it until we went to bed but without any conclusions being made. In fact, the more we talked, the angrier we became. By eight o'clock, there was nobody around, so

I went into my room to wait for a bath, and I had to wait a fair while for it, but eventually I got into bed. I think there were only two Sisters and one aide on.

On Sunday, I was awakened again by the man's voice, all along the hall, "Get up. Breakfast is in half an hour." He opened all the doors and banged them shut. Then he came to mine. He opened my door, and I'm afraid I was a little bit rude. As soon as he put on my light I said, "I like my sleep. Would you please put my light off and leave me alone?" He said, very quickly, "Only checking, love; Sister asked me to wake you." I just looked at him. He closed the door and went away. A few minutes later I heard him outside my room saying to another male aide, "Don't go in there mate," then he made a noise like a cat and they both went off laughing. When Sister came in to dress me I complained to her again. She apparently said something to him, after she dressed me, because he avoided me all day.

Sunday was very quiet except for lunch. It was supposed to be a barbecue, but it was windy and cold, so we had to have the food cooked inside, which was OK. However, just before lunch we were nearly all in the dining room when Sister came in and said, "You'll all have to imagine that you are sitting under gum trees with all the bush around you and the sun blazing down on you." She went on and on. When she went out we all burst out laughing. It was so silly and, the way she said it, anyone would have thought we were 'nongs'.

After lunch was pretty quiet. I guessed that people were tidying their rooms. About two o'clock, we were informed by different people that the heat was off. Something had broken down and we had no hot water and no heating, so the whole place was in an uproar. How were we going to have showers or baths or washes? How were we going to keep warm for the rest of the day and night? How was the staff going to function? Anyway, we did a slight freeze from then until about 7.00 p.m., when it was fixed. Mr O'Brien was there all the time, and he got the man from the boiler firm straight away. Sister was running around all afternoon putting extra blankets on all the beds. However, the rest of the afternoon was dead. I had dinner, and after wandering around for a while went up to my room. I was just getting undressed when the Sister, who was with me, was called away. I had a sheet over me. While Sister was away, the door opened and in came the man who awakened me the previous mornings. I gave him a dirty look, and he said, "Sorry" and walked out. I was fuming, so when Sister came back I told her. After bathing and putting me to bed she went to get my pills, and when she came back she told me that she had spoken to the man and had advised him of a new ruling. That from then on, a male attendant was not allowed to go into a female resident's room without a female attendant there with him. She was quite understanding about all of this, and quite prepared to work things out with all of us, and stay with it, until she got things right for us.

In the mornings you didn't know who was coming in to dress you, or at what time, but I didn't have to worry about male aides any more. So most days I just slept until the light went on. On the odd morning I woke up early, I used to pull my curtains back and watch the crows and kookaburras sitting on a fire hydrant, and the sun coming up. It was so lovely to be able to pull my own curtains over in bed.

During the second week, there was a more permanent staff, but you still didn't know who was coming through your door. This made it interesting, but also a challenge. They didn't know you, or what clothing to put on or take off. You had to talk to them without knowing their names, and keep on talking, so they would get to know all about you. Gradually the CP sorted the staff names out, and they returned the compliment.

I found it took me up to two hours in the mornings to get toiletted, dressed, and have my breakfast. Then go back to my room and have my teeth cleaned, and wash and makeup and be at the front door, to go to work at Centre Industries. This wasn't every day, but it was about seven out of ten. At night it took me at least three-quarters of an hour to have a bath, and get to bed with the light turned off.

A meeting was held with Mr Barry Fisher and John Morgan. They talked about the Committee and explained the function of it, urging people to go to the Committee or to themselves with any problems. Then we talked about other things which the Committee had discussed the night before. It was a good meeting, because Barry made us think. He went over the things which we had discussed, so we all would know exactly where we stood. It was a very lively meeting, and I think we all felt much more secure, and much more settled.

The meeting ended at 8.15, so the staff didn't shower or bath anyone that night. We were angry about this because we thought there were enough staff to do that in the time. However, I found out the next morning that there were only three female attendants on and one Sister on after nine, so Peter and I spread the news around, though we still felt there had been time to do some of the residents' baths.

