'De-mystifying spiritual care'

An exploration of the spiritual care of
people living with dementia
in care homes

January 2018

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Contents

"We need to de-mystify the word 'spiritual'.
People say 'Oh I don't believe in this', but
it's a broader and wider thing."

Care home manager

1 Introduction

1.1 This report describes the research dimension of a 2 year project funded by the Life Changes Trust and running between 2016 and 2018.

Faith in Older People

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

1.3 This current project builds on this experience with the Purple Bicycle Project which is a key element of this current LCT project. Through workshops we are providing guidance to a step approach to involving people experiencing dementia, their family and friends to enhance understanding of their specific spiritual care needs and the inclusion of those who support them in enabling them to be met.

1.4 We have also developed an eLearning course for care home staff to encourage their understanding of spiritual care. This is currently being widely disseminated.

The research project

1.5 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. For the purposes of this project, we used the definition of spiritual care (used by the Purple Bicycle Project[1]).

> '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.'

1.6 The first stage of the work was a research study to explore and describe the key ways in which residential care providers are currently delivering spiritual care to people living with dementia. The aim of the research was to map the scale and

[1] https://www.abdn.ac.uk/sdhp/documents/TPBP_Booklet_1.pdf

nature of spiritual care work (across the faith communities in Scotland) with people living with dementia in care homes.

1.7 The objectives of the research were to:

1. Undertake a scoping exercise with key stakeholders to inform the development of the research methodology
2. Undertake the research, ensuring wide multi-faith and geographical coverage
3. Produce a report which describes and analyses the findings
4. Use the research findings to inform the development of the overall two year project

1.8 The research was seen as having the potential to contribute to the following LCT outcomes:

- People living with dementia in care homes will be more likely to have their spiritual needs and aspirations acknowledged and actively pursued
- Families and carers of people living with dementia in care homes will better understand the spiritual needs and aspirations of their loved ones
- Faith communities will be better equipped to engage with the care home sector in providing spiritual support to people living with dementia
- Residential care home staff and managers will be better equipped to understand and meet the spiritual needs and aspirations of people living with dementia under their care
- Policy makers will be better enabled to develop appropriate policy that takes account of the spiritual needs and aspirations of people living with dementia.

2 Context

Dementia

2.1 Scottish Government figures[2] show that In 2014 there were an estimated 16,712 individuals newly diagnosed with dementia in Scotland. By 2020, this number is estimated to increase by 17% to 19,473. The age group with the most estimated diagnosis of dementia appears to be 80-84 year olds.

2.2 In 2017, the Scottish Government launched its third national dementia strategy, covering the period from 2017 - 2020. Its first strategy was published in 2010 focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment. The second focused on improving post diagnostic support and strengthening integrated and person centred support.

2.3 The strategy's vision is of a Scotland where people with dementia and those who care for them have access to timely, skilled and well-coordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them. It sets out 21 commitments around work on diagnosis, including post-diagnostic support; care co-ordination; end of life and palliative care; workforce development and capability; data and information; and research

Care homes

2.4 In 2016 there were 873 care homes in Scotland for older people, with 33,313 residents (ISD 2016 [3]). Between 2006 and 2016, adult residents with dementia increased by 42%.

2.5 Over this ten year period, there was a 7% increase in private sector care home places (29,619 to 31,583). Public sector places decreased by 28% (6,216 to 4,502), with voluntary sector places also decreasing by 28% (7,476 to 5,376).

Faith communities

2.6 The following figures (from Interfaith Scotland) provide an indication of the size of the principal faith communities in Scotland.

[2] http://www.gov.scot/Resource/0051/00511467.pdf
[3] http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/2016-10-25-CHCensus-Report.pdf

Table 1: Faith communities in Scotland

	% of Total Population	Number
Church of Scotland	32.4	1,718,000
Roman Catholic	15.9	841,000
Other Christian	5.5	291,000
Buddhist	0.2	13,000
Hindu	0.3	16,000
Jewish	0.1	6,000
Muslim	1.4	77,000
Sikh	0.2	9,000
Another Religion	0.3	15,000
All Religions	56.3	2,986,000

2.7 NHS Education for Scotland indentified the following trends within faith communities in Scotland in its publication 'Spiritual care matters' (NES 2009[4])

- There was a decline in regular church going, with 4,100 congregations in 1984 reducing to 3,700 in 2016
- They noted an increased willingness to talk about 'spiritual things'
- There was a new confidence within small faith communities to 'be themselves'
- There was also evidence of a growing acceptance of humanistic philosophy and values.

2.8 The 2016 Scottish Church Census[5] revealed that:

- The number of people who regularly attend church services in Scotland has fallen by more than half over the last 30 years (around 390,000 regular churchgoers, down from 854,000 in 1984)
- 42% of churchgoers were aged over 65, and 40% were male
- 7.2% of Scotland's population regularly attend church, down from 17% in 1984

[4] http://www.nes.scot.nhs.uk/media/3723/spiritualcarematterssfinal.pdf
[5] http://www.brierleyconsultancy.com/scottish-church-census/

3 Methodology

3.1 In undertaking the research, we employed a mixed methods approach, involving both quantitative and qualitative methods.

Scoping

3.2 In order to inform the research design, we carried out 12 scoping interviews with a range of key stakeholders, including Scottish Care, the Scottish Social Services Council, the Care Inspectorate, NHS Education for Scotland, Edinburgh Interfaith Association, Interfaith Scotland, Scottish Ahlul Bayt Society, and three care home managers.

3.3 The interviews explored the critical contextual factors that the mapping should take account of, data availability, confidentiality and ethical issues, barriers to gathering the data, and potential risks. (See Appendix for the interview topic schedule).

Advisory group

3.4 A small advisory group was set up to support and guide the research, consisting of:

- Maureen O'Neill, Director, Faith in Older People http://faithinolderpeople.org.uk/
- Professor John Swinton, the Centre for Spirituality, Health and disability, Aberdeen University http://www.abdn.ac.uk/sdhp/centre-for-spirituality-health-and-disability-182.php
- Harriet Mowat

3.5 The advisory group played an important role in commenting on drafts of the online survey tools, and providing feedback on the early findings of the survey.

