



Spiritual Care for People with Dementia in Care Homes

The Purple Bicycle Project

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BIOGRAPHIES

HARRIET MOWAT

Harriet Mowat has spent much of her professional life working with and thinking about the care of older people. She worked as a care attendant and nursing assistant as a young woman and then after a PhD in social administration from Edinburgh University, became an academic member of staff at a variety of universities north of the border. Each academic post allowed her to focus more particularly on the spiritual care of older people. The last few years of her working life were spent in running a small research and development business and it was during this time that she mainly worked with health care chaplains, care staff in old age homes and conducted a number of projects with Professor John Swinton via Aberdeen University. She has recently published a book "Freedom of years" BRF 2017 with her husband Donald. She has now retired and apart from the odd lecture or away day, spends her time practicing what she has preached, trying to grow older in a good spirit.

MAUREEN O'NEILL

Maureen O'Neill was Project Co-ordinator for this Life Changes Trust project. Maureen has been the Director of Faith in Older People since 2007. She was previously the Director of Age Concern Scotland (now AGE Scotland), She has served as a board member on a variety of voluntary sector organisations concerned with homelessness, alcohol related problems, mental health and poverty. Maureen served as a UK appointee to the European Economic and Social Committee in which she was the President of the Social Affairs Section and is currently the Chairperson of an independent care home for older people. She was awarded the OBE in 2019 for services to older people and the voluntary sector.

LYNDA WRIGHT

After 11 years in parish ministry as a Church of Scotland Deacon and three years leading programmes for guests at the Abbey on Iona for the Iona Community, Lynda set up and ran a small retreat centre in Fife for 18 years. During this time, she led many retreats based on the Enneagram model of understanding personality and became increasingly convinced of its value in contributing to our understanding of ourselves and others. For the last eight years, Lynda has been a member of the Spiritual Care Team for NHS Fife, specialising in Care of the Elderly. Lynda facilitated the working sessions on the Enneagram.

Introduction

This report describes the workshops designed for care homes around the Purple Bicycle approach. This practical approach was part of a two year project funded by the Life Changes Trust on 'Spiritual Care for People with Dementia in Care Homes'. It is helpful to read the reports of the two elements in tandem to get a strong understanding of the potential for the development of spiritual care. *De-mystifying Spiritual Care* is an exploration of the understanding and delivery of spiritual care in care homes (Simon Jaquet).

The Purple Bicycle approach is aimed at enabling spiritual journeys for people with dementia. In constructing this collaborative project, it was important to combine the research element with practice. This offered a creative approach to the complex topic of spiritual care for people with dementia in care homes and engaged staff in exploring both their own spiritual needs, how they felt about ageing, and different ways of engaging with those experiencing dementia, their family and friends.

Since its inception in 2007 Faith in Older People (FiOP) has worked extensively with health and social care staff to fulfil its aim of 'developing a better understanding of the importance of the spiritual dimension to the well-being of older people'. During this time, it has undertaken an action research project on identifying the training needs of staff in residential care (Delivery Spiritual Care: Harriet Mowat 2009). It has undertaken a project to address the spiritual care needs of older people in care homes (Helen Welsh 2015), and an appreciative enquiry into spiritual care delivery in NHS complex care units (Ruth Aird and Maureen O'Neill). It also produced an issue of Insights for IRISS on 'Spirituality and Ageing: implications for the care and support of older people' (Harriet Mowat and Maureen O'Neill 2013). In 2018 FiOP produced a 'Care Cameo: Spiritual Care is Everyone's Business' for Scottish Care (Lesley Greenaway, Simon Jaquet and Maureen O'Neill.)

Over this period, it has also provided training and education for care homes on spiritual care with an emphasis on people experiencing dementia.

We wish to thank the following participants:

Cameron House Care Home

Clarkston Care Home

Clashfarquhar Care Home

Elder Homes (Cluny Lodge and Chamberlain)

Marion House

St Andrew's Church Carluke

Walker Health Care



Background

In September 2017 a small Edinburgh based charity Faith in Older People (FIOP) was awarded funding by the Life Changes Trust (LCT) to both investigate and put into practice the delivery of spiritual care in residential care for older people. The emphasis was on caring for those living with dementia.

The Life Changes Trust commissioned a two- year project from a consortium of four organisations (Faith in Older People, University of Aberdeen, Simon Jaquet Consultancy Services Ltd, and Mowat Research). The project aimed to improve the quality of life of people living with dementia in care homes in Scotland - by increasing our understanding of the role of spirituality, faith, and religion in their lives, and by encouraging the provision of an environment that actively worked to lift the spirits of those with dementia and their relatives.

