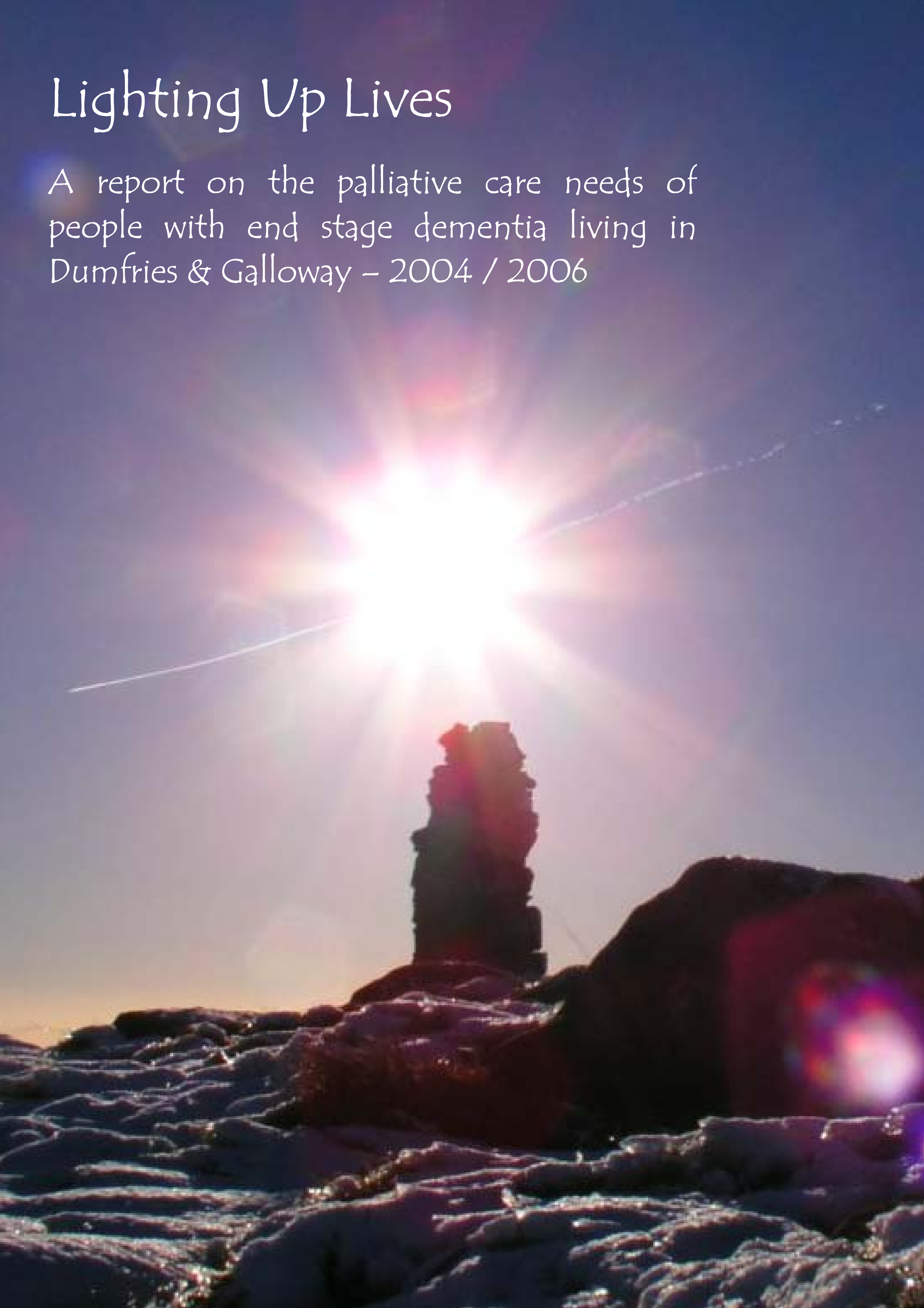
Lighting Up Lives

A report on the palliative care needs of people with end stage dementia living in Dumfries & Galloway – 2004 / 2006



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Contents

Executive Summary

1. This report is part of a two-year project funded by the Big Lottery Fund and carried out by Alzheimer Scotland with the backing of the Health Board.
2. It is the culmination of two years work and has involved a mapping process to identify where people with end stage dementia are living in Dumfries and Galloway and an assessment of their met and unmet palliative care needs.
3. There are thought to be 2290 people with dementia living in Dumfries and Galloway. 28% will have end stage dementia.
4. The information for this report was gathered from semi-structured interviews with 33 care managers, 34 care staff and 37 informal carers, over a 15 month period between 2004 and 2006.
5. The total number of people identified with end stage dementia was 363. This represents just over half of the people thought to have end stage dementia in Dumfries and Galloway. It excludes those in acute, psychiatric, and community hospital settings, the 6 homes who did not take part in the survey and an under recording of those people living at home. 11 people were under 64 years old.
6. At least 160 people had high levels of physical needs in addition to their dementia, and were severely cognitively impaired with limited verbal skills.
7. People with end stage dementia were living in all types of care settings.
8. Most people recognize that a palliative approach to care encompasses life and death when an illness becomes non-curative and the report therefore seeks to identify life and death issues.
9. The report attempts to look at met and unmet palliative care needs in terms of physical, emotional, social, spiritual and comfort and uses the philosophy of both palliative care and person centred care
10. Physical care needs were successfully met most of the time but there were still occasions when these needs were unmet. All settings struggled to meet spiritual needs either religious or the wider spiritual needs. Emotional needs were also identified as difficult for a number of residents – boredom and anxiety were particular problems.
11. Pain was identified as a particular issue for a number of residents and staff found it difficult to assess pain in people with end stage dementia
12. Activities were provided in most care settings but were not often appropriate for people with end stage dementia
13. There were a number of issues involving training; the quality, quantity and resources available to ensure all care staff were trained in dementia and related topics. Staff were often expected to attend training in their own time.
14. Informal carers varied in how much they wanted to be involved with the care once their relative moved into long- term care; this was not always appreciated by care staff. The carers also described difficulties in finding out information about their relative and a number of relatives could not remember being asked about their relatives' history and individual likes and dislikes. Care workers sometimes had negative views on the carer's role.
15. Reviews did not always take place even when carers had asked for them.

16. In many settings the key worker system was not well developed
17. The homes that had regular input from a GP practice were able to offer a more proactive rather than a reactive service and care staff felt better supported
18. Lack of medical information was highlighted as a major barrier to providing person centred care and made the management of pain even more difficult to achieve. In addition there was a lack of physical health checks.
19. A lack of dental services was also described. Poor dental care has an overall effect on nutrition and well being
20. The majority of informal carers who cared for the person with end stage dementia at home felt they were able to meet the core areas of care. However they did describe a lack of support from the statutory services and often felt they had to 'fight' for appropriate care packages. They also described a lack of suitable respite care and of not having a care assessment in their own right.
21. Whilst most of the buildings were clean and homely more could have been done to create a dementia friendly environment.
22. There were specific difficulties identified when the person with end stage dementia was in an acute hospital setting.

In order to improve the quality of care for people with end stage dementia living in Dumfries and Galloway there are seven main recommendations: -

1. There has to be recognition of gaps in specific palliative and dementia care of the most dependant group of people with end stage dementia whose physical and verbal communication needs are greatest.

2. Commitment to dementia training and related topics for staff in all care settings with the eventual aim that the training is accredited is vital. Staff should be paid for attending training.

3. Carers must be allowed to be involved in the care at a level they are comfortable with, and some form of partnership with the care setting should be adopted to ensure all parties agree on the level of involvement. Carers must be fully supported if they decide to look after the person at home.

4. There has to be a commitment to a change of culture and training of staff within the acute hospital setting. Ways to support staff should be explored such as the liaison service developed by The North Cumbrian Trust or the Alzheimer Scotland Nurse Project currently being piloted by The Royal Alexander Hospital Paisley.

5. Relevant medical information must be available in all care homes, as without it they will have difficulty managing symptoms including pain and be unable to give

truly person centred care. Proactive rather than reactive medical care should be provided.

6. For recruitment, retention and development of care staff there are fundamental financial implications. Care staff’s pay must be reviewed.

7. To help people with end stage dementia make sense of their surroundings every effort must be made to make dementia friendly environments for them to live in.

LIGHTING UP LIVES
A REPORT
ON THE PALLIATIVE CARE NEEDS OF PEOPLE WITH END STAGE DEMENTIA IN DUMFRIES AND GALLOWAY

1. Introduction

The challenge of providing a good quality of life and death for people with end stage dementia is one that all involved in the care of people with end stage dementia should address. Much of the recent emphasis of care of people with dementia has focused on the earlier stages of the illness and early interventions. Sadly there are no cures for dementia and in the final stages the person may be unable to walk, lack all verbal communication, and be unable to do anything for him or herself. It is essential that the same attention be given to people in the later stages of the illness. Adopting a palliative care approach to care will help to enhance the lives and eventual deaths of people with end stage dementia in all care settings and recognise the relatives' role and needs.

This report looks only at the palliative care needs of people with end stage dementia in Dumfries and Galloway, and the definition used of end stage dementia is based on the Global Deterioration Scale.[1]

The report includes details of the mapping process, which was undertaken to ascertain where people with end stage dementia were living. The process covered a variety of care settings, as well as including people who were being cared for in their own homes.

It also includes details of assessments of palliative care needs that were achieved by a series of semi-structured interviews to gain different perspectives of these needs. The interviews were with care home managers, care home staff and relatives of people with end stage dementia. It did not include direct involvement with the person with dementia because of ethical issues.

Background information on how the existing services met the palliative care needs of people with end stage dementia was obtained. This was from old age psychiatrists, the Over 65's Team Adult Services, Community Mental Health Teams (CMHT), a home care service, the Care Commission, the psychiatric assessment unit for people over sixty-five at the Crichton Royal Hospital and a Community Hospital in Dumfries and Galloway. The development worker also undertook background reading of recent research. See the Glossary on page 67 for definitions used in this report

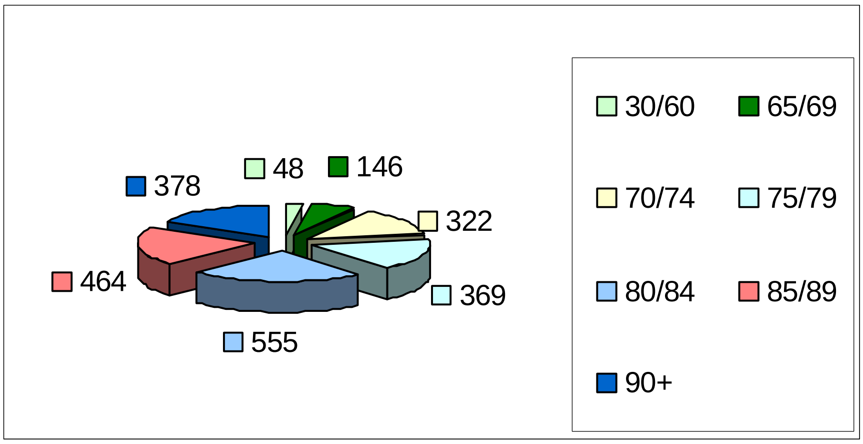
Recommendations in this report are made using firstly the philosophy of person centred care that was developed by Tom Kitwood and others.[2] Person centred care goes beyond physical care and attempts to see the person first, involving all aspects of their lives including emotional well being and preserving dignity. Secondly the philosophy of palliative care described by Dame Cecily Saunders 'You matter because you are

you……..to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.'[3]
The main aim of the project was therefore to reflect the life and death needs of people with end stage dementia and their families who still have some of the dementia journey to travel and for whom the active stage of dying may or may not have started.

1.1 Dementia

Dementia is the gradual loss of brain function. The most common cause is Alzheimer's disease but there are many other forms of dementia including vascular dementia, alcohol related dementias, Lewy body dementia and Picks disease. Each person with dementia is different. How their illness affects them depends on which area of their brain is affected. Dementia can affect every area of human thinking, feeling and behaviour. The progress of the illness is difficult to predict, but generally it starts slowly with a gradual deterioration, and it can go on for ten, fifteen or more years. This means it is hard to give relatives or the person with dementia much idea of a timescale of what they can expect and when, or how exactly the disease will affect them.

Chart 1: The age breakdown of the number of people in Dumfries and Galloway with dementia



The total no of people in Dumfries and Galloway with dementia is 2291

This information is based on population projections used by Alzheimer Scotland.[4] The methodology using EURODEM is described in Planning Signposts for Dementia Care Services and provides the most accurate way to assess the number of people in Dumfries and Galloway with end stage dementia and suggests:

- 30% will be mild cases
- 42% will be moderate
- 28% will be end stage[5]

2. Methodology

2.1 Methodology used to map where people with end stage dementia are living

Permission was sought from the Caldicott Guardian[6] to collect relevant information on: -

- Diagnosis
- Age
- Ethnicity
- Gender
- Mobility

The Care homes were identified from a list provided by the Care Commission, As a result of the **Regulation of Care (Scotland) Act 2001**, there are no legal differences between residential homes and nursing homes: they are all now known as 'care homes', and will be referred to as such in this report.