Quantitative research

Online survey

3.6 We designed an online survey for care home managers, informed by the comments we received during the scoping interviews. The survey was then piloted with eight people who had agreed to provide comments. Five responses were received.

3.7 The survey was publicised by Scottish Care who emailed 646 members directly, as well as sharing it on social media. It was also publicised by the Care Inspectorate via their website. Follow up emails were sent by Scottish Care, FIOP and Simon Jaquet Consultancy Services Ltd.

3.8 The survey was initially open from 24 February to 31 March 2017. It was decided to extended the closing date to 15 May in order to maximise the number of returns.

3.9 We received 92 returns representing 89 separate care homes.

Qualitative research

Interfaith dialogue seminar

3.10 An interfaith seminar was held In partnership with Interfaith Scotland, in order to hear the views of several of the faith communities in Scotland on the interim findings from the research.

3.11 Those attending included representatives from:

Interfaith Scotland
Scottish Sikh Women's Association
Cosgrove
Muslim House
Salvation Army
Edinburgh Interfaith Association
Faith in Older People
Council of Christians and Jews (West of Scotland branch)
Baha'i community
Hamilton Old Parish Church of Scotland
Iona Community
Hindu community
Methodist church
Jewish community
St Mungo museum of religious life and art
Scottish Ahlul Bayt Society
Muslim Council of Scotland
Scottish Roman Catholic church
Renfrewshire Interfaith Group
Kagyu Samye Dzong Glasgow

Telephone interviews

3.12 As part of the online survey, we asked respondents if they would be interested in taking part in a telephone interview in order to explore the issues raised by the survey. 42 respondents said they would, and they were emailed to invite them to participate. In all, 11 care home managers were interviewed by telephone - seven from the independent sector, two from the local authority sector, and two from the third sector.

3.13 The interview was an opportunity for the care home manager to explain how they addressed spiritual care issues with people living with dementia. Areas of discussion included the following (the full topic schedule can be found in the Appendix):

- What they saw as the spiritual needs of residents living with dementia
- What kind of spiritual care they offered to residents living with dementia, and how this might be different from the spiritual care for residents who are not living with dementia
- Who was involved in spiritual care, and what roles they played
- How spiritual care for people living with dementia could be improved

Case studies

3.14 We asked care home managers during the telephone interviews if they would be interested in a case study visit. The purpose of the case study was to help us understand in greater depth the reality of caring for the spiritual care needs of someone living with dementia. We hoped to gain a very personal picture of how this is undertaken in practice.

3.15 Four care homes were identified (one in Stonehaven, one in Renfrew, one in Lanark, and one in Glasgow), and they were asked to facilitate discussions with:

- The resident him or herself (accompanied by a member of their family or staff)
- Other family and friends
- The care home manager
- Other staff
- Volunteers
- People involved in their faith community
- Outside professionals

3.16 The focus for the case study visits was twofold: to explore what raises the spirits of the person living with dementia in the care home; to identify how you find this out.

Stakeholder seminar

3.17 In September 2017, we invited representatives of a range of national stakeholder groups and organisations to attend a seminar to hear the research findings and to discuss their implications for the policy and practice of work with people living with dementia.

3.18 Those attending included representatives from:

Edinburgh Interfaith Association
Ahlul Bayt Society
Alzheimer's Scotland
Scottish Care
National Dementia Carers Network (NDCAN)
Ahlul Bayt Society
SSSC
AGE Scotland
Scottish Government
Interfaith Scotland
Evaluation and Professional Development Services
Faith in Older People

3.19 The Care Inspectorate, the Scottish Dementia Working Group, and NHS Education for Scotland were invited but were unable to attend. A follow-up meeting was subsequently held with the Care Inspectorate.

Limitations

3.20 We decided to adopt an iterative process to the research, allowing each stage to build on the strengths of the previous stage. We relied on participants self selecting for their participation. This had the strength of enabling us to build a small but committed constituency (which was useful for other aspects of the overall two year project), but could be seen as creating a bias towards care homes which were already 'signed up' to the value of spiritual care.

3.21 The 92 care homes which responded to the survey (covering all but three local authority areas, and reflecting the three sectors - independent, local authority, voluntary sector) can be seen as contributing to a purposive, rather than a formally representative, sample.

4 Quantitative findings: online survey

Introduction

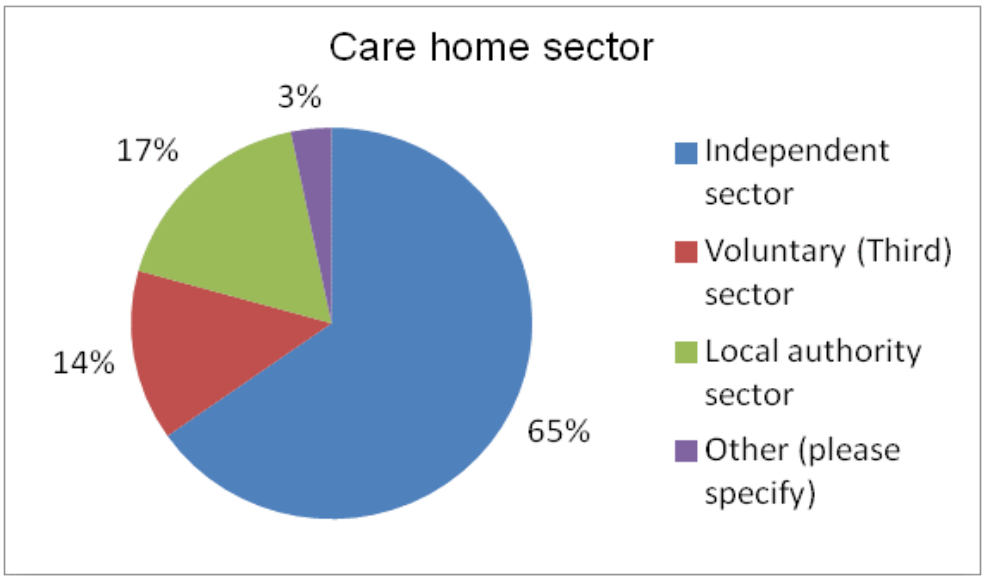
4.1 This chapter describes the findings from the online survey completed by care home managers. Quotes are taken directly from individual responses.

