

**Humane Caring: Quality of Life Issues for  
Those Elderly People Wanting to Remain in  
Their Own Environment.**

**By**

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## **Abstract**

It is a truism ... the older people get the more unique they become because ... every day they live and learn. Many elderly people who want to remain in their own environment have this lived experience of becoming uniquely who they are to call upon when making a decision concerning their future and where they want to live during their last years. They know that their environment is a part of them and without it they will flounder and lose control. My concern is that there are many families and health professionals who choose, for various reasons, not to support these elderly people in their decision to remain within their own environment.

Through my weaving with their stories I have learned to remain in focus among the maze of phenomena and have discovered that I and am able to objectively explore This concern which I have identified as that of Humane Caring: and captured in the title of my thesis ... Quality of life issues for those elderly people who want to remain in their own environment.

This thesis explores the issues surrounding the elderly remaining in their own environment and why remaining 'At home' becomes so essential for them. There are many elderly people who have moved to residential care settings on the advice of others and have paid the price; that of freedom. There are many valid reasons why the elderly cannot and do not always remain in their own environment. I have explored and identified these within the context of my work with aged people which I consider need to be recognized when planning for the future care of the elderly people in New Zealand.

## Dedication

### Caring

I care about you in a troubled wind  
when you find it hard to hold on  
    your dreams blow away  
    your hopes don't seem to stay  
my strength with you till the calm

I care about you in our city's jungle  
when you're afraid because you've lost your way  
    when the loneliness entwines  
    the fragile web of your mind  
I'll show you the path, then I'll stay

I care about you in the games people play  
when you've played the best you can  
    for when people cheat  
    or you are constantly beat  
with my caring we'll win the next hand

(Rinder, 1971, p.17)

To Robert, Alice and Kerry  
    Audrey and Fred  
        With my love.

## Acknowledgements

I thank those most dear to me, that of my family who have supported me through my years of journeying in nursing. To my husband Robert for his endless patience and encouragement for without him I could have never survived the journey. To my children Alice and Kerry who, even though so young, have been so patient while I have studied. To Audrey and Fred Hyslop my mother and father who have phoned regularly to offer support and encouragement. To my brother Tom Hyslop who has nurtured my computer skills and my computer at all hours of the days and nights that I have studied.

I could not have completed this paper without my accounts of the individuals that I have encountered over the years in my nursing practice. Encounters with these people have helped to shape my caring phenomenon in nursing and have been the inspiration for my writing.

From my heart I would acknowledge my friend Margi Martin who possesses a unique aura of love and support from such a distance. It is with her encouragement in freedom of expression that I have been able to complete this paper.



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## Introduction

The following paper is a written account of the journey I have taken over the years since the beginning of my practice which has enabled me to stand where I stand today in nursing. I cannot write about this journey without weaving in my 'stories' as they are a crucial part of this journey. This journey is written in a language that is meaningful to myself for without that this paper would hold no purpose and would only represent a written piece of work that has no linkage to my practice and would not be a truly holistic account of the journey I have taken over the years.

During my training I experienced 'caring' in many shapes and forms and through this time I sifted, sorted and pieced these caring shapes together until they formed a pattern of caring that merged with my own thoughts and beliefs. A picture emerged of a 'caring' in every sense of the word and from then I was able to apply this picture to many scenes; many environments and many human to human relationships which over the years have been part of my practice.

Over the years in my nursing practice I have experienced intermittent twisting, torturing, nurturing and shaping and these phases have moulded me and through them I have achieved an invaluable amount of learning. The type of learning is unique to myself and I consider enables me to care in a unique way.

I have cared for the elderly within institutions for many years until I became exhausted and bewildered by bureaucracies and found myself being twisted and tortured more than nurtured and shaped. The result was 'the balance' became unhealthy. I searched for a caring relationship that was more meaningful and



fulfilling in the human to human relationship with the elderly. I began to care for the elderly within the community, within their own environment. On the surface this appeared to be the answer to what I was looking for but the more I explored and experienced, the more I had to acknowledge the inconsistencies and unfairness and inefficiencies in this form of caring also.

There were elderly people within the community who were not having their needs met; who were being pressurized to conform to other peoples demands and were being bombarded by profiteering and cost cutting agencies. Elderly people who wanted to remain at home and saw this as their right but could not advocate strongly enough for themselves in order to achieve this goal. Many elderly people wanted a particular quality of life and needed to be assisted to preserve this state of being and lifestyle. I had so many concerns that needed to be explored in relation to what was a healthy environment for these elderly people to live in? What did 'Quality of life' actually mean to them? I began to sift and search the literature to find an answer to this.

'Quality of life' for the elderly is a very individualized concept. Many elderly people 'accommodate' their interpretation of this phenomenon themselves as their body declines in an effort to try to remain in their own environment. Quality of Life is subjectively and socially based on every elderly person's right to remain in their chosen environment. We believe Society exists to ensure every individual has this right upheld yet we live in a society where resources continue to be poured in to institutionalized care in place of and without any balancing of resources in the community. In my community Elderly people whose health is declining who

remain at home are less likely to acquire the support that is required to maintain them in their own environment.

The population of elderly people is increasing and with more elderly people living to a greater age and wanting to remain in their own environment there needs to be a very clear case made for adequate resources and support for these people to be able to achieve this goal.

## Background

Before I can begin to write about what is important to me in nursing I need to reflect on what has influenced my thinking thus far. My nursing practice today is a result of past experiences which have shaped me, my spirit, my mind and my body. As a nurse who cares deeply for those with whom I come into contact, these parts of me exist, cannot be separated and play an essential role in how I relate to other human beings.

As woman contribute their knowledge to the world, change will be inevitable. One way in which nurses are likely to contribute to positive change in gender, ethics, and politics influence the public domain is through exploration of the value and limitations of an ethics of caring for their profession. Because nurses participate in the public domain as members of a profession, they are in a position to contribute important insights about how an ethics of caring could positively influence the practices of nursing, ethics, and politics (Condon, 1991, p.15).

To illustrate my interest and concern, I have woven many stories of human to human relationships that I have encountered along my journey. Such writing in Nursing can

...generate a body of knowledge with substance and depth about the phenomena of concern to nursing science: health processes of whole human beings, families, and communities, lived experiences of health and human becoming, human-environment energy field patterns, self-care, and caring practices. There is no other science so devoted to or singularly well-prepared

for the study of these phenomena (Cody, 1996, p.87).