Co-operation from the care homes was sought and a questionnaire sent out for the care staff to complete. A definition of end stage dementia, and a description of high mobility needs were provided. The staff were then able to decide which residents were to be included.

A similar process was followed with those people with end stage dementia who were either living at home or within specialist dementia National Health Service (NHS) care.

This information was collected over a ten- month period (February to November 2004) Anonymity was maintained throughout this process.

2.2 Methodology used to identify met and unmet need for people with end stage dementia

A semi-structured interview for care managers and also members of their care staff was designed and a pilot study completed.

Care managers and staff were then interviewed in all identified care homes where people with end stage dementia were living. The care manager selected the member of care staff to be interviewed. In two instances an overall manager with responsibility for a group of homes provided the information for all the homes/units under his/her control. On some occasions it was not possible to interview care workers because of the workload in the care home.

A similar interview process was repeated for carers who were caring for someone at home or within a care setting. Carers were identified either through the care homes, CMHT's, elderly care teams or were already known to Alzheimer Scotland. A good sample was obtained but it was not always possible to identify a carer for each setting.

The length of stay in long-term care varied between eight weeks and six years, with an average of between one and a half to two years. The maximum time a carer had cared at home for their relative was 12 years and the relationships included partners, siblings, nieces, nephews and friends.

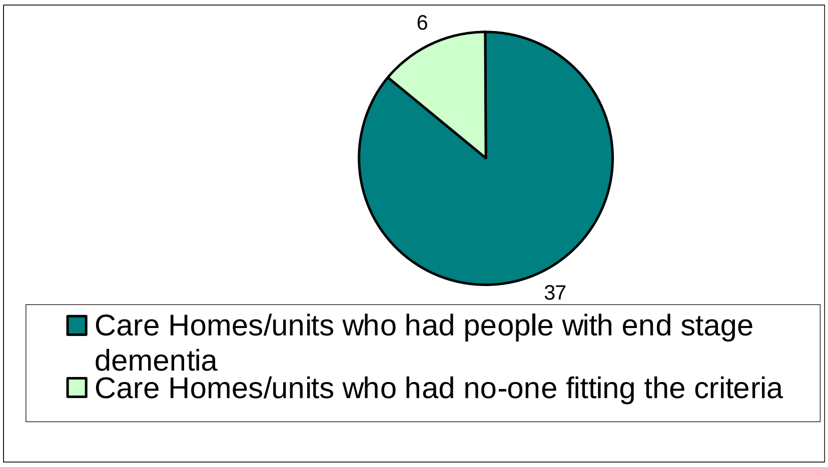
The aim of the interviews was to gain different perspectives of how successfully needs were being met for people with end stage dementia.

The interviews attempted to understand how: -

- The core areas of care as described in the WHO definition of palliative care were being met [see Glossary page 67]
- Successful was the person centred approach to care
- The impact that the management, design of premises and other services may have on meeting palliative care needs of people with end stage dementia

3. The mapping process in care homes

Chart 2: Number of care homes



Some care homes had more than one unit and six homes said they had no one fitting the criteria, although it was unlikely that they did not have anyone with end stage dementia and they may possibly have not wished to take part in the project.

The total number of care home places in Dumfries and Galloway is 1209

3.1 Number of people identified with end stage dementia living in care homes

The total number of people identified by the staff with end stage dementia was 330. This is unlikely to be a precise number, as despite being given a definition of end stage dementia it will be open to interpretation by the staff who completed the forms. It does, however, provide a good indication and 'a snap shot' of the number of people with end stage dementia living in care homes in Dumfries and Galloway during a 10 month period in 2004.

3.2 Breakdown of mobility needs of people in care homes with end stage dementia

End stage dementia can be seen to fall into two categories:

- Those who are still mobile and may have behaviour that the staff find challenging.
- Those who are immobile and have high physical needs and because of this, their behaviour is less of a challenge to staff. Measuring the degree of immobility, provided an indication of high physical needs.

The care managers were asked to identify the number of residents who either required the support of two people to walk or who were unable to walk at all i.e. those with high dependency needs. These are people who fall into the second category of end stage dementia and may no longer have behavioural problems related to their dementia, but whose physical needs are more paramount. They may be totally inactive, with very limited verbal communication skills and severely cognitively impaired. Reaching people in this advanced stage of the illness is very difficult. Staff and relatives described people in this group as *'no longer having problems with their dementia'* and are truly the forgotten ones described by carers as *'the less bother you are the less you are seen to'* or *'her light has gone out'*

High mobility needs is an indication of increasing frailty and susceptibility to life threatening illnesses such as infections and pressure sores. 154 (46%) people with end stage dementia were described as having high mobility needs and this figure may represent an under recording as two homes did not provide information.

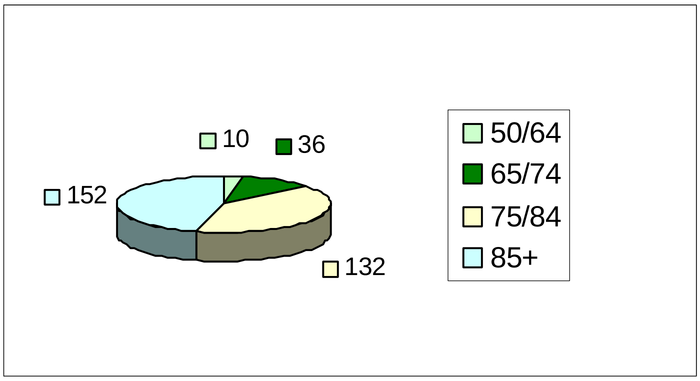
Many of these people were living in general frail elderly care homes; where there was no specialist dementia input such as is found within the Elderly Mentally Impaired (EMI) Units.

It is possible to conclude that approximately half of people with end stage dementia will have complex physical needs and probable profound communication difficulties. Their palliative needs will therefore be greater as they could be assumed as being closer to death.

3.3 Ethnic background

The number of people from ethnically diverse backgrounds is small but their individual cultural and language needs still need to be addressed.[7] Over 300 people were identified as British in ethnic origin (figures were not provided by one home). Nine people were from outwith the United Kingdom and only four people were identified as not having English as their first language.

Chart 3: Ages of people living in care homes with end stage dementia

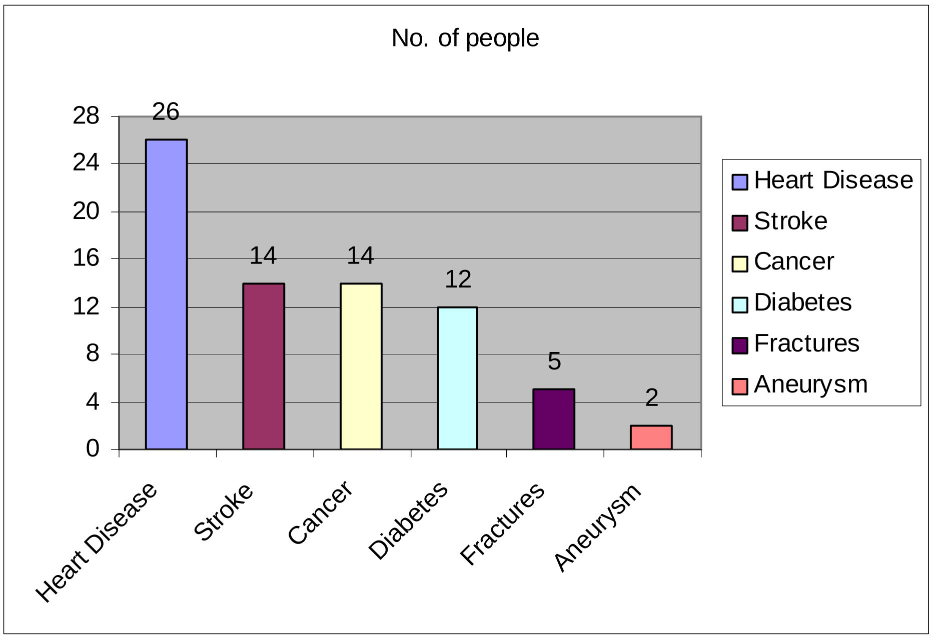


The total number of people, identified living in Dumfries and Galloway with end stage dementia was 330.

3.5 Gender break down of people with end stage dementia living in care homes

228 people with end stage dementia were female and 90 male (figures were not provided by one home). This reflects the increased life expectancy of women.

Chart 4: Other life threatening illnesses



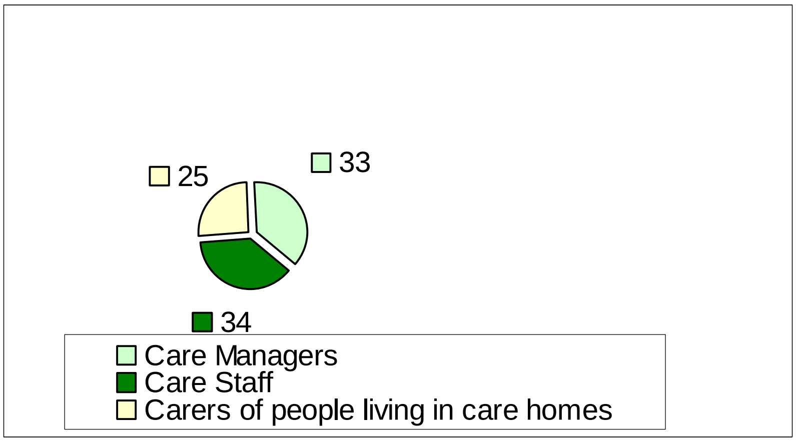
There is the potential for an under recording of other life threatening illnesses as care homes did not always have this information. However, it does serve to reinforce that people with end stage dementia may have, in addition to their dementia, a variety of other life threatening diseases.

3.5 Mental Health Problems and Learning Disabilities

Eight people with end stage dementia had pre- existing mental health problems and four had learning disabilities. These small numbers means there is the potential to overlook their specific care needs.

4. Meeting the core palliative care needs of people with end stage dementia within care homes

Chart 5: Number of interviews completed



The first part of the interview process attempted to draw out how well the managers, care staff and informal carers thought care needs were being met in terms of: -

- Physical Care
- Comfort (pain)
- Emotional (well being)
- Spiritual Care
- Social interaction

Two carers were able to provide their experiences of more than one setting

4.1 Physical Care

Carers were asked if they were satisfied with the standard of physical care provided for their relative.

Chart 6: Standard of physical care

Standard of Physical Care	**Number of relatives**
Good standard of care	16
Mostly good standard of care	7
Poor standard of care	2 + 2*

* Two carers described problems that were resolved by changing the care home.

- The majority of carers were very satisfied with the standard of physical care provided, and two commented it was actually better than when they were at home.

'They keep her safe and warm'

- Those carers who felt it was not always possible to maintain a high standard of physical care described things like *' an institutionalised hair cut'* or *' it is not easy they try hard' ' it's not up to my standard'*. It is however disturbing to find two carers who were extremely dissatisfied with the standard of physical care and a further two who described problems in a previous care setting.

Case Study 1

One carer described her relative as not always having his own clothes on, sitting in a wheelchair all day, and on one occasion being tied into it by his belt. She claims the wheel chair was not only uncomfortable for him but also in a poor state of repair. She also described how on admission he was able to walk but this soon changed, he was so 'doped', she thought he was dying.

Case Study 2

The carer felt that her mother was fairly clean but 'grimy under her fingernails' She also reported that recently her mother had been taking her shoes off and seemed unsteady on her feet. It was only when she investigated her feet that she discovered her mother's toenails 'were curling over her toes and she also had two large painful corns'. The care home advised her that the podiatrist had left and they were not allowed to cut toenails.
She was concerned that despite all her efforts her mother's glasses were either lost or broken.
Also her teeth had been lost for long a long time and no action had been taken to replace them.

A further two carers had been dissatisfied with the physical care their relative had received. They have moved to another home where they were now satisfied. One described the first home as *'not being able to cope with her'* and at the review meeting she was discussed *'as if she was not a person. They said they would give her another chance… she was ill… I cried all the way home.'*
The other carer found in the first home she was *'so drugged she could hardly stand up.'*

Recommendations

- Ongoing training in dementia care is essential to equip care staff to provide a consistent standard of physical care
- Continued close monitoring of care standards by the Care Commission is necessary
- Appropriate assessment and placement is essential
- Carers should not be afraid to speak out if they are dissatisfied. An atmosphere where complaints are dealt with without fear of repercussions to their relative must be fostered in all settings

4.2 Nutritional Needs

The care managers, care staff and informal carers on the whole felt that the nutritional needs of residents were well met and systems were in place to monitor and prevent weight loss. Nobody reported artificial means of maintaining hydration or nutrition. This report makes no attempt to assess hydration needs.