Respondent profile

Sector

4.2 We asked respondents in state which sector their care home was in, and these are shown in the chart below. The percentages roughly reflect the national breakdown of older people in care homes (independent 76%, local authority 11%, third sector 13%).

Chart 1: Care homes by sector



Local authority

4.3 We received responses from every Scottish local authority except three.

Table 2: Survey responses by local authority

Local authority	Responses	
	%	No.
Aberdeen City	2%	2
Aberdeenshire	10%	9
Angus	4%	4
Argyll & Bute	2%	2
Comhairle nan Eilean Siar	2%	2
Clackmannanshire	0%	0

Dumfries and Galloway	2%	2
Dundee	0%	0
East Ayrshire	1%	1
East Dunbartonshire	1%	1
Edinburgh	10%	9
East Lothian	4%	4
East Renfrewshire	1%	1
Falkirk	3%	3
Fife	4%	4
Glasgow	9%	8
Highland	3%	3
Inverclyde	1%	1
Midlothian	0%	0
Moray	1%	1
North Ayrshire	7%	6
North Lanarkshire	3%	3
Orkney	1%	1
Perth & Kinross	3%	3
Renfrewshire	3%	3
Scottish Borders	2%	2
Shetland Islands	3%	3
South Ayrshire	2%	2
South Lanarkshire	7%	6
Stirling	2%	2
West Dunbartonshire	1%	1
West Lothian	1%	1
Total	100%	90

Profile of care homes

4.4 We asked respondents to provide an idea of the size and scale of their care home. Numbers of residents ranged from 10 to 116, with the number of staff reflecting this. Most care homes had no volunteers, although a small minority had significant volunteer teams.

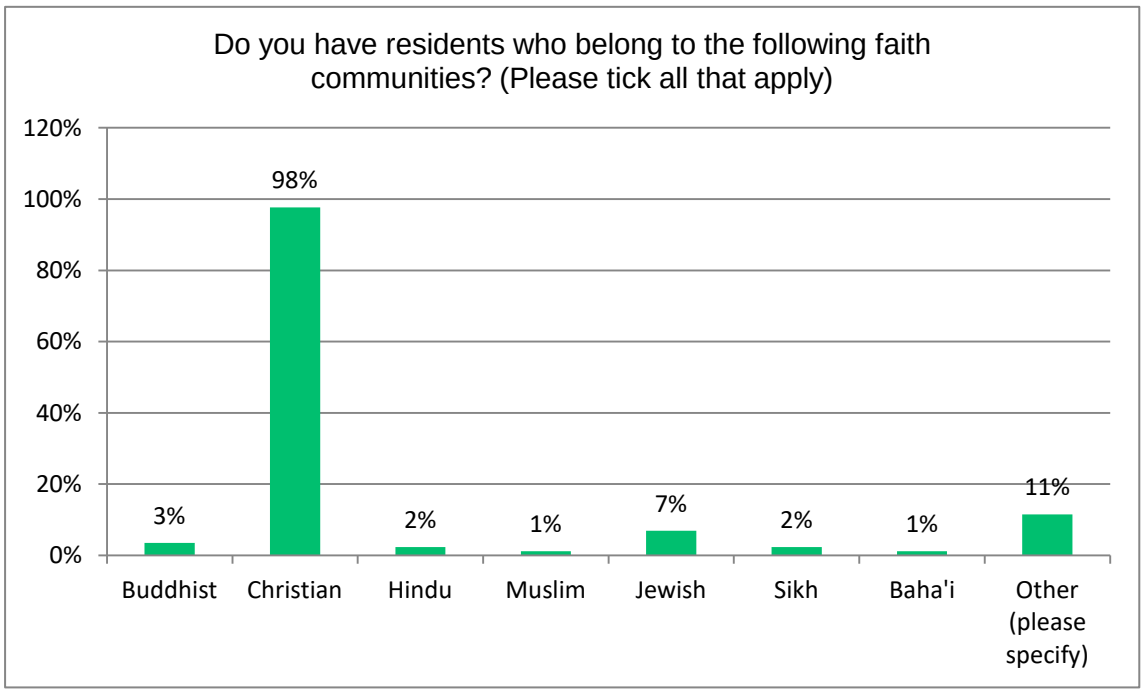
Table 3: Numbers of residents, staff and volunteers in care home

	Residents	Full-time staff	Part-time staff	Volunteers
Max	116	140	104	20
Min	10	10	9	0
Average	45	30	10	0

Faith communities

4.5 We asked respondents to say whether they had residents from the main faith communities. The responses indicate the percentage of care homes with residents from the respective communities, not the overall percentage of faith community members in care homes.

Chart 2: Members of faith communities in care homes



Understanding of spiritual care

4.6 Managers were asked to rate the following descriptions of spiritual care. Responses indicated a strong preference for descriptions which focused on holistic care and addressed relevant needs for the resident. By contrast, more overtly 'religious' functions, such as making religious texts available, were seen as less important.

Table 4: Care home managers' understanding of spiritual care

Please rate the following statements as descriptions of what spiritual care means for you. (1 = best description, 5 = least good description)	**Weighted average**
Caring for the whole person	1.12
Listening to what a person sees as important	1.27
Creating a sense of well-being	1.45
Supporting someone at the end of life	1.48
Helping someone deal with times of stress or challenge	1.52
Respecting a person's religious beliefs	1.57
Giving a person the chance to meet a priest or religious leader	1.81
Making scripture or holy books available	2.01
Helping a person to attend religious services	2.06

Supporting the whole person

4.7 We asked respondents to describe in their own words how they understood spiritual care. The greater majority (70%) said that supporting the whole person was the priority. They emphasised the need for a holistic approach to meeting needs (mind, body, spirit)

"Spiritual care is supporting the person holistically. Their emotional support and spiritual support is as important as their physical care."

