

Beyond Barriers

Developing a palliative care approach for people in the later stages of dementia

An Alzheimer Scotland Partnership Project

Project and evaluation reports



 principles into
practice network

Winner of Principles into
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Alzheimer Scotland
Action on Dementia



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Part 1 – The Beyond Barriers Project

Introduction

The Alzheimer Scotland Beyond Barriers Project set out to improve palliative care for people with dementia living, and dying, in care homes. The project addressed the challenging issue of providing high quality care to people with dementia living in care homes who are approaching the end of their lives.

Beyond Barriers took an innovative approach, involving both care home staff and relatives in a training programme which put communication with the person with dementia at the core, and supporting staff to improve practice through action learning.

'[I gained] a greater understanding, a sense of not feeling alone with this'
Relative

Beyond Barriers was a two-year project commencing in April 2007, funded by the Scottish Government. The project was delivered by Alzheimer Scotland, with the support of the Care Commission's Nurse Consultant for older people in care homes, and was independently evaluated by the Dementia Services Development Centre.

Part 1 of this report describes the background of the project, how it was developed and delivered, and the substantial impact it has had on the practice of staff, the experience of relatives of people with end-stage dementia, and the experience of people with dementia during the last stage of their lives.

Part 2 of the report contains the findings from an independent evaluation carried out by the Dementia Service Development Centre.

About dementia

Dementia is the gradual loss of brain function. The most common cause is Alzheimer's disease, closely followed by vascular dementia. There are many other forms of dementia including vascular dementia, alcohol related dementias, Lewy body dementia and frontotemporal dementias (including Pick's disease).

Dementia can affect every area of human thinking, feeling and behaviour, and eventually it will also affect physical functions. Each person with dementia is different, and how their illness affects them will depend on the type of dementia and which areas of their brain are affected, and how they cope will depend on psychosocial and cultural factors.

The progress of the illness is difficult to predict, but generally it starts slowly with a gradual deterioration, and continues with progressive loss of abilities over a period of years. Estimates of life-expectancy following diagnosis vary, but the illness can go on for ten to 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 illness will affect them. Dementia is, however, an incurable and terminal condition.

A UK based research study has shown that almost one third of people who died over the age of 65 years had some form of dementia.¹

Dementia in Scotland

It is estimated that in 2009 there are between 60,000 and 67,000 people with dementia in Scotland, between 1380 and 1645 of whom are under 65. By 2031 it is projected that there will be approximately 102,000 to 114,000 people with dementia in Scotland², a 70% increase. Approximately 30% have mild dementia, 42% have moderate dementia and 28% have the later stages of dementia.³

The most recent figures (2007) suggest that Alzheimer's and other dementias were the third most common cause of death for women (fourth in 2004) and sixth in men (ninth in 2004).⁴ The classification of underlying cause of death is based on information collected on the medical certificate of the cause of death, together with any additional information provided subsequently by the certifying doctor. It is important to bear in mind that these figures will probably represent a lower number than the actual numbers of people dying from dementia as there is significant under-diagnosis of the disease and previous research shows a low recording of the diagnosis on death certificates.⁵

End stage dementia - the dementia journey

Quality of life and the eventual dying process for people with dementia in the later stages of the disease are arguably neglected areas of dementia care. There is no doubt that for many family members, friends and people with dementia this stage of the illness may be a sad and lonely time⁶.

The illness may last many years and the journey will be an individual experience both for the person with dementia and their families; but there are common features if the illness runs its course. As dementia is an illness most common in old age, many people with dementia may die earlier in the illness of an unrelated cause.

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia⁷ describes people in the later stages of dementia as having severe memory loss. Their verbal skills will be very limited and they will be orientated only to self; this means that they will lose the ability to respond to their environment. The ability to make judgements or solve problems will be lost, and they will have no independent function inside or outside their home. They will also lose the ability to walk without assistance and ultimately be unable to sit without support. They will need help with personal care and are likely to be incontinent. Swallowing may be impaired. This stage of the illness may last several years.

Dementia Palliative Care

The link between palliative care and dementia, or the acknowledgement that dementia is a terminal illness, is relatively recent. Julia Addington Hall wrote in 1998 'despite the progressive nature of dementia, it is not widely recognised as a terminal illness'⁸. She went on to describe a number of important underpinning principles of palliative care and dementia:

- importance of sensitive communication

- quality of life
- whole person approach
- respect of autonomy
- care of the person and family.⁹

A palliative approach to care provides a holistic approach to life and death that does not diminish the more accepted gold standard of dementia care - person centred care - but rather enhances it.

It may be argued that a palliative care approach may only be applied in the later stages of the illness. However, the family and the person with dementia need support in the early days of diagnosis and help with planning and coming to terms with a life-limiting illness. Support of a palliative nature is therefore necessary right the way through the illness until the eventual bereavement.

Although the Beyond Barriers Project concentrated on those people who have reached the end stages of the illness much of the Beyond Barriers course is applicable to *all* people with dementia.

It is also important to consider that not all people die *of* dementia but that many die *with* dementia. Cox and Cook¹⁰ identify three distinct groups of people with dementia in need of palliative care:

1. those with a medical condition that is not related to dementia at any stage of the illness
2. those with a complex mix of mental and physical problems where dementia is not the primary cause of death
3. those with complications arising from end stage dementia.

Furthermore, the long trajectory to death¹¹ and the difficulties in diagnosing dying¹² increase the challenges in ensuring that a palliative care approach to care is recognised and implemented for people with dementia.

Person-centred care

'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.' Tom Kitwood and others developed this philosophy.¹³ This model of care has done an enormous amount to shape and influence the care of people with dementia. While this remains the centre of care for people with dementia the palliative care approach complements this model.

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:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness; 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.¹⁴

Background to the Beyond Barriers project

Unmet need in care homes

In 2006, Alzheimer Scotland completed a two-year study examining the palliative care needs of people with end stage dementia in Dumfries and Galloway. The study found that 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 to be difficult to achieve across all settings. It also noted that a third of relatives felt that recognising and managing pain was an issue and that training for staff on communication with people with dementia was lacking. The report pointed out that discussions with family around end of life choices and preferences were very limited and restricted to the very terminal phase of the illness.¹⁵

The study highlighted a number of recommendations to ensure a palliative approach to care. One finding of the study was the need for support and education for care home staff.

At the time of planning this project there were significant factors influencing the care home sector. The Dumfries project had ended and the Care Commission had recently appointed a nurse consultant for care homes across Scotland. The nurse consultant introduced the care home learning network for staff in care homes as well as initiating a number of national practice development projects. A practice development project focusing on nutrition in care homes had the following key features:

- it identified key champions in the care home setting
- it provided education
- it encouraged sharing of learning via the learning network
- it supported staff in implementing learning in practice through action learning.

This model of practice development was used in the Beyond Barriers Project.

Developments in palliative care

Until recently palliative care has mainly concerned itself with patients who have cancer, but there has been growing recognition that palliative care should be part of the overall care for other groups, such as people with dementia, and be an integral part of the services they receive. In recognition of this, in 2006, the Scottish Partnership for Palliative Care produced, at the request of the Scottish Executive, national practice statements for general palliative care in adult care homes in Scotland.¹⁶ Each care home received copies of these standards. There is clear evidence, however, that guidelines alone are insufficient to change practice and that education and further help to sustain new skills in practice is required.¹⁷

The Review of Palliative Care Services in Scotland by Audit Scotland in August 2008¹⁸ identified that 'specialist palliative care should be available to patients with complex needs while general provision should be available to all'. One of the key messages from the report identified that 'most palliative

care is provided by generalist staff in hospitals, care homes or in patients' own homes. Palliative care needs are not always recognised or well supported. Generalists need increased skills, confidence and support from specialists to improve the palliative care they give to patients and their families.'

The recent Care Commission report, *Better care every step of the way*¹⁹, supports these findings. The report covers inspections of over 1,000 care homes for adults and older people during 2007-08 in which Care Commission inspectors paid special attention to palliative and end of life care. They found that 43% did not recognise that they should be delivering palliative and end of life care to residents with life limiting illnesses.

The importance of involvement

There has been a growing recognition in health and social care over recent years that service users themselves should be more involved with shaping services, as should their carers. Similarly, there is recognition that relatives of care home residents can play a key role in the care of the resident.

However, some relatives are uncertain as to what their caring role is when their loved one is moved to a care home. Relatives often report a lack of confidence in communicating with their relative who has dementia. The Dumfries and Galloway study recommended that carers should be afforded the opportunity to be involved in care home care at the level they are comfortable with and that a partnership between care home and relative is needed. There is some evidence that if staff and relatives work in partnership to deliver care and have a shared set of goals then care can be improved.²⁰ It is for this reason that relatives were included in the joint educational programme of the Beyond Barriers Project.

The Beyond Barriers Project

The Beyond Barriers project aimed to develop current care practice by supporting staff and relatives to meet the palliative care needs of people living in care homes who are in the later stages of dementia during the last 24 months of their life.

The project consisted of two components:

- an innovative three-day course for both care staff and relatives providing both groups with equal opportunities to learn together
- a further five free half-day sessions of supported learning to enable staff to implement their learning in practice.

There was no charge for attending the course and for the action learning, although freeing staff to attend, backfilling and paying travel expenses were a cost to the care homes.

The project was delivered in two phases, a pilot phase, during which the materials were developed and piloted with three care homes, and the rollout phase, which aimed to deliver the programme to 100 staff and 50 relatives, from 50 care homes across Scotland.

Project objectives

The objectives of the Beyond Barriers project were:

- to develop, implement and evaluate an education programme that focuses on communication and is linked to Scottish Vocational Qualifications (SVQs)
- to provide relatives with an equal opportunity to participate in the education programme
- to enable staff for whom English is their second language to participate fully
- to support and to enable care home staff and relatives to influence the practice of other staff within their care home
- to support and to enable care home staff and relatives to use their learning in practice
- to provide the opportunity to develop staff members' and relatives' perspective of each other's roles.

Reference Group

A reference group of experts in palliative care, dementia and the care home sector was formed to guide and inform the progress of the project. Members brought expertise from a range of disciplines and from across the UK. The reference group met six times, and members contributed in between meetings by contributing to and commenting on project plans and materials.

Pilot Phase - April to November 2007

The pilot phase took place in Dumfries and Galloway. Two staff and two relatives from three care homes (12 participants) were invited to take part in a programme of learning including the three day course and an additional five

days of supported learning (action learning) for the staff. For this phase care homes were selected to reflect different types of care settings and included both nursing staff and social care staff. The pilot course covered homes in rural and urban areas and consisted of a not-for-profit company, a large care home organisation and a privately-owned care home.

There was internal evaluation as well as external independent evaluation by the Dementia Services Development Centre and information gained from both processes was used to reshape the training for the rollout phase.

Two key lessons were learned from this pilot:

- **Group dynamics**

It became apparent that more attention needed to be paid to the emotional needs of relatives, some of whom became angry, frightened or upset at times. Staff, too, experienced emotional reactions and some felt anxiety about working so closely together with relatives. Following the pilot it was decided that there should be two facilitators for the course, one to lead the course and one to support relatives.

- **Presenting learning materials**

Course participants felt overwhelmed with the number and size of handouts they were given and it was therefore decided to develop workbooks.

Rollout Phase - November 2007 to March 2009

The programme was rolled out nationally with the aim of creating 100 key learning and development champions recruited from care homes across Scotland. All registered care homes for older people in Scotland, approximately 960, were invited to take part and 460 responded in a positive way, although the project had capacity for only 50 to 60 care homes.