This was a creative approach to the complex topic of spiritual care, attempting to combine research- based practice (The Purple Bicycle project) with a mapping exercise of current attitudes to and practices of spiritual care in residential homes in Scotland. The intention was that each arm of the project would learn from the other and that the ideal of applying research to practice could be furthered.

The Mapping Exercise

The aim of the research element was to explore and describe the key ways in which residential care providers in Scotland are currently delivering spiritual care to people living with dementia and to map the scale and nature of spiritual care work (across the faith communities in Scotland) with people living with dementia in care homes.

A full report of this mapping research *De-mystifying Spiritual Care* (Simon Jaquet) which combined qualitative and quantitative methods should be read as a companion to this report. The report you are reading at the moment focuses on the practice of spiritual care and shows how the research findings fed into the evolving training and development work.

Both arms of the project were seen as having the potential to help families and carers of people living with dementia in care homes have a better understanding the spiritual needs and aspirations of their loved ones as well as of themselves.

We believe this is a fine example of linking research and practice. We have identified the links throughout this report.

The Purple Bicycle: spiritual care in practice



“If it takes a village to bring up a child, it also takes a community to look after vulnerable older people”. (A.A. Gill)

The Purple Bicycle (PB) Project is a person- centred spiritual care resource developed by Professor John Swinton and Dr Harriet Mowat at the University of Aberdeen. The Purple Bicycle project has developed over a period of time as a result of several layers of action research which have helped refine and improve it. It was originally funded by the United Kingdom Arts and Humanities Research Council.

It came to be called Purple Bicycle because the practice involved suggests the idea of movement, change and journeying together towards a new place where we can all enjoy and delight in life. The image of the rather wobbly tandem conveys the uncertainty of the future direction of travel and of who is leading whom. It calls up the fragility of life. The colour purple is both soothing and striking and can be a reference to wisdom and maturity.

The Purple Bicycle project is a step by step way of helping our most vulnerable elderly people living in residential settings to feel they belong. To be included you just need to be in the room; *to belong you need to be missed if you are not there*. The approach enables a sense of belonging by sharing stories, lifting spirits and encouraging hopeful attitudes.

The Purple Bicycle project gives the person with dementia, carers, relatives and friends an opportunity to review and sustain relationships that are meaningful and sincere. It provides guidance and support for those involved in care for older people with dementia.

The Purple Bicycle project brings together caring practices that are often found individually within organisations that care for older people. Its unique contribution is that these practices are presented as a linked and coherent expression of care and concern for the spiritual lives of people with dementia. It also assists relatives and friends who are sometimes at a loss as to how best to visit and support the person living with dementia.

The Purple Bicycle is an approach to spiritual care. It consists of a purposeful six step process which we have called a journey. This journey is travelled by people with dementia alongside those who love and care for them.

The Six Steps

STEP 1 Building the Picture

STEP 2 Finding an Attentive Community

STEP 3 Gathering Stories

STEP 4 Reflecting on the Stories

STEP 5 Making a Spiritual Plan

STEP 6 Reflecting, Reviewing, Revisiting

These steps involve gathering together a group of friends or relatives and staff around the person living with dementia who are able to tell good stories about the person to try and identify who the person is and what matters to them. These are not just reminiscence stories, but the purpose is to try to get at the values and supports that the person has drawn on through their life. The stories are then thought about and those aspects of the stories that seem to have been particularly important to the person with dementia are identified. These aspects are then turned into spiritual care practice.

These stories help the group understand the person and what is important to them in terms of meaning and purpose of their lives. For example, someone who has always been a church goer might be sadly missing the liturgy from their Sunday services. Someone else who has not had a religious background at all might have spent many years walking the hills and particularly enjoying their garden. For each of these people the story needs to be told, heard and shared so that some of the enjoyments and meaning from these practices can be converted into helpful and meaningful practices in the home setting. The person who has walked the hills for years will no longer be able to do that but they might enjoy watching films, looking at pictures or hearing sounds that remind them of these times and that trigger some joyful memories. Similarly the person who has always gone to a church service might enjoy and value hearing some of the liturgy on a Sunday perhaps as a recording. These informed spiritual practices are not complex, but they do require interpretive thinking around the stories.

The Purple Bicycle Project is a resource for all, not just for those who belong to a Faith Community. As such, it can and should be used as part of daily care practice rather than an additional “activity” for people interested in “such things.”