There were however a few issues identified:

- ➢ Some homes did not have the necessary equipment to weigh people who were unable to weight bear.
- ➢ Sometimes there was an insufficient number of staff on duty to feed large numbers of residents. There were however a number of creative ways used to try to overcome this problem e.g. using ancillary staff and having split shifts
- ➢ Difficulties in ensuring that people who walk a lot received adequate nutrition
- ➢ Pureed food was felt to be unappetizing.

Recommendations

- Each care home must continually review and assess how well it is able to meet the nutritional needs of people with end stage dementia

4.3 Comfort - management of pain

The management of pain is an essential component of good palliative care but research shows that pain in the elderly and in particular people with dementia is poorly managed.

The European Pain Survey 2004 describes the prevalence of chronic pain to be around 18.1% of the general population, however an epidemiological survey carried out in Grampian suggests that the prevalence of chronic pain may be as high as 46% and that the prevalence of pain increases with age in both sexes.[8]

There is also evidence that people with dementia, living in care homes, do not receive as much treatment for pain, as those with normal cognition[9] ‘It has also been identified that ‘unqualified staff providing direct care to the elderly resident in nursing homes may not be educationally prepared to undertake many complex tasks including pain management.'[10]

The Care home staff and managers interviewed were generally aware that pain was an issue for people with dementia but their approach and understanding to the control of pain and the effect pain may have on behaviour was inconsistent:

- 11 out of 35 care workers felt that often pain was an issue for residents
- 8 carers out of 25 identified pain as being a problem for their relatives and one described their relative as being very *'brave'*
- Assessment of pain was usually a judgement made by a senior member of staff based on observation or advice from the GP.
- Only one member of staff linked observation of behaviour as a possible indication of pain
- No assessment tools were used, but there was a lot of interest expressed in developing the use of such a tool
- From Chart 4 page 14 it is possible to conclude that many of this group of people will be suffering from other debilitating and painful illnesses

Recommendations

- Training is provided for managers, care staff and health professionals on understanding and assessing pain in people with end stage dementia
- The implementation of pain protocols is essential to improve the management of pain
- Medical information is made available to inform staff of illnesses which may increase the likelihood of pain

4.4 Emotional Needs (Well being)

Care home staff were asked to give a generalised overall impression of emotional needs of the people in their care.

They were able to identify more than one emotion displayed in residents and, this could vary depending on the time of the day, how the person was feeling and interactions with other residents.

The emotions described were – happy, contented, sad, frightened, frustrated, anxious and bored.

Chart 7: Care home staff’s overall impression of the emotional health of their residents

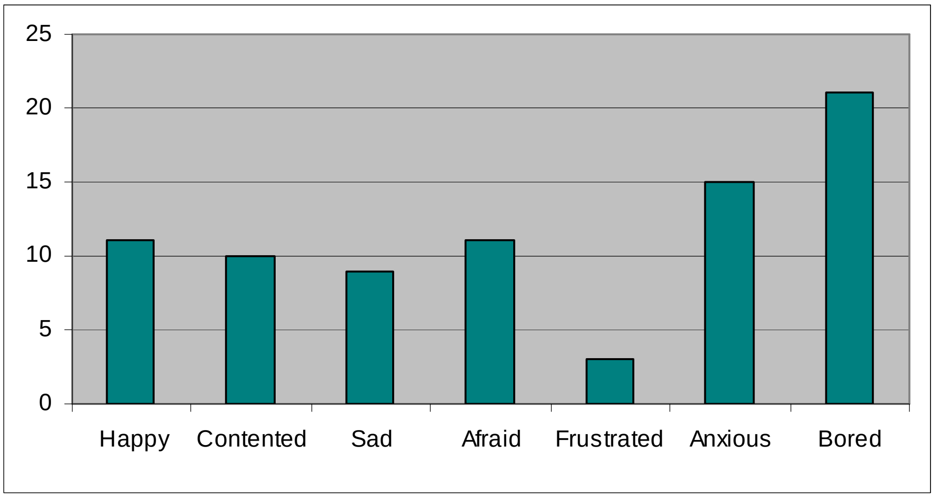
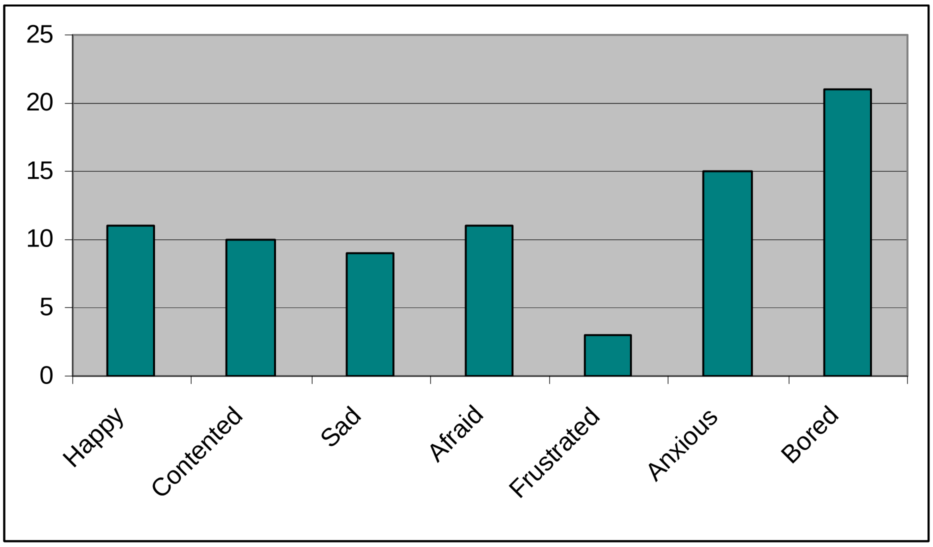


Chart 8: Carers’ view of the emotional health of their individual relative within the care home



Carers gave a more specific description of the emotional state of their particular relative.

Residents were observed to experience a range of emotions depending on the kind of day they were having, the environment they were living in and the kind of person they were before they developed dementia.

One relative was not even sure if her mother still had emotions. While others had low expectations of what was possible and described their relatives as *‘past being bored.’*

Staff perceived, in general a greater degree of residents’ happiness. This may have been because residents can become distressed at visiting time or that the care staff simply wanted to believe that the residents were happy. Conversely the carer may have had difficulties coming to terms with their loved one being in long term care and they were therefore uncomfortable with the idea that they could be happy.

Both the care staff and the carers thought the residents were sad a lot of the time. One carer described it as the person being *‘flat.’*
Care staff felt that many of the residents were frightened a lot of the time, while relatively few carers thought this to be the case. It may be that the resident was less frightened when there was a familiar face present.

Relatively few care staff or relatives identified frustration as being a problem but it is possible that this figure is under recorded, as anxiety and frustration are sometimes difficult to distinguish.

Both groups identified anxiety to be a big problem for the resident. For some residents the degree of anxiety was perceived as being extreme. One carer described her mother as being *‘in hell.’*

The carers found it much harder to say how contented the person was and made comments like *‘he isn’t aware of the situation’ ‘he seems doped.’*
Both the staff and the relatives identified a large number of residents who were bored and one relative commented *‘he is not an empty space’* indicating that she still thought he was able to do things.

However subjective these assessments are it is interesting to note that the perceived levels of negative feelings identified by both staff and carers suggests that it is difficult to meet the emotional needs of people with end stage dementia

Recommendation

- Only by continually reviewing practice and seeking ways to enhance care to develop a more holistic approach will it be possible to meet emotional needs, and therefore address palliative care needs

4.5 Overall Spiritual Needs

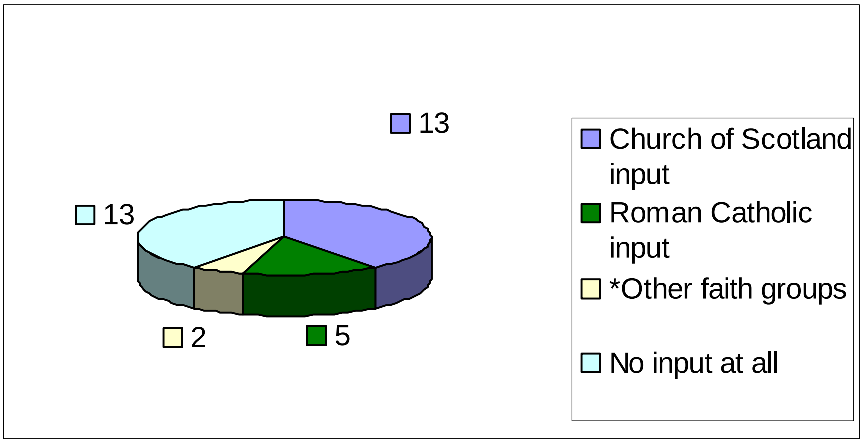
All people have a spiritual dimension to their lives. ‘It is of the essence of every person whether or not they have a religious faith.’[11] Spiritual needs can therefore be broken down into the wider spiritual part of our lives, *and* religion. People with dementia need to be ‘accepted, loved, given worth and honour, to be befriended and listened to, to receive grace and mercy, and to “rest in God” however that may be articulated. In fact they have

just the same needs as anyone else.'[12]
There have been projects aimed at developing appropriate forms of services, and concentrating on the importance of familiar hymns, prayers and rituals. There are resources available and evidence of them bringing peace and comfort to people with end stage dementia.[13]

Issues surrounding and questions about religious and spiritual needs were included in the interview process.

4.6 Religious needs

Chart 9: Involvement of local churches in the care homes



* Buddhist and Christian Brethren
Dumfries and Galloway is not an ethnically diverse area see Table 2.3

Only two of 33 homes felt they had good support from the Church of Scotland with the minister visiting regularly or providing support.

One home has a strong religious connection and has very frequent services. The remaining 12 homes that have church services are at best once a fortnight and at worst once a year. In two homes the services have stopped completely because they are seen as a *'waste of time.'* Where services were held they are poorly attended and are not really suitable for people with end stage dementia, as little attempt had been made to adapt the service to their needs. Managers felt that Church Ministers and Elders did not really know how to cope with people with dementia and had little understanding of the illness.

One manager described how one of her residents who was previously a Church Elder received the church magazine in the post and this was now her only contact with the church. The manager felt that this was an inadequate response and a visit from the elder would have been more appropriate.

4.6.1 Carers’ views on Religious needs

Eight out of the 25 carers interviewed said that their relative had always gone to church and now felt that their religious needs were not being met at all. One gentleman who was still aware of his religion and had always been a practicing Catholic had not received communion since admission to the care home.

Two of the carers described how their relatives had a strong faith and had been Church Elders but there were nothing appropriate for them now in the care setting. Another relative described how her mother had always said her prayers at night but thought it was unlikely the care home staff would help her to say them now. Other carers felt that is was no longer possible for the person with dementia to have a belief in God.

Recommendations

- Carers need support and encouragement from care staff to help their relative find ways to support their religious beliefs
- Awareness raising about dementia to faith communities should be provided. This would enable them to have an understanding of dementia, and therefore the confidence to be involved. As well as a basic understanding of dementia and communication it should include advice on appropriate forms of service, perhaps concentrating on ritual and the familiar aspects of worship.
- Care plans must address and meet religious needs

4.7 Spiritual Needs

Many care managers found spirituality a difficult concept and sometimes were unable to separate it from religious needs. Care managers acknowledged there was a big gap in meeting these needs and one manager said that the care plan on spirituality *‘remained blank’* because staff did not know how to complete it.

4.7.1 Carers’ views of Spirituality

Carers also found spirituality a difficult concept and only two carers thought these needs were being met. The remainder were either uncertain or did not think they were being met at all. Those carers who had some idea described *‘music as a powerful influence’* or *‘the staff make her smile’* or that *‘he loved fresh air and nature’* (this particular gentleman had never been outside since admission to the home).

Recommendations

- Care staff need help and support in finding and understanding their own spirituality and this could be achieved through training, only then can they hope to help with people with end stage dementia maintain their spirituality

- Care staff require training on spirituality to enable them to develop a spiritual dimension to care plans
- Carers need support and encouragement to help them find ways to support the spiritual needs of the person with dementia and their relative

4.8 Social needs

Social needs are part of our human experience. To laugh, love and have fun and to interact with other human beings is essential to our sense of wellbeing. For people with end stage dementia whose language and cognitive skills are severely impaired it is sometimes difficult for them to experience the ordinary social interactions that we all take for granted and which are so important when facing the advanced stages of any illness.

4.8.1 Carers' view of social needs

Only five out of 25 carers thought that their relative's social needs were being met and the remainder of carers had low expectations that it was possible to meet these needs. However, on the whole carers thought the staff had good interactions with the residents.

Recommendations

- It is important for relatives themselves to understand that they have a vital role in meeting social needs
- Both staff and relatives may need help in developing their communication skills with the person with dementia
- There is a need to encourage staff to acknowledge what is actually possible and to build on this.

5. Person centred care

Professor Tom Kitwood revolutionised the care of people with dementia. He advocated seeing the person first, recognising the need to maintain personhood, and raised the expectation of well being in the person with dementia. His widely published work has resulted in a major change in care practice and the consensus is that it can improve the quality of life for the person with dementia.