4.8 A key dimension was respecting and supporting what the resident values and believes in, and helping them to practice this. Respecting a variety of beliefs (not just religious) was seen as crucial

"I don't see spiritual care solely related to religion at all. More the need to be seen as a whole person and an individual. The need for care to be planned and delivered in a holistic and person centred way which promotes general wellbeing and quality of life. The emphasis on dignity, respect and individuality."

4.9 Supporting individuals' sense of agency was important, and especially helping residents to experience love, hope, and happiness.

"Meeting the spiritual needs of the person by listening to them and the people important to them about what and who is important to them giving them joy, happiness, peace, love, laughter whatever brings about the essence of the person and ensuring staff and friends relatives provide the opportunities for them to experience these on a regular basis."

Supporting and facilitating religious faith and observance

4.10 A quarter of respondents (24%) saw supporting and facilitating religious faith and observance as how they understood spiritual care.

"We encourage residents to keep up their religious beliefs, attend church events, celebrate religious occasions, keep in touch with friends from church."

End of life care

4.11 End of life care was mentioned by a few (3%) as the key dimension to spiritual care.

"Supporting a person to practice his faith and provide comfort and encouragement and meaning in life, particularly in our case as he nears the end of this life. "

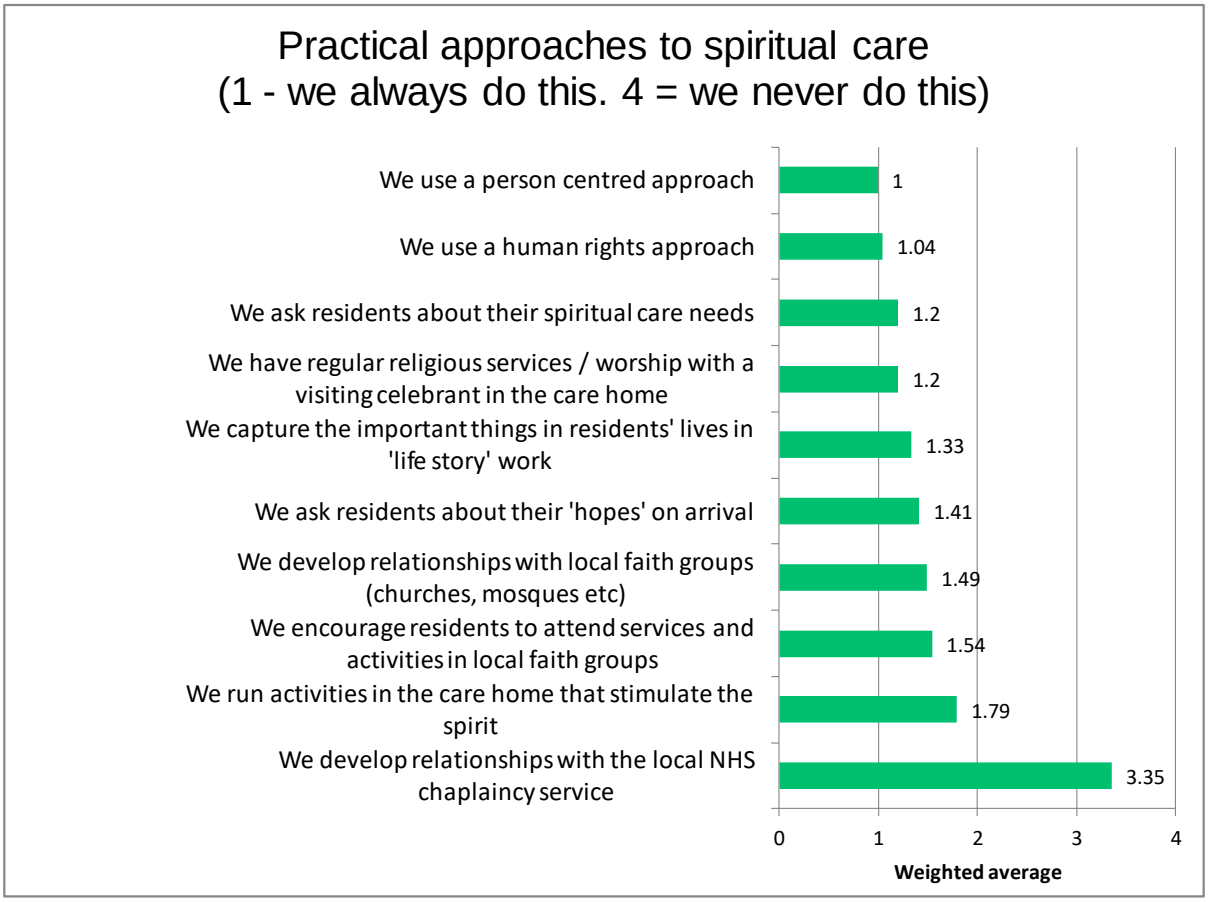
Practical approaches to spiritual care

4.12 We asked managers to provide some information on what spiritual care 'looked' and 'felt' like in their care home.

Different approaches to spiritual care

4.13 Respondents were asked to indicate the regularity with which they undertook the following activities. Most of these were, in effect, regular aspects of their practice. Relationship building with the local NHS chaplain, however, was not seen as important.

Chart 3: Practical approaches to spiritual care in care homes



Chaplain's role

4.14 We asked about the role of the chaplain. This tended to be interpreted as a minister or priest (rather than an NHS chaplain for example), with 74% of homes saying they had a minister or priest visiting the care home on a regular basis.

4.15 88% of care homes provided a regular service of worship, which usually took account of denominational differences.

> "We have regular church services roughly every month and chaplains take it in rotation to provide a service. We also have a church elder from the Catholic church to bring communion to Catholics on a regular basis."