The version of the resource we used in this project has been designed primarily to support people with established dementia. By this we mean **people who are beginning to lose their verbal ability to tell their story and who need others to help them to tell their stories well.**

All people with dementia can be the beneficiaries of spiritual attention and we know that as the disease progresses attending to people’s spiritual needs becomes more complex and requires more time and watchfulness.

“Waiting with” and “being alongside” people are acts of spiritual care. These spiritual care practices have meaning and purpose in that they form the basis of compassionate relationships one with the other.

Living in the present moment is a skill and a gift that is central to caring with and for people with dementia.

The Purple Bicycle Project draws on such practices to provide a structured approach that helps *all of us* together to recognise and respond to the needs of people living with dementia.

More information about the Purple Bicycle workshop process can be obtained from Faith in Older People.

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In Simon Jaquet’s mapping research *De-Mystifying Spiritual Care* he shows that the notion of spiritual care is still poorly understood. Most respondents in his study understood ‘spiritual’ as the same as religious. One of the tasks of this combined research into practice study was to find ways of overcoming the rather narrow and therefore limiting way in which religion and spirituality are understood. We wanted to show that spiritual care is at the heart of all good care. Whether or not we adhere to a religion we are all spiritual beings in the sense that we seek meaning and purpose to our lives. Indeed, we would go further and assert that good spiritual care is the precondition for all other kinds of caring relationship.

Person centred care is now a key aspiration of health and social care services and organisations. This can only be accomplished if compassion and dignity are encouraged. Spiritual care is the cornerstone of person- centred care.

A Historical Perspective

The work reported here resides and emerges in a wider socio- economic context of course. It is helpful to rehearse this and remind ourselves that we are part of a wider, longer journey towards greatly improved care for very frail older people.

Residential care has historically been as a last resort. Peter Townsend’s research *The Last Refuge* acted as a wake- up call to the conditions in residential care post war. Townsend showed how the poor house had segued into the local authority provision for older people retaining its judgemental and charitable purview. Townsend’s work prompted several important and influential research studies and together these influenced social policy.

At the same time there was focus on the nature of institutional life and the power of the institution to degrade and dehumanise individuals. In particular, Irwin Goffman's seminal work "Asylums" showed how easy it is to treat vulnerable people in groups badly. Consequently, in the 60's and 70's there was social policy reaction against institutional care, the shutting of many psychiatric care facilities and a move towards community care. There was also experimentation with different types of community living. By the time the 1990 Community Care Act was passed living independently in one's own home was the primary goal, care by family and friends and community was written into law, and residential care was established firmly as a Cinderella service; meaning poor funding, poor training for staff and poor social value ascribed by society.

It is no coincidence that we have, at the same time, moved away from the model of religious community with its routines and rituals. It was of course religious community living which foretold hospice style care to which we are now trying to return. The church led the way in challenging the view of undeserving poor elderly and the Christian values of charity, love and hope acted as an antidote to the industrialisation values of productivity and value linked to economic worth. Neither side provided perfect models and the warring factions within the church with their differences of opinion about undeserving and deserving individuals, labour and productivity, all played a part in contributing to the current situation of residential care of older people.

The Current Context

Despite all the warnings of an ageing population we seem to have been taken by surprise at a policy level and at a personal level. Our parents are living longer. "Child" carers are now often well into their 60's and 70's of people who are living into their 90's and 100's. The longer we live the more likely we are to suffer the vicissitudes of age which includes cognitive decline. Extended morbidity means that the ageing population will demand the greater share of the welfare provisions. This breeds resentments. The meaning of ageing is unclear to those who do not see themselves as ageing. The increasing number of those in the fourth age, where activities of daily living are challenging, has not been accompanied by an increasing consideration of funding, support and meaning and purpose of later life. We are just now starting to catch on to the challenge of ageing.

The recognition of dementia as a mental illness rather than an inevitable condition accompanying ageing, and the increasing focus on care and potential treatments has propelled those living with and caring for people with dementia into a more prominent position. This hasn't alleviated the fears over dementia, but it has shone a light on the need for good compassionate care for those who are unable to care for themselves and this higher profile has led to very good work and research in a variety of areas.

The Commitment to Excellent Care

Whilst appreciating that older people would prefer to stay in their own home there is an obvious need to develop and sustain good residential care for those who simply cannot

manage at home. It is now recognised by the Scottish Government that part of that good care includes developing a stronger understanding of what is important to these very frail relatives and providing them with person centred care. Eliciting and acting upon the way in which individuals make meaning out of their situations is to respond to their spiritual needs. Trying to work with the spiritual needs of individuals would support a more comfortable and accepting transition as they take their journey into living with dementia.