It is sometimes seen as the 'holy grail' of dementia care that will, if practiced, enhance the quality of life and eventual death of the person with dementia. However, David Sherd has commented in his article The Emperor's New Clothes 'that across the UK, other than in small pockets, it is hard to find significant large scale evidence of people with dementia receiving truly person centred care.'[14]

As a person centred approach overarches and is central to palliative care (meeting physical, social, emotional and spiritual needs) it is therefore necessary to look at some of the components to make care person centred.

The three areas that were looked at were: -

- Flow of information, as well as the sharing of information this included the involvement of carers in reviews, the key worker role and the value of home assessments, prior to placement
- Communication between care home staff, professionals, and carers
- Activities

5.1 Flow of information

As the person with dementia is often unable to express themselves fully, it is essential that there is a good flow of information to and from the care manager, care staff, relatives and health and social care professionals about the person e.g. their strengths, needs, likes, dislikes and life history to enable their care to be truly person centered.

The information from this survey was collected prior to the introduction of the single shared assessment, which should provide a single point of entry to community care services and avoid bureaucracy, duplication, delay and provide a holistic structured approach to assessment. Once this tool is fully introduced across the region it is hoped it will improve the flow of information.

5.1.1 Care home managers’ views on the information they were given from carers and professionals

All the care homes say they try to get additional information from informal carers. Some good examples were the development of life story work. (This involves recording relevant aspects of the individual’s past and present life to support the individual in their present situation.) Also asking informal carers to be involved in care planning Two homes pointed out that carers did not always co-operate with providing information and it was difficult to obtain if there were no family members.

Information received from the Social workers and Community Psychiatric Nurses (CPNs) was generally seen to be good and helpful but there were some regional variations and one manager from a nursing background found the terminology used by social workers made it difficult to work out what was required from a nursing perspective.

Other criticisms were that the information was sometimes out of date and this was especially a problem if the person was admitted for short- term respite care.

A widespread problem was the lack of medical information provided by both GPs and Dumfries and Galloway Royal Infirmary (DGRI). All managers felt this made it very difficult for them to manage residents effectively and that this could lead to assumptions being made based on the medication they were given.

This lack of information was also evident in the mapping process, [Chart 4 page 14]. 12 managers identified recent problems with people being discharged from the hospital and some care home managers (previously residential homes) found it particularly difficult, as the discharge letter was sent to the GP practice rather than to them.

The managers had no experience of the single shared assessment forms, and remained sceptical that they would improve the situation. Whilst they hoped this tool might help with new admissions they felt it would not improve the quality of information about existing residents.

5.1.2 Sharing of information with staff

The managers described a variety of means of sharing information, these included regular supervision, reading through the care plans and in the larger homes, team working. A few homes used reporting sessions.

5.1.3 Care staff’s views on the information they were given to make their care person centred

11 care staff thought the amount of information they were given about the person was sufficient and the remainder either thought it was insufficient or variable in content.

Person centred care was an unfamiliar term to many care workers but with a little explanation the majority understood what was meant by the term, albeit some more instinctively than others, but two had no understanding of the concept at all.

Some care workers interviewed thought they had enough information to make their care person centred and there was some evidence of good practice e.g. using life story work and getting the relatives to share information with them on the social background.

Those who thought they had insufficient information felt it was either *'skimpy'* or *'they always need more'* or they did not *'have time to read the notes'* and some felt that the care plans *'were not detailed enough'.*

The workers who found that the information provided was variable felt that it often depended on where the resident was coming from, if there were relatives who could help, and the type of admission, e.g. emergency or planned.

Many felt that the lack of medical information made it difficult to make the care person centred.

Although the care managers felt there were systems in place to ensure information was passed on to the care staff, it was apparent from discussions with care staff that they were not always effective.

5.1.4 Carers' views on the amount of information they were able to provide

11 out of 25 carers were either not asked or could not remember being asked for information about the person, including their hobbies and interests. Carers that were asked felt that it had made no difference to the care of their relative.

'We made a big picture of the family tree but its not there anymore as it was broken so we took it away'

'She likes tea without milk and lots of sugar, but however many times you tell them they can't do it'

It is interesting to compare the perspectives about the flow of information. Despite the care managers' belief that they are consulting carers, the evidence from the carers does not always support this. They may have been asked but perhaps had not realised or they were asked at a time when they were too distressed to take it in, or they may not have been asked at all.

It was disappointing that not all care staff understood the term person centred care, and that some of them did not feel they had enough information to make their care person centred. This is fundamental to understanding and meeting the needs of the people with end stage dementia.

Recommendations

- An increased understanding of person centred care among care staff must be developed
- Managers should ensure effective systems for passing on information
- A more systematic approach to collecting information from relatives should be developed. The use of a person profile is one way this could be achieved
- The idea that relatives are part of a partnership with the care home should be explored
- Further monitoring should be undertaken to establish the success of the single shared assessment and revised discharge process
- Medical information provided on discharge should go directly to the care homes in addition to the GP

5.2 Assessment

Assessment by key workers from care homes, prior to placement can complement the information provided on admission and provided an insight into the person with dementia's background and life history.

Care managers were asked if they were involved in the assessment process of new residents, as this is another valuable way of building up a picture of the person and gaining information.

A varied approach to assessment was described. 19 managers described routinely assessing the person prior to admission, sometimes within the care home or at the person's own home. 11 managers either did no assessment prior to admission or only carried out an assessment occasionally. Some managers found assessment was too time consuming or was dependent on the location the person came from. There was also a particular problem if the person was admitted for respite.

Most managers thought assessment at home was of benefit, but one manager felt it took a few weeks to assess the person and that it was easier to achieve this once the person was in the care setting.

It would appear more usual for a manager or owner to carry out assessments rather than an actual member of the staff who would be looking after the person once they were admitted.

Recommendation

- Senior care staff or key worker who are going to be involved in the care of the person should play a part in the assessment process and visit the person at home prior to placement.

5.3 Communication

Dementia eventually robs many people of their ability to communicate in a way understood by others, and often their behaviour becomes a desperate attempt to make their wishes known. Understanding these behaviours as a means of communication requires a high level of skill. To ‘believe that communication is possible’ is central to all effective dementia palliative care, without two-way communication in whatever form, the wellbeing for the person cannot be achieved. [15]

Whilst communication skills can be taught, there is no doubt that some carers are more empathetic and ‘have developed themselves into people who instinctively live their lives with the ability to connect to another’s feelings’ but this is not always the case.[16]
For the very passive group of people with end stage dementia, the ability to reach them becomes even more difficult and perhaps because they make no demands this is less recognised and therefore less attempts are made to communicate with them.

5.3.1 Care staff were asked about their own communication skills

None of the staff gave any indication that they were aware of the in-depth knowledge or skills involved in maintaining effective two- way communication with people with end stage dementia. Some staff found communication difficult, others felt they could get by with experience, or trial and error.

Many care staff felt that they knew the people they cared for so well they were able to understand their needs, and this could suggest a complacent attitude towards understanding or listening to the person with dementia. Equally it did it not explain how they communicated with a new resident.

The training provided to care home staff on communication skills was limited. Several of the staff had completed Scottish Vocational Qualifications (SVQ’s) and whilst there is a communication module it is not specifically related to dementia. Some of the staff had completed courses on dementia, but for some it was a number of years ago and may not have included communication skills.

Relatives generally felt that staff interacted well with the residents, but that often the TV was on too much and music and the noise level was generally was too high.

Recommendations

- Staff have specific training to enhance communication skills in conjunction with training on behaviour and person centred care
- Where possible to follow up training by commissioning a dementia care mapping audit (Dementia Care Mapping is a tool to measure effective communication and interaction between staff and the person with dementia)
- Provide quiet environments when attempting to communicate

5. 4 Activities

Providing care beyond physical care is dependent on giving life purpose. Recently published work recognises that quality of life and well being are attainable goals for people with dementia ‘where once there was an emphasis on custodial care, safety and physical tasks, there is now a recognition that people in long term care settings are sentient beings with emotional, social and occupational needs.’ [17]
Providing meaningful activities is part of enriching the lives of people with dementia and making life worth living and most care homes that took part in this project were committed to providing some form of activities.

5. 4.1 Who provided activities?

The philosophy of activities being ‘everyone’s responsibility’ and an activity is ‘anything you do’ was described in several homes but making it a reality was more difficult to achieve. Some care workers were *‘reluctant to get involved’* and commented that ‘*young care workers don’t see it as their role.’*
One group of homes provided in house training on activities for all staff, as it was not their policy to employ activity co-ordinators. In other homes the idea that an individual could be employed for a few hours each week to provide activities to all residents of all cognitive abilities throughout the home was often mentioned, but it was difficult to see how such a few hours for so many people could be of benefit especially for people with end stage dementia.

In some units providing activities was not seen as the responsibility of the care staff. Other staff would have liked to take the residents out more, but for some units this was not possible because of insufficient staff, *‘We are encouraged to meet basic needs not to provide activities. I miss being able to take them out for a coffee, there is no social side once you are in, sadly there is no escaping’*

Where staff were employed specifically to provide activities for people with dementia they were often untrained and several activities posts were vacant. Care managers often reported difficulties in recruiting adequately skilled and experienced activities staff.

5.4.2 Type of activities available

The activities took different forms e.g. events, entertainment and group activities and were mainly enjoyed by the more cognitively intact residents. Only a few homes were able to offer one to one activities that were person centred, or provided stimulation involving the senses such as smell, taste, touch, sound etc.

5.4.3 Appropriate activities for people with end stage dementia

There was a low expectation that activities were possible for this group of people. One care manager thought people with dementia were not interested and *'just want to sleep after lunch'.* Generally managers identified a big gap in providing appropriate one to one activities for people with end stage dementia. Activities usually took place in the afternoon or evening, and did not take into account when the person would be most receptive.

5.4.4 Carers' Views on Activities

14 out of 25 carers thought there were activities available in the care homes, although were not sure if their relatives joined in. Some of the carers' comments were:

> *'There is a list up but I have yet to see anything taking place'*
> *'The TV is always on and the staff watch the soaps in the evening – the music is always too loud'*
> *'I was led to believe there would be trips out but they did not happen'*

None of the 25 carers interviewed thought there was anything specific for their relative:

> *'She joins in to a limited extent but it is theory rather than practice'*
> *'She goes to the sitting room when there is entertainment but sleeps through it … she likes classical music really'*

Some carers thought that their relative was no longer able to benefit from activities or they were not interested and had no expectation that anything was possible.

Carers provided stimulation themselves in a number of ways for example having grandchildren or pets to visit, providing treats to eat, taking them for a walk or a drive, or simply holding their hand and chatting to them and reminiscing about the past. Two carers described taking things in for their relative to hold *'she liked cuddling a soft toy but it was soon lost.'*

Informal carers generally found visiting very difficult and some said they would like to take their relative home but were too scared of not being able to cope or that their relative would not want to go back to the care home and would have needed support from a paid carer to make it work.

In assessing emotional needs [Table 7/8 page 20] many carers described their relatives as being bored and linked this to the lack of appropriate activities.

Recommendations

- Each person should be individually assessed to provide the most appropriate type of activity
- Activities/stimulation must be person centred and take into account the person’s previous interests and life history
- Activities should take place at a time of day that suits the individual person
- The provision of activities and stimulation must be seen as a necessary core skill for all staff
- Activity workers must have training in dementia, communication, person centred care, difficult behaviour and activities
- Carers should receive help and encouragement from care staff to provide activities and stimulation
- Activities should inform care plans, reinforcing the value and strengths of the person
- To make the provision of activities / stimulation a reality there needs to be training, and financial and management commitment

6. Carers' needs

Palliative care not only provides a holistic approach to care for the person with the non - curative illness but also supports the family. There is relatively little research exploring the feelings of carers once somebody has gone into long term care, but there is a growing awareness that 'older people and their relative are largely unprepared for the reality of nursing home life.'[18]

6. 1 Carers views on keeping their relative at home

- 15 informal carers would have wanted to keep their relative at home *'I know I had reached breaking point but I still think, if it had been possible things would be different and he would not have gone down hill so rapidly'* (the carer described how with the existing care package she was unable to cope and on occasions was frightened)
- Nine informal carers who would not have wanted to keep them at home. *'We had such a stormy relationship the last year she was at home. I hated her, I am glad she has lived long enough for me to love her again. All the bitterness has gone'*
- Many carers would have liked to keep the person at home but felt it was impossible either because the person would not settle in their home or that they recognised that they could no longer cope. One gentleman said that he would have needed to *'win the lottery, move to a big house and employ 24 hour care'*
- The carers who felt they did not want to keep the person at home had all considered it but felt that it was either too difficult or that their homes were unsuitable
- Carers said they would have needed either 24 hour care or large care packages to make keeping the person at home work

Chart 8: Person with dementia's wishes about going into long-term care described by their relative

Person with dementia's view of care homes	**Number**	**Comments**
Happy to go into a care home	3	*'Her Mum went into care. She would not have wanted to be a burden'*
Would not have wanted to go into care	16	*'My mother made us promise never to put her in a home'*
Not able to discuss	6	*'We thought we would go on forever'* *'She never looked ahead or thought about the future'*

The carers were asked how they felt about placing their relative in care setting and how it feels now. (The length of time the relatives had been in long term care varied from 8 weeks to 6 years)

Carers' Comments
'It was taken out of my hands, it made it easier' *'Slightly better still tearful at times'* *'I have been through the grieving process but I still feel guilty'* *'I am more used to it now, I used to cry all the way home'* *'It feels just as raw as it did the day he went in three and a half years ago'* *'I feel sad and angry if only I knew then what I know now I would have tried harder to keep him at home'*

From asking these questions it is possible to conclude that in many cases long term care was neither the wishes of the person with dementia nor the carer. Also over half the carers interviewed continue to carry the burden of the decision to place their relative in long- term care for many years to come.