Selection of care homes was carried out to reflect a broad geographical range and the same mix of types of home as the pilot phase. Care homes which were not selected were invited to register their continued interest and names were placed on a waiting list.

Each set of education and support sessions catered for five to eight care homes with each care home delegating two members of senior staff. They were then encouraged to involve two relatives in the education sessions. The courses were grouped into three six-month tranches which took place in May, September and November 2008.

The project exceeded its target of reaching 50 care homes, with 85 staff participants, in spite of difficulties for homes in freeing up staff to attend. Despite the challenge for care homes of recruiting relatives, the target of 50 was almost attained, with 46 relatives participating.

Beyond Barriers education course – attendance

Number of care homes invited to attend the course	77
Number of care homes finally participating in the course	55
Total care home staff participating in the course	85
Total relatives participating in the course	46

The Beyond Barriers Education Course

Focus

The focus of the course placed communication at the heart of the sessions. It acknowledged the importance of person-centred care and examined how a palliative care approach could enhance quality of life at this stage of the illness. In addition an important aspect of the course was for staff and relatives to gain an understanding of each other's roles.

An open approach was adopted that dying *with* dementia or *of* dementia will occur, which accepted that dementia is incurable and that for those people who reach the later stages, the illness will be terminal.

Course materials

The development of the course materials was influenced by the *My home life* review of literature relating to care homes²¹ and by the relationship-centred work of Mike Nolan in which he describes a six senses framework²² to enable person-centred care to be effective in care homes. This framework has three key components, the person with dementia, the staff, and the relatives, and describes how to achieve a balance between these groups.

The course materials were developed from a number of sources which included:

- Alzheimer Scotland's Learning and Development Unit which was a rich source of resources to deliver the more generalist aspects of the course
- Alzheimer Scotland's previous work in palliative care and its *Lighting up Lives* report which provided knowledge, expertise and resources for the more specialist aspects of the course
- the Dementia Services Development Centre who were also able to provide information and resources
- the Bradford Dementia group who were helpful in providing resources.

The proposed course materials were circulated to two members of the reference group for critical reading. Once this process was completed permission was sought to reprint relevant articles, tools and poems. This material now forms the basis of the workbooks.

Course delivery

'I feel that this programme should be introduced to all care homes so that people have an understanding of palliative care and dementia' Staff member

'This has been an enlightening experience' Relative

'I now have better understanding of what's ahead for myself and my mother'
Relative

The course consisted of a three-day joint education programme for senior care staff and relatives. Following the learning from the pilot, two experienced members of the Alzheimer Scotland Learning Development team facilitated the courses, one to work with and support the family members in the discussion groups and one to lead the sessions.

Pre-course reading on dementia was sent out to all participants. The course encompassed current thinking on dementia palliative care, and use was made of a variety of appropriate assessment tools.

Methods of training used were formal teaching sessions using PowerPoint presentations, DVDs, and practical demonstrations. Use was also made of peer group discussions and mixed group work, often coming at the same topic from different perspectives. An example of this was when relatives and staff were divided into their peer groups and were asked to comment on a case history of a lady with dementia who only had a short while to live. Their remit was to identify issues for the person with dementia, for the relative and for care staff, which then formed the basis of a discussion. It was interesting to see how differently the two groups perceived the situation. For the relatives it was a more emotional and instinctive approach, while the care staff focussed on practical issues.

Course content

The course had three main themes in relation to a palliative care approach to care:

- communication and the person with dementia
- communication and relatives
- communication and end of life issues.

It focused on communication with the person in the later stages of the illness (people whose life expectancy could be up to 24 months) and with their relatives, and investigated and explored:

- HOW we communicate: staff with staff, staff with the person with dementia, and staff with relatives; and
- WHAT we communicate about.

Beyond Barriers course content

Day 1	Communication and the person with dementia Quality of life and what palliative care really means Communication skills for people with the later stages of the illness Communication through spirituality and music Communication tools including the Pool Activity Level tool ²³
Day 2	Communication and end of life issues Making ethical decisions Planning for the future – advance statements, welfare power of attorney End of life issues Management of pain
Day 3	Communication and relatives Relatives' role and needs Making visiting a good experience Loss and bereavement Receiving and making complaints

Ethnic and cultural diversity

One of the objectives of the course was to ensure that those staff for whom English was their second language were able to participate fully. The workbooks were designed to be an accessible resource to assist staff to follow the sessions in the books without having to rely entirely on the spoken word.

There were one or two people on the majority of courses who were in this category. Most had an excellent command of English and were able to fully participate in the sessions.

The staff felt able to describe some of the racial discrimination they had to cope with from socially disinhibited residents and this issue was challenging for the entire group.

Staff and relatives felt that too many staff with limited English had a negative impact on care as residents and other staff struggled to communicate.

A role play exercise designed to highlight cultural backgrounds generated discussion about how important it was to understand these differences to have effective communication. One member of staff shared with the group how difficult she found the attitudes to death and dying in this country.

It is interesting to note that very few staff with English as a second language chose to participate in the action learning. It would be a matter of speculation as to why this should be, but this form of learning relies entirely on the spoken word and can be quite daunting if the person is not confident in expressing themselves to a group. It is also worth noting that only three people with English as a second language returned their forms for the external evaluation,

making it difficult to assess how successful we were in meeting their needs or in changing their practice.

Workbooks

Workbooks were developed for each day for use by both relatives and staff and were linked to knowledge evidence requirements for Health and Social Care SVQs. Comprehensive notes were provided for the facilitators.

Every effort was made to ensure that the material used was accessible for people for whom English was an additional language and a full glossary of terminology was included.

Change in practice

To help focus staff and relatives on areas where they might be able to change practice within the care home setting they were encouraged to identify areas of care they would like to develop. Staff and relatives were encouraged to add their ideas to a list as they occurred throughout the three day course. These were recorded as 'Big Ideas'; see [Appendix A](#) for a summary of these ideas. This information was used to help each member of staff create an Action Plan ([Appendix B](#)).

Relatives were also encouraged to contribute to the 'Big Ideas' and they put ideas they felt able to implement on a postcard, which was sent out to them a month later to encourage them to take their ideas forward.

Supportive learning - action learning

'It can be better to encourage staff to think through a problem and discuss it rather than presenting them with a solution' Staff member

The second component of the project was to give staff members five half-day support sessions in the form of an Action Learning Set. While training may offer personal development for care staff it will not necessarily bring about a long-term change in practice. This may be for a variety of reasons including staffing issues, unsupportive management or staff set in their ways both in terms of attitude and practice.

Action learning can be described as²⁴ 'a continuous process of learning and reflection that happens with the support of a group or 'set' of colleagues, working on real issues, with the intention of getting things done'. The purpose of action learning is to enable staff to become more effective in their work.

Action learning involves a group coming together for a specified period of time. Within the group each individual (set member) comes to the set both to learn about their individual issues and to facilitate others to learn. The focus of the process at any one time is on an individual. The group enables the individual to learn from experience and move to more effective action.

The follow-up action learning sessions were attended by about half the original group. For those who took part they proved very rewarding and a very effective way of learning. While the members of the set could bring any issue to the group they were encouraged to concentrate on things they had

identified in their action plan; staff brought a range of issues which were often directly related to the course. Using action learning techniques the sets were able to take issues forward and either enable changes in practice or help support the individual to find a solution to a problem. Some staff found difficulties in transferring learning and facilitating changes within their care home, but felt more confident in their own practice.

'I am doing my job more confidently now and I am able to express my opinion to other care staff and hopefully they are listening to me' Staff member

It was evident that staff participating in the action learning became more self-assured and learned to think issues through in a more constructive way.

'I have learned that I can be more assertive and I have more confidence in myself. Also that other homes all have similar problems and hopefully we have all been able to give some input on how to handle problems within other group member's care homes' Staff member

'I have learned not to give up too quickly on problems that I encounter and that my problems are not unique' Staff member

Relative involvement

'This programme gave me the knowledge and confirmation that I can do and am doing everything I can to make the life for my loved one brighter, peaceful, loving and comfortable' Relative

There is much anecdotal evidence that, as the illness progresses and communication with the person with dementia becomes even more difficult, some families may visit less often and for shorter periods or may stop visiting at all. If this barrier is to be tackled, it is essential to find ways to help relatives communicate, and ensure that the importance of their unique contribution to enhancing the quality of life is recognised. For the person with dementia they are a connection to the past and for staff they may hold the key to unlock vital links to understanding the person's needs.

There are other relatives who, despite finding it difficult, continue to visit daily. It is important for them to feel that visiting is still worthwhile and that they can continue to make connections with the person they love. One relative's experience highlights this point.

A gentleman was visiting his wife daily but felt communication was no longer possible in any real sense. The only recognition he had from her was when he fed her a chocolate drop. After attending the course he changed the way he approached her. Rather than sitting on a chair next to her, he made sure he had eye contact with her and when she needed her hands cleaned from the chocolate, instead of just wiping them he used it as an opportunity to massage her hands. He was surprised and delighted when she started to rub his hands and smile at him.

Challenges

A number of challenges were encountered during the project, which provided useful lessons for future work.

Challenges of involving care home staff

There was overwhelming enthusiasm for the project from care homes, although it was not always easy to engage with staff, for a number of reasons, principally relating to practical issues such as being unable to contact staff not on duty.

Although there was no charge for the course itself or for the action learning, freeing staff to attend, backfilling and paying travel expenses were a cost to the care homes. In addition there were competing priorities for care homes, which needed to meet statutory training requirements as well as being involved in the Beyond Barriers project. These challenges may have been exacerbated by the ambitious length of the course, which lasted three days with five additional half day supported learning sessions, making full attendance a substantial commitment for staff and care home managers. To support the project some staff came in their own time.

For some homes there were additional geographical constraints; while every effort was made to provide venues throughout Scotland there is no doubt that some care homes were disadvantaged as they were faced with too long a journey, and there was no budget to meet transport costs.

There were particular challenges in explaining the innovative nature of the course content and the concept of relatives' involvement. In addition some care homes which had already had training in generalist palliative care did not recognise the significance of Beyond Barriers' specialist focus on palliative care for people with dementia.

Communicating with interested care homes was sometimes challenging as it often relied on information being passed on within the home. It could be difficult to speak to the right person and email was not always successful.

Despite agreeing to take part, not all care homes were able to participate as anticipated, possibly because of staff availability or competing priorities. As time went by, especially in the third tranche, there had been a loss of focus on the project by some of the homes and the momentum to attend was lost.

Course preparation, content and delivery

Participants were given pre-course information and a benchmarking questionnaire to complete. Although the information was sent to the homes, the staff and relatives attending the course did not always have the information or had been unable to read it prior to the course.

The information had been intended to ensure that everybody on the course had a basic understanding of dementia; on several of the courses it was necessary for the facilitators to provide this basic information.

It had been hoped that the information provided in the questionnaire would enable facilitators to address training needs. It was interesting to note that staff generally felt in these initial questionnaires that their care homes met

most of the palliative care needs of their residents. This did not seem to reflect subsequent discussions during the course on best practice in palliative care relating to people with dementia. This was illustrated by one member of staff who said:

'You will be amazed at how much you thought you knew but didn't!'

Both registered nurses and social care staff participating were surprised that so much of the course was about affirming life and understanding and supporting relatives' needs, and that end of life issues were only a small part of the course. Staff would have liked more in-depth material on this aspect of care but within the context of the course and the relatives' involvement it would not have been appropriate. It did, however, highlight the need for more a comprehensive session for staff on the management of the physical symptoms of dying.