The standard of care in residential homes increases and improves all the time. Staff are committed and well trained. It is a very hard job. Care staff are, on the whole, extraordinary people who are dedicated to the people they work and who go extra miles to help support their care home dwellers.

The work is hard physical work and at times emotionally very taxing. Staff are dealing with the rough end of ageing and death. Although staff would like to spend more time sitting with and being with residents, there is precious little time to do this. Often, staffing levels are a challenge. There is also, as there is in all caring professions, a pressure to record and form fill which takes time away from the primary work of caring for the older residents.

The Scottish Government has emphasised a human rights approach to health and social care which encompasses faith and spiritual care which are also highlighted in the Dementia Strategy and Palliative Care Delivery framework.

The work reported here resides within a context of growing awareness and concern about the way in which we care for our most vulnerable, and recognition that those with dementia are not separate from us but increasingly likely to *be* us.

What is spiritual care?

This stimulates thinking about what good spiritual care might look like.

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Spiritual care is the care of the spirit. The definition used in this work and in the mapping research is

'Spiritual Care involves developing a genuine relationship between individuals. Within this there is an acknowledgement that the clinical picture of dementia is not all that can and should be known, and that human lives are mysterious. There is more to living well than simply caring for our bodily needs. Spiritual care acknowledges the presence and importance of such things as joy, hope, meaning and purpose as well as the reality of disease, suffering, disappointment and death. This means that spiritual care is much broader than any one faith or religion, and is of relevance to everyone.'

Spiritual care is everybody's business and involves the acknowledgement that as we live our lives, we ponder our meaning and purpose and that as we grow older this pondering becomes more pressing. Good care acknowledges that even those with little capacity to

express this have these needs. Sharing the mystery of life is good spiritual care. This means that staff and relatives are also required to recognise the mysteries of life and to think in terms of meaning and purpose for themselves as well. Hence the idea of the tandem, the joint journey where one helps the other. This is a different way of thinking about caring relationships and one that is difficult to “train” or teach.

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Simon Jaquet’s report *De-mystifying Spiritual Care* p38. Clearly the way in which staff can be trained in spiritual care depends on their understanding of what it means and how it might apply to their situation. There are practical difficulties shown in the study that are around time constraints, the perception of the value of the training in spiritual care to the general running of the home; a doubt about the relevance and value of spiritual care to day to day practice. This is what might be called the “Added value” idea of spiritual care. Where spiritual care is viewed as something that can be added on if everything else is done. It is seen as an activity and disappointingly as something that can be recorded. This added “value model” does not address the fundamental re thinking required to develop caring relationships built on the mutual enquiry about purpose and meaning of life.

There are lots of creative and interesting practices, shown in the course of the mapping exercise, that happen at an individual level. There is not yet a movement to see spiritual care, the identification of sharing of meaning and purpose as basic to all care.

Core skills and values

- Help manage change
- Help retain identity
- Help sustain trust
- Help sustain hope
- Encourage belonging
- Afford dignity
- Offer as much freedom of choice as possible
- Foster the ability to notice things
- Be attentive
- Be open to wonder and mystery
- Make links between different stories
- Be able to hold the story for the other person

Focusing on the wider residential care community

Based on the mapping findings, the Purple Bicycle project tried to increasingly tap into what was already being done and build on that.

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In *De-mystifying Spiritual Care*, it became clear (p37) that there was real potential for the role of faith communities, both Christian and other faiths. There is a growing awareness amongst church congregations of the need for support for their ageing populations and according to the mapping survey 75% of all homes have some kind of nominal connections with local churches in the form of provision of religious services and pastoral support. However, the realisation of this support into action is often wanting. The mapping exercise recommended that there was more proactive recruitment of volunteers from faith communities locally so that there could be a growing relationship of mutual benefit, increasing the capacity of the local care home team to provide excellent care.

The Purple Bicycle process identified relatives, established volunteers and local church pastoral carers who were already interested in this kind of care and thought in this kind of way. We encouraged them to champion the spiritual care practices and, in some cases, join the Purple Bicycle workshops.

The details of the relationship, the commitment and safeguarding matters would all have to be discussed and established but the principle of more support from a wider community is a good one.

We found that training was easier in situ than removing staff to a residential “away” time. The question about the value of any kind of training is usually, is this going to make my life easier and are the goals of the organisation better met? The answer to this in the context of spiritual care is “probably not”. This is because focusing on the relationship and the story does mean more time is required and a re-prioritising of the importance of tasks. The goal of the organisation is often not just to provide good care but to provide it economically, adhering to health and safety regulations. Spiritual care as a foundation for good care makes no obvious impact on the bottom line. Trying to convince hard-pressed staff that it's worth taking two days out to learn about how to lift someone's spirits, when there are so many forms to fill, beds to make, meals to deliver and so on is a hard sell. It is therefore, as we have noted above, sometimes better to focus on the relatives and volunteers and “friends” to make the case. In this group priorities are different. This group of people can help the staff enormously if they are able to find a way to become part of the residential community.