6.2 The Care Manager's perspective of the carers' involvement in the care of their relative once they were a resident in long -term care

Managers were asked to give ways in which they involved the carer in the care home setting. 13 out of 33 managers said they mainly used one to one contact to talk to carers but that sometimes it was difficult. Others described involving carers through their participation in developing care plans for their relative. Some Managers assumed that carers did not want to be involved in physical care.

6.2.1 Care staffs' views of the carer's role once the person was a resident in the care home

A number of staff thought it was important to involve and support relatives, also that visiting was important, *'Their face lights up when they get a visitor' 'it helps staff morale'* Other care staff expressed the idea that relatives do not want to be involved, *'It's hard for them to accept and they don't know how to cope'*

A widespread problem seemed to be that there were significant numbers of people who received no visitors or that as the dementia advanced the families visiting patterns changed often becoming more infrequent.

Over half of the care staff interviewed expressed a negative image of relatives:

Care Staff's Comments
'They have a small role they are often uncomfortable and expect too much from us, they try to shift the guilt and think we should do more' *'Sometimes they are critical of the care –they transfer their guilt'* *'Relatives are quite self centred'* *'It is demoralising for staff when relatives don't visit'* *'Their visit often upsets the resident and we have to sort it out afterwards'* *'Visitors are really bystanders it is no longer their responsibility'* *'Staff don't get support from relatives'* *'Some are dumped here, families feel guilty'*

6.2.2 The carers' perspective

Informal carers expressed a range of views on the degree of involvement they wanted in looking after their relative:

- 14 informal carers felt involved in the care, two in practical ways and they were all happy with the level of involvement
- Five would have liked to have been involved *'No it's been taken away from me I would like to do bits for him' 'It would be a way of upsetting staff'*
- Six were happy for the care home to take over

Recommendations

- Informal carers must be seen and treated as individuals, with recognition of their own particular needs and relationships within the family
- Training is required to help bring about a change of attitude and give staff a greater understanding of carers needs
- Clear boundaries and guidelines need to be established with each family on an individual basis
- Carer partnerships with the care home need to be established, perhaps in the form of a 'contract'
- Staff should develop a plan to effectively involve informal carers, at a level they are comfortable with, throughout the course of illness

6.3 Support provided for carers

The carers were asked if they shared their feelings with the care staff
15 out of 25 carers said they did not share their feelings with care staff:

> *'No they have enough to do but sometimes I leave worried and upset'*
> *'Never discussed my feelings with the staff but they have never asked, sometimes they put their arm round me and are friendly'*
> *'No I don't like to bother them'*

The staff were asked to describe what support they provided for relatives:

- Some homes offered relatives business meetings where aspects of running the care home are discussed but were not seen as a means of carer support. The uptake and interest in attending such meetings was low.
- 6 carers had support from Alzheimer Scotland Support Groups and found them helpful
- The remainder of carers mostly felt they could manage with family and friend's support.
- One carer felt that support groups were '*not her thing*'
- Managers reported trying to get support groups running but there was not the support from the families

Recommendations

- Carers should be routinely made aware of any support available within the home and support which is provided by external organisations
- Staff should be aware that support groups are not necessarily a static thing and may be dependent on a particular group of residents at any one time, and because there has been no interest in the past it may not always be the case
- Training is provided for staff on group work
- One to one support should be encouraged with the key worker

6.4 Keeping carers informed

Over half the carers did not feel they had sufficient information about their relative.

Comment from carers
'Yes they are sensitive they don't overburden you' *'They always seem cagey I sense it is not the whole story'* *'I would like more information,* *I feel they are holding back'* *'It was sometimes difficult to find the right time and person'* *' No I didn't trust what they told me'* *'No it's difficult to find information out, don't always tell you if they have fallen and often don't seem to know …don't trust them'* *'I feel they are not allowed to say what really happens if there is a fall I get conflicting accounts of what has happened'*

Recommendations

- A culture of openess should be fostered in all care homes
- Sharing of accident reports and involving the relative in care planning is essential
- The key worker role should be developed to involve the carer more

6.5 Reviews

Reviews should form a key part of keeping the carer both informed and provide a regular forum for them to discuss their concerns and feelings in an unthreatening and constructive way.

The majority of care managers say that the review process to assess the success of a placement is generally carried out within the first two months and then at six monthly intervals, to which carers are invited. However, three homes did not hold reviews at all. All care homes stated that they reviewed the care plan internally on a regular basis (usually monthly) It is generally the remit of the social workers to organise reviews however they report having difficulty in keeping up with them on a regular basis.

6.5.1 Carers' experience of the review process

The majority of carers had not regularly been involved in a review process, which would appear to be in direct conflict with what the care managers said. Three carers had tried to arrange reviews but only one had been successful. Many informal carers said they would have liked to be involved and would have welcomed the opportunity to discuss how well their relative was getting on *'I would like to know if she was any bother and if there is more I can do'*

Recommendations

- As social workers appear to be unable to organise reviews on a regular basis owing to other pressures perhaps a review process could be developed in house inviting social work/GP/District nurse input if particularly relevant
- Reviews should occur at least yearly but preferably three to six monthly depending on the individual resident
- Monthly reviews of care plans should be shared with the carers
- Carers must be invited to and be a part of all reviews
- Carers must be able to have a review if they request one
- Reviews should not be a negative experience, but provide opportunities to discuss positive achievements as well, and these should be reflected within the care plan

6.9 Key worker

Key workers form an essential link and means of communication with relatives. Many of the communication difficulties and support mechanisms for carers can be overcome if there is an effective key worker system in place. The key worker system can also build on trust and developing relationships with the carer. The key worker can provide a familiar face and a reassuring word for the carer. Equally the role of key worker can also be of benefit to the staff as it can provide them with job satisfaction. All the larger care homes visited operated a key worker system but half the carers interviewed did not know who this was.

Recommendations

- The key worker system needs to be fully developed in all care settings and training and support provided to help them develop their role
- All carers must be able to identify and have a relationship with their key worker

7. Organisational and management factors that influence the quality of care for people with end stage dementia

There are number of organisational and training issues that will impact on the quality of care provided by care home staff, and thus affects how well the palliative care needs can be addressed.

7.1 Training

Whilst training may not be a ‘panacea to ensuring that person centred care is practiced’[19] it is certainly a key element in ensuring that staff are equipped with the necessary skills to allow them to find their job fulfilling and to feel supported and valued.

The Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002 states in relation to training that staff should have training ‘appropriate to the work they perform’ and ‘suitable assistance, including time off work, for the purpose of obtaining further qualifications appropriate to such work.’ By questioning the managers and their staff it is possible to see how successful they were being in meeting the regulations and what extra help was required to enable them to meet training requirements.

- 21 homes said they provided training on dementia
- [1At least 10 homes were not providing any training on dementia

The managers interviewed were not always able to say how frequently training in dementia care was repeated and were often unclear about the actual content of the training. The training was from a variety of sources and took different forms, ranging from workbooks, in house, talks given by Community Psychiatric Nurses and external courses. A number of homes are supporting staff through the Scottish Vocational Qualifications programme although the modules may not necessarily be dementia specific.

Care staff were on the whole keen to have training. Where dementia training was provided it was concentrated within specialist dementia units.

7.1.1 Resource implications

Care homes struggle to meet the financial implications of mandatory training and they see dementia training as an additional financial burden. In addition to the actual training costs there are additional costs in covering the rota, and therefore in many cases training is in the workers own time and unpaid.

7. 1. 2 Quality of training

The quality of training appeared to vary considerably and often did not include key issues such as communication and behaviour. In addition care staff reported that their training was infrequent and not extensive enough.

An example of a successful training programme has been identified in North Cumbria Mental Health and Learning Disabilities NHS Trust where a comprehensive training programme is delivered to care homes, backed up by dementia care mapping and outreach teams to help and support care homes. Whilst this training programme is not yet accredited, it is anticipated it soon will be.[20]

Recommendations

- There must be an overall strategy for the dementia training of care home staff throughout all care homes providing care for people with dementia
- There must be a commitment to work towards an accredited dementia training programme for all care home staff
- To improve the standard of care there must be some overall responsibility and financial commitment to help with the provision of dementia training
- Social Services and the Health Board should consider taking some responsibility for the financing of dementia training as in North Cumbria
- The implementation of a service similar to the North Cumbria project would be beneficial where a rolling programme of training was offered to care homes

7. 2 Recruiting and retaining staff

Although not specifically asked six managers described difficulties in recruiting suitable care staff. One described difficulty in attracting *'the right sort of person'* and another said that there was a huge problem in recruiting *'despite paying £6 per hour with enhanced payments for unsocial hours'.* Trying different shift patterns did not necessarily attract dedicated staff. Another described *' struggling with bank staff and quality of staff available'*

Smaller more rurally isolated homes found that they did not have such problems in retaining staff and had a constant workforce. This may be because there were limited employment opportunities in the area.

7. 3 Staffing levels

The majority of homes found the minimum levels of staff recommended by the Care Commission inadequate to care for people with end stage dementia and therefore they provided more care staff dependent on workload. However, some homes had no flexibility in the number of staff per shift and worked within Care Commission Guidelines. These homes appeared to struggle, with one manager describing it as a *'nightmare and that tempers get frayed.'*

Two smaller homes found there were problems on a back shift because of people *'sun downing'* (people with dementia often become restless in the late afternoon or early evening) and there were insufficient staff to cope. Another home had difficulties at night when extra staff were necessary but not economically viable.

7. 4 Shift patterns

A number of homes used a 12hour shift pattern and although some staff liked the amount of time they had off it was not universally favoured. Staff complained that it was very tiring, and made continuity of care difficult. It was especially a problem in the late afternoon when people with dementia are tired and perhaps at their most restless and the staff were also tired *'some nights I have had enough I try to be patient'*

7. 5 Support for care workers

The majority of care staff interviewed felt they were well supported, either within their teams or from a senior or care manager, however six care staff said they did not feel supported or had to ask for support. The support took many forms such as peer group support or regular one to one supervision. The majority of care staff had yearly performance appraisals.

Recommendations

- Shift patterns and number of staff available should reflect the needs of the people with dementia for example if there is a particularly restless resident, managers must take this into account
- The Care Commission should review the minimum staffing levels and encourage the use of a sliding scale related to the work load
- Increased training, support and remuneration could help to reduce the turnover of staff and improve staff morale

8. External support services

8. 1 General practitioners

General practitioners (GP's) play an important part in managing the health of elderly residents in care homes. The approach in Dumfries and Galloway to medical input to homes varied from practice to practice, but was generally reactive rather than proactive. The care managers pointed out that there were no regular physical health checks for the residents.

Some residents were able to keep their own GP whilst in other settings there was a GP allocated to the home. This worked particularly well in one care home funded by the NHS because regular clinics allowed the doctor to have an in depth knowledge of the person.

The regularity of visits also varied; some homes had weekly visits or phone calls whilst others relied on call outs. Care managers reported to feeling better supported when the GP had a regular visiting pattern.

Care Managers relied on the support of the GPs and many had good relationships with the particular practices involved with the home. Only two homes described the service they received from the doctor as poor. Consistency was highlighted as a problem with particular concerns about the lack of continuity that the service NHS 24 Hour Direct gave.

Case study A view from a Care Manager
'Sometimes we feel isolated and left to cope. There was a recent incident when we were screaming out for help; eventually there was an admission to hospital but not before four visits by different doctors prescribing different medication. The Staff took it personally, and they were aware that they were not coping. The Management committee - listened but did nothing. We were screaming out for help but nobody came…we were perhaps sending out mixed messages because we did not want admission to hospital… but we felt let down

8. 2 Review of medication

Whilst it was more likely that a regular review of medication took place in care homes where there were nursing staff present it was not necessarily the case. In most homes medication was not reviewed regularly; research has shown 'the elderly receive 45% of all prescribed medication, 78% of which is issued as repeat prescriptions. This potentially represents a huge problem as elderly patients in care tend to be at high risk from inappropriate prescribing, either from an unsuitable choice of drug, dose or duration of treatment or from inadequate monitoring'[21]

Monitoring of all medication is vital for people with dementia but perhaps even more so given the widespread use of neuroleptic drugs. The SIGN guidelines 22 states in relation to neuroleptic medication: - **'**the prescriber must be continually aware of the risk of side effects and balance his risk against any perceived benefit. Treatment should normally be short term and should be regularly reviewed. The dose should be reduced as soon as possible and treatment stopped if it is no longer essential'[22]
There was no attempt to measure the use of neuroleptic medication in this project but the staff indicated that the drugs were often used for long periods, and said reviews of medication either did not happen or only happened because the care staff were proactive in arranging them.