When I look back now and see myself leaving school at the age of seventeen and entering the nursing profession I would never have dreamed that my thoughts and feelings of that time would be

**twisted**

**tortured**

**nurtured**

and

**shaped**

to paint the picture that I place before you in this writing and at this time.

As I began my journey I never gave any thought to the 'caring' side of nursing.

There was so much to learn, so many tasks to complete and so many people to please. There was no subject which taught the 'caring' side of nursing and so instead I learned about many medical and surgical conditions, anatomy and physiology, biology and how to perform 'tasks' which formed the basis of my clinical experience.

My first encounter with anyone elderly was in performing the task of sponging an eighty five year old gentleman.

*It was 9am in the morning and I was to gather with 4 other students outside one of the wards where we were to practice the task of sponging a patient with our tutor. The man whom we were to practice on was very elderly, very frail and contractured and for a reason unknown to me could not communicate. All six of us gathered around the bed and the task began. There was no communication with the elderly man and the tutor instead, painstakingly began*

*to take us through the procedure of giving this man a bed sponge. I could tell that the man was in pain because even though he never opened his eyes during the whole procedure, his facial expressions were changing all the time. After two hours we were finally finished the task and we all agreed that the elderly gentleman 'looked nice and clean and comfortable'.*

Knowing what I know now I would have described the man as 'pale clammy and exhausted'.

*The next day we were to meet outside the same ward to play a more active role in the task of completing a bed sponge. On entering the ward we were told that the man that we were practicing on the day before had died during the night and one 'humorous' remark was made by a nurse that maybe it was because the students 'were let loose on him the day before'.*

I never forgot that comment.

*We continued to practice on other elderly people and each day I re-entered the ward wondering if these elderly people had survived the night.*

"As care is reduced to instrumental tasks, human relationships can get lost, and caregiving can be depleted of its emotional force and spiritual meaning"

(Stone,1999,p.61).

Knowing what I know now, I feel ashamed that I was so naïve as to never question what we were doing. Knowing what I know now, why wasn't informed consent available all those years ago?

At this point I was scared of the elderly, communication was difficult, they were often uncooperative and they were hard work to look after.

As I continued with my training I 'worked for' and 'alongside' many experienced Registered nurses. By quietly observing I learned from some that there was more to nursing than 'tasks to be performed'. One particular 'sister' was in charge of a ward full of very sick, frail elderly people.

*As I entered the ward I noticed that something was very different. The ward was quiet and had a feeling of relaxation, happiness and peace about it. There was no usual hustle and bustle. I wondered where all the staff could be. I found them all in the ward office having a cup of tea before the day began and discussing what was required for the day. This was new to me as I had always just been told what to get on with but this day I was invited to have a cup of tea with everyone else.*

*The sister in charge took me with her while she took her shoes and stockings off, donned an apron and delighted in showering a ninety two year old nun. They were both singing hymns in the shower and laughter abounded when either got the words muddled or they were out of tune. I could not believe my eyes when the sister then proceeded to wrap her arms around this elderly lady and kiss her on the cheek. The elderly lady sat there with a smile on her face for quite some time after the procedure had ended. As the weeks progressed I began to change my opinion of the elderly.*

This sister showed me a new dimension to nursing and one that I liked more than anything else that I had been taught or that I could have read in a book. This was what I wanted to be like. This was what nursing was going to be like for me. I was fortunate enough to have experienced it before I had completed my

training.

In Noddings' (1984, 1992) view, "caring is learned". It follows that caring must be taught, and Noddings views this instruction as "an important task within the caring relationship" (Crowley,1994,p.77).

It was soon after I registered as a nurse that I began to find myself caring more and more for elderly people. For the next seventeen years I provided care for the elderly within institutionalized settings.

## **Institutional Care**

I cared for the elderly in institutional care settings for seventeen years. During this time I was in a position where I could teach others to care for the elderly. My main aim during this time was to ensure that all the elderly people that were within the institutions were well cared for 'in every sense'. I taught others nurses and caregivers how to provide holistic care for those elderly people. I taught them how to enjoy caring for the elderly as I had discovered this art. "Nursing as a basic human science sheds a unique light on the human condition. The highest duty of a nurse scholar is to nurture that body of knowledge and to disseminate it for service to humankind" (Cody,1996,p.88).

During these years I continued to study, which enabled me to teach others what was current and relevant. My mind, my spirit and my body was gradually changing and preparing for further

**twisting**

**torturing**

**nurturing**

and

**shaping**

I had thought for so long that if I was able to provide excellent care for the elderly people within these institutions then I would be satisfied. My mind, my spirit, my body would be well served.

**How wrong I was.**

As I continued to study I began to ask more questions. I began to change faster than those around me were prepared for. Gaps began to widen and I felt uneasy.



I saw so many inconsistencies and unfairness; so much material and human resource wastage and a change in philosophical focus in institutions, all of which were often detrimental to the elderly that I was caring for. In an article written by Deborah Stone she talks about 'Bureaucracies of Care'. She refers to organizations providing care, being more interested in pleasing their shareholders than pleasing the people who are getting and giving the care (Stone,1999). "All of a sudden, the goals of staying in business, balancing the books, and lowering costs displace the goals of making patients feel cared for and improving their wellbeing" (Stone,1999,p.64). I was part of a multidisciplinary team which over the years changed its focus from what was best suited for the individual person to setting time frames for certain medical conditions which established that people had to be discharged by certain dates. I argued that ...

"...agencies seem to have had to shift their goals from providing care to terminating care" (Stone, 1999,p.64).

I became disillusioned and frustrated after many battles fought on behalf of individuals and their families to have people remain in their own environment were lost. I became disillusioned and frustrated that individuals and their families were not being listened to. Where management became part of the multidisciplinary team the bureaucratic voice was dominant and favored. One incident started me searching for more answers. There were many such incidents but this one 'stuck in my mind' because after this I could never quite 'function' the same again.