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De-mystifying Spiritual Care suggested that whilst care home managers are open to the idea of training staff in spiritual care “there is such a pressure on homes, due to reducing budgets and unfilled posts which means that any new initiative related to spiritual care will need to be sensitively introduced if it is not to be regarded as yet another “scheme” imposed from the outside and making unreasonable demands on staff time and energies” (p38 9.22). Starting where the residential home staff are, supporting and encouraging them in current practice and enlisting help from trusted volunteers are two suggestions that come out of the mapping exercise.

Sustaining the spiritual conversation

- Spiritual talk only surfaces occasionally
- Have to learn to spot it and hold it until the next appearance
- Both formal sessions and informal “spontaneous” talk is important
- Stories and narrative help generate both the context of the spiritual and its meaning

The Purple bicycle workshops

What did we actually do?

The Purple Bicycle arm to the project undertook to train 60 people associated with care in residential homes across Scotland. The intention was to introduce the Purple Bicycle concepts as a series of steps and to encourage the participants to develop a specific plan based on the particular circumstances in the different homes. The outline action plans are reproduced in table form below. Following the workshop there was a period of reflection then action based on the plan which was reviewed at three months with support from the workshop leaders. The leaders were available for phone discussion, meet up or email exchange.

“I wasn’t really sure what to expect of the two days but have definitely been inspired by the insight into a way in to spiritual care.”

All participants received a workbook before the workshop which covered the nature of the Enneagram, the nature of dementia and the structure of the Purple Bicycle. As far as we could tell most participants had read the material before coming to the workshop.

The workshops ran over two days with sessions on ageing generally, the nature of living and working in residential care, the nature of spiritual care, what was happening already in each of the homes, a method of understanding each other called the Enneagram and then a full description of the Purple Bicycle programme. The workshops were interactive and dynamic in the sense that the leaders had the skills to focus on particular aspects of residential care that emerged as important to the participants.

The six workshops were all very particular in tone. The first two were held in an hotel setting and involved an overnight stay with collective meal , three were held in situ over two days in the residential homes and then the final one was held in a church hall.

The workshop format was more or less the same for each venue although some ideas evolved over the time of the training sessions. For instance we realised that having some greater context to the training and the way in which we think about ageing, helped the staff make the connection between themselves and their own ageing, which in turn helped them think about the ageing of their residents. Making a human link between self and other seemed to be the key to understanding the importance of the ageing journey and its spiritual nature. We therefore increasingly started and remained focused on the participants, their stories of ageing and their personal experience of caring before we moved on to the more general aspects of the PB. We also introduced the importance of story as a more determined heading and tried different ways to capture this as the workshops evolved. The use of the Enneagram model of personality which is both a psychological and spiritual tool was undoubtedly increasingly captivating for the staff.

The workshops were unanimously very well received. There were very few negative comments and on paper this was initially enormously encouraging for future commitment to the action plan.

[The various overheads and presentations that we used as well as the full evaluations received are available for review at FIOP]

The final question in the evaluations asked about follow-up learning and what participants thought they would benefit from next. There were a variety of responses here. These included:

- Follow up reading
- More about the Enneagram
- Another day later on to review what has been done

“The subject of faith in older people was clearly addressed. The 6 steps were very helpful. Also liked the Enneagram.”

Practical Issues

There were a number of practical issues which we dealt with in different ways.

1. Recruitment of staff to the training days:

Despite heroic efforts on the part of FIOF Director to find interested homes across Scotland the response was very poor. Given that this was a free opportunity to learn about spiritual care which most homes across Scotland acknowledge to be of importance and value, it is interesting that there was such little actual response despite email, mailed information with follow up telephone calls. The aim had been to involve care homes in different parts of Scotland but in the end recruitment took place through contacts and word of mouth.

2. Relationship between staff members. We noticed that in some instances the staff and volunteers did not necessarily know each other. Also that staff participants tended to come from across the staff body and particularly in the larger homes they worked in teams which did not always link up. Obviously, there were some who knew each other well. This prompted us to think about the nature of team work in the homes and how better knowledge of each other and how teams work might help think about a collective approach to spiritual care. It also allowed us to think in terms of teams including volunteers and relatives and friends. The work with the Enneagram conducted by Linda Wright proved to be extremely useful and showed that a little insight into oneself and one's own ageing helped understand the behaviour of others. We found that helping the staff think of themselves as teams lead to creative ways of thinking.