As had been anticipated, the facilitators were constantly challenged by the group dynamics because of the mixed make up of the groups. They found the first sessions particularly difficult, when not only did care home staff not know each other but there was also the added impact of relatives within the group. However, generally the groups gelled well and were soon working as a team. When individual participants had special needs it often became a team effort to support them.

The challenges of action learning

Despite sending out detailed information about the course, including the additional five half days, the staff attending were often unaware of the follow-on days of supported learning. Not all care homes participated and those that did found it difficult to commit to all five sessions. To try to improve uptake various timescales of the sessions were tried including weekly, fortnightly and monthly, but unfortunately this did not seem to make a difference to attendance.

It is a matter of conjecture as to why more homes did not see the need to be involved in this part of the course but, in addition to the time commitment required, action learning is a relatively new concept within the care home sector and perhaps management and staff were unaware of the potential benefits to be gained both on an individual and organisational level.

The concept of action learning was new to many of the staff, and as is common with action learning, some staff attending the sessions needed encouragement to take part. However, in most cases they successfully overcame their initial difficulties with support.

The size of the group was also an issue. Sometimes it was too small and this made it difficult for the set to have fresh issues to bring to each session.

The challenges of relatives' involvement in the beyond barriers course

A variety of approaches were adopted to ensure relative involvement, which included a poster (see [Appendix C](#)), media release, and leaflets describing the project. Support was also offered to care home staff and a leaflet devised to help them recruit relatives to attend the course (see [Appendix D](#)). However, it remained a challenge to involve relatives.

Some residents simply did not have any relatives, while others lived away or worked. Others were not comfortable with the idea of attending a course with staff and were perhaps uncomfortable and uncertain about the content of the sessions.

Staff themselves had concerns about this form of joint learning and some were reluctant to identify relatives. Sometimes they brought a relative to the second day once they had a clearer idea of what the course was about. Some staff tended to select relatives they were comfortable with while others brought along relatives who clearly had issues with the care of their relative.

The target set for the project was the involvement of 50 relatives, in recognition of the fact that it would be more complex involving relatives than staff. This proved to be the case. In reality, rather than having two relatives from each home (each course consisted of five to seven care homes, which would have meant ten to 14 relatives) the maximum number of relatives attending any course was ten and the minimum was one.

This variation was challenging for the facilitators as a balance had to be maintained and where there were few relatives, it was important that they had adequate support and did not feel isolated. It was also essential that there was a flexible approach to relatives attending the course and that they could opt out of any of the sessions.

It should be noted that in addition to those relatives identified by care homes attending there were a small number of relatives who had expressed an interest in taking part but whose care home had not wished or was unable to be involved. The knowledge and understanding this group of relatives developed during the course gave them the courage to go back to their care homes and make suggestions about care practice. An example of this was a relative who was able to convince the staff that the 'difficult' behaviour staff were experiencing by her relative was because she was in pain.

The rewards - enabling change in attitude and practice

'It has made me see the whole person and not just the disease. I have changed the way in which I view people with dementia; you forget they do have values and opinions' Staff member

'I have learnt that there is more to dementia than just a loss of memories and behaviours. I have been enlightened as to my practices and understanding of dementia' Staff member

Throughout the course there was a rigorous internal monitoring of how the course material was to be used to change attitude and practice within the care home setting. As previously mentioned staff and relatives were encouraged to contribute to collecting 'Big Ideas' which were recorded each day and which included both large and small topics. Ideas ranged from remembering to introduce themselves by name each time they spoke to a person with dementia to sharing good practice of how the staff let other members of the team know if a resident had died. A summary of Big Ideas is contained in [Appendix A](#).

At the end of the course staff and relatives were asked to reflect on the course by completing three questions, which were:

- what have you learned from the course?
- what would you tell other people about the course?
- what would you change as a result of attending the course?

These questions elicited some useful responses.

What have you learned from the course?

'There is a gap between carers and staff/residents which needs to be closed. It's important to stop and evaluate what I am doing. Are there other ways to do it?' Staff member

'A feeling of support, care and confidence' Staff member

'A better understanding of what the future holds for my mother and myself'
Relative

What would you tell other people about the course?

'We need to be more open in discussions with regards to death and dying with continued discussions with relatives and service users' Staff member

'To see things from the staffs' point of view not just the carers' Relative

'Good to hear family members' views' Staff member

'This course is worthwhile from all disciplines' perspectives. It allows staff and relatives to understand each other's role and respect them as individuals' Staff member

What would you change as a result of attending the course?

'Need for stimulation and activities' Staff member

'Involve more relatives in dementia training/education' Staff member

'End of life planning – forward planning – reflecting individuals' choices at end of life' Staff member

'Communicating with my mother when she talks about her parents' Relative

'Involve relatives more in planning and assessment.' Relative

The rewards of relatives' involvement in the Beyond Barriers course

'The course was stimulating, thought provoking, educational, purposeful, helpful and FUN' Staff member

'The best part of the programme was different opinions from staff and carers' Relative

'It has helped me to relate to my Mum's life and to help her to live more. It will also help me to relate knowledge from the course to my family members who visit less frequently.' Relative

The course was developed to use the experiences of both staff and relatives as a learning tool. The staff sometimes found it difficult to adapt to this new way of learning rather than being 'taught to but learning from'.

Seeing things from a different perspective was a powerful experience for both staff and relatives. The relatives' views were the catalyst for many of the changes the care homes made and for increased awareness and understanding of relatives' needs. There was much laughter, as well as tears and anger, and ultimately a sense of participants coming together and of strength gained through acknowledging and understanding each other's perspective. One of the relatives whose husband has subsequently died reported being able to get comfort by remembering some of the discussions that had occurred on the course.

It was evident in the action learning sessions with the staff the effect working with the relatives had on them, as one staff member described:

'Having relatives on the course has been enlightening, interesting and gave me time to think and put myself in the relatives' shoes'

Key themes to emerge from the course and the supported learning sessions

Operational

Care home staff reported the project was successful in changing practice in their care homes. Much of the ability for staff in care homes to change practice was associated with the support from management. Issues in some homes, such as understaffing, reliance on agency staff, a high turnover of staff or a culture where staff have worked in the same setting for many years and have entrenched attitudes impacted on the ability to bring about change.

Relatives' involvement

Relatives did not always have a clear idea of their own role once their loved one had gone into care and care home staff had not always thought about the relatives' role or their emotional needs.

Before the course, involving relatives had been perceived by staff as being difficult to achieve.

A palliative care approach

For many of the staff and relatives the concept of seeing dementia in terms of a non-curative and terminal illness was a new one and that the idea that a palliative care approach may be beneficial had not been considered as having any relevance for people with dementia. The course demonstrated the willingness of relatives to discuss these sensitive issues.

Care home staff and relatives working together

There was an enthusiasm and willingness to participate in the course and the honesty and commitment demonstrated cannot be underestimated. Staff relished the opportunity to work together and share good practice. Relatives did not have an understanding of the pressures experienced by care home staff until attending the course.

Communication

Once the language skills of the person with dementia were diminished communication was a real issue for both staff and relatives and both groups benefited from addressing this in the course. Communication was often also seen to be difficult between staff and relatives, staff and staff, and staff and other professionals visiting the care home, such as GPs. **The course had a direct impact on improving communication between staff and relatives and was also helpful in enhancing other communication by improving staff confidence.**

Spirituality

Understanding of spiritual aspects of care including spiritual assessment, completing a spiritual care plan and giving people with dementia a spiritual

content to their lives was something many staff and relatives felt they were not achieving.

Planning care

Planning care and ensuring the wishes of the person with dementia were kept to the forefront was a key concern for all participants.

End of life issues

Working through end of life and ethical and legal issues was an area of practice that the participants found helpful to discuss and for relatives and staff to see from each other's perspective.

Managing pain

Knowledge about assessing and managing pain varied but knowing when someone was in pain clearly remained an issue. Relatives had little knowledge about the importance of recognising and treating pain. Only some care home staff were aware of pain assessment tools.

Link between boredom activities and communication

Boredom and lack of activity for people in the later stages of dementia was identified by many relatives and also acknowledged to be an issue by staff.

Outcomes of the Beyond Barriers education and supported learning sessions

The link between a palliative care approach and dementia is a fairly recent one and for many care staff the concepts and ideas were new and exciting and gave 'food for thought'. The course challenged staff to bring about a change in practice both in the quality of care their residents receive and at the end of their lives. For relatives it gave recognition of their role, knowledge, empowerment and, most of all, courage to carry on. One of the most frequently used words to describe the course was 'enlightening.'

The project demonstrated that it is possible to have meaningful discussions about ethical and end of life issues, and for some relatives this was an important part of their individual journey. Staff also gained confidence in dealing with these sensitive issues and saw for themselves relatives' emotional needs and dilemmas.

Staff have improved understanding of relatives' needs

Increased understanding of relatives' needs and improved communication between staff and relatives is a key outcome. The course gave staff a clearer understanding of the relatives' role and staff changed their approach. Some staff have learned to involve and trust relatives once thought of as 'difficult'.

Some care homes have established carer support groups in addition to residents' meetings; one group is being run by a relative.

Some care homes have looked at how they share information with relatives and are making the reviews more relevant.

One care home manager described how a relative was complaining about poor mouth care: previously the manager said she would probably have just tried to reassure her. She has now introduced a chart to share with the relative to show when mouth care has been carried out, which has improved the level of understanding between the relative and the staff.

Involving relatives was a real challenge and required determination to ensure success but the rewards were tremendous both for the relatives themselves and for the shared learning experienced with staff.

Relatives' trust of staff has increased

Some relatives' visiting patterns have changed. One anxious relative who used to visit for a few minutes several times a day 'to check up on the staff' now visits more infrequently but stays longer. Another relative, who struggled with her mother being in a care home, following the course felt she could now 'trust the staff' and went to Australia for a holiday - something she would have never considered before.

A few relatives have taken the initiative to develop support sessions for other relatives; for example, a relative who attended the course is now working with another relative who is particularly anxious.

Staff and relatives are better able to communicate with people with dementia

Both relatives and staff were able to develop their skills in communication with the person with dementia and find new ways to make connections. Many homes introduced the PAL tool²⁵ (an occupational profiling tool), improving understanding of the cognitive and communication needs of people with dementia.

There are many examples of relatives enjoying a better quality of relationship and visits. One relative reintroduced music into her visits and another started reading again to her relative. In addition relatives and staff developed better understanding and trust of each other.

Staff and relatives have better understanding of spiritual needs

Understanding the spiritual needs of people with dementia has been an important aspect of the project, with individual care home staff making a real impact on this aspect of care. This is one of the areas where there has been the greatest number of initiatives, including:

- Introducing spiritual assessments
- Reaching out into the community to ask for help from a wide variety of denominations and religions
- Trying to organise or access additional training for all staff
- Relative organising religious services
- A relative introducing saying 'God Bless' when she said good bye to her husband
- A young care worker with no particular faith discussed with her residents to see if they would like someone to say the Lord's Prayer with them. She felt some found peace from saying it together and had a more settled night.

Staff have improved the quality of life for residents

The development of ideas relating to improving the quality of life through music, reading, one-to-one activities and visual stimulation has been fully explored and many of the ideas generated have been implemented in some of the care homes; for example:

- The PAL tool has been widely introduced and has been an effective means of tailoring activities to meet individual needs
- Staff have made simple resources for their residents to touch and feel
- Pictures on ceilings and mobiles to give stimulation have been introduced
- Doll therapy has been introduced in some homes; in one they have developed a nursery corner where there is a rocking chair and a 'baby' in a cot – this has reduced anxiety so much for one lady that her sedation has been significantly reduced.