## Emily

*Emily was eighty eight years old. She had lived by herself for the last twenty three years when her husband had died suddenly. I met Emily when she was transferred to our assessment unit. She had previously been in another assessment unit for the previous eight weeks following a stroke. As a multidisciplinary team, our instructions were to assess Emily for rest home care. Emily's stroke had left her unable to communicate. Emily knew herself what she wanted but was unable to communicate her needs. She was very determined to be independent so working with her was to be a challenge. Emily was not always reliable in using her walking frame and because she was at risk of falling, I had to keep reinforcing to her the fact that she would be much safer using her walking frame. She always said "Yes, Yes, Yes" with a smile on her face and then later I would see her walking without it. Emily used to screw her nose up at the walking frame as if she didn't like it. She was a proud lady and I wondered if the frame to her was too obvious, too bulky and kept reminding her of her lack of independence. I referred Emily back to the physiotherapist and asked if she could be further assessed for a walking stick.*

*Emily returned from physiotherapy with a walking stick and a grin from ear to ear. She did not use it all the time but used it more than she had her walking frame. I spent a lot of time with Emily, trying to get her to communicate her feelings. We had a family meeting coming up and decisions were to be made about her placement. I wanted to get some understanding of what she wanted*

*so I could support her at the meeting. Emily had not performed well at her one and only kitchen assessment which was set up in the institution. The physiotherapist, occupational therapist, management and her son thought that she would be safer in an institution. Whenever I had mentioned a Rest Home to Emily in the past she would frown and say "No, No, No" and always point out the window.*

*Emily started calling "You, You, You" whenever I went past her door and when I went in, she would never be able to communicate to me what she wanted. At these times we used to try so hard to achieve understanding and writing was no good because she couldn't even spell out one word. I used to try and get her to point to letters or pictures and to use a typewriter but all this with no success. After trying all these things I decided it would be better to concentrate on her facial expressions for confirmation of questions asked. I could not rely on 'Yes' 'No' because she used to get them mixed up all the time. Soon we became pretty good at communicating. We had lots of laughs as I was guessing her needs and we had lots of cuddles. Very occasionally when I just could not understand what she wanted, we would just hold each other - quietly in support of each other's frustration.*

*One day, Emily was extremely agitated and started calling out "You, You, You". I stopped in my tracks when I heard this because I realized that even though She couldn't see me, she was calling for me so I went down to be with her. She let out a big sigh and started pointing out the window and saying "Him, Him, Him" She looked so desperately angry. I wondered if her son had arrived*

*for the family meeting. I explained to Emily that I would contact Cathy the social worker to see if her son had arrived. Cathy confirmed for me that Emily's son Trevor had arrived about a week earlier and was staying in Emily's house. On further investigation I found that Trevor had visited Emily for the first time the evening before. Emily remained very agitated and kept pointing out the window. I thought she wanted to go home so I told her I would make some arrangements for her to go home for a visit and told her that I would go with her. I talked with Cathy and we both decided to go with Emily.*

*When we pulled up the driveway, the car had not quite stopped when Emily opened up her door. That gave me a bit of a fright because without someone beside her, she would have just got out. Emily was on a mission; she had that look of determination on her face. She checked firstly that all the flowers were still in the garden. It was as if she was counting them to herself. Satisfied, Emily went inside and Trevor met us in the kitchen. Emily pushed past Trevor and went straight to the second drawer down on the china cabinet. She then proceeded to look through the items in the drawer one by one. When she had finished, she turned to Trevor, pointed her finger and shouted You, You, You. Trevor wanted to know what she was going on about and that made her even more angry. She picked up her stick and started shaking it at Trevor all the time yelling You, You, You.*

*We tried to calm her down but she was angry. Something was obviously missing. Emily went back to the china cabinet and began searching through the*

*other three drawers then grunted, walked away and began walking from room to room shifting things as if putting them back in their place. She was making sounds like she was accounting for everything in the house. We went in to the bathroom and Emily studied the bath for ages. I knew what she was thinking, she was working out how she could get in and out of it by herself. We finally ended up in the wash house. Something was not right I could tell by the look on her face. In the corner was a blanket on top of a pile of something. Emily went straight to the blanket, lifted it up and there underneath was a pile of empty beer bottles and wine bottles. Emily 'tut-tutted' and shook her head. After this Emily went straight to the lounge and sat down. It was obvious she just wanted to sit down so we all sat in quietness.*

*When she was ready Emily got up and headed out the back door for the car. Our family meeting arrived and I accompanied Emily to it. The aim was to decide whether Emily was to go home or be transferred to residential care. Everyone put their ideas forward outlining reasons for or against Emily going home. 'Yes' Emily was at risk of falling, 'yes' she was not safe to boil a jug and 'yes' Trevor wanted Emily in care. I could hear all the logical and safe reasons why Emily should not be at home but Emily was very vocal in trying to communicate to the other's that 'home' was where she wanted to be. I asked if Emily was going to be less likely to fall if she was in an institution. The reply that I got was that 'no' she wouldn't be but that she would be more likely to be found more quickly. I asked why she couldn't advertise and get someone to live in with her at home. Trevor was really opposed to this idea. I*

*was told that time was an important issue here. Emily had already been in an assessment bed for ten weeks, four weeks too many according to management. Emily and I were outnumbered and resthome care it was to be.*

*The next day I helped Emily to pack her belongings and I took her over to the resthome. I will never forget the feelings inside me as I was taking Emily to live where I knew she did not want to be. I helped Emily to set up her room. She was very uncooperative and was indifferent as to where I was placing things for her. We sat for a while on the bed and then I had to leave. The look that she gave me was as if to say 'you were my only hope'. I felt a lump develop in my throat and tears pricked at the backs of my eyes. I arranged for Cathy to take her home from time to time so Emily could pick up the odd things she wanted before her house was sold. I visited Emily every day. At first when I visited her she was always awake and pleased to see me. As the weeks went by she was often asleep in the lounge.*

*Emily had been in the rest home for four months and during this time she had fallen a few times. On one occasion she fell and broke her hip. Emily never recovered from this fall and died a few weeks later.*

Emily never liked being in the Rest Home.

Emily was living in a place where she did not want to be and that was not her own environment.

Would Emily have been any safer in her own environment?

Would Emily have been happier in her own environment?

I had so many unanswered questions. I needed to explore and find those answers

so that I could confidently provide the care that satisfied my philosophy. I believe that the elderly have rights to remain in their own environment. Is this really their right even if they are unsafe? Who is supporting them in this right? It was time for me to move on. I could no longer function in the caring way that I believed to be my right and have regard for the basic human right of the individuals that I came into contact with. I needed

### **Nurturing**

and

### **Reshaping**

to be able to care confidently once more.