As the week went on, we got more organised. Such as, we would name the time for our baths or showers with a female attendant, and she would come at that time or as close to it as she could. I always got out the things for my bath, except when they were not within reach, or I wasn't feeling too well. I think the other girls would do the same. It was quite a thrill to get things out of a drawer by myself, even though I dropped things at times. Then I'd call one of the other residents to pick it up for me – the spirit of 'help each other' was very strong. It still is.

As we were dealing with nurses and aides who had little experience of cerebral palsy, I typed a paragraph containing some hints on helping when I spasmed, and I kept several copies in the drawer of my dressing table to hand out when necessary.

'When I spasm all over badly, the first thing to do, other than a Valium, is to put my head forward on some pillows on the bed. If that does not work, try to bend me up on the bed, turning me over on my right side in a foetal position and hold me hard in that position until I relax. This is hard work so you may need some help. If you hold my head forward and my knees up you may find it easier.

Feeding me when I am spasming - occasionally I can't chew or swallow, food or drink, unless you put my head right forward. If you hold my chin up firmly all the time when I am eating or drinking, this may work. If it doesn't, it is best to leave the meal until later. Usually I would skip it altogether because it is too hard for me.

If I don't smile, it is not intentionally, as I find it very hard on these occasions to control my face muscles, except for the wink, which means 'yes' or a head shake which is 'no'. Thank you. Jenny.'

The girls decided to give Bev Chivers, on the next Saturday afternoon, a surprise shower tea on her engagement to be married - only for the girls and a few friends of Bev. So as Saturday approached, there were more and more whispers and quiet talking, and the hope was that Bev didn't find out. On the Friday night, I told Sister that I wanted to be woken at 7.30. There wasn't any sound in the morning, so I slept until that time, which was lovely. I got up and had breakfast, then went to the hairdresser, and on the way back picked up some cakes. We had tons of food, which Barry and his wife prepared after lunch, and as the time drew near, excitement mounted. After I was ready, I went down to see if I could help. I got the chairs fixed, and then I went in and out of the kitchen carrying food. However, there was a problem – the aides had got Bev ready too early and we had to keep her in her room, so we had to send people in to talk to her. When we were all settled about twenty minutes later, we shut the dividing doors and Bev came in. It was a lovely party, and Bev didn't suspect a thing! Everyone joined in. I nearly dropped a dish of biscuits, but they were rescued. We didn't have much dinner that night. The boys did though!

It was so wonderful to be able to sleep in the next morning; not very late, about eight o'clock. Then a very quiet day – we didn't have many staff.

On the Monday I was supposed to go home, but my parents had a meeting, so I spent another night at the hostel. During the day a friend rang at work and asked if they could come to the hostel that night. So I bought some chips from the canteen, got John Morgan to arrange for a couple of tins of beer, then went into my room to prepare things. Then a quick tea, back to my room to get some makeup on, and down to the front door to wait. Eventually they came, and I took them around the hostel quickly, because people were getting ready for bed. Back in my room I sat them down, and in a couple of minutes John brought the drinks along. I told Phyl and Don where the glasses were and I gave Howard the chips, which I had put into a dish. We just talked. I couldn't help thinking what a difference it was from my previous life at the Children's Hostel. It was so lovely to have your friends in private, and to entertain in your own room. They stayed just on an hour. Then I saw my first visitors off at the front door, and went back to my room where the girls bathed me and put me into bed. Funnily enough, it was one of the earliest nights I had in those two weeks.

Reading through this account, I seem to be complaining about the staff and the organisation, which I don't mean to be. My object was only to point out some of the difficulty that I personally experienced. They have done magnificently with untrained staff, when we consider the difficulties of fifty CP, each with their physical handicaps, personalities and severe lack of speech, trying to turn them into a living family, in two weeks.

SPASTIC
CENTRE



Jannifer McLeod meets The Empress of Iran, Shah Banou, Fara Diba, accompanied by Audrie McLeod.