There is better understanding of end of life care and advanced planning

The project demonstrated that it is possible to have meaningful discussions about ethical and end of life issues, and for some relatives this was an important part of their individual journey. Staff gained confidence in dealing with these sensitive issues and saw for themselves relatives' emotional needs and dilemmas.

Some staff are looking at using the review process to create better planned care. For those people who still have capacity they are introducing advance statements and, for those with incapacity, involving relatives to gain a greater understanding of their wishes. One home introduced a statement of values adapted from the Alzheimer Scotland advance statement template.

The project has had a significant impact on the understanding of end of life care in both staff and relatives.

- Some participating care homes were already using the Liverpool Care Pathway as a way of managing the final phase of life and others adopted it
- A number of homes looked at better ways of recording and using information about powers of attorney
- Following sessions on end of life care and ethics, one relative who was distressed that her father in law had not been given artificial feeding felt reassured that this was the best decision.

There is better management of pain

Management of pain was one of the key issues originally identified as important in palliative care in dementia. The project has improved practice:

- Some homes not previously using a pain tool have now introduced one
- Some of the staff used their action learning sessions to do further work on pain issues and now have a far greater understanding of successfully managing pain
- Relatives who were previously unsure if their relative suffered pain now understand what behaviours may be expressing pain and are able to alert staff to potential episodes of pain
- One care home has worked with GPs to prescribe all the residents with paracetamol to be given if the staff feel the person is in pain. Pain in this care home is now being considered as a primary cause of behaviour which challenges. There is now a calmer atmosphere in the home and the residents are having their pain needs met.

Staff are sharing the learning with colleagues

Care home staff have taken ideas back to their individual care homes from the course and have been disseminating the material to their colleagues. Some staff have introduced training sessions on the Beyond Barriers Project and are keen to disseminate the information they gained on the course. The care homes who took part in the course have been given copies of the facilitator's notes and a number of homes have purchased the presentations.

Some staff have had discussions with GPs in relation to advance planning of care and management of pain.

There is a set of new resources specific to palliative care in dementia

The workbooks developed for the project are linked to knowledge evidence requirements for Health and Social Care SVQs. The books bring together the current thinking on a palliative care approach for people with dementia and provide a valuable tool.

Staff have increased confidence following action learning

Challenging operational issues came to light during the action learning sessions and while many of these were beyond the remit of this programme it became clear that staff finished the course stronger and more confident in dealing with difficult situations.

Conclusion and recommendations

The Beyond Barriers project was successful in improving palliative care for people with dementia living, and dying, in participating care homes. The innovative approach of involving both care home staff and relatives in a training programme brought challenges but proved to be both rewarding for relatives and to bring an additional and lasting change in relationships.

The programme itself was externally evaluated by the Dementia Services Development Centre and received a positive evaluation which forms Part 2 of this report. The evaluation concludes with the recognition of the many benefits staff and relatives of people who have dementia experienced by taking part, and the recommendation that the programme should be available to all care homes.

The link between a palliative care approach and dementia is a fairly recent one and for many care staff the concepts and ideas were new and exciting and gave them 'food for thought'. The project challenged staff to bring about a change in practice both in the quality of life their residents receive and at the end of life. For relatives, it gave recognition of their role, knowledge, empowerment and, most of all, courage.

Communication was always at the heart of the sessions. Relatives and staff were able to develop their skills of communication with the person with dementia and find new ways to make connections. In addition through developing an understanding of each other's needs the course generated a real sense of working together. The project lived up to its title and truly went 'beyond barriers'.

The project demonstrated that it is possible to have meaningful discussions about ethical and end of life issues and for some relatives this was an important part of their individual journey. Staff also gained confidence in dealing with these sensitive issues and saw for themselves relatives' emotional needs and dilemmas.

Involving relatives is a real challenge and requires determination to ensure success but the rewards are tremendous both for the relatives themselves and for the shared learning experienced.

The number of care homes able to take part in this project is a small percentage of the total number of care homes in Scotland and there are many more homes and people with dementia whose staff and relatives could benefit from this type of course.

Those course participants who took part in the supported learning found that it had a positive impact on learning and more importantly in changing practice; this model of learning should be used more widely.

The future: Alzheimer Scotland Palliative Care Initiative

The work of the Beyond Barriers Project is recognised as valuable, and as having a wider application than care homes. It will now be taken forward during 2009-10 by the Alzheimer Scotland Palliative Care Initiative, funded by the Scottish Government and NHS Education for Scotland (NES). This one-year capacity-building programme will build on Beyond Barriers and will provide training for staff providing education in NHS and social care settings. Alzheimer Scotland's partners will be NHS Dumfries and Galloway and the University of the West of Scotland.

The initiative will develop the workbooks to meet the needs of a wider range of health care and social care professionals and embed the practice embodied in the Scottish Government's new Living and Dying Well action plan.²⁶ The workbooks will be accredited at SVQ level 3 and published. Alzheimer Scotland will provide a one-day course and a day of supported learning for 60 trainers, with the opportunity for these staff to purchase places in action learning sets. The course will equip the staff to deliver the training.

This initiative will allow wider dissemination of the work of Beyond Barriers and will build the capacity of a range of organisations to cascade high-quality training on dementia palliative care to their staff and to support them to improve practice.

Recommendations

The learning from the project has resulted in a set of recommendations:

- **All care home staff should be trained in dementia palliative care**
- **There should be acknowledgment that dementia is a life-limiting illness and a more open approach by care professionals about discussing death and dying**
- **People with dementia should be recognised as having palliative care needs, and be supported by care staff who are aware of the additional challenges of palliative care in dementia, including dementia-specific approaches to communication, capacity and pain control**
- **Action learning should be more widely available to staff in care homes to enable and support staff to share and change practice**
- **Relatives should be seen as true partners in care, with their own individual needs**
- **Relatives should be given information and support about the later stage of the illness**
- **Relatives and care home staff should plan care together**
- **Relatives should be encouraged to have a key role in the education of care home staff.**

Part 2 – External Evaluation by the Dementia Services Development Centre

Beyond Barriers: analysis of data and programme evaluation

1. The project

The Palliative Care in Dementia Project: Beyond Barriers set out to address serious deficiencies identified in the palliative care of people with dementia by developing the skills of care home staff to meet the palliative care needs of people with dementia nearing the end of their lives. Following on from the pilot study an education programme was developed to build on and bring together existing resources on palliative care and dementia care and develop a process which will support and enable care home staff and relatives¹ to influence palliative care practice. The project was commissioned by the Scottish Government through a partnership with Alzheimer Scotland and the Care Commission. Alzheimer Scotland is an SVQ Centre and all materials are linked to SVQs, which are key qualifications for social care staff.

The project involves an education programme consisting of four main themes: Communication; Palliative Care; Person Centred Care and Relationship Centred Care. The programme is delivered over three in-class training days for staff and relatives together and five action learning days for staff only. The areas covered during the three day in-class teaching sessions include communication, activities, financial and legal aspects, and ethics and planning. Handouts, videos/DVDs and CDs are used throughout the three day in-class teaching sessions. Teaching is delivered by experienced Alzheimer Scotland trainers. Through a method of learning called 'Action Learning', carried out by an experienced trainer in this area, staff are enabled to take forward and implement a change in care practice. Relatives may be asked to assist staff to implement this change.

The aim of the project was to develop current care practice by supporting staff and relatives to meet the palliative care needs of people with dementia.

The objectives of the programme were to:

- Develop implement and evaluate an education programme that focuses on communication, linked to Scottish Vocational Qualifications (SVQs).
- Provide relatives with an equal opportunity to participate in the education programme.
- Enable staff for whom English is their second language to fully participate in the course.
- Support and enable care home staff and relatives to influence the practice of other staff within their care home.
- Support and enable care home staff and relatives to use their learning in practice.

¹ The use of the term 'relative' throughout the project and this report will mean anyone close to the person with dementia including partners and friends.

1.1 The Role of DSDC

The Dementia Services Development Centre (DSDC) evaluated the work of the pilot project and the programme after its first roll out phase nationally and drew on this to make recommendations for the future.

This involved:

- Undertaking the evaluation of the pilot project and producing a report of findings and recommendations. (Completed – 20 February 2008 – All recommendations acted upon and implemented into the roll out phase of the programme).
- Undertaking the evaluation of the programme and producing a report of findings and recommendations.

1.2. Method

Relatives and staff were recruited by Alzheimer Scotland producing and sending out information on the programme to 960 care homes in Scotland. Approximately 460 expressed an interest in taking part. From the homes expressing an interest, 55 care homes were selected giving a mix of urban and rural, private and not for profit organisations, and single owners and large companies. The care homes were responsible for alerting and encouraging relatives to the training course.

Five Alzheimer Scotland trainers were involved in delivering the programme over ten sessions; one each in Dundee, Dumfries, Aberdeen and Inverness; three in Glasgow and three in Edinburgh. This part of the project was completed in December 2008.

Data collection to inform this report was gathered through pre-training questionnaires which were posted out prior to the commencement of training and returned to the trainer on the first day of the programme. The training evaluation questionnaires were completed by each participant on the last day of the three day training session and returned to the trainer. The action learning days' evaluation questionnaire was completed on the last day and returned to the trainer.²

Each questionnaire contained closed and open-ended questions. Some questions asked participants to rate specific areas of the programme. This was done using a 6 point Likert scale with 1, 2, and 3 representing negative responses and 4, 5, and 6 representing positive responses. Other questions required a Yes/No response, responses indicating level of satisfaction or open ended questions requiring a qualitative response.

² A copy of all questionnaires used in this report are at [Appendix E](#).

2. Relatives

2.1. Analysis of pre-training questionnaire

Prior to training, relatives were sent a questionnaire in order to identify current needs of their relative in the care home as well as any areas in need of further development.

Table 1. (N = 30)*

	All of the time	Some of the time	Rarely	Never	Don't know
You believe that some form of communication is possible with somebody who has severe dementia although they are no longer able to express themselves verbally	14	15	0	0	1
You have had opportunities to find out about dementia	16	9	3	1	0
You are confident that your relative will be able to remain in the care home to die where they are known to staff in a familiar environment	24	5	0	0	2
You feel if the situation was to arise you have sufficient knowledge to cope with situations where there is some disagreement/ethical concerns between key parties e.g. staff, GPs	13	14	2	0	2
You are aware that dementia may be a terminal illness and that it is quite possible that your relative may in the next 12/24 months sadly die from the illness	21	4	0	0	2
You are hopeful that your relative with dementia will die without distress	21	4	0	0	2

*Total number of returned questionnaires is 30, however, some questions were not completed by participants.

The above table shows almost all relatives reported positively to questions posed. However, although small in number there were some areas in need of development e.g. having the opportunity to find out about dementia and having sufficient knowledge to cope with disagreements between key parties.

Table 2 (N=30)*

	All of the time	Some of the time	Rarely	Never	Don't know
You feel the care home has an emphasis on good symptom control and tries to deliver quality of life for your relative	24	6	0	0	0
Your wishes are sought in relation to end of life care planning (e.g. advance statements; cardiac resuscitation; transfer to hospital or at review meetings)	18	6	1	3	2
You feel spirituality both expressed informally or formally through religion is recognised and supported as being an important aspect of care for some people with end stage dementia	14	7	1	0	4
Your relative's care plans are person centred and reflects their life's experiences	17	9	0	0	0
You are aware that staff have had training in palliative care and dementia	17	9	1	0	2
You have had the opportunity to speak about end of life issues and do not feel the staff are trying to avoid the subject of death and dying	16	5	3	2	0
You are confident that you will be contacted and kept informed if there are changes in your relative's health	26	1	0	1	0
You are confident that you will be consulted about care decisions	21	6	1	0	0
You are confident you will be involved in the care of your relative at a level you feel comfortable with	23	3	1	0	1
You are confident that staff feel able to advocate on the resident's behalf when they have distressing symptoms such as pain or anxiety	20	8	0	1	0

*Total number of returned questionnaires is 30, however, some questions were not completed by participants.