3. Misunderstanding/understanding of spiritual care as all about religion. This dominated the first day of all the workshop sessions and learning from mapping results we started with the staff's own understanding of spiritual and worked with that. We developed tactile ways of talking about what lifts spirits through the use of photographs and materials and found that the staff were able to relate well to these questions.

4. The use of time. It was to be expected that staff saw themselves as very busy and task oriented. They were encouraged to see the spiritual care as integral to the person-centred care approach rather than add-on but they found this hard. We tried to avoid the idea that spiritual care was an activity like singing or painting. Singing and painting can encourage spiritual thought and care. Many of them noted that they had never been in a workshop of this nature before where their opinions and practices were discussed in such detail. There was no right answer and no test at the end to see if they had "passed". All this was new to most of the staff involved.

The basis of the Purple Bicycle is to highlight ways in which good stories about residents could be drawn on to try and understand present wishes and to instigate ways of lifting spirits and providing a stimulus to meaning and purpose. We found that urging them to gather and record stories on behalf of their residents, whilst stimulating their thinking and

enthusiasms, in reality seemed quite a hard thing to do. Staff were already full of stories of their residents – this was not the problem – the problem was knowing how to tell others, how to extract the key aspects of a story and to turn this knowledge into loving spiritual care practice that could lift spirits and transform difficult moments.

5. Action plans. The last section of the workshop two days was to invite the participants to reflect upon what they had heard and learnt and then as a team devise a plan of action for their residential care organisation that might use some of these ideas and integrate them with what was already happening. These action plan sessions improved as the workshops progressed. The staff team were asked to develop an action plan at the end of the workshop. It was realised that this was a crucial element. A facilitated discussion drew on knowledge about the home and the feedback from the workshop sessions. The action plans were recorded and sent to each of the homes following the workshop.

Table of the action plans

Home 1	Home 2	Home 3	Home 4	Home 5	Home 6
Christian ethos. Church of Scotland: mixture of senior staff, care workers and volunteers	Care Staff, activities co-ordinator and senior staff	Church based group hosted by St Andrews. Spouses of people with dementia, church congregation members, minister	Care staff and manager	Care staff, manager and general volunteers not connected to the home.	Senior staff and care staff
Plan	Plan	Plan	Plan	Plan	Plan
Work with one identified resident using the PB steps. Roll out	“For the residents to be the best they can be. Developing a community of care and wellbeing”. Start with PB steps – develop staff awareness	Build relationship with care homes by helping congregation understand the importance of story and lifting spirits.	Using PB steps develop ‘life history’ and ask family and friends to contribute	Clarify what is already going on and what skills are available in the workshop group. Develop a booklet. Work with volunteers. Facilitate a well-being group.	Work with three residents. Use the PB steps generate stories. Monthly meeting to consider what actions from stories.

Key themes

There are some key generalisable themes that emerged from the plans which are helpful perhaps in identifying follow up training needs.

1. Find ways of transmitting/communicating the story of the resident to all staff

These ideas included:

- A Purple Bicycle style of 'what lifts your spirits' page in the notes available to all staff.
- Having a specific book for each resident into which insights and discussions can be written.
- Put something like a notice board in the individual's room with comments and pictures on it.
- A Purple Bicycle Box – like a memory box but which reflects what matters to the individual in terms of lifting their spirits.

“Be able to pass on the story and to help integrate it into the community of living.”

2. Make spiritual well-being a recognised concept which is fundamental to good care. This was the most difficult challenge recognised by the workshop participants. How do you recognise spiritual need and how do you make it ok to mention it and act upon it in the current residential care environment. Given the generalised misunderstanding that religion and spirituality are the same thing, there is a lot of work to be done with the staff to tease out the differences. The Purple Bicycle workshops and the mapping exercise are a part of this process. One suggestion was to form a well being group and to continue the discussion in this group. It was acknowledged that senior staff needed to model the spiritual care behaviour.

3. Use the same space differently. There was a general issue for most of the homes with lack of space to be creative and a lack of creativity about use of space. One home in particular had very limited space with difficult access to outside. Having interior designer advice might be very helpful.

4. Work with people moving in to the residential home and their family. This group of people were seen as particularly accessible at the beginning of their journey into residential care. Families were concerned to do the best for them and the PB model was an obvious one in which families and friends could be involved.