“What it is to nurse cannot be separated from what it is to care for and about others” (Tanner, 1990, p.71).

In an article written by ‘Bishop’ and ‘Scudder’ they summarize ‘Pellegrino’s’ work in this way .....

“... the most professional, moral autonomy grows from within rather than from reform of bureaucratic structure and rules that regulate professions”

(Bishop & Scudder, 1987, p.37).

## New Beginnings

I began to practice in the community setting and visited many elderly people that were continuing to live in their own homes, their own environments. Part of my responsibility was to assist these people to maintain their own independence, to remain in control and to offer them support in their decisions.

I thought at first that this would be a role that truly met my caring needs and would satisfy my philosophy of maintaining elderly people in their own environment if that was where they wanted to be. However the role was not quite that simple.

I was only one of many other people having an input in to these peoples lives. My role was to arrange for the support systems of household management and personal care which was to be provided. That role did not include the allocation of that support or other types of support. I was however in a position where I could request for more assistance or alternatively empower the individual to request a reassessment. On most occasions that this was required, neither myself or the client were successful in increasing the allocated amount of support. Some of the responses as follows:

*... We don't cater for peoples real estate choices. If they have two toilets then they will just have to choose which one they are going to use*

This was said when I told the assessment agency that the careworker could not get all the work done in the allocated time.

Another lady had broken her left arm and could not drive to the shops to get her groceries. Her husband had advanced Parkinson's disease; she had to cut his food



up for him and on occasions even feed him. When she asked for a little more time in addition to her household management time for someone to take her to the shops, as she had no family who lived in the same town, she was told that she could

*'get her husband to change gears for her while she was driving'.*

On rare occasions when I came to hear of what had been said, I made contact with the agency and in this case, managed to achieve an increase in hours for this lady.

I am sensitized then when careworkers contact me to report that they cannot provide the care that is required within the time frame that is allocated. I have many clients contacting me concerning the same issue. On many occasions I hear that careworkers are spending their own personal time with their clients and although this is not a recommended practice and there are policies and procedures written recommending that careworkers avoid doing this, I can see exactly why it occurs. The allocated hours of home support provide for tasks and because the careworkers are caring people their caring goes beyond what bureaucratic agencies have deemed as 'the time bound caring' necessary to support someone in their own environment. "Because of the impersonal goals of bureaucratic systems, care givers in institutions are frequently thwarted in their efforts to provide personalized holistic health" (Condon, 1991, p.15).

Home health care is a very specialized and personal form of care. In many instances a total stranger is entering the domain of a person who is in need of support to remain in their environment and therefore are very vulnerable and at

risk of experiencing a sense of 'loss of control'. "Caregivers must build rapport and trust before they can take care of their patients; and that's not just something that has to be done on the first few visits, when a client is new to home care" (Stone, 1999, p.66) and "When empathy, generosity, and reaching out to your fellow human beings are perceived as civil disobedience, we are a society in trouble" (Stone, 1999, p.70).

When resources are being allocated for home support, most politicians and policy analysts are concerned that if the government agencies fund increasingly more home support then this may have the impact of displacing much of the voluntary care currently offered (Stone, 1999).

Policymakers ought to worry instead about a different kind of displacement.

The displacement of caring relationships and social connections by narrow, task-orientated bodily maintenance; the displacement of empathy and affection by cool professionalism and calculated fiscal prudence; and the displacement of an ethic of responsibility for one's neighbors by an ethic of working to rule.

If we care about preserving the norms of reciprocity, trust and mutual aid that make us a community, we had better take better care of our caring work (Stone, 1999, p.70).

There are so many elderly people who want to remain at home and because some are better advocates for themselves than others then they are more likely to succeed in attaining a larger proportion of care. A study completed by Ely; Brayne; Huppert; O'Connor & Pollitt. which sampled one thousand five hundred and eighty five woman over the age of seventy five who lived at home in the city of

Cambridge (UK). They found that physically disabled woman received substantially more home support than was received by cognitively impaired woman (Ely; Brayne; Huppert; O'Connor & Pollitt, 1997).

Some elderly people living at home have assertive family members who can manage to secure additional home support for their elderly relative. Some elderly people do not know that they could be entitled to home support let alone how to access it.

Several key informants and correspondents commented on the difficulty of obtaining information: *"It's very hard to get reliable information on entitlements. People don't know where to go. Income Support does not advertise entitlements or grants. They need to know about their entitlements - they're always changing the rules. Staff are difficult to deal with. People need to be assertive and empowered to be successful"* (Dwyer, Gray & Renwick, 1999, p.52).

If a reassessment was requested then it can take between three and four weeks before that person is then seen. In some instances there could be numerous agencies involved in an elderly person's care. Each agency is separate from the other and each agency only provides the care that they determine falls within their contracted allocation. The following story reveals this dilemma.

## Mary

*Mary lived at home with her son who worked full time and did not participate in his mothers care other than to cook her an evening meal. Often he was away in the evenings and was not even there to do that. Mary had Alzheimer's disease, was doubly incontinent and always used to forget to take her medication. I was asked to provide Mary with seven day week care for the mornings when she needed showering and her medication administered. Mary was under the care of her general practitioner, the community mental health team, home care assessment agency and the home care provider. Because Mary's son was not always home in the evenings to supervise Mary taking her medication, it was decided to give all her medication in the mornings when there was someone there to supervise. Mary's condition deteriorated with her medication given in this way and so I got a call from the assessing agency to provide an additional hour of care in the evenings to get her an evening meal and supervise her taking her medication. This evening care was to be provided Monday to Friday. When I questioned why not for the weekends also, I was told that those extra two hours would put the assessing agency over their allocated hours. The community mental health team had no hours to allocate as they had used their allocation and that left Mary with fragmented care which enabled agencies to function within their allocated budgets.*

Mary's story reveals how bureaucratic systems focus on meeting targets and remaining within set budgets. There is a curious twist to this scenario. Some

elderly people are even being placed in institutions by families and bureaucracies to save time and money.

Excellent home care requires the intelligent use of available medical and supportive services. Unfortunately, placement in a hospital or nursing home is often an easier task than negotiation of the fragmented and unorganized fabric of home services necessary for maintaining person's in their own houses (Gurland, Breuer & Chachkes,1995, p.36).