Table 2 shows responses to questions relating to practices within the care home. Almost all relatives responded positively to the questions posed, with a

minority of respondents reporting less favourably on areas such as communication and involvement around end of life care and spirituality.

2.2. Summary of pre-training questionnaire

The vast majority of relatives reported positively to the questions posed. However, there were a few areas/issues which suggested a need for further development. These areas are mainly around end of life issues such as communication and involvement in planning care as well as delivering care. There are also some needs around obtaining information on dementia. Although there is a plethora of information available particularly through internet sources, some people report they are finding it difficult to obtain information. This highlights the need for staff to be aware that some relatives will rely heavily on them for necessary information and they should not assume that relatives will have the knowledge or the ability to access information via computers or indeed that they know of organisations such as Alzheimer Scotland which could give them information on request.

2.3. Analysis of evaluation of training questionnaire (N=32)

Questionnaires were received from 32 relatives who took part in the training programme. 23 of the participants were female and nine male. Most participants (14) were in the age group 51-60. Three participants were between the ages of 31 – 50 while the remainder were aged 61 and over.

Most participants (15) were daughters of the relative in the care home. There were also three wives, three sons, one son-in-law, two nieces, two carer/companions, three husbands, one partner and one who stated 'relative'.

Most (25) of the relatives being cared for were in the age group 80 and over, four were in age group 70 – 79 and three were between 50 and 69.

23 relatives had been in the care home from between one and five years, four had been in a care home for less than a year and three had been in a care home for six to ten years.

Most (24) participants were attending with connection to a care home, 5 were attending independently.

Q. What did you hope to achieve by attending this programme?

The replies to this qualitative question³ consisted primarily of an eagerness to gain more knowledge about dementia as well as a better understanding of the issues around dementia in its later stages.

Knowledge, confirmation that I can do and am doing everything I can to make life for my loved one brighter, peaceful, loving, comfortable

An understanding of what the final stages will be like in order to help my mother

³ A full copy of all qualitative question responses are located at Appendix E

Better knowledge, understanding

A greater understanding of the illness and the problems faced for caring in a care home environment

To have more understanding regarding the care of dementia sufferers

Knowledge and understanding about dementia – how I could be of benefit to my relative and her care home

More of an understanding of how methods for enhancing opportunities for people living with dementia can be improved in care homes

Q. To what extent has this been achieved

Table 3 (N=32)*

	Scale ranging from 6 (Fully achieved) to 1 (Not at all achieved).					
	6	5	4	3	2	1
Day 1 - were aims achieved?	10	14	2	1	0	0
Day 2 - were aims achieved?	12	10	3	0	2	0
Day 3 - were aims achieved?	17	11	3	0	1	0

*Total number of returned questionnaires is 32, however, some questions were not completed by participants.

Almost all relatives responded positively for all three days (4 or over).

Q. Please rate the quality of the three day programme; the presenter; the handouts.

Table 4 (N=32)

	Scale ranging from 6 (Very satisfied) to 1 (Very dissatisfied).					
	6	5	4	3	2	1
Quality of 3 day programme	24	4	3	0	0	0
Quality of presenter	25	3	2	0	0	0
Quality of handouts	21	7	2	0	0	0

*Total number of returned questionnaires is 32, however, some questions were not completed by participants.

All participants rated all of the areas positively with most rating each area '6 - very satisfied'.

Q. What do you feel about the length of the programme?

When asked about the length of the programme 3 commented it was too long; 3 that it was too short and 23 that the length of the programme was just right.

Q. What did you like best about the programme?

Participants were asked what they liked best about the programme. Many felt the opportunity to receive information about dementia in its later stages as well as meeting other people sharing similar experiences and fears was best. The opportunity to discuss issues with staff and learn of the challenges they also face was beneficial to many of the relatives.

Factual information – insight into dementia; also sharing experiences

The information and presentation and different opinions from staff and carers

The way the presenters put across the information. Sharing ideas and experiences with other people – both carers and staff

Exchange of views, both with carers and other relatives

The sharing of information between the ‘care homes’ and the residents families. Seeing both sides of the coin

Practical exercises, discussion and meeting others to exchange experiences, perceptions and ideas

The amount of information given and the freedom to express one’s feelings and concerns

Speaking with other relatives and sharing ideas/working with staff from care home to gain an understanding of their work/anxieties and achievements

Making me think about issues I had not considered

Q. What did you like least about the programme?

Reporting on what aspects of the programme they liked least, very little was directly related to the content or presentation but rather at the emotions the content stirred in people.

Emotionally stressful

Some discussion left me personally with feeling of guilt or inadequacy

Understanding role and responsibilities of relatives vis-a-vis care home staff

Emotion re end of life care

Sitting too long

Talking about death

Q. What are your views on relatives and staff attending the same training sessions?

Relatives were asked for their views on training with staff. Most felt this to be a very positive experience although one person commented at times it could be a little inhibiting if known staff were present.

Enlightening

Direct sharing of views between relatives/staff seemed useful

I think it is an excellent idea

Sometimes it was inhibiting when known staff were present

Helpful because each could hear how the other felt

I think it is very beneficial to have such communication going on between staff and relatives; greater understanding can be reached hopefully about the role (essential) each plays

Differing perspectives, enlightening and rewarding

Enlightening. Excellent in developing better relationships. Also felt it was a positive statement about partnership working

Q. To what extent will the knowledge/skills you have learned from the programme be useful to your visits with your relative?

All recorded they felt it would be useful, with 21 recording they felt it would be very useful. Many felt they had gained a better understanding and insight into the illness. Some also felt they had a better understanding of staff issues,

A better understanding of what the final stages will be like

New understanding and approach to situations

It has given me a boost in terms of the way I view my mother's condition. Instead of being sorrowful when visiting – I can be more cheerful and upbeat in my approach. Even though she is more or less bed ridden I know I can make a difference in small ways

Better communication/understanding

I intend not only to visit my relative on my visits. I'll visit the 'community' which is the care home. I hope to visit with a purpose – 'active' visiting!

Will support me to interact more with staff

It has made me realise that communication in any form whether verbal/non verbal is paramount

Making visiting positive enjoyable, comfortable

Q. To what extent would you recommend others with similar needs to your own to attend this programme?

When asked to what extent they would recommend the programme to others. All reported they **would** recommend it to others with 24 recording they would **fully recommend** it. They were also asked for suggestions in ways the programme could be improved.

I think a one off follow up session after a few months involving all who attended this course to exchange views on changes we have made and also to make a contact again with other family carers who attended

I have nothing that could be changed

The programme was great, it should be more readily available to more care homes

2.4. Summary of evaluation of training questionnaire

Questionnaires from 32 relatives who took part in the programme were returned. Almost all relatives felt the aims of the programme had been achieved. They found the programme to be interesting, informative and would be of benefit to their visits. They found training with staff to be enlightening and some feel they have a better understanding of the issues/challenges facing staff within the care home.

Most relatives feel they have a better understanding of dementia in general, and of end of life care in particular. For some relatives the programme has highlighted the importance of communication and that communication is more than the ability to verbalise feelings. Some felt the programme has renewed a sense of purpose to their visits. Overall the responses from the relatives were extremely positive for all aspects of the training programme and they would have no hesitation in recommending it to others.

3. Staff

3.1. Analysis of pre-training questionnaire (N= 35)

Prior to training, staff were sent a questionnaire in order to establish their current needs in their care home as well as identification of any areas in need of further development. The questionnaire was divided into two specific areas. The first area was on the dying phase while the second was on the last phase of life.

Table 5. The Dying Phase. (N=35)*

	All of the time	Some of the time	Rarely	Never	Don't know
The team are confident about recognising when somebody is dying.	25	10	0	0	0
Staff collaborate with families to discuss how much they would like to be involved with the care during the dying phase.	25	7	2	0	0
We have a shared care plan and specific goals to achieve a high quality of care.	26	2	3	0	4
Our residents with dementia die without distress.	22	12	0	0	1
All our staff have had training and are able to recognise pain in someone with dementia.	11	22	1	1	0
All our staff use assessment tools for managing pain.	15	14	4	2	0
Our staff feel confident to advocate on the resident's behalf when they have distressing symptoms such as pain or anxiety.	26	9	0	0	0
Staff regularly assess the support needs of families of dying residents.	23	8	4	0	0
Other residents in the care home are informed that a resident they know is dying or has died.	11	20	3	1	0
All staff are informed when a resident has died and no one finds out by chance.	21	12	0	0	1
Staff have the opportunity to attend the funeral and pay their respects to the family.	29	6	0	0	0
Residents have the opportunity to attend the funeral and pay their respects to the family.	10	14	3	5	2
People with dementia are allowed time to grieve and attend funerals if appropriate.	16	9	6	0	2
There is a forum for open discussion/reflection after a death to support staff and further develop the care given to dying residents and their families.	9	13	4	8	1

We allow families the privacy and time with the person but are available to offer support if necessary.	34	1	0	0	0
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*Total number of returned questionnaires is 35, however, some questions were not completed by participants.

Table 5 shows the majority of staff reporting 'All of the time' or 'some of the time' for all the questions. It does highlight areas in need of some development such as informing other residents of someone's death and giving them the opportunity to attend the funeral; the opportunity for open discussion among staff after the death of a resident; and the use of tools for assessing pain.

Table 6. The Last Phase of Life. (N=35)*

	All of the time	Some of the time	Rarely	Never	Don't know
All staff are aware that dementia is a terminal illness.	16	16	2	0	0
All staff are aware the path to death for someone with dementia can be a slow process and may last between 12/24 months.	8	19	7	0	1
An emphasis on good symptom control and quality of life underpins our care rather than a sense of 'striving to keep alive'.	25	9	1	0	0
Our staff believe that communication is possible with somebody who has severe dementia and is no longer able to express themselves verbally.	16	18	1	0	0
Our focus of care is person centred.	28	7	0	0	0
We have regular teaching on end of life care/dementia.	8	19	4	1	0
Residents'/families' wishes are sought in relation to end of life care planning (e.g. advance statements; cardiac resuscitation; transfer to hospital on admission; review meetings).	25	7	2	0	0
Do not attempt resuscitation forms are in regular use with our frail residents who have dementia.	9	7	4	12	0
Relatives who want to speak about end of life issues are encouraged to do so.	32	3	0	0	0
We do not try to avoid discussion on the subject of death and dying.	22	10	0	3	0
Spirituality both expressed informally or formally through religion is recognised and supported as being an important aspect of care for some people with end stage dementia.	22	9	3	0	0
Staff have an understanding of the Adults with Incapacity (Scotland) Act 2000 and are aware of	7	25	1	0	1

the role of the Welfare Power of Attorney.					
Residents remain in the care home to die where they are known to staff and in a familiar environment.	24	11	0	0	0
We regularly seek help and advice from other experts when it is required i.e. specialist palliative care nurses.	29	6	0	0	0
We feel able to manage situations where there is some disagreement/ethical concerns between key practices e.g. staff, GPs, families.	18	17	0	0	0

*Total number of returned questionnaires is 35, however, some questions were not completed by participants.

Table 6 highlights the need for further discussion and development around specific areas such as communication with people who have dementia; knowledge on the Adults with Incapacity Act; the use of DNR forms; as well as developing confidence to manage situations where there is disagreement between key personnel.

