

Living in a Nursing Home



Quality of Life

The Priorities of Older People with a Cognitive Impairment

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in association with
Dementia Services Information and Development Centre

Introduction

This booklet is based on findings derived from in-depth interviews conducted with a sample of 100 residents living in 4 different nursing homes in the Dublin and Wicklow area. The objective of the study was to explore the meaning of quality of life from a service users' perspective and to promote service responsiveness to residents' priorities. The sample was randomly drawn. Although by far the majority of these men and women had some level of cognitive impairment, most were well able to communicate their wishes and preferences. A total of 100 residents were invited to talk about their life in long term care. Issues explored during the interview included, aspects of daily life that were now considered important to these residents, what made them feel happy and sad, their relationships with other residents and with health service professionals working in the nursing home and their suggestions on what could be done to improve their quality of life. The recommendations made in the booklet are in direct response to the articulated needs of these elderly people whom we interviewed.



Impact of Moving from Home to a Nursing Home

Whilst there will come a time in some older peoples' lives where nursing home care is necessary, moving from living "at home" into a "nursing home" can have a profound effect on many older people, not least those with a cognitive impairment.



Older Person

For the older person, after the initial settling in period, some (especially those with a mild cognitive impairment) may begin to see the nursing home as their own home. Accordingly if they leave the premises for a short week-end break or family visit, they will be keen to return, as the home will offer security friendships and comfort. Others, however even after months or years spent in the same environment, will continue to crave their own homes. Research has shown that it is this group (those who continue to feel dislocated or unsettled) who are more likely to have an advanced dementia. They are also more likely to pose challenges to nursing home staff, being agitated and restless and sometimes asking repeatedly "when can I go home"? Developing ways to help improve this group of residents' quality of life can often prove a challenge.

Family Caregiver

For the family caregiver, the transition of a loved one, into a nursing home can also be very distressing and carers may feel unsure about the move - "am I doing the right thing?", "how do I know that the time is right?", "how can I live with the notion that I have let my Mum down?". Family caregivers may feel guilty, angry and sad and feelings of loss, akin to bereavement may not be uncommon. They may also have mixed feelings –relief yet anxiety.

Quality of Life

So how is quality of life defined and how do we know what residents in long-term care most value? Many systematic attempts have been made to develop an acceptable definition of quality of life particularly as it relates to older people. The term itself is somewhat akin to happiness –it is a subjective term with different meanings for different people. One definition of quality of life, proposed by the World Health Organization and the United Nations was derived from a broad definition of health. Here, quality of life is considered a broad-ranging concept, which includes domains such as physical health, psychological state, level of independence, social relationships and their relationship to the environment.

Quality of life for People with Dementia or Cognitive Impairment

In the context of cognitive impairment and dementia, perceptions about quality of life can vary considerably between different groups of people. For example, health service professionals' views about quality of life and dementia may differ quite considerably from residents' own views. A nurse may regard an individual's quality of life to be strongly associated with levels of pain experienced, the extent of his or her memory loss, physical functioning and independence, whereas the resident may be more inclined to associate his or her quality of life with frequency and quality of family visits, a feeling of remaining useful, or of carrying out meaningful activities and keeping active.

One expert has suggested that quality of life measurements in dementia care should include the following domains: (i) competent cognitive functioning (ii) the ability to perform activities of daily living (ADL) (iii) the ability to engage in meaningful use of time, social behaviour and (iv) achieving a favourable balance between positive emotion and the absence of negative emotion. Some have argued that as there is no cure for dementia, one of the main challenges in dementia caregiving, is deciding how to promote and maintain optimal well-being and quality of life.

Residents' Views on Factors which Promote their Quality of Life

Our recent research findings have demonstrated that what residents valued most were:

- **The Family** - Residents particularly valued frequent contact with family members and regular visits from close relatives
- **Intimacy** - Residents valued privacy and intimacy; they enjoyed being able to spend time on their own, when they so wished
- **Relationships** - Residents enjoyed socializing with other people and such interactions were reported as generating a great deal of pleasure. Residents had different "significant" people in their lives- these included staff members, old friends visiting and new friends made in the NH. Indeed sometimes any visitor – even the visitors of other residents played a significant role in their lives.
- **Keeping active, feeling useful and having meaningful activities** -Activities allayed boredom and were much appreciated. They provided great stimulus for those residents who engaged in them. For some, simply being able to help fellow residents was considered a meaningful activity. In other cases, just having open spaces within the nursing home which facilitated residents taking exercise was highly valued. Activities that took residents outdoors were particularly pleasurable, especially when such outings linked residents with people and places associated with their prior lives.
- **Religion and spirituality** – Religion either practiced through Mass, the Rosary, or prayer was deemed very comforting to many.
- **Staff and interactions with staff** - The nursing home staff and interactions with staff were also identified as a key factor influencing a positive quality of life for the residents interviewed. Results showed that nursing home residents with a mild to moderate cognitive impairment placed a high value on privacy and intimacy. They appreciated staff members taking a person-centred approach to their care; treating them with respect – knocking on their doors, listening to their preferences and whenever possible offering them choice. Residents often became very close to and fond of particular staff members.



How Nursing Homes can Enhance the Quality of Life of their Residents with Dementia or Cognitive Impairment

These findings on quality of life and what residents with a cognitive impairment most value have implications for staff working in nursing homes and for best practice.