5. Ensure that church/faith visitors are well versed in the workings of the residential care home and can work with the home staff

6. Be aware of what is already going on: there is always good spiritual care going on but it is rarely called that. Being more aware of what is already happening feeds in tot an atmosphere and philosophy of spiritual care.

“Being a spiritual team.”

Implementation and Follow up

Following the end of the workshop the Director of Faith in Older People wrote up the notes and sent a comprehensive account of the workshop, group work, enneagram spread and action plan to the care home.

The implementation of the plans was the least successful part of the project. The return to the “real” world of residential care deflated some of the enthusiasms seen in the workshops. Days off, sick staff, uncommunicative teams, discontented employees, very frail and declining residents meant that best and very well intentioned laid plans went awry. The immediacy of the care needs confronting the staff as they returned with excitement and the resistance to change conspired to make the final stage less hopeful. We know that the conservative staff in any organisation tend to reduce the impact of new training so that new ideas become watered down or ignored. If there is no mandatory requirement for a particular set of practices, such as safe guarding or moving and handling or hygiene there is a pull towards doing nothing. This PB workshop training was intended to show things differently and to link this to doing things differently. To that extent it is a beginning of a journey but certainly not a completed ambition. Changing ideas is much harder than changing specific practice.

Spiritual care is about acknowledging that each and every one of us has a spirit that needs lifting and nurturing if we are to flourish. It is basic to our relationships one to the other. The current climate of overstretch and busyness endangers the meaning of care and potentially reduces it to a set of achievable outcomes rather than a relationship.

The workshop leaders offered extra support, over and above the contracted support, and were available by telephone or email. However, despite these offers there was very little feedback and no appetite for an extra meeting. Overtures for visits or more help were not taken up for a variety of reasons and enthusiasms waned over a period of time.

It certainly seemed that although the staff left enthusiastic and encouraged they were soon thrust back into the realities of delivering care in challenging circumstances. So it is important to see these workshops and the combined research and practice project, described here as part of a journey, rather than a conclusive destination.

The general findings are:

- Spiritual care is often misunderstood as being only “about religion”
- Demystifying this perception is an important task when trying to provide excellent care for older people and those who are experiencing dementia
- Central to excellent care includes as the acknowledgement that we are all seeking meaning and purpose in our lives and that this search is a spiritual matter
- Very good spiritual care practice is evident across the sector although it is often **not** named as spiritual care
- Spiritual care is not seen as an essential part of the daily work of the staff providing care although it is often given unconsciously
- Great interest is shown by staff in the way in which spiritual care can be practiced and the benefit to their own well-being
- There are creative and exciting ways of including relatives and friends and volunteers in a spiritual care approach

Discussion

Reflection

We offered the workshop participants a simple reflective process by which they could think about what they were trying to implement. We have used these headings below to reflect upon the project.

What good things have happened during this project?

The mapping exercise and the qualitative interviews that fell out of it have been most enlightening and provided a really good underpinning of the work that has been going on for some time. The continued misunderstanding of spirituality as only religious practice is highlighted and the findings in the mapping have far reaching implications.

There have been some very important personal insights gained by the workshop participants and it is clear from the evaluations that this topic of spiritual care is of great interest to those who are wanting to improve their caring practice. Making the connection between the ageing of the residents and the care staff's own ageing has been a fruitful starting point for discussion of spiritual need.

The introduction of the Enneagram as a support to the Purple Bicycle process has been very successful. The Enneagram is clearly a useful way to help staff think about their spiritual caring role. The staff groups were fully engaged in listening to and learning about the enneagram.

The concepts of third and fourth age have been very helpful to the workshop participants and the understanding that the group of people they care for have particular needs and difficulties has been reinforced. It is also the case that this is a small group of people relative to the population as a whole. The staff knew that their own role was an important one and shone a light on how we can care for our most vulnerable.

What has been surprising?

Despite this project being carried out within a wider context where spiritual care in health and social care is gaining some traction, there is still very little practical interest in making the spiritual care of older people fundamental to the caring task.

The contrast between the enthusiasm within the workshop groups and the lack of follow up response thereafter was puzzling but knowledge of social care and its pressures explains it to some extent.

This is in some way linked to the original difficulty of getting homes and staff within them to come on the workshop in the first place. Again, a free course, offered by experts in the field might have been expected to attract care home owners and managers. Once they were at the workshop, they undoubtedly benefited but the recruitment process was difficult.

How has your understanding of spiritual care been influenced by your practices?

The definition of spiritual care that we used in the mapping exercise and in the Purple Bicycle practical steps remains a good one. We increasingly understand that spiritual care is present in many relationships within the residential care setting but that it is not necessarily called that. A more explicit understanding that we all have spiritual needs; to feel loved, have purpose and meaning and to belong are the basis of good relationships and good residential care. These should be the values by which homes are managed.