8.3 Sharing medical information

Many care home managers felt that they were given insufficient information about their resident's health problems and informal carers were often unaware of changes in medication but were usually contacted if there was a serious problem.

8.4 Overall medical care

The care managers were asked how willing doctors were to investigate other health problems and the majority found doctors were sympathetic and tried to make an informed judgment taking the carers views into account. Four managers thought there was still some element of an ageist attitude, this was perhaps more evident within the hospital setting, and a further two managers considered the doctors they dealt with were reluctant to investigate other health problems.

For care home staff to feel supported it is important that if a problem arises which the GP cannot solve then expert advice is at hand, and there is minimum distress to the resident and their relatives. The majority (22) of care managers were satisfied with the support they had from the psychiatrists. There were some regional variations and some care managers described the service as *'slow'* with referrals taking up to two weeks, this may have possibly been because the referral was via the GP. One manager identified the problems of a referral to a learning difficulties specialist.

Recommendations

- GPs should try and provide regular visits to all care homes. This would provide a better monitoring of health and a proactive rather than reactive approach to health care. It would also provide support for care home staff
- Greater use could be made of nursing services such as CPN's and District Nurses to provide monitoring of psychiatric symptoms and physical checks
- In some circumstances it may be more appropriate for a given practice to assume responsibility for individual care homes, as the benefits of continuity might outweigh the resident maintaining links with their own individual GP

- Policies to ensure monitoring and review of medication in all care settings should be developed
- SIGN Guideline 22 must be adhered to and wherever possible the use of neuroleptic drugs avoided
- Relevant medical information should be shared with the care home

8.5 Dental services

Dental hygiene is an important part of providing an overall palliative approach to care. Sore mouths and lack of dentures not only impinge on the nutritional aspects of care but also on dignity and wellbeing

The care managers gave a range of responses to the availability of dental services in the region and this reflected the shortage of dentists identified in the Draft Health and Community Care Plan 2005/2006.

The key issues identified were:

- Where a good relationship existed with local dentists or the resident had their own dentist there was no problem in getting treatment for the residents
- Access to the Nithbank Community Dental service was slow, made more complicated and slower by the process of referrals having to be made via the GP
- Once the Nithbank service were involved the service was slow; one manager said it had *'taken 17 weeks to get a replacement set of dentures,'* another manager described the community dentist *'having extracted someone's teeth weeks ago but had never returned to take impressions'*
- In some areas there was no community dentist available at all
- Seven managers found it impossible to get a dentist for residents
- Other managers identified the difficulties the residents faced who had their own teeth and the difficulties of trying to maintain dental hygiene

Recommendations

- Until more dentists can be recruited, the current referral process to the community dental service should be reviewed and consideration given to making people with dementia a higher priority.

8.6 Community nursing services

The care managers were asked about their experiences of the community nursing services including Community Psychiatric Nurses, District Nurses, and Macmillan Nurses.

The majority (32) found the services provided were helpful and supportive. The negative comments were that the CPN service was sometimes slow and that they were difficult to contact. Two managers pointed out that the advice and training provided by CPNs was helpful. One manager suggested that there should be specialist dementia support nurses for the homes to access and this perhaps serves to highlight the difficulties that CPNs are faced with; how much is it their remit to train and support care home staff?

Managers tended to have a limited experience of the Macmillan Nursing Service.

9. Environmental factors

9.1 Buildings

The information gained for this section was through general observation when completing the interviews.

Throughout Dumfries and Galloway there are a variety of buildings used for care homes, varying from purpose built units to isolated rural grand houses. There is a number of specialist dementia units and larger homes are often divided into smaller specific units to allow residents to move from one area to another as their needs change. This is to be welcomed as it is generally agreed that if people are to be moved then it is 'as infrequently and as purposefully as possible.'[23]

9. 2 New Builds

There has been much research into designing dementia friendly buildings, and specialist units and there is obviously a conflict between the ideal and what is possible and compromises often have to been made. Despite advice having been sought for a number of new builds there appears to have been lost opportunities.

Whilst there have been attempts to create small homely units, it was disappointing to find that the staff found that the small dementia units lacked space, particularly in the public areas, including the dining areas which were so small that it was impossible for relatives to join them for meals.

The lighting was also poor in the corridors of a number of the new builds. Insufficient use appears to have been made of the design principle of immediate visual access.[24] There are well documented ways of identifying doors and toilets but the use of this was not widespread in the homes visited, nor was colour used to help counter the adverse effects of sensory deprivation. The sitting areas were small and background noise often loud. Carers commented that TVs/radio were often on and that there was no escape from "noisy" residents. Personal effects in rooms were encouraged in most settings, which was encouraging, and many homes had a safe garden as a feature.

9. 3 Older buildings

Older buildings presented their owners with additional challenges associated with maintaining buildings that were sometimes listed. They often found it difficult and expensive to heat. In addition there were sometimes difficulties in meeting planning regulations.

Many homes suffered from fussy decoration, with highly patterned wallpapers. Research shows 'walls should be solidly and imaginatively, though neutrally coloured…the use of patterned wallpaper should be avoided on the whole as it is known that some patterns cause problems'[25]. Also there were highly patterned carpets, 'heavy patterns can give the impression that there are holes in the floor or that there are changes in the level'.[26]

Another very common feature was long confusing dark narrow corridors. The residents did however have more space to walk about and the dining areas in older buildings tended to be more spacious.

There were many homely touches and some examples of innovative thinking for example a fire door painted with a mural.

The homes were generally clean and well maintained, with the exception of a small number of homes that appeared to suffer from under investment. However good the care staff managed to provide, a poor environment has a detrimental effect on the overall well being of the residents and of carers involvement. Hiatt notes 'Good design attracts staff members and supports their efforts, and residents with dementia may be aided by design more than any other group.'[27]

The survey of where people with end stage dementia are living in Dumfries and Galloway identified that many people were living outwith specialist units, in homes where there were frail elderly people who were cognitively intact. These residents were often described by care staff as being intolerant of people with dementia, and staff are constantly trying to balance the needs of the physically frail with those of people with dementia.

Recommendations

- Any future developments must utilise all the available knowledge on creating dementia friendly environments
- Care home owners should be encouraged when refurbishing buildings to use dementia friendly designs and colours

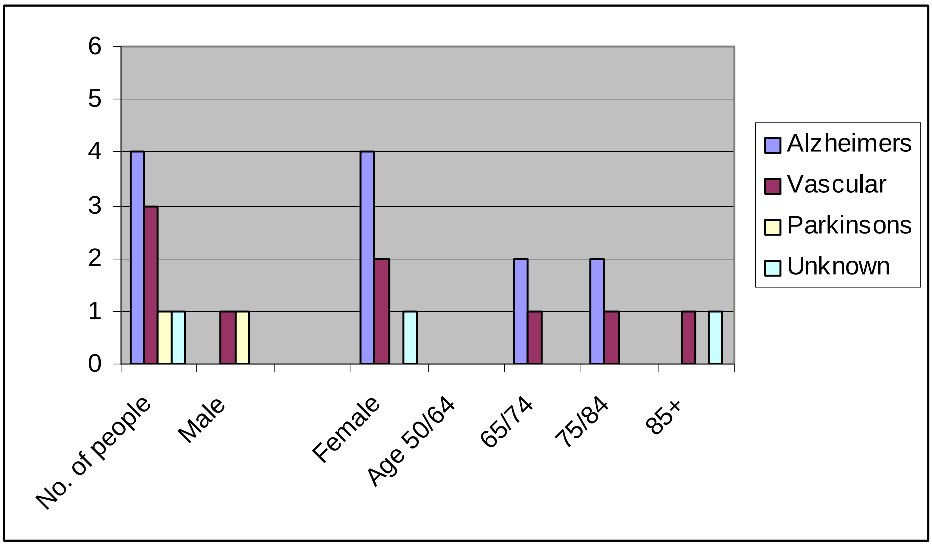
10. People with end stage dementia who are cared for at home

> *'We are both swimming out to sea she is in the water and I am on the raft… we just carry on'*

A total of 14 people with end stage dementia were identified as living at home and nine carers agreed to take part in the interview process that took place over a six- month period in 2004.

This is a small sample and doesn't truly reflect the number of people being cared for at home. It was difficult to access carers to interview in the community and although efforts were made to identify them through the CMHT's and Adult Services Teams contacts were not forthcoming for various reasons. People were eventually identified through individual Social Workers, CPN's or were known through either the Dumfries or Wigtownshire Alzheimer Scotland Services. The scope of the project did not allow time for contacting individual GP practices.

Chart 10: Mapping process – people with end stage dementia living at home whose carer was interviewed



10.1 Other life threatening illnesses

Five out of the nine people had no other life threatening diseases.

Chart 11: Carers' relationship to the person with end stage dementia

Relationship	**Number of people**
Wife	2
Husband	2
Sibling	4
Friend	1

10.2 High mobility needs

Carers identified that six of the nine people with end stage dementia had high mobility needs. They had to cope without moving and handling training and even though the person may have been assessed as requiring two people to move them, the carer will be expected to manage on their own if the person required moving at a time that no care was available.

Recommendations

- Training is provided for carers in moving and handling and effectively managing hoists etc
- Carers should not be expected to work outside the Health and Safety Legislation

10.3 Housing

Eight of the carers lived with the person who had end stage dementia and one managed a complex care package which allowed her mother to live in her own home. They lived in a range of places from rural isolation to towns and in a variety of styles of housing, from a purpose built adapted house to a housing association flat. The suitability of the housing did not seem to preclude the carer from managing to keep the person at home if they were determined.

10.4 Length of time caring

The shortest time that a relative had been the full time carer was 18 months and the longest time was 12 years. Two carers described how the process had 'crept up' and described the last three to four years as intensive.

10. 5 Views on the caring role

The views on the most difficult part of being a carer varied, but there were some common themes to emerge. These included loneliness *'the silence is the hardest part,'* the loss of freedom and feeling restricted, tiredness and loss of sleep. Coping with the physical aspects of caring was also an issue, for one husband it was the cooking, for others it was taking over the management of the physical needs without appropriate training. Coping with emotional upsets, especially when the person they cared for became angry *'he grips my hand if he wants to hurt me'* was also a problem.

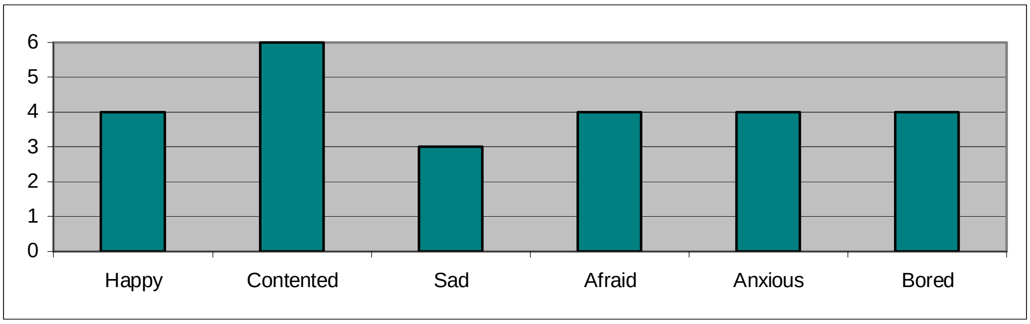
The most positive part of providing the care was described in different ways but each carer found strength and pleasure in different things, some very small but the two overriding positive themes were the unique relationship they had with the person and appreciating when there was recognition *'she smiles when she sees me' 'getting her true character to shine through.'* Secondly the importance of keeping them in their own home *'looking after her where she would want to be' 'she doesn't say a lot… just occasionally "my home.''*

The reasons given for caring for their relative at home also varied, three carers felt they could do a *'better job'* and provide a better quality of life *'She has not given up. I will make sure she stays at home come what may even if her needs change I will fight for nursing care.'* Two carers had a bad experience with a care home and a further two carers felt they were financially better off keeping the person at home.

Recommendations

- The wishes of carers who want to keep the person in their own home should where possible be respected and supported

Chart 12: Carer's views on emotional needs of the person with end stage dementia



Although the carers could not give an impartial view of their relatives emotional state they identified higher levels of contentment and happiness than families found when their relatives were in a care home setting. This is similar to how care home staff viewed their residents' emotional wellbeing [Chart 7 page 20]

However, even when the person is cared for in their own surroundings by their loved ones sadness, fear, anger, anxiety and boredom may still be present.

