Responding to the Challenge

“A pro-active response to the changing cohort of dementia care residents”

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Living with Dementia –Positive Solutions

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Abstract

Title
“A pro-active response to the changing cohort of dementia care residents”

Aim
To develop a cohesive approach to preparing the staff and environment to cope with the challenges of meeting the needs of (dealing with) this younger cohort. (of dementia residents) This study applies particular focus on four residents who currently live in one of our facilities.

Main Message
Uniting Church Homes, as part of their strategic directions, has been implementing new initiatives to increasingly meet the needs of residents with special needs, particularly those with dementia. A Dementia Care Project has been in operation since July 2003 and has been building upon the philosophy of a person centred approach to cater to the unique challenges faced when providing care to residents with dementia.

During the operation of this project, it became evident that demand for dementia specific places/beds has been growing and that increasingly those on the waiting list are of a younger age group than has been the case in the past (i.e. less than 75 years of age). In response to this, the Dementia Care Project has applied the principles of business excellence to develop a cohesive approach to preparing the staff and environment to cope with the challenges of meeting the needs of (dealing with) this younger cohort. (of dementia residents) This study applies particular focus on four residents who currently live in one of our facilities.

A multi-pronged approach was adopted to ascertain training needs. Focus groups were held to establish the perceptions of all stakeholders regarding:

- Personal care needs;
- Physical needs;
- Social needs;
- Emotional needs; and
- Environmental needs.

In addition, information was collected from occupational health and safety reporting incidents, care conferences, continuous improvement suggestions and dementia care mapping.

The result of this research allowed for the development of:

- Organisation-specific training tailored to respond to resident’s personal, physical, social and emotional needs.
- Environmental responses such as bedroom furnishings, seating, security and fencing with an emphasis on meaningful occupation.

Feedback regarding this initiative has been positive, in particular staff satisfaction with the focus on the individual and social aspects of care.
Responding to the Challenge

Introduction

In 2003, UCH identified that we needed to improve our response to people with behaviours of concern especially those with dementia.

Hence the introduction of a specific dementia care project driven by a coordinator and guided by a reference group. The key objective of the reference group was to provide strategic direction and input into the project and to develop an evaluation framework.

It was comprised of a regional manager, a care manager, an allied health coordinator, our training manager and of course the project coordinator.

The role of the dementia care project coordinator was to provide leadership and advocacy for dementia services within UCH.

To establish how to proceed in achieving the goal of the strategic plan it was necessary to discover

- what difficulties and
- what knowledge our staff had in responding to those with dementia,
- were our policies relevant and workable
- what effect did the environment have in relationship to care.

To achieve this used the Fishbone diagram:

- Policies – were staff able to identify relevant policies and were they relevant to their workplace
- People – what sort of training did they want about dementia and other related topics such as restraint and the effect of rosters and agency use.
- Documentation – social history, inappropriate referrals/admissions and time allocated to document.
- Environment – physical and social barriers, effect of increased needs and aggression.

This was the first time anyone had actually surveyed the staff and the information gained was very valuable.

From this information we were able to develop an informal philosophy and a model of care based on Tom Kitwood’s work – Dementia Reconsidered – the Person Centred Approach which aligns itself with our Mission statement.

Education was developed around acknowledging the five psychosocial needs as symbolised in the ‘Flower’ with the petals representing:

- Comfort;
- Attachment;
- Identity;
- Inclusion; and
- Meaningful occupation.

To achieve this we concentrated on the 10 positive strategies by dividing them into groups

1. Working together – recognition, negotiation and collaboration
2. Playing together – fun, relaxation, timalation and celebration
3. Being in tune together - facilitation, validation and holding

Validation was then achieved by using dementia care mapping.
Dementia Care Mapping is a way of looking at care underpinned by the person centred approach – an approach that allows the person with dementia to be active and interactive rather than a passive recipient of care – it is the only tool we have that evaluates from the residents perspective.

This gave us some qualitative evidence encouraging us to question our assumptions as to:

- How we go about our business
- How we develop our policies and procedures
- How we address individual needs

It was during one project where we had identified that residents spend 40% of their day involved in eating and that we were missing opportunities to increase interaction and enjoyment. The observations resulted in making changes to our meal delivery – encouraging choice at the time and leading to reversal with the main meal being served in the evening.

Apart from highlighting areas where we could improve meal time enjoyment for our residents with dementia it identified changing activity needs and changes that would improve the environment. Importantly it also identified we were not meeting the needs of those who were younger and had a diagnosis of dementia.