What might you try next?

We would want to actively encourage the dissemination of the Purple Bicycle to volunteers in church and other faith congregations and amongst relatives and friends who are often looking for a way of being (and belonging) within their relative's home. This seems to be the best way to develop a community of care with an emphasis on spiritual well being and lifting spirits. As a national organisation Faith in Older People has the obvious central role in doing this work.

LINK



In *De-mystifying Spiritual Care* (Simon Jaquet) (p40) it is recommended that the Scottish Government should recognise the importance of including the spiritual dimension in policies affecting older people and ensure consistent implementation across relevant policy areas. This should include the active involvement of the faith communities in policy and implementation debate.

We feel that open discussion with church communities and other faith communities will yield much good will and provide a "work force" who will be glad to work with care home managers to help provide a spiritual perspective. There are barriers to break down in both settings which will pave the way for more person centred approaches to care.

The basis of good care and all good relationships is to honour the spiritual dimension in the other person and to recognise that we are more than our illnesses and declining bodies. We are all spiritual beings looking to make sense of life's difficulties through finding meaning and purpose in our lives. Each person is unique and searches in unique ways through their own story. Our role as carers to each other is to help each other with this search.

Outcomes

In the original proposal we identified five groups who would benefit from this work.

- People living with dementia
- Family and carers of people living with dementia
- Faith communities
- Residential care home staff, managers and workers
- Policy makers at local and national government levels

People living with dementia will be able to have their spiritual needs and aspirations acknowledged and actively pursued.

We have shown in this project that the spiritual needs of people, even with advanced dementia can be elicited through story and acted upon in order to lift the spirits of those involved.

Families and carers of people living with dementia will better understand the spiritual needs and aspirations of their loved ones.

We have shown that the workshop training and subsequent engagement with staff and relatives has encouraged new ways of understanding and acting upon the needs of people with dementia in their care.

Faith communities will be better equipped to engage with the care home sector in providing spiritual support to people living with dementia

We have shown that the workshop training helps people in church congregations to understand the process of dementia and the idea of spiritual care better and stimulates them to think about fresh and relevant ways of engaging with people who live in residential care.

Residential care home staff will be better equipped to understand and meet the spiritual needs and aspirations of people in their care.

There is no doubt that care home staff enjoyed, learnt and developed their thinking and practice around spiritual care and its value to the quality of life for the people they cared for. They were able to identify clearly the nature of spiritual care and the practice that might lead to the lifting of spirits and therefore the improvement in quality of life.

Policy makers will be better enabled to develop appropriate policy that takes account of the spiritual needs and aspirations of people with dementia.

We hope that this work will encourage further emphasis on the importance of spiritual care and build on the human rights approach already evident in the Scottish Government policy.

Recommendations

- That the Scottish Government should recognise the importance of including the spiritual dimension in the policies relating to older people and ensure consistent implementation across relevant policy areas. This should include the active involvement of faith communities in policy and implementation debate.
- There needs to be a much stronger emphasis in the training of health and social care staff on spiritual care which would greatly enhance the ability of hard-pressed homes to provide a spiritual care approach.
- The tried and tested six step Purple Bicycle approach to eliciting and forming an action plan is workable and valuable and there is the potential to incorporate it in training and the development of spiritual care plans.
- That there needs to be much more discussion and collaboration between faith groups and residential homes about spiritual care to ensure that those of faith can continue to practice it with support. That care homes ensure the inclusion of friends and relatives in eliciting the individual resident's spiritual care needs which can provide a fulfilling focus for both parties.

(Further information referred to in the text can be obtained from Faith in Older People)

Voicing the spiritual: Checklist

- Are you making time to have conversations?
- Do you know everybody's name?
- Can you say something about all the people you work with in terms of their life experiences or background?
- Are you telling people about your own experiences?
- Can you remember something about previous conversations with this group/this person?
- Have you eaten a meal, shared food or drink with this group/this person recently?
- Have you exchanged photos or tokens with this person or group?
- Is there prayer in your relationship with this person or this group?
- What is the easiest context in which to connect with this person or group?
- How are you helping this person/this group with their spiritual lives?

Summary and Conclusions

This report along with the mapping exercise, *De-mystifying Spiritual Care*, which accompanies it, has sought to describe and explain and put into practice the recognition of the spiritual nature of care and the importance of good relationships between cared for and carer.

The two arms of this project have worked together to provide information from surveys which has fed into the practice and the workshop content.



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