Jill Chaloner writes about her experience with the health system concerning her mother (aged eighty eight) who suffered with Alzheimer's disease to reveal how her mothers placement was being manipulated and 'cost driven'. Previously her mother had been living at home and receiving home support services four times a day. After an admission to hospital and being treated for an infection, she was not sent home even though deemed medically fit. The social worker kept putting off the discharge and Jill Chaloner's mother was deprived of all personal belongings which made her angry and uncooperative. Eventually an assessment was completed and the psychiatrist recommended a return home with the same care package as on admission.

A discharge date was set and at this point the social worker revealed the truth. Months before the hospital admission, the social services had made an internal decision not to finance the previously existing care package solely on cost grounds. The social worker admitted to me that they were trying to cut costs for the more expensive--that is, file most needy clients. She said that they thought that it would be less cruel to move my mother to hospital, then

to a psychiatric unit, rather than straight to the unit from home (Chaloner, 1998).

Also I have visited elderly at home who feel that they are being pressured by many people who want them to go into care when all they want is to be living in their own environment. The following stories reveal that people are pressured to go in to care against their will, this has devastating effects.

## Mrs Jones

*Mrs Jones was a new referral and I could not get her by phone as she was very deaf and unable to hear my calls. I went out to visit her and knocked on the door. I could hear voices inside so knew that she was at home. Soon after a lady answered the door and informed me that she was Mrs Jones's next door neighbor. I explained who I was and why I was there and she let me in to visit Mrs Jones. Mrs Jones was ninety three years of age and lived by herself. Once I had adjusted her hearing aid so that she could hear me I proceeded to explain who I was and why I was there. The referral had said that she needed assistance with showering and some housework. Mrs Jones was adamant that she did not want any assistance and that she was fine to manage with the support of her neighbor. When I asked her why she did not want any support, she began to tell me what had happened to her previously.*

*Just over a year ago Mrs Jones had fallen and broken her hip. She was admitted to hospital and underwent surgery to repair her hip. Mrs Jones was transferred to the assessment and rehabilitation ward where it was decided by the staff and Mrs Jones's daughter that she should be discharged to a rest home. Knowing that Mrs Jones did not want this they told her it was so that she could continue her rehabilitation. As the months went by Mrs Jones kept asking when she was going home. Everyone kept telling her it would be soon. Eventually Mrs Jones got tired of being put off and decided to discharge herself from the rest home in time to be home for Christmas.*

*Mrs Jones had been nine months in the rest home and now she was home she*

*did not want anyone interfering in her life. She had made up her mind to stay at home and was not going to run the risk of anyone 'tricking' her again. Mrs Jones explained to me how her daughter visited every week and every week they argued because her daughter wanted her to go back to the rest home. Mrs Jones began to wish that her daughter would stop visiting because she got so upset every time she came to see her. Mrs Jones only trusted her next door neighbour because she had always been so supportive and honest with her.*



## Louise

*Louise was eighty six years old and had lived by herself ever since she had left home when she was eighteen years of age. When I visited Louise for the first time she looked very distressed and told me that she was very worried because all those that she came in to contact with were telling her that she needed to move in to a retirement village. Louise had no family but had some friends that she visited when out driving in her car. She was frail but negotiated her house very well without a mishap because she was familiar with her surroundings. She was paying someone to do her gardens and was receiving two hours of household management assistance. Louise's doctor had suggested that she consider moving to a retirement village as she was getting frail and living in a large house that was on a hill with a big section may soon become too much for her to manage.*

*Soon after this Louise made contact with a rest home manager who owned two rest homes with adjoining retirement villages. She went to have a look at one apartment but was put off because there was no garage for her car and the apartment was so small that she would not be able to take all her possessions with her. She told me that she wished that she had never done this as ever since that time, she had received numerous phone calls from this person wanting to show her what accommodation was available. Louise asked for my opinion as to what she should do and my advice to her was that as long as she wanted to remain in her own home then no one could make her leave against her will. She said that I was the first person to have given her that*

*advice.*

*Louise remained at home and approximately two months later she was found in bed and had died in her sleep..... at home.*

I was so glad that I had been to visit Louise that day and that she had decided to remain at home as that was where she really wanted to be.

## Mrs Smith

*As I sat in the passengers seat of the car, I read the information that I had before me. "Mrs Smith ... lives alone ... aged ninety eight ... very hard of hearing ... suffers from stress incontinence ... requires assistance with a shower and household management and has daily treatment to both legs due to vascular insufficiency". I became aware that my colleague was asking for the address of Mrs Smith and so I read, "116 City View St". It wasn't long before we pulled up*

*outside Mrs Smith's letterbox. I had already installed in my mind a picture of what Mrs Smith was going to look like and imagined that her house was a grand old place. My imagination could not have been further from reality as I was soon to realize. We got out of the car and began to climb the steps that led to Mrs Smith's front gate. I lost count of these steps somewhere after seventy but eventually we came to her front gate only to find that we were faced with yet another flight of steps. As Mrs Smith's house came into view I couldn't help but notice that the gardens were all overgrown and the outside of the house was in bad need of repair.*

*On the roof there were some sheets of new iron dotted here and there but never painted. For the rest, it looked like the last remains of the original paint was easing its way off to reveal large patches of rusting iron. I knocked at the front door but there was no reply. So I tested the door to see if it would open and sure enough it did. I stepped inside. It was very dark and there was a distinct smell of stale urine. I called out for Mrs Smith but could only hear the television going and it was very loud. I called again as I walked down the*

*hallway until I was standing at the door to the dining room. I could see Mrs Smith sitting in the dim light and at that moment she also saw me.*

*Mrs Smith got up out of her chair and came towards me. I explained who I was and why I was there. She was quite deaf and so I had to repeat myself once more. Once Mrs Smith understood who I was and why I was there, she gave a smile and become very welcoming. She ushered us in to her lounge where it was much brighter and she sat down on a chair in the corner.*

*Mrs Smith had some towels spread on the floor and a basin with a cloth in it sitting next to them. For years she had suffered with chronic varicose ulcers and now the skin on her legs was very fragile and needed daily treatment. My colleague sat and talked to Mrs Smith while I went and filled up the bowl with warm water.*