10.6 Activities carers were able to provide for their relative with end stage dementia

The majority of carers interviewed provided a rich and varied life for their relative and there is no doubt that they were able give the person with end stage dementia a greater sense of worth and wellbeing than may be possible within the care home setting. However, for two carers it was still difficult to achieve appropriate stimulation for their relative and they perhaps needed more help and support to engage with their relative. Carers described a variety of activities, involving the person in family life, reading to them or sitting with them and reading a book quietly, talking or having a laugh with them, taking out for rides in the car and creating picture boards. Also feeding them, was important and was sometimes the only real way they felt involved and connected to the person

10.7 Meeting core care standards

The carers were asked the same questions as care home staff and relatives of people with end stage dementia in other settings. The majority of carers felt they were able to meet the person with end stage dementia's needs in terms of physical, emotional, spiritual and social need *'she still knows me and smiles and holds up her hands to me.'* There was however some unmet need, with two carers describing difficulties coping with anger and anxiety. Another carer felt that although the person she cared for had been a church member, the minister seemed unable to help and three thought it was impossible to meet spiritual need

Whilst this is not an impartial view of the care provided, carers tried to give an honest opinion of the care they gave**.** In comparison to care in other settings, most of the carers were more able to meet the core elements of care and thus provide a more palliative approach to care.

10.8 Nutritional Needs

Ensuring the person had enough to eat was very important for the carers. One described how upsetting she found it if her relative did not eat. They went to great lengths to ensure the person had an adequate diet. Two described feeding the person and another of providing finger foods and another of using the meals on wheels service to ensure the person she cared for had a hot meal at lunch time.

10.9 Family Support

Four families provided practical support. Three families visited but were not actively involved either because they lived too far away or did not want to be involved. Three families found it difficult to cope or were busy with their own lives.

Even from this small sample it is possible to see that families react in different ways and because there is a family network it cannot be assumed that they will necessarily support or help the main carer, or person with end stage dementia.

10.10 Respite Care

‘Respite care is described as any service of limited duration that benefits a dependent person. Respite care should be a positive experience for the cared person and the carer….. respite care may extend from a few hours to a few weeks’[28]

The respite care available to carers ranged from short breaks away from the home in residential settings, daycare and input from care agencies.
Research shows that ‘many carers of people with dementia still only have limited access to a break from caring and that a single type of respite service, however effective is unlikely to be effective in meeting carers ongoing needs. Also quality standards may need strengthening, in order to reduce variability in quality of, and access to, services’[29]

All of the carers described it as either being difficult or very difficult to have free time, and described only getting free time *‘when he sleeps’* Another described feeling *cut like a piece of cheese and always watching the clock'*

10.11 Access and success of respite care – short breaks away from home

- Only one carer had found respite care completely satisfactory and took advantage of it three times a year.
- Three expressed emotional difficulties with the whole idea, feeling guilty, and problems of letting go.
- A further three felt it was not necessarily beneficial to the person with dementia. They described poor standards of care - dehydration, thrush infection, pressure sores, and of being unwell on return home. This had made them apprehensive about accepting future respite care.
- Two carers would not entertain the idea of respite care outside the home. One fearing that his wife would not have the one to one attention she was used to and the other did not feel there was an appropriate home close by. . One had successfully managed a night away with 24 hour care in the home. A Proper Break also identifies that many carers ‘voice a need for greater access to in home respite’ and this was also identified by this group of carers [30]

Recommendations

- More creative ways of providing respite care should be provided including within the person’s home, where familiar faces and surrounding will be less stressful for the person, and therefore more reassuring for the carer
- Respite care, to be of value must meet the needs of both the carer and the person with dementia
- The quality of respite care within the care home settings should be addressed

10.12 Day care

Carers place a high value on day care services. It is perceived that they are benefiting both the carer and the person they look after and there is some evidence that day care attendance may have an effect on the eventual entry date into long term care.[31] Alzheimer Scotland specialist daycare meets the needs of people with moderate dementia but not necessarily people with end stage dementia who have high physical dependency.

There comes a point in the illness when because of physical frailty, or simply because the illness has advanced so far, that the practicality of sending someone to a different environment for a day, or simply the journey itself, becomes impractical.
Whilst it may still fulfill the needs of the carer in providing respite, it may not be of any benefit to the person with dementia. It seems strange that at this end stage point of the illness, the carer has less access to suitable respite and no specialist service available to meet the specific needs of the person they are caring for.

10.13 Access to day care

- One person had never had day care, it had been offered but she had not enjoyed going
- Two people were still able to attend Alzheimer Scotland day care and it was beneficial as it provided respite for the carer, and stimulation for the person with dementia.
- Six people had previously had Alzheimer Scotland day care but reduced mobility had meant that it was no longer possible for them to go to this day care provision. They had been offered an alternative day care within the care homes but it had not been very successful. Three carers declined to send the person to another day care, one for financial reasons. Where possible they were offered additional services such as Crossroads but carers pointed out they no longer had so much free time, as it was for fewer hours,
- The remaining two did use the service within the care homes, one described it as *'a baby sitting service,'* another described a real struggle to get him to go.

Recommendations

- When day care no longer meets the needs of the individual person, a similar number of hours of specialist care and stimulation should be provided within the person's own home
- Greater recognition by the statutory sector of the need for appropriate services and respite for carers
- If the carer has made the decision to care for the person at home until they die then these wishes must be supported.

10.14 Home care agencies

The packages of care provided varied and the size of them reflected the complex needs of people with dementia in this group. It was evident in a number of cases that the resolve of the carer to keep the person at home was not to be underestimated; they described fighting for the care package, or falling out with the social worker and in one instance the fight to have Direct Payments.

There were examples of innovative care packages:

Case Study 1
The most complex case was a daughter whose conviction to keep her mother in her own home supported by carers was to be admired. Her mother with the help and support of the social services has the maximum amount of care allowed; in addition the daughter used her mother's savings of £600 per month to augment the care provision. She felt her mother was happy in her own home. This would not have been possible without the determination of the daughter

Case Study 2
A lady who was determined to have the care package which suited her and her husband's needs had to fight for two and a half years to access direct payments to enable her to have the care she wanted

Other carers also described complex packages of care and one had a night sitter that was helpful. A common theme was the fight it had taken to get what they wanted and of disagreements with social services and other health professionals. The process was often described in terms of a struggle. This may have perhaps been because the professionals felt the time had come for the person to go into long term care.

Carers described needing greater flexibility in the services provided, a greater continuity of the carers providing the care and of the care provided being less restrictive. The carers described the help they would have liked as being, help with the housework, garden, shopping and a night sitter but they would not like to have to pay more money for this help.

Recommendation

- A commitment from health and social services professionals to keep people with end stage dementia at home without carers feeling they have to 'fight' for services

10.15 Carers' Assessment

Since 1996 carers have had the right to an assessment of their own needs. The **Community Care and Health (Scotland) Act 2002** gave the assessment process more strength; it gave carers a legal right to an assessment of their needs and is their chance to discuss with social services what help they need with caring. It is also an opportunity to discuss any help that would maintain their own health and learn to balance caring with other aspects of their life, such as work commitments and family life.

Despite the legislation only one of the nine carers was aware of having an assessment of their own needs and this was only because the carer had insisted on it. She felt it had made no difference to the amount of help she was given.

10.16 Carer Support

The carers did not necessarily have support from groups. Sometimes they did not have enough spare time to come or they were held at inconvenient times. However three carers did attend support groups and found them helpful.

10.17 Support from professionals

There was a mixed picture of support from the professionals with the majority of carers feeling largely unsupported. The overwhelming impression was that there was no real commitment from health and social services professionals to keep people with end stage dementia at home and without the determination of the carers it would not have happened.

10.18 Carer access to information and training

Carers were coping with complex physical care needs in addition to the problems associated with dementia. Whilst there is much information about dementia available, it was interesting to see how well informed carers were and if they thought there was further training that they would have found helpful.

10.19 Information on Dementia

Only one carer did not feel they had sufficient information about dementia, the remaining eight thought they probably had enough information. One felt there should be more publicity about dementia, and another thought it was not always possible to follow the advice given

10.20 Courses attended

Three of the carers had had previous nursing experience, which they described as invaluable. A total of five carers had attended courses on dementia and had found them at least in part helpful. One described the course as coming too late in the course of the illness and another that training on moving and handling was not specific enough.

Four carers had had no training and one pointed out that she was expected to deal with a new style of colostomy bag without help and was also having difficulty managing the incontinence despite the use of pads.

Recommendations

- The benefits of courses and information is recognised as a form of support and empowering carers
- Appropriate respite care should be provided to allow attendance of suitable courses
- The primary care services provide greater support and recognition of the difficult role that carers are providing
- Carers must be made aware of their right to an assessment

11. Psychiatric and acute hospital services

It was not a specific aim of the project to look at the care of people with end stage dementia received in acute/ psychiatric hospital settings and how well it met the person with end stage dementia palliative care needs. However, as many of the people with end stage dementia were frail and ill these services formed an integral part of their care.

11.1 Psychiatric Assessment over 65's Unit

This fourteen-bedded unit provides acute assessment of older people with mental health problems. The charge nurse was the only person interviewed (carers and care homes did not provide any additional information and seemed satisfied with the unit)

The Charge Nurse felt there were good levels of trained and untrained staff. He described pain control as the first line of treatment for behavioural problems and careful use of antipsychotic medication often involving the practice of withdrawing drugs from people on admission.

He identified a good thorough assessment that is shared with others as important, (and was commented on by staff in many other care settings as being extremely useful.) Also the need to involve relatives and a person centered approach was adopted at all times.

He was aware of the challenges he and his team faced and some are in common with other settings. These included an increasing number of people admitted who were very ill and often overmedicated and in his opinion they should have been hospitalized earlier. On some occasions there was evidence of malnourishment in some of the people admitted from care homes. Only a very few people are able to go home perhaps, three or four per year. He felt this number could be increased if there were more community services available

He identified that sometimes there was unwillingness of some departments to investigate other physical health problems, and of difficulties in finding a dentist. There was also a lack of occupational therapy and specialist physiotherapy.

There were some core areas of care that he found difficult to meet in particular the religious and spiritual needs, and providing activities

He described the building as old fashioned, where there are few quiet areas and dark corridors.

He also pointed out that the unit is only available to people over 65 with dementia and felt that people under 65 with dementia should be able to access the same specialist service as the over 65’s.

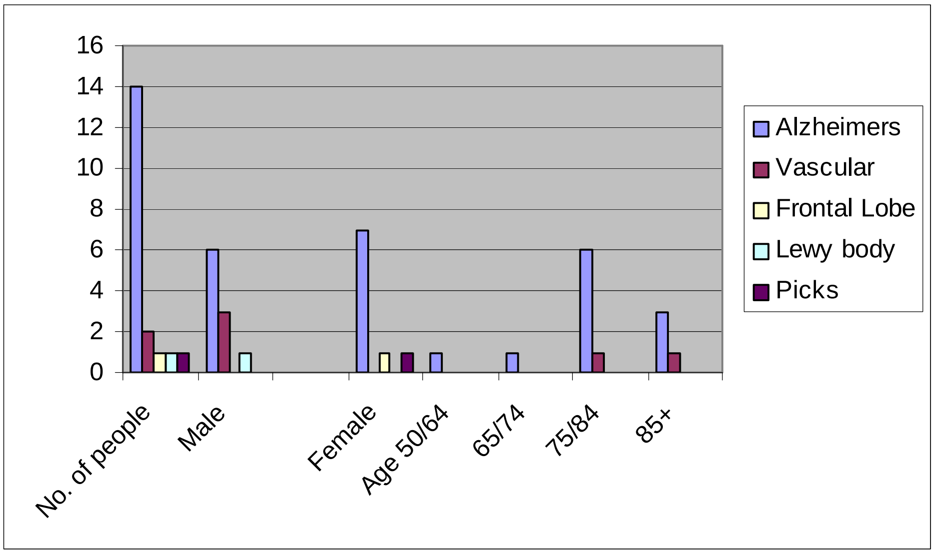
11.2 N.H.S Intermediate care for people with end stage dementia

The care provision for people with end stage dementia within the NHS consists of two Intermediate Care Units, one in the west of the region and one in the east. These units were originally designed as Domus units and were a model of care when 'a priority was given to staff levels and training and a domestic setting' and were seen as a resident's home for life[32]. There is also a small unit located within Lochmaben Community Hospital.

In addition there are 16 beds for people with end stage dementia contracted out to Well Care, Allan Bank. Information about these beds is included in the mapping and interview process on care homes, as although funded by the health board, they are registered with the Care Commission and are subject to **The Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002**

The admission policy to the units is psychiatrist led, and at the time of admission the person with dementia would have specific behavioural problems. However, as the illness progresses these needs change and this has led to a change in the use of the units. They are now seen as providing intermediate care (as the needs change the person is reassessed and moved to a more appropriate setting) and no longer follow the philosophy of the Domus Units. There is currently a review in progress to reassess the use of these beds.

Chart 13: Mapping process



The same process of collecting information was used with the care homes.
In contrast to the care homes staff were able to provide an accurate diagnosis

11.3 High mobility needs

At least 10 (figures were not collected for Lochmaben Hospital) of the 19 people with end stage dementia had high mobility needs and were physically very dependent, perhaps suggesting that it is difficult to move somebody at such a late stage in the illness.