3.2. Summary of pre-training questionnaire

The pre-training questionnaire was designed to give a base line of current practices around end of life care for people who have dementia. Results show that discussion on end of life care; communication with residents and relatives on end of life issues; knowledge about the Adults with Incapacity Act; and opportunities for staff to openly discuss a resident's death are areas that could benefit from the training.

3.3. Analysis of evaluation of training questionnaire (N=64)*

Demographic information

Although 64 questionnaires were completed the demographic section on a number (23) was not. This may be due to staff feeling apprehensive at the possibility of being identified. The demographic break down of the 41 who did complete this section is as follows:

40 were female.

Most (22) were in the age group 41-50, four were aged between 20 and 30, seven between 31-40 and eight were in age group 51-60.

Job titles included senior care officer; charge nurse; care home manager; care assistant; senior carer; staff nurse; team leader; senior support worker and social care worker.

The time they had worked in the area of care of the elderly ranged from one year to 33 years with the Mean length of time 13 years.

The time worked in their present facility ranged from one year to 23 years with the Mean length of time being seven years.

27 reported having an SVQ qualification the remainder (14) had nursing qualifications.

Three did not have English as their first language but all reported they had been able to 'fully participate' in the programme.

Q. What did you hope to achieve by attending this training programme?

Many of the staff hoped to build on their existing knowledge of dementia and end of life care. They also wanted to learn new skills and improve on their current practice as well as gain an insight into the issues/challenges affecting relatives.

To build a more meaningful relationship between families and the professional carer

A better understanding of dementia

To improve knowledge, understanding and build on existing skills

The opportunity to take something positive back for the benefit of residents and staff

A wider understanding of dementia and palliative care. Learn new skills to improve practice and pass onto staff

A better understanding of the subject, some new ideas and different points of view that I could put into practice

Tips and ideas to provide better up to date care/activities. To understand relatives' needs in greater detail. Fuller understanding, improve holistic care

A much better understanding of palliative care needs

An understanding of how care staff and relatives can work together. A better understanding of end stages of life with dementia

A better understanding/insight to dementia and relative involvement. An insight into palliative approach to the condition

A greater understanding of how I can bridge the gap between staff expectations and relative's expectations to focus on the resident

Q. To what extent has this been achieved?

58 rated the course positively (between 4 – 6) with very few (six) rating it 3 or less. Seventeen felt it had been fully achieved (rated 6 on the scale).

Q. Please rate whether the aims for each of the training days were achieved and give comments on each.

Table 7 (N=64)

	Scale ranging from 6 (Fully achieved) to 1 (Not at all achieved).					
	6	5	4	3	2	1
Day 1 - were aims achieved?	23	28	3	5	0	0
Day 2 - were aims achieved?	26	28	8	1	0	0
Day 3 - were aims achieved?	24	27	7	3	0	0

*Total number of returned questionnaires is 64, however, some questions were not completed by participants.

Table 7 shows that almost all participants rated the training days positively. As well as rating the three days of the programme staff were asked to make comments on each day. Most are extremely positive.

Day 1

Very informative

The musical activity showed how effective some of the very simple things in life can be so reachable even in the very late stages

This session reinforced my thought on what can be done regardless of the stage of the dementia

Relative involvement is of the utmost importance

Found the involvement of the relatives in the programme educational, enlightening and courageous of them

I found it very interesting and informative to hear how relatives felt

Gives you a chance to reflect on current practice, what you lack and what can be learned and implemented

Have gained more knowledge in managing later stages of dementia, lots of useful information to feed back to staff in the unit

Day 2

Many useful points that I hope to implement/change within my care home

Informative and interesting

Sensitive issues covered but well covered

To ensure that families are more involved in the end of life care if they wish to be

Now have useful information to take back and disseminate.

Day 3

I looked at this from a different perspective after listening to relatives' comments

Learned to understand the impact dementia had on a relative

This session helped me acknowledge the importance of communication for everyone

We tend to forget that relatives know our clients very well and must take their input on board

Highlighted the importance of involving relative and carers in the compilation of care plans and needs assessment

Very, very important

Will communicate to involve resident's relatives a lot more and ask for their help and more information on their relative

Q. Please rate the quality of the 3 day programme; the presenter and the handouts.

Table 8 (N=64)

	Scale ranging from 6 (Very satisfied) to 1 (Very dissatisfied).					
	6	5	4	3	2	1
Quality of 3 day programme.	38	19	5	1	0	0
Quality of presenter.	43	16	1	1	1	0
Quality of handouts.	39	20	2	1	0	0

*Total number of returned questionnaires is 64, however, some questions were not completed by participants.

Table 8 shows the majority of participants reported on the quality of each of the different aspects positively with most rating each as 'very satisfied'.

Q. What do you feel about the length of the in-class programme?

The vast majority of participants (59) felt it was just the right length, one felt it was too short and four felt it was too long.

Q. What did you like best about the programme?

Participating staff were asked what they liked best about the programme. Many commented they enjoyed having the relatives present, the open discussion and the different ways to communicate. Many also commented how interesting and informative they found it.

Open discussion and helpfulness and knowledge of the facilitators

Having the relatives present

View point of others

Spending time listening to the views of others

The sharing of ideas and experiences

It was relaxed and presented in an interesting and thought provoking way. I have learned and gained from the experience. Feel more motivated to improve practice

Q. What did you like least about the programme?

When asked about which aspect they least enjoyed many commented on issues either around the venue, catering or on sitting for a length of time. Few negative comments were directed to the content of the programme.

Not much interaction on a learning level

Sitting in one place for most of the day

Felt there was not enough on actual palliative care

Having to complete the course. Felt we could continue working together on any task

The fact that so few homes were represented

Looking at some of our working practices and actually seeing you may have been doing something wrong and making you feel you maybe have failed in some way i.e. not discussing end of life enough

Q. What are your views on relatives and staff attending the same training session?

Most staff commented they had enjoyed the experience of training with relatives and had found it enlightening.

Enlightening – most definitely

Very useful ideas gained to change practice. Once or twice felt quite defensive!

Think it worked out well

I think it helped each part to see things from the others' point of view and this we can take away and learn from

It was good to see things from a relative's perspective

Enlightening, interesting and gave us time to think and put ourselves in the relatives' shoes

Q. Do you feel more confident in working with and supporting relatives?

Participants were asked if they felt more confident in working with and supporting relatives. Sixty two felt they did feel more confident with two reporting they did not.

Q. In what way has training influenced the way you now deal with people who have dementia in general and at end stage care?

Many felt they have more understanding and that they feel more positive. Some feel it has enhanced their practice and that they take more time to interact with client and relatives.

In general:

In future I will be more aware of all needs – residents', mine and families'

More understanding

Have more insight and understanding

The importance of stimulation regardless of stage of dementia

Makes me much more aware of involving relatives

Deeper awareness of their feelings

More time to listen

Take things a bit slower if possible

More insight and understanding

Reinforced current awareness and gained further knowledge

End stages:

Many staff feel the programme has given them more confidence, understanding and knowledge in dealing with people who have dementia at the end stages.

More aware

Have more confidence

You think about the person's other needs not just about personal care

To remain positive at all times regardless of the situation

Have more insight and understanding, sensitivity is needed

Respect and dignity paramount

More relaxed, confident

Better understanding

Q. To what extent would you recommend others with similar needs to your own to attend this programme?

Almost all (59) reported they would recommend the course to others.

Q. To what extent will the knowledge/skills you have learned from the programme be useful to you in your place of work and in what way?

The majority (58) felt the knowledge and skills they have learned from the programme will be useful in their work place.

Staff were asked to comment on what way the knowledge and skills they had learned would be useful to them in their place of work. Many felt they were now able to pass information on to staff and implement the skills learned and to offer better care and more support.

Pass on information to other staff and carers

Improve communication with relatives, expand advance statements, organise training for staff, organise info for relatives and people with dementia

Will be able to pass skills etc on to other staff

It has given me more confidence to tackle issues with staff and residents

I shall be able to pass on the knowledge/skills – build on existing skills. Found pointers for further learning

It has made me more aware and increased my understanding of residents' and relatives' needs

I can use this learning to share with colleagues and relatives in a bid to improve current care provision

Very useful in guiding and supporting staff within the dementia unit of our home. Lots of information to feed back and discuss

Q. Please make comments on how the programme could be improved or any other comments you feel may be relevant to this evaluation.

Some felt more interaction could be introduced. Some felt it could have been longer but most felt it had been a positive and motivational experience which should be offered to all care homes.

I think this programme should be introduced to all care homes so that people have an understanding of palliative care

Possibly a bit longer to cover the work books more extensively

I learned a lot. Very informative

The programme was excellent and should become a standard for all care homes in the future to give better care and understanding for all

I think this should be ongoing to all and maybe more places, but overall this has been a brilliant course, thoroughly informative and very useful

I have really enjoyed the course and learnt a lot from it. Looking forward to putting it into practice

3.4. Summary of evaluation of training questionnaire

Almost all staff reported very positively on all aspects of the training programme and felt it had covered a wide range of topics. They felt it had been extremely beneficial to train with relatives and it had given them an insight into caring for someone with dementia from a relative's perspective. The training had also highlighted the importance of communication with the person with dementia at all stages of the illness but in particular in the latter stages when verbal communication may be lost. Training had also highlighted the importance of involving relatives when making up care plans and also in actively participating in some aspects of care. Some commented training had increased their confidence and motivation. Almost all agreed they would recommend the training to others.

4. Analysis of evaluation of action learning questionnaire (N=30)

Action learning is a process where staff can be supported to bring issues about developing practice to a group who can help them, through facilitation to unpick these situations, and develop new ways of thinking that will help them develop an action plan for change. There were five half day action learning sessions which took part over a three month period.

Returned questionnaires from the Action Learning days totalled 30.

Q. How would you rate the Action Learning Days as part of the programme?

Staff were asked to rate the action learning days. All (30) felt them 'useful' with just under half (13) reporting them as 'very useful'.

Q. Do you feel the Action Learning sessions have enabled you to take forward, in an effective way, some of the points you have learned in the education programme?

All (30) felt the action learning days had enabled them to take forward, in an effective way, some of the points they had learned in the education programme.

Q. What did you like best about the Action Learning Days programme?

Many felt discussion around issues which were shared by others had been useful as well as making them think and viewing issues from another perspective.

There are others in the same boat as you – good to talk things over – in confidentiality

Being able to discuss various things with others giving input

It enabled me to look at my dilemma in a less tunnel like manner. I feel Action Learning is a very positive, reflective way to deal with many situations especially supervision

Finding out you are not the only one with a specific problem and discussing the issue with other people

Sharing problem/issue. Being listened to, asked the right questions to think things through differently

Q. What did you like least about the Action Learning Days programme?

The issues which they liked least were mainly to do with presenting and admitting they had problems/issues. Some felt the time between each meeting could be shorter.

The fact there was three weeks to a month in between days

I felt they run a bit too lengthy

When I have to tell my own problem, I could not solve myself

Initially talking to a group and acknowledging you had a problem you could not deal with alone

Having to do a presentation

It was a difficult concept to understand at first because it was new

Q. What barriers do you see in implementing training in your work place?

The factor which many felt would be a barrier to them implementing the training into their work place was 'time' and staff attitudes to change.

Time to fit it in, as you know 'time is our enemy' but will make a concerted effort to implement training

Getting staff to take on board the benefits to all the team and of involving relatives right from admission – changing the way things are done is scary

Staff attitude. Process of change

Time, expense, not being able to train all staff

Some staff objecting, but by working together less barriers

Q. Has the length of training been difficult for your care home to commit to?

A third (10) felt the length of training was difficult for the care home to commit to. Most (28) reported they were being paid to attend, however, a number commented they were attending on their day off.