*As I walked back into the hallway, I noticed a dried trail of urine stain on the carpet and it went from the dining room, along the hallway and into the bathroom where the toilet was. I had to enter the bathroom to fill the basin up with water and found that the urine stains led right up to the toilet. I filled the basin with water and went back into the lounge. The lounge was amazing. The ceilings were high and covered with imprinted designs and the wallpaper looked like it was the original paper that had ever been hung. The roof must have been leaking at some stage because there were large brown water stains running down the wallpaper. The floor was covered in gray carpet with large red roses on it. I could tell that it would have been very expensive carpet in its day. On the wall was a huge marble fireplace and hanging above it was a*

*picture of Mrs Smith in her wedding gown. How beautiful she was.*

*Mrs Smith saw me looking at the picture and told me that she had married when she was twenty years of age and had been with her husband for seventy years. They had the house built for them five years after they had married and had lived in it ever since. The view out of the lounge window was magnificent and she could see right over the city. She said that she did not want to leave her house even though her daughter tried and tried to persuade her to live in a rest home. I began to help Mrs Smith put her feet in the bowl of water, knelt at her feet and began to wash them. After I had dried them I began to apply some prescribed cream to her legs and then massage them for her.*

*While I was doing this she was telling my colleague how she had not left the house for years. There were too many steps and she loved her home so much that she did not mind staying there. Mrs Smith's daughter did her shopping for her but every time she visited she tried to talk her in to moving in to a rest home.*

*As I spent time in that room with Mrs Smith I could understand why she did not want to move. This was her home her environment. As we were leaving and nearing the car, my colleague made the comment "People like her should be in care". I felt sad at this comment after hearing what Mrs Smith had just been saying.*

I was so disappointed. When I hear many health professionals within the home support agencies and family members making these statements.

Carolyn Chambers Clark looked at the lives of 28 older adults aged 57-83 who completed a questionnaire based on a self-care wellness model. As part of this study she looked at how these adults managed their stress. The most reported stressor was that of family problems including “People trying to get me to spend time the way they want me to” (Clark, 1998, p.356).

## Mrs Brown

*I had read Mrs Brown's notes and found that she lived down a back section and so I began to walk down a long driveway until I got to house number 354D. I knocked at the door and heard a voice call for me to come in. Mrs Brown was sitting in her bedroom on the edge of her bed. She had a very small bedroom which had very little furniture and was situated next to the lounge. The only view that she got from this room was out onto a large wooden fence. Mrs Brown was ninety five years old and had been living in this house with her daughter, son in law and three teenage grandchildren for the last two years. The house had been old and had been beautifully renovated and extended. I did not rush Mrs Brown and I think she sensed that I was not in a hurry and began to talk about her situation. Three years earlier her daughter had persuaded Mrs Brown to sell her house and with the money, her daughter would renovate her own home and extend it so Mrs Brown could live with them.*

*All of Mrs Brown's money was spent to renovate and extend her daughters house. The extended part of the house had a beautiful large bedroom with its own bathroom and Mrs Brown had thought that this part of the house would be for her. When it was time to move in, Mrs Brown was given the smallest room in the house and all the teenagers were in the bedrooms closest to hers while her daughter and her son in law had the new part which was at the far end of the house and could be shut off from the rest of the house. Mrs Brown hated living where she was. She said that it was so noisy and she had no privacy. Mrs Brown missed having her possessions, that were lifelong, around*

*her as they were sold at an auction and the money was used to help renovate her daughters house. Mrs Brown began to make a move to get her clean clothes ready for after her shower. When we made a move towards the wash house I thought that she was going to put some dirty clothes in there but tucked in the corner was a toilet and a shower all in the same room. We had to make our way through lots of boxes and dirty linen before we reached the shower. There was hardly any room for Mrs Brown let alone myself and here we found ourselves squashed into this tiny room while I assisted her to shower and get dressed. Each time we wanted to switch places I had to move out into the wash house. Mrs Brown explained that she had to sit on the toilet to get dressed because there were no rails for her to hold on to. Her towels had to lay on the floor. After she was showered and dressed we went back to her room and while she brushed her hair Mrs Brown explained that if she had the money, the possessions and was not so old then she would leave her daughter's place and live by herself once again. She said that she had made a mistake and was now unhappy with where she was living. I had no answers for her, could only empathize and that felt quite inadequate. Mrs Brown set herself up with some handy craft and I said goodbye leaving her in her room by the window with the outlook onto a large wooden fence.*

Mrs Brown had been led to believe that she could not manage in her own home by herself and it would be better for her to live with her daughter than to go into a rest home. Mrs Brown thought that she would be happy with her daughter but was not. Mrs Brown was living in a place that she



did not want to be. This was not her own environment and she was to spend the rest of her days in a place that was not her own.

There have been research studies which indicate that caring for an elderly family member can be an extremely arduous task. The family members caring for an elderly member can become angry, depressed, resentful, chronically fatigued, anxious, isolated and the other family relationships deteriorate. (Bergman-Evans, 1994; Berry & Murphy, 1995; Cantor, 1983; Chenoweth & Spencer, 1986; Cox & Monk, 1993; Krach & Brooks, 1995; Montgomery, Gonyea & Hooyman, 1985; White-Means & Chang, 1991).

There are cultures where the children are expected to care for their parents in their old age. This relationship is referred to as 'reciprocity' which serves to emphasize familial responsibility (Homans, 1961). Often as the elderly persons dependency increases, the caregiver experiences feelings of resentment that lead to guilt (Braithwaite, 1992; Brody et al, 1978; Huston, 1990).

A paper completed by A.F. Running uses 'self narratives' to critique a book titled "The Measure of My Days". In this paper eight elderly people over the age of eighty six were asked to read and express their opinion on this book. One person states that 'she prayed that she wouldn't be a burden to anyone' and another stated that 'she would rather go to a nursing home than live with her children' (Running, 1996).

## Rose

*Rose was eighty two years old, was managing just fine at home by herself and required only two hours household management each week to keep her house in clean and tidy condition. One day Rose phoned me to say that she had been visited by a person from the nearest rest home and they had offered to buy her house from her if she wanted to move in to their rest home. Rose went for a look and signed the agreement selling her house to them and in return, buying a unit at the rest home. Previously there had been no mention of Rose going to a rest home. Rose was entitled to make her own decisions but I wondered was this just good salesman talk and does she regret her decision today?*

“Institutions afford security, stable financial support, facilities, and resources to their members. If one receives these benefits, then one usually pays the price - often loss of some individual freedom” (Bishop & Scudder, 1987, p.38).