### Going about our business

- **Dementia Care Mapping (DCM):**
  - DCM conducted at several sites and identified younger people’s needs were not being met
  - Staff found it difficult coping/adapting with the mix of frail age and younger people with dementia
  - Activities programmes geared to older age group

- **Anecdotal evidence** – from other managers who noted an increase in the number of enquiries about placement of those who were younger and had a diagnosis of dementia.

- **Increase in resident incidents** mainly attributed to younger group – 20% of all incidents were related to aggressive responses with 90% being attributed to our younger residents with dementia.

- **Enquiries from the community** – within a week of putting this abstract together we had 3 enquiries for placement in our secure area – ranging from 47 – 63 years

- **Organisation wait list** – increased numbers not just at this particular facility but throughout the organisation.

### Preparing for the challenge

Having identified the issue we realised the project was too broad and involved too many variables to address at once.

- **Needed to redefine our age group**
  - Most of the enquiries/wait list were in this group – 60-75 years
  - Stable – pre war and up to 1945
  - Mainly Caucasian
  - From the our local area

- Areas of care were established and again we encountered a huge task and sought to refine the topic further.

- Establish areas of need to be considered
— **Personal care** (routines and rituals);
— **Physical** (fitness and well being);
— **Social/cultural/spiritual** (influence of social mores);
— **Emotional** (impact of family); and
— **Environmental** (importance of function and access to outdoors).

As people with dementia find it difficult to express their needs in relationship to these care issues, we needed a control group of people of the same age without a diagnosis of dementia.

**How did we go about this?**

As we were not a group of researchers, we needed to find a method that suited a naturalistic form of enquiry that didn’t require a minimum number of participants.

The Phenomenological approach was selected as it looks at:

> “Everyday experience and an interpretation of the meaning of those experiences for individuals”
> “Where meaning can only be understood by those who experience it.”

**The Phenomena’s**

11 people were interviewed all selected at random – between 60-73 years of age.

- 30% male;
- 70% female;
- 3 married and with original partner;
- 2 never married;
- 5 were divorced with no current partner; and
- 1 widow

They were interviewed using three to four set questions which related to each area of care – questions were open ended and allowed interviewer to prompt or interviewee to ramble.

Below we have summarised some of the findings.

**Personal care**

- Meals – all wanted cereal and toast for breakfast, light lunch and main meal in evening preferring an formal setting
- Grooming – Morning ritual very important and all were emphatic about their appearance
- Coping with changing body functions was interesting – mainly fear of losing vision and did not consider diabetes as a health issue

**Physical care needs**

- Keeping fit – none were motivated by competition but more by fear of losing mobility, or from a medical condition and spent time adapting to new forms of exercise or by social contact and by a feeling of general well being
- Coping with health issues - 50% had some form of arthritis, 30% had diabetes that was diet controlled and 20% had hypertension – all very aware of health issues and took a proactive approach with their GP overwhelmingly being the first point of contact

**Social needs**

- Contact with the community – mainly through work whether it be voluntary or paid, casino, Church groups and sport (not necessarily in that order!)
Meaningful occupation – work. 60% were in paid employment (which will please the pundits in Canberra!), while other pursuits included gardening, reading, walking the dog, fishing, golf, volunteering, family tree. Watching TV was not high on the list of occupations but live theatre was important to 45%, with the computer beginning to take hold;

Cultural/spiritual – church. Over 60% not only attended services but Church groups provided their main source of social support – mostly traditional Church.

Emotional needs

Role of the family – this had an enormous impact on ability to maintain relationships, with the father being cited as having the most positive impact.

Support systems – in spite of the fact that 35% found their family had a negative impact on their level of confidence, all made a conscious effort that their children would not have a similar experience.

What makes life worth living – work and being included with their family and being able to contribute to their welfare or to the community as a whole.

Environmental needs

Use of space – bathrooms and bedrooms to be functional and private and the majority preferred having one family area that is used for everything

Access to outdoors was the only question where 100% expressed a need to be able to have easy access to outdoor areas – fresh air!

Colour/ambience – all preferred pastels. Is this the era of the Billy Connolly’s Beige people??!! Good lighting, no floral prints mainly coordinated plains and plaids.

This information was collated and a hypothetical developed using information from the study.

The original intention was to focus on 4 residents in the facility but:

- Two moved to high care facilities
- Felt staff may feel intimidated if issues raised were not supported
- Opportunity to look with open mind
- Use of hypothetical:
  1. Aged 67, married with two children and one young grandchild and an elderly mother
  2. Dementia plus diabetes and CAL
  3. Semi-rural
  4. Community minded – Church, volunteering;
  5. Outdoors – garden and environmental projects;
  7. Non-compliance with medications.
  8. Wandering – especially in the evening.

Information would then be developed into training sessions.