I would have preferred if dates were closer together

Needed to cover shifts in order to attend

I was unable to attend all sessions which was a pity. Though gained a lot from sessions I was able to attend

Q. Have you been paid to attend or are you attending in your own time?

Most (28) reported they were being paid to attend. However, some commented they were attending on their day off.

Sometimes came on my day off

Paid but coming on my day off

Days that I was off duty. Some days I was off and others I was on duty

Partly in my own time

Being paid.

4.1. Summary of evaluation of action learning questionnaire

Just under half the number of staff who attended the in-class three day training sessions attended the action learning sessions. From conversation many felt the time needed for this part of the programme may have been difficult for some of the staff/care homes to commit to. Some felt it was a large commitment of time to be made when they didn't know anything about action learning and therefore were committing to something they knew nothing about.

The majority of staff who attended the action learning days felt they had benefitted from them. They felt it would enable them to take forward to their work place learning from the training days. Some felt that discussing problems in an action learning manner, although challenging at first, was definitely beneficial. Many felt that a barrier to implementing learning would be time constraints and attitudes of other staff members. Overall the action learning days were viewed very positively.

5. Conclusion

The vast majority of staff and relatives who took part in the training found it to be very beneficial. Both groups agreed the experience of training with each other was very useful. Many of the staff found the comments and views of the relatives to be a useful complement to a professional input. They felt it alerted them to the different perspective relatives have on the person with dementia from their own perspective. It also highlighted to many staff the need to involve relatives more in the day to day care of the person with dementia. Relatives felt training with staff had been enlightening and had drawn attention to the issues and challenges facing staff.

All participants felt the content of the training programme to be comprehensive, informative and interesting. Most felt the length of the in-class teaching course to be 'just right'. Some staff felt the time between each action learning day was too long. However, the time limit was set for three – four weeks in order to give staff time to implement a change and bring any problems they were having to the next meeting.

Some care homes attending had no relative representation. As mentioned in the introduction, encouraging relatives to take part was left entirely to the individual care home. There is no way of knowing how vigorously each care home tried to recruit relatives to the training. In conversation, comments were made that sessions/staff would have benefitted by better representation from relatives.

Action learning days were available to staff only. Approximately 50% of staff attended these days. It is unclear why all staff who attended the training did not attend action learning. Of those who did attend, the response has been very positive. Staff reported they felt it would be beneficial to them in implementing aspects learned from training into their place of work.

This is the first programme of its type. It bridges the gap between staff and relatives by training them together. It values carers and encourages relatives to take an active part in caring for the person with dementia. This innovative programme can best be summed up in the words of one staff member.

'The programme was excellent and should become a standard for all care homes in the future to give better care and understanding for all.'

6. Recommendations

- Recruitment of relatives to the programme needs further consideration and development.
- A follow up session should be considered to identify issues arising since training.
- Barriers to staff attending action learning days should be identified and acted upon.
- Length of time between action learning days should be discussed and revised if necessary.
- An interesting piece of research would be to investigate any differences between those who attended action learning sessions and those who did not as to changes in practice.
- The evaluation of this programme has highlighted the many benefits staff and relatives of people who have dementia have experienced by taking part. The programme should be available/accessible to all care homes.

Appendix A - Summary of Big Ideas

Communication with the person with dementia:

How can relatives understand different behaviours?

Do staff introduce themselves each time they meet the person with dementia and remind the person of their own name?

Should staff help relatives to communicate better with their relatives?

Wider issues of communication:

How do we engage with GPs?

How do staff ask the right questions to get the right answers?

How do we ensure information is disseminated?

Spirituality:

How can we make care more spiritual?

How do we gather information about individuals spiritual needs?

How do we record information on spirituality so that it is not just about death? but around living –What gives the person contentment and peace?

Use the King James Bible!

Why not mixed religious services?

Quality of life:

How can we introduce quality into the lives of people with end stage dementia?

How do we challenge negative perceptions about quality of life?

Do some people not have a quality of life?

Activities:

How do we introduce the PAL tool?

Are there cheap ways to introduce stimulation?

Why is there no occupational therapy/ physiotherapy input?

How do we get managers/owners on board to buy resources?

What activities are there for the end stage of dementia?

Could there be a better use of music?

Better information gathered on individual's preferences around music

Relatives' needs

Why is there only a phone call made with bad news never good news?

How do we get the carer job description out to everyone?

Do we give relatives copies of up to date care plans?

Why isn't accident form shared with the relatives?

Can relatives be given a room to spend the night together in a care home?

Social occasions outside the home for staff/relatives

What support do care home staff give to carers?

Management of symptoms

Introduce a pain tool

Improve pain history

Why shouldn't everyone be written up for paracetamol?

Do all the staff interpret resident's pain in the same way?

What policies and procedures and training are in place to ensure staff manage pain adequately?

On end of life

Would the Liverpool Care Pathway be a useful tool to introduce?

Is there bereavement support?

Where are Welfare Power of Attorneys and Financial Power of Attorneys recorded; if so do staff look at the certificate?

Should completion of form AWI S47 be more widely used for a wider range of treatments? (Adults with Incapacity (Scotland) Act 2000)

On planning care

If there are residents in the early stages of dementia should staff be encouraging them to organise a welfare and financial power of attorney?

Encourage advance statements; have 'end of life' discussions early on?

Could end of life discussions form part of reviews?

On staff

Recognise it's OK to be fallible!

Family responsibility to give staff as much information as possible

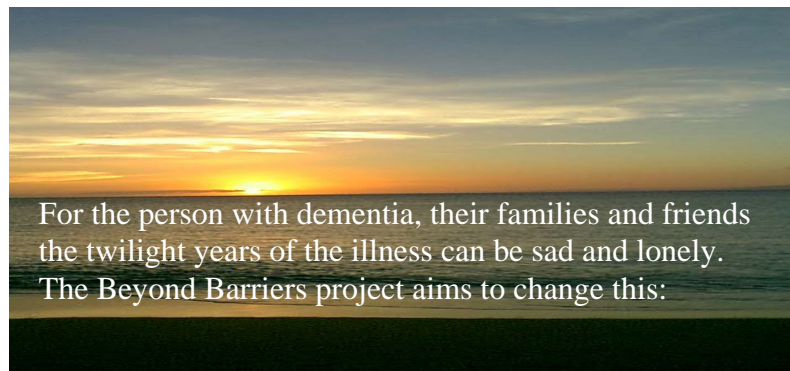
Why do so many staff go off sick?

Why do nursing/care staff have laundry and cleaning duties?

Appendix B Staff action plan format

Areas for Improvement	Priority 1	Priority 2	Priority 3
What specific actions are going to be taken to improve?			
What will you measure to know you are succeeding?			
What target do you want to achieve on your measure?			
What is/are the key date(s)?			
Who is responsible for this, (even if they are not personally doing the work)?			
Outcome			

Appendix C – Poster publicising Beyond Barriers to relatives



We need help from family members and friends to make this possible: take part in a free three day education programme

- Share knowledge and experience with care staff from your care home and others
- Meet other carers and staff and understand each other's roles
- Develop your skills and knowledge in communicating with your relative
- Take time to think and understand more about the final years /months of the illness

Together we can make a difference to your loved one's life and when the time comes help you to be prepared

Beyond Barriers is a project to develop current practice in care homes by supporting staff and families to meet the palliative care needs of people with dementia

For further information please contact your care home manager or Jenny Henderson at Alzheimer Scotland Tel 01387 261303 or jhenderson@alzscot.org



Appendix D – Involving relatives in the Beyond Barriers project: a guide for managers of care homes

Why involve relatives?

A summary of the current research on family involvement provided by Gaugler 2005 draws the following conclusions:

- Families do remain involved; they do not abandon the person with dementia although visiting may become difficult because of the changes brought about by the dementia
- Family members may continue to experience stress, burden and guilt
- Family members are keen to preserve the identity of the person
- Family members advocate for the person
- Some family members like to provide hands on care
- Care homes that see family members as people with needs are most likely to achieve good relations with family members
- There are some indications that family involvement has positive outcomes for the person with dementia.

A quotation from the Care Commission's Framework for Engaging With People Who Use Care Services and Carers 2007-2010

'The Care Commission sees the engagement as being about making sure that all those who have a stake, interest or say in care can have their voice heard....Engagement is more than informing or consulting. It is about getting people who wish to or choose to, directly involved. The Care Commission firmly believes that service users and carers must be provided with opportunities to engage at a level and a degree that suits the needs of the individual.'

Getting relatives involved in the Beyond Barriers Project

We do appreciate this may be difficult, and some relatives may find it upsetting, but for others it is a way of facing the future and remaining involved with their relative. There are also practical reasons why it is difficult, relatives may live away or not visit frequently or be working. Transport may be another issue and while we do not have a specific budget for transport costs we would look sympathetically on any requests for help.

What relatives and staff say who have already taken part in the project

Relative 'It has given me heart to carry on'

Staff ‘ I suppose I do feel more confident, it is good to hear from relatives. It showed us we need to work more closely with them’

‘I realised their expectations are totally different. The case study we did in class showed we looked at it so differently from the family’

How can you help to encourage and involve relatives in the project?

- Display the poster as prominently as possible
- If you have a relatives’ group tell them about it
- If you have a newsletter include information about the project
- You may want to give out individual leaflets—please contact us if this would be helpful
- Individual approach is often the best way.

What happens if you are unable to identify a relative?

Please contact us as soon as possible and we will try to help you. If you are unable to identify anyone we may feel it is necessary to offer your place to another home that has relatives who are able to take part.

Remember

For people with dementia and their families the twilight years of the illness can be lonely and sadlet’s all work together to make it better

Appendix E: Questionnaires - external evaluation

Relatives' pre-training questionnaire

Could you please put a tick in the square that you think relates most closely to your needs and those of your relative in the care home. We appreciate these may be difficult questions and you may feel unable to complete the form, so please only do as much as you feel comfortable with. Your answers will help us to collect base line information to identify any areas of further development. All information gathered will be treated in strictest confidence. **Please complete and bring with you on Day 1 of the education programme.**

Last phase of life	All of the time	Some of the time	Rarely	Never	Don't know
1. You feel the care home has an emphasis on good symptom control and tries to deliver quality of life for your relative					
2. You believe that some form of communication is possible with somebody who has severe dementia although they are no longer able to express themselves verbally					
3. You have had opportunities to find out about dementia					
4. Your wishes are sought in relation to end of life care planning (e.g. advance statements; cardiac resuscitation; transfer to hospital or at review meetings)					
5. You feel spirituality both expressed informally or formally through religion is recognised and supported as being an important aspect of care for some people with end stage dementia					
6. Your relative's care plans are person centred and reflects their life's experiences					
7. You are confident that your relative will be able to remain in the care home to die where they are known to staff and in a familiar environment					
8. You feel if the situation was to arise you have sufficient knowledge to cope with situations where there is some disagreement/ethical concerns between key parties e.g. staff, GP's					
9. You are aware that staff have had training in palliative care and dementia					
10. You have had the opportunity to speak about end of life issues and do not feel the staff are trying to avoid the subject of death and dying					
11. You are aware that dementia may be a terminal illness and that it is quite possible that your relative may in the next 12/24 months sadly die from the illness					
The dying phase	All of the time	Some of the time	Rarely	Never	Don't know
1. You are confident that you will be contacted and kept informed if there are changes in your relative's health					
2. You are confident that you will be consulted about care decisions					
3. You are confident you will be involved in the care of your relative at a level you feel comfortable with					
4. You are confident that staff feel able to advocate on the resident's behalf when they have distressing symptoms such as pain or anxiety					
5. You are hopeful that your relative with dementia will die without distress					

Thank you very much for completing this questionnaire [Adapted from Bridges Initiative, Hockley et al 2004]

Staff Pre-training questionnaire

Could you please put a tick in the square that you think relates most closely to the needs of staff in your care home. This will help us to collect base line information to identify further development needs. All information gathered will be treated in strictest confidence.