4.16 In 28% of care homes, the priest or minister offered 1:1 visits and support to individual residents, including end of life care. The more pastoral aspects of this inter-denominational work made use of lay people and elders in 10% of care homes.

> "We do not have one chaplain but have several lay preachers who come to the Home up to four times a week to conduct services, lead devotionals, and sing hymns."

4.17 Ministers and priests also fostered links to the local churches in 6% of cases.

> "Provides a church service three Sundays out of four. Residents can be taken to local places of worship if they so wish/request."

Examples of practice

4.18 We asked respondents to give practical examples of spiritual care that had been provided over the past three months.

4.19 Slightly surprisingly (given their broader definitions of spiritual care), 40% provided examples where the focus was on supporting religious observance. This included examples which took place in the care home, as well as in the community

> "We assist residents with transport arrangements to attend places of worship if unable to attend by themselves. Staff shall act as escort."

4.20 40% also gave examples of supporting end of life care.

> "With a service user who was receiving end of life care, we sought to continue to encourage a sense of security and safety, respecting her need for privacy and dignity throughout, maintaining her individuality, and supporting her with her final wishes. This included time with family and friends who were important to her."

4.21 A relatively small number (14%) spoke about promoting positive inclusion and well-being.

> “A couple in our home used to enjoy going out for Sunday lunch with their daughter (who is registered blind). Whilst the weather is not so good their daughter has been spending Sunday lunch with her parents at the home instead. As the weather improves we hope to facilitate visits to their local restaurant for the three of them."

Training and development

4.22 We asked care home managers about the training on the provision of spiritual care that their staff received, and what might be useful for the future.

Current training and development

4.23 A significant minority (42%) said that no training had been received. 43% had benefited from informal, 'in-house' training which had been included as part of other training. This included e-learning (43%). The range of other training courses which covered some aspects of spiritual care included: holistic approaches, palliative care, person centred support, dementia, values. One respondent listed a very broad ranging set of training that included some spiritual care.

> "SVQ Anticipatory Care Planning, Talking mats, Promoting Excellence: Dementia Skilled Practice, Outcome Focused Practice, and Core Values, Palliative and End of Life Care, Good Conversations/Making good conversations better."

4.24 While some training was available, it was not always straightforward to implement the learning.

> "We did a project a couple of years ago where two staff were trained to pass on to other staff the skills they learned but they had difficulty realising the importance of it and carrying it on. The families were involved and felt it worthwhile."

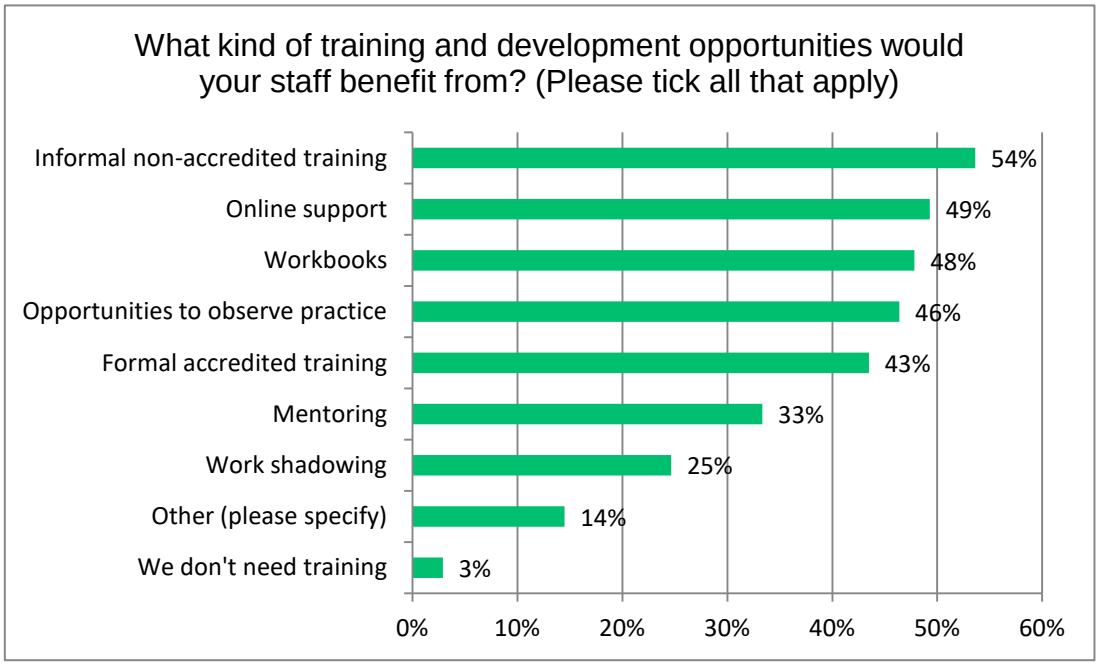
4.25 End of life care was seen as containing some aspects of spiritual care.

"Minimal training. There will be palliative care training for staff that is scheduled and this will include spirituality."

Potential future training and development

4.26 We asked managers what kind of training and development opportunities would be helpful for their staff in the future. There was a preference for informal, non-accredited learning opportunities. Only 3% said they did not need training.

Chart 4: Staff training and development needs



Aspirations for the future development of spiritual care

4.27 We asked respondents to say how the spiritual care needs of residents could best be met in the future. There were two main themes which emerged: strengthening the links with residents' home communities, and developing the skills of the workforce

Closer links to home communities

4.28 Over a third of managers (37%) said that they hoped to develop and strengthen links to local faith groups, and through them, to residents' own communities. A crucial part of this was enabling residents to retain links with their own faith groups and to attend services there.

"I would like to provide regular support from their chosen churches and would also like to be able to help them attend their own church and be in contact with the congregation and church activities."

4.29 Further support for faith services and visits by the minister or priest in the care home was also seen as desirable. The use of ICT to enable residents to share services remotely was also mentioned.

"Using the technology available to us. We will be encouraging our residents through skype and streaming."