There are those elderly people who make the decision to move into some sort of supported living, who thrive and remain very happy and contented with their living arrangements. However, there are those people who are placed in institutions against their will.

## Mr Tucker

*I visit two elderly gentlemen in a rest home where they have chosen to go and are very happy. They have been friends of mine for many years and so whenever I can I call to visit them. Every time I go to visit them, there sitting in the corridor by the lounge and watching the exit door is Mr Tucker and every time I arrive he asks me if I know when his wife is coming to take him home. Mr Tucker originally came to that rest home four years earlier for respite care to give his wife a break and she put him there knowing she had no intention of taking him home and this had been arranged with the manager of the rest home. The reason why Mr Tucker is in that rest home is because his wife leads a very active life and he does not and never has. He is frail and prone to falls and because she is out every day she does not feel that he is safe to leave at home by himself. He would not agree to day care but would, with a lot of persuasion, go into the rest home to give his wife a break.*

This was the last time he was ever in his own home.

I have seen so many situations where elderly people have been institutionalized because they are assessed as being unsafe to remain at home. A lot of these elderly people agree to move to a rest home because friends, family and health professionals are advising them that that is what they should do. In my experience elderly people who leave their home to move into institutional care, and do so under these conditions, are never truly happy. They always talk about their home and how 'that is where they would rather be'. They seem to lose their purpose and meaning of life which can cause them to decline even further in

their health. Jacqueline Wiles writes about this concept of elderly people being placed in institutional care because they have been assessed as being unsafe to remain in their own environment. She writes about a man who gave up and died because "Death was the only thing over which he could retain some control" (Wiles, 2000, p.48). There are many elderly people who

...cannot adjust to institutional life and the resulting isolation and despair is concealed from the outside world under a blanket of their removal to a 'place of safety'. I know that in such cases most relatives and practitioners act with the best intentions. However, by focusing on the duty to protect an older person from physical harm, the emotional risks may be overlooked (Wiles,2000, p.48).

In an article written by Leslie Milk she talks about moving her mother into a retirement facility and then into an assisted living facility. She talks about how her mother hated the idea of moving from her home environment and how it took a lot of reasoning to get her consent. When she was sorting through her belongings to establish what she could take and what she could not she wrote ... "To mother, each discarded item - a straw tote bag bought on an island vacation, a bar cart used to serve cocktails to company - was a piece of her life now branded useless and unimportant" (Milk, 1999, p.94). Leslie Milk's mother was moved to the retirement village and from then on she deteriorated very quickly "...She refused to talk for days...Mom seemed disoriented, exhausted, defeated" (Milk, 1999, p.94). Eventually she had to be moved to an assisted living apartment and as soon as she was housed there "Mother immediately talked about wanting

to leave” (Milk,1999, p.96).

Diane Naughton writes about families who struggle with keeping their elderly parents safe while allowing them independence, and the corresponding anger of the parent.

Many elderly resist change, declaring that the only way they’ll move out of their home is horizontally. Seniors often fear nursing homes more than death. In August, a Florida jury acquitted a 68 - year - old woman of attempting to murder her daughter, who had talked of putting her in a nursing home (Naughton, 1999, p. 99).

Safety as the top priority in an assessment is a concept that needs to be questioned. When assessments are completed by the health professionals, the assessment includes activities of daily living scores and does not have a score for the emphasis that is rated by the individual on remaining in their own environment. If an elderly person cannot make decisions about their own life then there is a serious breach of basic human rights (Wiles, 2000).

On many occasions I see elderly people at home in unsafe conditions and when I suggest that something could be done to improve their safety, they often refuse. It may be a mat with upturned edges or the lack of a rail or walking stick for stability. These elderly people are fiercely independent and do not want to be associated with any change that alters their self esteem or their environment. I console myself in the belief that these elderly people have rights and should be able to make their own decisions concerning themselves and their environment.

## Quality of Life

There has been much research completed on assessing what is the Quality of Life (Q/L) indicators for those elderly people who want to remain in their own environment. The measures of quality of life have often been founded on focused definitions and objective criteria such as 'health-related' quality of life (Farquhar,1995a) and the purpose of quality of life in research in nursing has mainly been to survey or measure the health-related quality of life in patients with different symptoms or diseases (Rokne Hanestad, 1993). To measure the quality of life in the older person to health-related criteria limits the meaning of quality of life and if more broader measures were used, then a more accurate picture of Quality of life would emerge (Farquhar, 1995b).

Every elderly person views their quality of life differently because every person's lived experience is unique to them. A health professionals measurement of quality of life is often different than that used by the older person (Clark, 1995; Koch et al, 1995; Porter, 1995). Health professionals are striving to measure quality of life by using quantifiable data whereas older people are more concerned with the issues of self-identity and preserving the meaning in their lives (Clark, 1995; Porter, 1995).

Ebrahim et al (1993) argue that the simplistic approaches adopted by professionals fail to capture the complexity of caring for older people. They believe that the search for scientific measures of Q/L should be abandoned as the models produced are inappropriate and insensitive (Lundh & Nolan, 1996, p.1249).

There is enough evidence to suggest that elderly people cope with aging much better than previously thought (Brandstadter, Wentura & Greve, 1993).

The elderly are able to adjust to the aging process and make adjustments to their surroundings and lifestyle in order to remain in their own environment. These adjustments are described as: assimilative, accommodative and immunizing activities. 'Assimilative practice' is where people aim to maintain their current activities, goals and aspirations. This may be achieved by continuing to keep fit, remain attractive and continue to set and achieve goals. As the elderly person's aging process continues and prevents them from being able to achieve this assimilation process then the accommodation phase becomes important.

'Accommodation' is the process whereby elderly people accept adjustments to their goals, aspirations, fitness, their appearance and how they see themselves. They may therefore give up the goals that have become too difficult or reduce their expectations or make favourable comparison their achievements with other around them. Once again as the aging process continues and if 'accommodation' tactics are failing then the elderly resort to the strategy of 'immunizing'. This process is where the elderly person's values and beliefs become threatened and they see themselves as becoming different. The elderly begin to be selective and sift through information which they can apply to themselves and ignore the rest. This 'immunizing' process also is where the elderly people replace the setting of goals for the future with looking back into their past achievements. (Brandstadter & Greve. 1994).