There are a similar percentage of heavily physically dependent people with end stage dementia within the intermediate care settings as in the general care home population.

11.4 Information from the interview process

A manager, worker and relative were interviewed in each of the units using the same semi-structured interview in care homes. In addition the manager from Lochmaben hospital provided information. It was clear that staff were able to meet the physical needs of people with end stage dementia, but despite an improved assessment process, a good key worker system, and medical knowledge, there were similar problems in meeting other areas of care such as spiritual care or developing a wider palliative care approach.

The intermediate units have a specialist role in meeting the needs of people with end stage dementia with specific behavioral needs that may not be managed within the care homes. Maintaining the units as intermediate care (i.e. moving the people when their needs changed) has proved difficult and the staff found the mix of residents difficult to ‘manage’ and thought their skills could be better utilised with the people who had more challenging behaviour.

The managers identified similar difficulties of retaining and training of care staff, and said that although there were various packs and videos available there was little time to provide training. One unit described employing care staff without experience stating instead that they simply took on ‘just the right sort of people’. Both care workers interviewed identified the lack of training in dementia care and staff development as a big problem.

11.5 Acute Hospital Setting

The information in this section is from comments made by care staff, those who had relatives in care, or who cared for them at home and three carers who were recently bereaved

The difficulties of caring for someone with dementia within the acute hospital setting have been well documented. In addition the care of people in general hospitals was addressed locally in an unpublished paper prepared by Dr Gary Morrison on behalf of the Joint Advisory Group in September 2000. He identified the view from the carers was that the care of people with dementia in Dumfries and Galloway Royal Infirmary ‘was poor’ and ‘staff felt too busy to deliver individual care and to have an inadequate knowledge about dementia. Carers often felt ignored and excluded’[33]

The paper identified a number of ways to improve the service provided to people with dementia. It was therefore interesting to gain the views of relatives and care home staff some five years later. Care staff and relatives were not asked specific information about the acute services but wanted their views to be heard.

No attempt was made to interview hospital staff to assess how well they thought they were meeting the palliative care needs of people with end stage dementia, but it was clear from both carers and care staff that the hospital environment was often seen to be detrimental to the health and wellbeing of the person with dementia. Problems were identified during all stages of the hospital admission. Whilst this evidence is largely anecdotal the concerns were too widespread to be ignored.

11.6 Admission

Care staff were often reluctant to send people to hospital, and one group of homes encouraged relatives to provide a letter stating that they did not want their relative to go to hospital. One manager described having to wait for hours in the Accident and Emergency Department with the person on a trolley.

11.7 Hospital Stay

- All carers interviewed perceived the hospital experience for many people with dementia as traumatic and frightening. One carer described her mother being in four wards in less than a week then finally being discharged to a community hospital
- Carers and care staff described the difficulties of ensuring that the person with dementia was fed and of having to visit at meal times to feed their resident or relative. Care staff also tried to visit to feed the person. One carer complained to the ward staff that his wife had not been fed and was told *'they were too busy feeding three others'* Other managers gave examples of people coming back from the hospital dehydrated and malnourished
- Managers pointed out that often people when they returned to the care home had MRSA infections
- Four people described the problems encountered following a fractured hip all describing a similar experience: *'they sent him home as soon as possible.. he was a difficult patient .. he kept calling out for his wife. They never tried to get him walking again, he had no physiotherapy, his wound was badly infected and he had a pressure sore and he seemed very sleepy'*
- Carers often found that the difficulties associated with the dementia were not taken into account, and staff appeared only interested in meeting the physical needs of the person. In some cases carers felt they even struggled to meet these needs, they stated *'he wasn't clean, fed or shaved and his mouth was dirty. They made me feel that he was a nuisance at night' 'It was a nightmare that will live with me forever'*
- Relatives described some of the staff as having a *'poor attitude'' they treated her*

like a naughty schoolgirl' and of the staff not having the experience to deal with dementia and *'resenting her going into other peoples' lockers.'* Another described the staffs' approach as *'patronizing'*

- Relatives described feeling '*in the way'*
- Care staff described how somebody who was only slightly incontinent on admission was catheterised on return to the home, and felt that hospital staff thought catheterisation was often seen as an easy option

11.8 Discharge

Staff and relatives also described a number of issues at the time of discharge:

- Staff felt that people were sent back to the care homes too soon, and had insufficient discharge information. Care staff were not routinely involved in the discharge process

- When people returned to their own homes carers often gave distressing accounts of poorly thought out discharge processes, of not being involved in this process and of not being able to cope when the person came home because of poorly thought out care packages or care packages not being in place on discharge

There is a liaison RMN with responsibility within the DGRI but this post has a limited remit.

A model of care that is proving helpful is one pioneered by the Cumbrian Heath Board, providing an acute hospital liaison service. Outreach workers work alongside hospital staff, helping them to manage the person with dementia and they also link up with the discharge process.

Another model of providing specialist dementia input into hospital care is a three year pilot scheme providing a specialist clinical nurse in an acute hospital to be known as an Alzheimer Scotland Dementia Nurse. It will be based in the Royal Alexandra Hospital Paisley and will be funded by Pfizer Ltd for the first three years with an undertaking from the Health Board to continue funding the post after the initial three years.

The recommendations are in line with those made in Dr Morrison's report.

Recommendations

- Admission to hospital should be prevented if at all possible
- Nursing staff should receive more training in dementia care
- Ratio of staff to patients needs to be addressed when caring for somebody with dementia
- The need to take into account the diagnosis of dementia must be stressed
- People with end stage dementia should be moved between wards as little as possible
- Staff must ensure that people are well nourished

- The discharge policy, including when the person is being discharged to a care home, has now been reviewed but further monitoring is necessary.
- Whilst there has been some progress in the flow of information and systems have been put in place there is still more work to do to ensure the information gets to the most appropriate person
- Development of a similar services such as the Cumbrian outreach service and the Alzheimer Scotland Dementia Nurse

12. End of life issues

This section will look at the end of life issues of people with dementia in all settings, including those who are at home. Three carers who were recently bereaved were also interviewed and their experiences are included.

From Planning Signposts it is estimated that at least 200 people with dementia out of 100,000 will die each year.[34] They die at all stages of the illness and may die from other causes other than dementia. There are no figures available for the number of people with end stage dementia who die each year.

One of the difficulties in looking at the palliative care needs of someone with end stage dementia is that 'despite the progressive nature of dementia it is not recognised as a terminal illness and it is unlikely that it will be acknowledged as a contributing cause of death.'[35] The evidence for this is to be found in several studies on causes of death identified in death certificates 'Dementia is under reported on death certificates in the UK by around 30-40 per cent, with some studies suggesting that as many as two thirds of people who die with dementia do not have it recorded on their death certificate and researches have concluded that 'as a cause and contributing cause of death it is not so much overlooked as ignored.[36]

It is therefore not surprising that relatives, care staff and professionals are reluctant to discuss the eventual death of the person with dementia but 'What happens to individuals late in the course of dementing illnesses, the process of their death and dying, and how those most closely affected cope with their grief are, and must continue to be, crucial areas of concern for dementia care workers and educators'[37]

An additional difficulty faced by care workers, relatives and doctors is the trajectory of death that people with end stage dementia face. Lynn and Adamson have argued that it is a long slow process with no overwhelming disease process that makes the actual diagnosis of *dying* very difficult to predict.[38]

The Care Commission is keen to see relatives on admission to care homes giving end of life instructions. These may include practical funeral arrangements and instructions about life prolonging interventions. For many care managers this seems to be an inappropriate time, for other managers it was not a problem and funeral directions are dealt with as a matter of course

When interviewed several carers welcomed the opportunity to talk about the eventual death of their relative and were keen to have a better understanding of what they might expect as the disease progressed. Carers were asked about end of life issues and if they had thought about how they would handle decision making about life prolonging interventions and most of them had given it some thought and were keen to take into account their relatives wishes. There was no experience of welfare power of attorneys among the carers interviewed.

Relatives comments on life issues
'Keep him comfortable' *'I was quite taken aback the first time I was asked – the doctor made it sound as if he was too old for treatment. The decision should be from God. I have been thinking a lot about it lately; about his quality of life and trying to make sense of it- it's good to have the opportunity to talk. It's difficult to cope when there are so many close calls'* *'She would not want to be kept alive* [and] *always talked about the blue pill'* *'I was angry when the Dr prescribed antibiotics when as a family we had made the decision for no further active treatment'* *'It's difficult to make a decision she was very ill a little while ago* [and] *the doctor misread the situation and thought she was dying but she recovered he didn't come back to us.* *'I haven't been asked but it's not difficult. For the first couple of months she just wanted to die. She has had enough. She doesn't want to be here any more'* *'She has no value to her life now'*

- From the variety of comments, it is clear that this is a very difficult area to explore but it does demonstrate that families are thinking about the eventual loss of their relative and are, perhaps more open to discussing it in a sensitive way than is commonly believed.

- For many, these issues had not been discussed with the care homes until their relative was very ill and this may or may not be the most appropriate time.

12.1 End of life

It may be the case that people with end stage dementia are sent into hospital for the last few days or weeks of their lives. Three carers were able to share this experience and were full of praise of the staff, their understanding and high standard of care. It is at this stage of the illness that perhaps the palliative care approach is most keenly identified and understood by staff in the acute care setting.

It is interesting that these same carers who were critical of the care prior to this final illness, were full of praise for the staffs' skill and kindness. It is possible to conclude that because the person is compliant and the physical care and comfort are paramount, the staff are able to demonstrate their skill and expertise in this area of care.

Nevertheless the question remains whether if the same support could not have been provided either in the person's own home or within the care home where there were familiar faces and surroundings. The Liverpool Pathway has been developed by the Marie Curie to transfer the hospice model of care to other settings and is recommended by the NICE guidelines for supportive and palliative care.[39] With further research, which is currently being undertaken by the Bridges Initiative, this could be of benefit within Dumfries and Galloway and reduce unnecessary admissions to hospital allowing a more peaceful and dignified death.[40]

13. Overall Conclusions and Recommendations

1. The evidence gathered in this project identifies, regardless of the care setting similar challenges in providing a palliative care approach to care for people with end stage dementia. Some settings are more successful at meeting physical care needs than others, but meeting the emotional, spiritual, and social needs and providing the essential sense of purpose for living would appear difficult to achieve across all setting
2. There are a number of factors to be considered to ensure a palliative approach to care. These include the sharing of relevant medical information, medical support, management and environmental issues.
3. For families whatever way they remain involved, either by taking the decision to place their loved one in care and their subsequent involvement in that care, or if they decide to keep the person at home, the need for greater understanding and support is clear from all care staff and professionals.
4. Whilst most of the buildings were clean and homely more could have been done to create a dementia friendly environment.
5. There were specific difficulties identified when the person with end stage dementia was in an acute hospital setting.

In order to improve the quality of care for people with end stage dementia living in Dumfries and Galloway there are seven main recommendations: -

1. There has to be recognition of gaps in specific palliative and dementia care of the most dependant group of people with end stage dementia whose physical and verbal communication needs are greatest.
2. Commitment to dementia training and related topics for staff in all care settings with the eventual aim that the training is accredited is vital. Staff should be paid for attending training.
3. Carers must be allowed to be involved in the care at a level they are comfortable with, and some form of partnership with the care setting should be adopted to ensure all parties agree on the level of involvement. Carers must be fully supported if they decide to look after the person at home.
4. There has to be a commitment to a change of culture and training of staff within the acute hospital setting. Ways to support staff should be explored such as the liaison service developed by The North Cumbrian Trust or the Alzheimer

Scotland Nurse Project currently being piloted by The Royal Alexander Hospital Paisley.

5. Relevant medical information must be available in all care homes, as without it they will have difficulty managing symptoms including pain and be unable to give truly person centred care. Proactive rather than reactive medical care should be provided.

6. For recruitment, retention and development of care staff there are fundamental financial implications. Care staff's pay must be reviewed.

7. To help people with end stage dementia make sense of their surroundings every effort must be made to make dementia friendly environments for them to live in.

Glossary: Definitions used in this report

1. End stage dementia

'By this stage of the illness the person will have severe fragmented memory loss. Their verbal skills will be very limited and they will be orientated only to self. The ability to make judgements or solve problems will be lost, and they will have no independent function inside or outside the home. They will need help with personal care and are frequently incontinent.'

2. WHO Definition of Palliative Care

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

1. provides relief from pain and other distressing symptoms;
2. affirms life and regards dying as a normal process;
3. intends neither to hasten or postpone death;
4. integrates the psychological and spiritual aspects of patient care;
5. offers a support system to help patients live as actively as possible until death;
6. offers a support system to help the family cope during the patients illness and in their own bereavement;
7. uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
8. will enhance quality of life, and may also positively influence the course of illness;
9. is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'[41]

3. Carer

There are various definitions of a carer but for the purpose of this report the definition used will be 'the carer is a person who provides regular ongoing support to an entitled person/s in an informal, unpaid capacity'[42]

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