Staff training and capacity building

4.30 A third (33%) of the managers responding to the survey stressed the need for effective staff training, development, and capacity building, in order to provide staff with the necessary skills and understanding. Specific training courses were suggested on dementia care, spiritual care, relaxation techniques (for example mindfulness), person centred care

> "Enabling service users to 'live well' and 'die well'. Continued staff training in dementia and the spiritual care of a person with dementia. Engaging with local faith groups if appropriate. Finding ways of enabling people with dementia to speak about their own spiritual lives."

Challenges

4.31 Recognising that care home managers are under considerable pressure, we asked what the principal barriers to offering meaningful spiritual care were. Not having enough time to devote to this was the main challenge, although this could, on occasions, lead to positive integration of spiritual care into routine activities.

> "The biggest issue is time, staff are stretched just completing the personal care tasks, eating, drinking etc. We try and include spiritual care within activities we provide however staff struggle with how to implement this."

4.32 Some reported that getting the minister or priest to visit could be problematic.

> "A few residents like to keep links with their church. This is usually through elders visiting or newsletters . We tried to get a priest to visit regularly for one of our residents but were unable to."

4.33 While maintaining links with the church and local community was seen as important for many residents, this was sometimes a significant challenge, with transport issues being a major problem.

4.34 Staff confidence, capacity and understanding of spiritual care was described as a challenge, with different staff having different level of awareness of how they could best offer spiritual care.

4.35 Obtaining the relevant spiritual care information from the resident on admission was sometimes described as difficult. This often depended on family members, who did not always provide the relevant information.

5 Qualitative findings: interfaith seminar

5.1 In partnership with Interfaith Scotland, we held an interfaith seminar (which attracted 30 participants) in order to explore the implications of the interim findings from the online survey, and to discuss the potential role for faith communities in providing spiritual care for people living with dementia. This chapter outlines the main findings from the interfaith seminar.

Participant profile

5.2 The following organisations participated in the seminar.

Interfaith Scotland
Scottish Sikh Women's Association
Cosgrove
Muslim House
Salvation Army
Edinburgh Interfaith Association
Faith in Older People
Council of Christians and Jews (West of Scotland branch)
Baha'i community
Hamilton Old Parish Church of Scotland
Iona Community
Hindu community
Methodist church
Jewish community
St Mungo museum of religious life and art
Scottish Ahlul Bayt Society
Muslim Council of Scotland
Scottish Roman Catholic church
Renfrewshire Interfaith Group
Kagyu Samye Dzong Glasgow

Views from the faith communities

Initial response to findings

5.3 Participants felt it was important to distinguish religious practice from spiritual care, with the latter being more inclusive. There was a strong sense that some of the survey responses would have been 'crafted' in line with what managers felt they 'should' be saying about spiritual care, rather than necessarily reflecting the reality of current practice.

5.4 They stressed the value of gathering and recording stories, rituals and routines that pertained to the different faith traditions. These resided to a large degree with older people. The move to a care home for an older person could be an interruption to this process.

5.5 Participants commented that there was a lack of practical examples of spiritual care in the survey returns. Where examples were given, they tended to be passive rather than active examples. There was surprise that no-one had mentioned music and its powerful effect on people living with dementia..

5.6 There was some concern at the apparently low response rate to the survey (at that stage 77 responses had been received). We explained that for an unsolicited online survey, an almost 10% response was acceptable.

'Fit' with own experience of people living with dementia

5.7 Participants commented that the spiritual care needs of people living with dementia tended to change as the dementia progressed. They stressed that what was needed above all was kindness.

5.8 They recognised the importance of faith communities as 'gateways' into the wider community.

5.9 There was a feeling that training would be needed for ministers, priests, and other faith community elders as well as for volunteers to help them to understand both the constraints and the potential for becoming more intensively involved in work with people living with dementia. It was felt that there was a lack of understanding in the heads of faith communities about the characteristics of dementia. The challenge for people of faith living in a secular society was recognised.

5.10 An outreach service run by Glasgow museums was mentioned. This made use of 'sensory boxes' (one of which related to a wide cross-section of faiths). They could be lent out to groups.

5.11 Participants again stressed the importance of familiar sounds and objects, and of recounting stories from within the faith community.

How faith communities can assist with spiritual care of people living with dementia

5.12 Participants suggested a range of ways in which faith communities could support the spiritual care of people living with dementia in care homes:

- Establishing links at local level between local faith groups and care homes - so that faith groups could advise care home on faith issues, and care homes could advise care homes on faith issues
- Developing volunteer roles for working in care homes, and offering training to raise awareness and build skills
- Gathering stories from residents 'so our grandchildren know who we are'
- Helping residents attend places of worship
- Faith groups being prepared to adapt in order to accommodate the needs of people living with dementia

6 Qualitative findings: telephone interviews

6.1 Following the online survey, we conducted 11 telephone interviews with senior staff in care homes to explore in greater depth some of the issues raised in the survey. This chapter outlines the main findings from the telephone interviews. Quotes are taken directly from individual interviews.

Respondent profile

6.2 11 senior staff were interviewed (8 care home managers, 2 Senior Social Care Workers, 1 Education & Dementia Coordinator). 7 worked in independent care homes, 2 in local authority care homes, and 2 in voluntary sector care homes.

Spiritual needs of residents

6.3 Respondents acknowledged that spirituality should be understood in a broader context than any one particular faith tradition. However this understanding needed to embrace faith related issues.

> "Most people see spiritual care as religion but it isn't. Some residents have religious views. for others, their needs are met if they take part in an activity such as smelling the flowers or seeing the sea.'

6.4 Spiritual needs were described by most as the need to affirm a person's individuality, to understand what makes them unique, to be connected to others, and appreciated. Most made use of terms such as 'holistic care' and 'well-being'.

> "Spiritual needs are everything about that person that makes them who they are. It's not one specific thing. We need to get to know their life story - the physical, emotional, and social aspects. It's holistic."

> "It's important to know as much as possible about the people in care, so their social, mental, and physical needs can be met."