Using qualitative research studies, Lundh and Nolan (1996) provide further data to

support these concepts of 'assimilation', 'accommodation' and 'immunization' and found that "...older individuals who are able to employ 'accommodation' have a good subjective quality of life" (Lundh & Nolan. 1996, p.1291).

The interpretation of 'Quality of Life' for the elderly can only be described by the individual themselves and as discussed, each person is unique and has their own set of life experiences. Each person's personality and attitude helps them to form values and preferences to judge their quality of life.

There are others who would measure a person's total wellbeing by the measurement of happiness. "When a man says that he is happy, he means that he has a happy life, a life in which all his objectives form a harmonious and satisfying whole" (Simpson, 1975, p. 175) and "...a person's being happy represents the highest assessment of his total condition" (Austin, 1968, p.52). Research completed by Shin and Johnson which looked at the meaning of 'happiness' and established grounds for its proper use in scholarly research found that happiness is ...an important conceptual tool for assessing the quality of life through the eyes of the beholder...that happiness is a concept relative to individuals, their unique needs and resources and to the culture and environment in which they function as social beings (Shin & Johnson, 1978, p. 491).

Additional research completed by Levin (1994) assessed the relationship between life satisfaction in the elderly and their internal and external environments and found the following for those people who needed assistance with activities of daily living ...

Surprisingly, physical disabilities do not necessarily mean that quality of life is



diminished...socialization and a sense of mental and physical control count more than total self - sufficiency ...to be happy in old age one should wish for many friends and involvement in many activities, rather than aspiring to total self sufficiency. In fact, a career lasting long past the so - called retirement age might be more of a guarantee of happiness than anything else (Levin, 1994, p.17).

Nurse theorists Johnson, Rogers, Levine and Roy were from the school of thought where their focus in nursing was on outcomes and the end results of the caring process of nursing. These theorists “conceptualized the goal of nursing care as bringing back some balance, stability and preservation of energy or enhancing harmony between the individual and the environment” (Meleis, 1997, p193).

## Homecare

Homecare is an option and for many elderly people it is the only acceptable option when faced with the alternatives of living with family or moving to residential care. For these elderly people there needs to be adequate resources and support for them to remain in their own environment within the community.

(Chris Tuffnell) wrote for the New Zealand Home Health Association in 1999 that:

“Homecare has been practised for at least 2000 years. It is only in the past 150 years or so that the developments in medical science led us to create the large constructions of bricks and mortar for ‘health’ care with their raft of elite disease treating practitioners, relegating homecare to back-stage. From being holistic and support orientated, treatment and care became compartmentalised and separated from the “patient”...” (Tuffnell, 1999, p.1).

In a study completed by Richmond and Moor in the ‘Waitemata Health’ area a cost comparison was made between those living at home receiving case-managed care and those living within institutions. It was found that those living at home were more satisfied with their living arrangements and when the cost of secondary care was included, the weekly cost of the home care was less than residential care by \$154.52 (Richmond & Moor, 1997).

“...Sweden and Denmark have been deinstitutionalizing their elderly and developing sheltered housing units and home help services. In 1989, Denmark prohibited further construction of additional nursing home facilities (Cates, 1993) and in Great Britain, the Community Care Act of 1990 encouraged

development of community services instead of nursing homes. Despite an increase in the number of elderly people, these three countries have held constant or reduced the number of instances of institutionalization of elders (Coleman, 1995)” (Murashima, Zerwekh, Yamada & Tagami, 1998, p.2).

Admission to institutional care often follows an admission to hospital for an acute injury or illness rather than from a slow deterioration in function and health (Hennessy,1996). If elderly people are discharged home from hospital, before they are fully recovered from their illness, without adequate support then they are at risk of developing even further illnesses which result in readmissions (Branch & Jette,1982). The result is that post discharge admissions to nursing homes is likely to be greater as these elderly people are much more frail. (Weinberger & Oddone, 1989). It is essential therefore to have adequate home support arranged for these elderly people prior to their discharge from hospital. Following discharge from hospital, I have visited elderly people in their own homes only to find that the required support has not been put in place resulting often in a compromise in safety for the individual.

‘WHO has urged the relevant governments to develop policies and programmes to strengthen the family and community base; and to support the elderly while promoting active and healthy ageing with social safety nets. Putting the elderly in institutions is not recommended’. (Kumar, 1999, p1339).

“Given the resources, just about any kind of care can be provided to a person or family at home” (Tuffnell, 1999, p.1).

As part of the New Zealand Health Strategy in June 2000, it has been identified

that improved co-ordination is required for older people. And that the Ministry of Health will develop a strategy to address this issue (King, 2000). In the same month as Annette King Minister of Health (2000) published her Health Strategy, Ruth Dyson, Minister for Disability Issues in New Zealand announced that there would be an additional \$2.8 million dollars to provide much-needed additional hours of home maintenance or personal care support. This funding was intended to support those people who would otherwise require residential care, particularly Maori and Pacific people. This is a step in the right direction for supporting those whose decision it is to remain in their own environment.

I believe that in New Zealand there needs to be greater efficiencies of care and resource allocation. There needs also to be a common goal between agencies to maintain the elderly in their own environment if this is their chosen place to live. Then and only then can a truly humane form of caring exist.

## Conclusion

During my years in nursing practice I have experienced many human to human relationships with elderly people who have the potential to become very vulnerable unless empowered to take control. I have cared for many elderly people who have been over powered by bureaucratic money making and cost cutting agencies. Health professionals are practicing in an ideal environment which enables them to empower the elderly people to take control of their own life decisions and then to support these people in those decisions. There are many elderly people who want to remain in their own homes, their own environments and are not being supported to do so. These people often get conflicting advice from different agencies who visit them which results in their care often being fragmented and lacking in a common goal.

Each elderly person living in their own environment is unique and has their own life experiences and therefore their quality of life should be measured according to this lived experience. It is every elderly person's right to remain in their own environment and by taking this right away and placing these people in institutional care they are denied that basic human right. To remain in their own environment, the elderly people require adequate resources and all agencies working for a common goal.

The Ministry of Health in New Zealand is aware of the needs of the elderly in the communities within New Zealand and are developing strategies to address these needs. In my opinion it is essential that when developing these strategies that not only resource allocation is considered but also that the efficiencies within

the existing systems are explored.

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