First, our findings about the importance of family members' visits would suggest that open-door visiting policies should be encouraged whenever possible. Appropriate visiting spaces should as best as possible be allocated in nursing homes to facilitate visitors.

These settings should promote privacy, during visits. Primary caregivers sometimes notice a void in their lives after an elderly relative enters long term care. Accordingly, nursing homes should attempt to whenever possible, promote the involvement of these family members in the life and culture of the nursing home.

Secondly, the environment including sleeping quarters and bedrooms were identified by many as important to quality of life. In certain cases, where single rooms were available and personalized, this helped residents feel more at home and allowed them have the intimacy and privacy they required. Several residents spoke about the freedom of being able to return to their own room when they felt like it and enjoy the privacy that such afforded.

Thirdly, relationships with outsiders were also considered very important to some elderly residents who often enjoyed seeing new faces come into the nursing homes. Initiatives that facilitate these relationships, such as voluntary workers coming into the nursing homes, or transitional students doing work placements within and approaches that encourage residents maintain links and sustain relationships with significant people outside the NH may help promote a positive quality of life.

Fourthly, having staff available to organize and deliver regular activity programs, promoted feelings of well being and self-esteem. Some residents enjoyed the fact that there were open secure spaces inside and outside the nursing home where they could walk safely. Activities which enabled residents maintain their former hobbies and interests including gardening, doing domestic chores, reading and music were also considered very important to many of these elderly men and women. For several people interviewed, religion was also an important determinant of quality of life. Therefore approaches that promote appropriate and regular times for religious practice within nursing homes should be encouraged.

Fifthly, having a confidante, and being able to enjoy a good social life, or simply having company, companionship and someone to talk to, were identified as important components of quality of life.

Underpinning each of these findings is the need for staff training in dementia care and the importance of on-going training on topics including assessment, communication, activities, challenging behavior, palliative/end of life care and advanced dementia.

Factors that undermine Quality of Life for Residents

Our research findings have shown that factors perceived to adversely affect quality of life in long-stay care included:

- **Different losses** – the loss or death of friends, fellow residents, family members, own health losses, or change/loss in a particular lifestyle were identified as the main source of sadness and distress for nursing home residents. For smaller numbers, depression and isolation were recurrent problems.
- **Leaving the family home** – particularly where residents had spent a large part of their earlier lives was identified as having a definite negative impact on quality of life. Many residents expressed an explicit desire to return home.
- **Lack of stimulation and boredom** – boredom and the absence of social engagement – the belief that here was nothing to do or nothing to look forward to in the nursing home, generated feelings of hopelessness and at the extreme could lead to depression.

Policy and Practice Recommendations

- **On-going assessment** – All residents living in long stay care should be regularly assessed. Assessment should be holistic and should record both residents' retained abilities, (the activities of daily living they can still do or hobbies and activities they can still be pursued) as well as any disability arising due to a cognitive impairment. A review of residents' psychosocial well being should be part of any on-going assessment. Apart from monitoring residents' physical health status, there is also a need to regularly assess residents' memory and cognitive status after they have been admitted to long-term care, as several older people are likely to develop a cognitive impairment after Nursing Home admission or advance from having a mild cognitive impairment to developing a dementia. Assessment should also include screening for some common age-related mental health problems such as anxiety or depression.
- **Activities** - Our findings on aspects of life, which appeal to residents with a cognitive impairment, suggest that nursing home activities need to be wide-ranging and tailored to individual past interests, life stories and needs. Activities can be domestic or therapeutic, they can be done on an individualized - one to one basis, or delivered in group settings. Examples include, art, crafts, cooking, dance, drama, music, games, simple puzzles and sports. All activities should have a purpose and engage all five senses. Several of the residents in this study, really enjoyed helping fellow residents they believed were more disabled than they themselves. Promoting policies that help residents to feel useful and to fulfill their time in a meaningful way will also help to improve quality of life. Staff need to be rewarded for their creativity and for introducing activities that are effective and that promote residents' quality of life.

Residents with more Severe Cognitive Impairment and Advanced Dementia

Residents with advanced dementia and those with a more severe cognitive impairment are more likely to have multiple and complex needs. They are a particularly vulnerable group since usually they have much greater difficulty communicating their needs to staff and family caregivers and once confined to bed or lacking verbal communication skills, their psychosocial needs can easily be overlooked. Often staff working with those with a severe dementia fail to see the importance of doing activities with them and think there is no point. However we now know that activities even if very simple remain vital for people with advanced dementia. The goal of the activity here is to communicate with the resident and to make some connection, (through touch, sound or visual stimulation) that can enhance the personhood of the individual and bring out the best in that person. Some responses to look for here include facial expressions, the opening of the eyes and other eye contact, body or hand movement and improved alertness. Depending on the residents' needs, activities here can be sensory stimulating and or sensory calming. When we witness a strong hand-grasp, observe a smile or giggle, see a head turn in the direction of sound or hear even one isolated word being uttered, we know we have made a difference and have contributed to improving the quality of life of that person experiencing the final stages of the dementia process. Nursing home staff always need to keep in mind the multiple and unique needs of this group of residents with advanced dementia. More resources now need to be set aside to further promote these residents' quality of life.



Acknowledgements

Our thanks to the staff who participated in this study and the residents who gave us their time and who shared their experiences with us. Special thanks to Home Instead Senior Care who kindly supported the graphic design, printing and distribution of this booklet.

This research study was supported by a grant from the Atlantic Philanthropies

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A T L A N T I C
Philanthropies



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www.dementia.ie