6.5 Most of the care homes interviewed recognised the need to address faith and religious needs specifically, and to make some provision for them. Most had arrangements with local churches for a minister or priest to visit the care home and hold services and provide individual support to residents.

6.6 Spiritual needs tended to be assessed informally as part of the initial assessment process, and then on an ongoing basis as part of care planning. This wasn't always seen as a straightforward process.

> 'It's important to realise they still have spiritual care needs although they can be hard to recognise.'

6.7 Interviewees described a growing trend for people to be entering care homes with later stage dementia. Staff were therefore increasingly reliant on family and friends for identifying spiritual (and other) needs, as communication with the resident became increasingly difficult. The ability to articulate their spiritual needs became more limited as their dementia advanced. Other, non-verbal, techniques were

mentioned, for example 'talking mats'. There was a commitment to ongoing communication.

> "It's important to maintain their sense of self, to nurture who the person is or was and recognise what was important to them."

6.8 Underpinning many of the comments was a view that 'spiritual need' was not a term familiar to many staff and residents.

> "On a map of needs, spiritual care would be off to the left at the top. People don't know what it is."

Examples of spiritual care practice

6.9 Examples of spiritual care given by respondents tended to fall into two categories: explicitly faith related; non faith related.

Faith related

6.10 Regular (communal) services were offered - on a monthly or weekly basis. This usually included communion or mass. 1:1 pastoral care was fairly widely available to residents when requested. This might be a response to to the onset of more pronounced dementia.

> "Sometimes we need to change our way of doing things, for example adapting communion to 1:1 because they don't like crowds."

> 'With dementia it's more 1:1 based - more about being there and reacting to the person.'

> "People living with dementia are more easily distracted. so that's why we do 1:1 work. Touch is important - you sit and hold their hand. you're looking for more non-verbal things. If they're not reacting, you maybe do a hand massage.'

6.11 Examples were also given of residents being taken to a local church. For those not able to attend a church locally, respondents described the use of religious music in the care home, for example watching 'Songs of Praise', or having religious music played when going to bed.

> "The musical side gets more reaction from the residents. The majority of the residents like to sing hymns."

Non faith related

6.12 A variety of examples were given of non faith specific spiritual care. Life story work, helping to identify what it important to the person, drawing on the family's knowledge and experience, was cited by several people. Music, in a broader context, was mentioned, with its potential to create a lifeline to deeper memories and emotions. 'Playlist for life'[6] was referenced on many occasions.

> "People living with dementia use music more. It brings calm to the soul. One lady plays a mix of religious music when she goes to bed. We were asked to do this by the family."

[6] https://www.playlistforlife.org.uk/

6.13 Other examples of people making deeper connections included contact with animals and pets, and opportunities to 'be themself', for example walking barefoot on grass, and baking.

> "A lady who was a baker arranged to bake - but not in the kitchen. It was a real spiritual need for her."

Differences for people living with dementia

6.14 In exploring whether spiritual care for people living with dementia needed to be seen in a different way as compared to those without dementia, there was a consensus that the main difference is not in what is offered, but in how it is provided.

> "The needs of people living with dementia aren't different but need to be approached differently. It's not what we deliver but how we deliver it is different."

> "It's not different for a person living with dementia. You look at the whole picture and get to know them in a different way. You need to be more creative. You get to know the person, their family, people in faith communities."

6.15 The priority for the person living with dementia was for them to feel safe and secure, and this might require some adjustment to care processes. In many cases it became progressively more difficult to communicate with them, as they were less able to express what they wanted. Some also might appear to change their mind.

> "A lot is based unfortunately on assumptions. People living with dementia may not get the same opportunities to express themselves. A person without dementia can better express what they want. A sound knowledge of the person helps to counter that."

6.16 People living with dementia tended to prefer quieter spaces and 1:1 activities, rather than group experiences.

> "We have a lady with mid stage dementia. She's always enjoyed painting and drawing, but her needs are changing as her cognitive function changes. She appreciates a quiet space and enjoys sorting out her pencils into colours. Before, she would have drawn. Now she likes a quiet supportive environment with one or two people."

6.17 They valued physical contact such as holding hands or hand massage. Staff needed to be more creative and imaginative in their responses, and more skilled in communication.

> "It requires an additional level of skill, particularly if communication is difficult. We apply all the principles to everyone - tone of voice, not over-complicating, not too many involved questions. You take more time. Spirituality is what makes us human and unique."

People who provide spiritual care

6.18 We asked interviewees to say who was involved in spiritual care for people living with dementia in care homes, and how their roles differed. All agreed that the resident

needs to have a say in his or her own care, but this became increasingly challenging as the dementia progressed.

> "It's important not to discount the people living with dementia. There is a tendency to do this. We must recognise that even though the person has dementia, they have many strengths and capacities. We need to seek their views. As the dementia progresses, you're more reliant on other people."

6.19 Family members and friends provide important links to the past and to the resident's home community, but can find it increasingly difficult to cope with the changes they observe in their relative. It was commented that not all interventions are helpful - they sometimes speak inappropriately for the person. One manager described how the roles of family and friends differ from those of care staff.

> "Friends and family have a completely different relationship with the resident. They are emotionally involved with the person living with dementia. It's alright to have dementia, but if it's mother who doesn't recognise you, it's hard. Their journey is different. They know their relative isn't going to get better. We have a professional relationship - we come, we work, we go home."

6.20 From the staff perspective, there was usually a key worker or named nurse who established a relationship with the resident. Most care homes had an Activity Coordinator who was responsible for an activities programme, including trips to church. Domestic staff often had a special relationship with residents, based on ordinary human interactions.

6.21 The value of the volunteer as a 'semi-outsider' meant that sometimes the resident was able to say to them what they would not say to staff.

> "They're not seen as staff with an official role. The residents discuss on a different level. They'll tell a volunteer they've got a pain, but not tell the care staff - they don't want to 'trouble the staff'."

6.22 There were various examples of volunteers - young people doing their Duke of Edinburgh award, relatives of former residents, people helping out in the garden.

> "'Provided they're trained and supported, they can be a great asset. they are often relatives of previous residents who've continued after they've lost their mother or partner."