Raising staff awareness

An invitation was given to all staff who volunteered their time – about 35% responded from all designations and included our GP - all for the price of a few Pizzas!

An external facilitator also volunteered her time.

The hypothetical person and information from the study was read to the participants along with the protocols for the focus group.

This group was based on the National Schools Association ‘Inside/Outside Planning’.
Inside / Outside Planning

- 5 people formed the inner group who worked on the hypothetical and were observed by the outside group who could listen, take notes but not interrupt
- They were asked to consider social, spiritual, emotional and environmental needs in the context of the phenomenological information and the 5 psychosocial needs that are embodied in the PCA. It was decided to leave out physical needs as this will part of a further study with our Physio.
- They established the issues and looked at solutions
- After 20 mins the group reversed their roles.
- At the end of the session the groups rejoined and a spokes person delivered the summary of issues and suggested solutions
- Together with the facilitator they identified training needs

### What were the issues?

- Coping with health changes – coping with the need to take daily medication for diabetes and reduced physical fitness due to CAL;
- Separation from family and home environment – husband and frail aged mother, semi–rural to city living, and coping with visits from a young grandchild;
- Spiritual needs – need to continue contact with Church and Church groups;
- Meaningful activity – volunteer and involvement in Church committees and outdoor activities – gardening and environmental projects;
- Maintaining contact with the community and friends;
- Need for privacy – staff found this challenging as the need to respect intimacy was an important part of the relationship with her husband;
- Importance of access to external areas;
- Familiar environment – adapting to the concept that a bedroom is just that not a bedsitter – where to put her belongings?
- Coping with change of roles – no longer in charge and leading the community.

### What were the solutions?

- Promote visits by friends and family – develop smaller private nooks internal and external that encouraged entertaining small buffet areas - not just confined to own room;
- Need to consider children friendly areas too – small playground;
- Familiar items from home in communal living space not just in her bedroom;
- Access to a computer, email;
- Outdoor areas to become more functional and aesthetic promoting meaningful activity – lavender patch, vegetable gardens and worm farms;
- Spiritual activities – less formal, faith discussions, assist with setting up for services – being included, not just a visitor;
- Meaningful daily occupation – some control over care needs and input into daily activities of the hostel;
- Highlighted the importance of social information prior to admission – and how do we gain people’s trust to give us this information.

### What were the training needs?
In this era of where there is often a fear of being sued staff found that the training they would most benefit from in preparing for the younger group would be:

- Clarification of the issue of the resident’s right to take a risk as opposed to Duty of Care
  - Legislation -related to RCF;
  - Intimacy –not just in relationship to married couples but between residents particularly if one or both were married to other people;
  - Elder abuse –understanding what could be termed as verbal, physical, emotional and financial abuse.
- Understanding activity
  - What constitutes an activity – both formal and informal
  - Freedom to indulge
  - Social and historical time lines to increase understanding
- Environment
  - More information on impact of colour, space and light
  - Privacy –how to maximise privacy in a residential care facility
  - Outdoor areas –more about gardens.

A second Focus group was held at another facility to assist with validating the results

- More literal in their identification of issues
- Basically identified the same education needs especially about Rights and responsibilities
- Identified 2 learning styles which we would need to factor into our packages
  - More abstract and wider vision type learning
  - More literal and task oriented learning style

### Progress to date

- **Original goals**
  - **Design training** in response to residents personal, physical, social/emotional needs
  - Main area of need had not previously been considered as significant – Resident’s Right to take a risk and Duty of Care.
- **Environmental responses**
  - The facility is due for a major refurbishment and the study identified areas of focus particularly with soft furnishings and access and design of outdoor areas – the greater emphasis on external areas which is often an after thought of a major project
  - Functional use of rooms –bathrooms and bedrooms. Privacy only. Open family areas and formal dining in the evening –this certainly questions our current practice.
- **Policy direction**
  - Reinforced the Person Centred Approach as the basis for a model of care that ensures we address the needs of individuals.

### Future Directions

What has been presented today is in actual fact a progress report which has raised more questions of how we go about our business including the need to focus on those with special needs eg. Down Syndrome, dementia associated with Alcohol and Drug abuse

Some of our findings which had been largely anecdotal in nature have been:
• Confirmed by Access Economics Report -revised version March 2005
  — Noting an increase in dementia especially those over 70
  — More men than women in this age group
  — Highlights the need to review our activity programmes
  — Results of therapy/activity survey – confirmed the increased emphasis on physical activities
In conclusion our Phenomenological study identified areas where we need to improve our response
• Importance of physical activity
• Influence of family and the need to provide support systems
• Relevance of meaningful occupation
  — Importance of appearance

  We may not be able to say we are ready
  but we are on the way!

References

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