Please complete and bring with you on Day 1 of the education programme.

Last phase of life	All of the time	Some of the time	Rarely	Never	Don't know
1. All staff are aware that dementia is a terminal illness					
2. All staff are aware the path to death for someone with dementia can be a slow process and may last between 12/24 months					
3. An emphasis on good symptom control and quality of life underpins our care rather than a sense of 'striving to keep alive'					
4. Our staff believe that communication is possible with somebody who has severe dementia and is no longer able to express themselves verbally					
5. Our focus of care is person centred					
6. We have regular teaching on end of life care/dementia					
7. Residents/ families wishes are sought in relation to end of life care planning (e.g. advance statements; cardiac resuscitation; transfer to hospital on admission; review meetings)					
8. Do not attempt Resuscitation forms are in regular use with our frail residents who have dementia					
9. Relatives who want to speak about end of life issues are encouraged to do so					
10. We do not try to avoid discussion on the subject of death and dying					
11. Spirituality both expressed informally or formally through religion is recognised and supported as being an important aspect of care for some people with end stage dementia					
12. Staff have an understanding of the Adults with Incapacity (Scotland) Act 2000 and are aware of the role of the Welfare Power of Attorney					
13. Residents remain in the care home to die where they are known to staff and in a familiar environment					
14. We regularly seek help and advice from other experts when it is required i.e. specialist palliative care nurses.					
15. We feel able to manage situations where there is some disagreement/ethical concerns between key parties e.g. staff, GPs, families					

The dying phase	All of the time	Some of the time	Rarely	Never	Don't know
1. The team are confident about recognising when somebody is dying.					
2 Staff collaborate with families to discuss how much they would like to be involved with the care during the dying phase.					
3. We have a shared care plan and specific goals to achieve a high quality of care.					
4. Our residents with dementia die without distress.					
5. All our staff have had training and are able to recognise					

pain in someone with dementia					
6. All our staff use assessment tools for managing pain					
7. Our staff feel confident to advocate on the resident's behalf when they have distressing symptoms such as pain or anxiety					
8. Staff regularly assess the support needs of families of dying residents					
9. Other residents in the care home are informed that a resident they know is dying or has died					
10. All staff are informed when a resident has died and no one finds out by chance					
11. Staff have the opportunity to attend the funeral and pay their respects to the family					
12. Residents have the opportunity to attend the funeral and pay their respects to the family					
13. People with dementia are allowed time to grieve and attend funerals if appropriate					
14. There is a forum for open discussion/ reflection after a death to support staff and further develop the care given to dying residents and their families					
15. We allow families privacy and time with the person but are available to offer support if necessary					

[Adapted from Bridges Initiative, Hockley et al 2004]

Thank you very much for completing this questionnaire

Beyond Barriers: Education Programme Evaluation (Relatives)

Thank you for attending the 'Beyond Barriers: Education Programme'. We hope you have benefited from participation in the 3 day event. In order to ensure continued success with future programmes, we would be please if you would take the time to complete the questions below.

Where scoring ranges are given, please circle the score that most closely represents your views. The other questions require you to tick an appropriate box or to give written comments.

1. What did you hope to achieve by attending this training programme?

2. To what extent have you achieved this?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

The Programme

3. Day 1 of the programme aimed to cover connecting with the person with dementia in the later stages of the illness to improve the quality of their remaining life.

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

4. Day 2 of the programme aimed to give information on ways of making the end of life as peaceful and comfortable as possible.

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

5. Day 3 of the programme aimed to cover communicating with relatives and understanding relative's needs.

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

6. Please rate the following:

Quality of the 3 day programme Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

Quality of the presenter(s) Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

Quality of the handouts Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

7. What do you feel about the length of the programme?

Too short [] Just right [] Too long []

8. What did you like best about the programme?

9. What did you like least about the programme?

10. What are your views on relatives and staff attending the same training sessions e.g. did you find it prohibitive or enlightening?

11. To what extent would you recommend others with similar needs to your own to attend this programme?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

12. To what extent will the knowledge/skills you have learned from the programme be useful to your visits with your relative?

Very useful

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all useful

In what way?

About you

Are you: Male | Female |

What age group are you in?

20 -30 [] 31 - 40 [] 41 - 50 [] 51 - 60 [] 61 - 70 [] 71 – 80 [] over 80 []

What relation are you to the person with dementia?

What age group is your relative in?

Under 50 [] 50 – 59 [] 60 - 69 [] 70 -79 [] 80 and over []

How long have they been in their present care facility?

Less than 1 year [] 1 – 5 years [] 6 – 10 years [] over 10 years []

Are you attending the programme independently of a care home? Yes [] No []

Please indicate your ethnic origin

- | | | |
|--|---|--|
| <input type="checkbox"/> Indian | <input type="checkbox"/> White – Scottish | <input type="checkbox"/> Mixed background |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> White – Irish | <input type="checkbox"/> I do not wish to declare this |
| <input type="checkbox"/> Pakistani | <input type="checkbox"/> White – Other British | |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Other White Background | <input type="checkbox"/> Any other ethnic group |
| <input type="checkbox"/> White Caribbean | <input type="checkbox"/> Other Black Background | Please indicate group below |
| <input type="checkbox"/> Black Caribbean | <input type="checkbox"/> Other Asian Background | |

Please make comments on how the programme could be improved or any comments you feel may be relevant to this evaluation.

Thank you for taking the time to complete this questionnaire.

Please return this questionnaire to the presenter at the end of the final session OR
post to:

Beyond Barriers: Education Programme Evaluation (Staff)

Thank you for attending the 'Beyond Barriers: Education Programme'. We hope you have benefited from participation in this event. In order to ensure continued success with future programmes, we would be pleased if you would take the time to complete the questions below.

Where scoring ranges are given, please circle the score that most closely represents your views. The other questions require you to tick an appropriate box or to give written comments.

1. What did you hope to achieve by attending this training programme?

2. To what extent have you achieved this?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

The 3 day In-Class Training Programme

3. Day 1 of the in-class programme aimed to cover connecting with the person with dementia in the later stages of the illness to improve the quality of their remaining life.

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

Comments:

4. Day 2 of the in-class programme aimed to give information on ways of making the end of life as peaceful and comfortable as possible and looked at ways to plan care including ensuring the wishes of the person with dementia were taken into account..

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

Comments:

5. Day 3 of the in-class programme aimed to cover communicating with relatives and understanding relative's needs.

To what extent was this achieved?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

Comments:

6. Please rate the following:

Quality of the 3 day programme Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

Quality of the presenter(s) Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

Quality of the handouts Very satisfied

6	5	4	3	2	1
---	---	---	---	---	---

 Very
dissatisfied

7. What do you feel about the length of the in-class programme?

Too short [] Just right [] Too long []

8. What did you like best about the programme?

9. What did you like least about the programme?

10. What are your views on relatives and staff attending the same training sessions e.g. did you find it prohibitive or enlightening?

11. Do you feel more confident in working with and supporting relatives?

Yes []

No []

12. In what way(s) has training influenced the way you now deal with people who have dementia?

- In general

- At end stage care

13. To what extent would you recommend others with similar needs to your own to attend this programme?

Fully

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all

14. To what extent will the knowledge/skills you have learned from the programme be useful to you in your place of work?

Very useful

6	5	4	3	2	1
---	---	---	---	---	---

 Not at all useful

In what way?

22. Has this training obligation been difficult for your care home to commit to?

Yes []

No []

Comments:

23. Have you been paid to attend or are you attending in your own time?

Yes []

No []

Comments:

About you

Are you: Male | Female |

What age group are you in?

20 -30 [] 31 - 40 [] 41 - 50 [] 51 - 60 [] over 60 []

What is your job title?

How long have you worked in the area of care of the elderly?

How long have you worked in your present facility?

Do you have a recognised nursing qualification (please specify)?

Please indicate your ethnic origin

- | | | |
|--|---|--|
| <input type="checkbox"/> Indian | <input type="checkbox"/> White – Scottish | <input type="checkbox"/> Mixed background |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> White – Irish | <input type="checkbox"/> I do not wish to declare this |
| <input type="checkbox"/> Pakistani | <input type="checkbox"/> White – Other British | |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Other White Background | <input type="checkbox"/> Any other ethnic group |
| <input type="checkbox"/> White Caribbean | <input type="checkbox"/> Other Black Background | Please indicate group below |
| <input type="checkbox"/> Black Caribbean | <input type="checkbox"/> Other Asian Background | |

Please make comments on how the programme could be improved or any comments you feel may be relevant to this evaluation.

Thank you for taking the time to complete this questionnaire.

Please return this questionnaire to the presenter at the end of the final session

Beyond Barriers: Action Learning Evaluation - STAFF

Thank you for attending the 'Beyond Barriers: Education Programme'. We hope you have benefited from participation in this event. In order to ensure continued success with future programmes, we would be pleased if you would take the time to complete the questions below.

Where scoring ranges are given, please circle the score that most closely represents your views. The other questions require you to tick an appropriate box or to give written comments.

Action Learning Days

1. Were you able to take part in the Action Learning Days?

Yes [] No []

If not , why not?

2. How would you rate the Action Learning Days part of the programme?

Very useful

6	5	4	3	2	1
---	---	---	---	---	---

 less useful

3. Do you feel the Action Learning sessions have enabled you to take forward, in an effective way, some of the points you have learned in the education programme?

Yes [] No []

4. What did you like best about the Action learning Days programme?

5. What did you like least about the Action Learning Days programme?

6. What barriers do you see in implementing training in your work place?

7. Has the length of training been difficult for your care home to commit to?

Yes []

No []

Comments:

8. Have you been paid to attend or are you attending in your own time?

Yes []

No []

Comments:

About you

Are you: Male | Female |

What age group are you in?

20 -30 [] 31 - 40 [] 41 - 50 [] 51 - 60 [] over 60 []

What is your job title?

How long have you worked in the area of care of the elderly?

How long have you worked in your present facility?

Do you have a recognised nursing qualification (please specify)?

Do you have an SVQ qualification? (Please specify) -

Do you have English as your first language?

Yes [] No []

If 'NO':

Were you able to participate fully in the programme?

Fully participate [] Partially participate [] Could not participate at all []

Please indicate your ethnic origin

- | | | |
|--|---|--|
| <input type="checkbox"/> Indian | <input type="checkbox"/> White – Scottish | <input type="checkbox"/> Mixed background |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> White – Irish | <input type="checkbox"/> I do not wish to declare this |
| <input type="checkbox"/> Pakistani | <input type="checkbox"/> White – Other British | |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Other White Background | <input type="checkbox"/> Any other ethnic group |
| <input type="checkbox"/> White Caribbean | <input type="checkbox"/> Other Black Background | Please indicate group below |
| <input type="checkbox"/> Black Caribbean | <input type="checkbox"/> Other Asian Background | |

Please make comments on how the Action Learning part of the programme could be improved or any comments you feel may be relevant to this evaluation.

Thank you for taking the time to complete this questionnaire.

Please return this questionnaire to the presenter at the end of the final session.

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