Beyond Barriers

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

An Alzheimer Scotland Partnership Project

'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

'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

principles into practice network

Winner of Principles into Practice Award 2009

Alzheimer Scotland

Action on Dementia

Introduction

The Alzheimer Scotland Beyond Barriers Project set out to develop current care practice in care homes by supporting both staff and relatives to meet the palliative care needs of people in the later stages of dementia.

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

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.

The link between a palliative care approach and dementia is a fairly recent one and for many care staff the 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 and empowerment.

This report summarises the impact of the Beyond Barriers project and the learning from it. The full project and evaluation reports will be available at:

www.alzscot.org/pages/beyond-barriers-palliative-care-report.htm [1]

Background

The acknowledgement that dementia is a life-limiting illness requiring a palliative care approach is relatively recent. In 1998 Hall described underpinning principles of palliative care and dementia including sensitive communication, quality of life, a whole person approach, respect for autonomy and care of the person and their family.[2]

One in three people can expect to die with dementia.[3] Quality of life and the eventual dying process for people in the later stages of the disease are arguably neglected areas of dementia care. An earlier study by Alzheimer Scotland found that some settings were more successful at meeting physical care needs than others, but meeting emotional, spiritual and social needs and providing a sense of purpose for living were difficult to achieve across all settings. 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. Discussions with family around end of life choices and preferences were very limited and restricted to the very terminal phase of the illness. One finding of the study was the need for support and education for care home staff.[4]

Support of a palliative nature is necessary right the way through the illness until the eventual bereavement. The long trajectory to death[5] and the difficulties in diagnosing dying[6] increase the challenges in ensuring a palliative approach to care for people with dementia.

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

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.[7] 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.[8]

The Review of Palliative Care Services in Scotland by Audit Scotland in August 2008[9] 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*[10], 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 Beyond Barriers Project

'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 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 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 guided by a reference group of experts in palliative care, dementia and the care home sector.

Following a pilot course, all registered care homes for older people in Scotland were invited to take part. 460 responded positively and 85 staff from 55 homes participated, together with 46 relatives.

'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*

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*

Training alone will not necessarily bring about a long-term change in practice; the second component of the project was five half-day support sessions in the form of an action learning set* for staff.

These sessions were attended by about half the original group. For those who took part the Action Learning Sets proved very rewarding and a very effective way of learning. Staff brought a range of issues to the sessions which were often directly related to the course. Using action learning techniques the sets were able to take issues forward and either enable changes

*Action learning is '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'. (McGill I, Brockbank A, 2006. *The Action Learning Handbook*. Routledge Falmer)

in practice or help support the individual to find a solution to a problem.

Staff participating in the action learning became more self-assured and learned to think issues though 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 members' 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

The involvement of relatives

'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 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

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 stop visiting at all, and some who continue to visit find it difficult to communicate.

The programme aimed to address this and to ensure that the importance of relatives' unique contribution to enhancing quality of life was 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.

One relative described how he visited 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, instead of just wiping them he used it as an opportunity to massage them. He was surprised and delighted when she started to rub his hands and smile at him.

The course was developed to use the experiences of both staff and relatives as a learning tool. Seeing things from a different perspective was a powerful experience for both staff and relatives. Relatives' views were the catalyst for many of the changes the care homes made and for increased awareness and understanding of relatives' needs.

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

'[I have gained] a better understanding of what the future holds for my mother and myself' *Relative*

Outcomes of Beyond Barriers

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 relative's 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.

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 tool[11] (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

Many of the ideas generated around improving the quality of life 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 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.

Conclusion

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 both to be rewarding for relatives and to bring a positive and lasting change in practice and in relationships. The external evaluation by Dementia Services Development Centre found many benefits to both staff and relatives and recommended that the programme should be available to all care homes.

The outcomes of the project show the benefits of addressing palliative care for people with dementia as a specific area with distinct features which make it different from generic palliative care, in particular issues of communication, capacity and the management of pain.

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 which could benefit from this approach.

The future: Alzheimer Scotland Palliative Care Initiative

The work of the Beyond Barriers project 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[12]. 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

- **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.**

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Members of the Alzheimer Scotland Beyond Barriers Project Reference Group

Iain Buchan, Chairman, Scottish Care, Dumfries and Galloway Branch

Colm Cunningham, Director of Operations, Dementia Service Development Centre, University of Stirling

Belinda Dewar, Nurse Consultant for Care Homes for Older People, Care Commission [to November 2008]

Kate Fearnley, Director of Personalisation, Alzheimer Scotland

Dr Katherine Froggatt, Senior Lecturer, Institute for Health Research, Lancaster University

Anne Macarthur, Carer Representative

Dr Lindsay Martin, Palliative Care Consultant, NHS Dumfries and Galloway

Elaine MacLean, Palliative Care Advisor, Care Commission

Isobel Pennie, Coordinator, Hospice As a Resource for Palliative Care Services (HARPS), Marie Curie Hospice, Glasgow

Susan Polding-Clyde, Nurse Consultant, Care Commission [from November 2008]

Pat Wallace, Director, Scottish Partnership for Palliative Care

Stephen Smith, Lead Nurse, Leadership in Compassionate Care Project, Napier University / NHS Lothian

Daniel Stoddart, Learning and Development Advisor, Scottish Social Services Council

The Beyond Barriers Education Course

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 (PAL) tool[13]

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

Communication and relatives

- relatives' role and needs
- making visiting a good experience
- loss and bereavement
- receiving and making complaints

This summary is based on the full report written by Jenny Henderson, Lead Field Worker, Alzheimer Scotland.

'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*

care commission

The Dementia Services Development Centre

Alzheimer Scotland
Action on Dementia

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