6.23 Faith communities provided another source of links to their past life and to their current local community, and a way to help them 'feel normal'. There was a risk that the person with dementia becomes less 'visible' once they moved into a care home.

> "If someone is in long term care, they can be off the radar in the community. If someone wants to maintain links, we try and get those links started again."

Areas for change and improvement

6.24 Managers felt there was a need for greater clarity about the term 'spiritual', and to develop a common, broader understanding of what it meant.

"We need to de-mystify the word 'spiritual'. People say 'Oh I don't believe in this'. It's a broader and wider thing."

6.25 Training and education on spiritual care were needed - both for care home staff and for people from the community who engaged with care homes.

"It's not a topic staff are taught about. We have a huge number of Spanish, Polish, and Romanian staff. Some wouldn't know what's appropriate. They could be taught everything else - but not spiritual care. We need to recognise it's an issue we should consider."

6.26 More people from the community (including the churches) actively visiting the care home and building relationships with residents would help 'normalise' life in the care home. There was a specific call for awareness raising in churches to enable them to play a role in supporting people living with dementia.

"The biggest thing would be more awareness among the churches. They see people at home, but it's difficult to get people from the churches to come to the care home. I don't know if it's fear."

"If people were prepared to visit, and develop voluntary relationships with the residents like elders in the church. But it's sadly lacking. Maybe because people feel uncomfortable with dementia.'

7 Qualitative findings: case studies

7.1 In order to follow up issues arising from the research already undertaken, and in order to have access to a wider range of interviewees, four care homes were identified for a case study visit. These were selected from care homes which had taken part in the telephone interviews and had indicated a willingness to be involved.

7.2 This chapter outlines the main findings from the case studies. Quotes are taken from individual interviews.

Respondent profile

7.3 The four care homes were located in Glasgow, Renfrewshire, South Lanarkshire, and Aberdeenshire. Their summary staffing and resident profiles are shown in the table below.

Table 4: Resident, staff, and volunteer profiles in four case study care homes

	Sector	No. of residents	No. of full-time staff	No. of part-time staff	No. of volunteers
1	Voluntary sector	21	6	27	8
2	Local authority	50	21	33	0
3	Independent	64	54	21	0
4	Independent	34	40	23	0

7.4 The everyday business of the care home was observed, meeting residents, family members, and staff. This included sitting in on a monthly residents meeting, and on a Namaste session with two women living with dementia. Semi-structured interviews were also held with:

Residents
Family members
Managers
Senior care workers
Activity coordinators
Care staff

Key areas of investigation

7.5 We decided to focus the case studies around two key questions which we hoped would enable us to understand with greater clarity some of the issues around spiritual care. The questions were:

- What lifts the spirits of people living with dementia in care homes?
- How do we know what these are?

7.6 Staff interviewed were able to make a relatively clear distinction between faith and non faith based spiritual care.

> “Most people see spiritual care as religion, but it isn't. Some residents have religious views. For others, their needs are met if they take part in an activity such as smelling the flowers or seeing the sea.”

> “Spirituality in the widest sense is about meaning, purpose, hope, direction - whether a recognised religion or not.”

> “It can as simple as this. In a recent conversation, a gentleman said he wanted to walk on grass in his bare feet.”

7.7 Faith based spiritual care was overwhelmingly Christian, with regular formal church services in the care home, attendance at services in the community, and 1:1 support by the priest, minister or church members.

7.8 The process of conducting the case studies enabled us to fill some of the gaps left in (and questions raised by) the online survey. The following sections outline what interviewees considered to be the key ways in which residents 'had their spirits lifted'.

Music

7.9 The most frequently cited activity that raised the spirits of residents was music. This took a number of forms. Singing was the most common, with residents enjoying all forms of music.

> “Music's a great therapy. We've seen examples of residents' well-being - facial and body expressions - completely change when they start to sing a hymn ... it takes them to a different place. You can see that when they start to sing.”

> "Residents just love singing. We've got the choir group, the church services. There's certain residents who'll just sing hymns in the unit anyway! Impromptu sing-alongs happen pretty regularly...Even if someone's distressed, especially in the dementia unit, or agitated with regard to personal care, if you start singing and they join in, it's good at relieving any anxiety as to what's happening to them."

> “We had an opera singer in to teach songs., it was quite funny because she was loud and quite 'opera-y'. I think the whole thing was a culture shock for residents, but they enjoyed the fun of it. She was getting them to do the breathing exercises - taking them out of their comfort zone. Because they can't do a lot of physical things, it compensates, they can get all their expressions and anxieties out.”

7.10 Moving to music and dancing was also an important method of engaging residents in communal activity.

> “They love to be involved - up dancing. We've got one lady here. She sits the whole day so quietly. You put the music on, get her up dancing and she's a different person. Her head's up.”

7.11 Music was described as triggering memories from the past, but also building social solidarity in the present.

> “We got her daughter to tell us what music she liked when they were living with her, and it was Mick Jagger - which surprised us all as we didn't see her as a Mick Jagger fan.”

7.12 It was striking that, by contrast with one of the enduring stereotypes of residential care, not all residents want to sing songs from the second world war!

"We ask them what they like (the Activities Coordinator has a questionnaire), and Daniel O'Donnell tops the list! Somebody wrote the Rolling Stones in the recent questionnaire. You see the changes. Sometimes I think - that music's too old maybe - world war one and world war two type things. I think we had one lady who put the Sex Pistols!"

Children and intergenerational relationships

7.13 The presence of children in the care home brought a fresh burst of life in many residents. These might be relatives, but were as likely to be children from local schools or nurseries. Sometimes this was a relatively passive activity, and the pleasure was largely vicarious.

> "One wee boy and four wee girls [from the nursery] came in. We got them familiar with the place, and then got the beachball out, beanbags, skittles. Even just playing amongst themselves, all the residents loved it."

7.14 But several examples were given where there was a more conscious interaction between the residents and the children. This had the potential to produce a rich dialogue - in this case, with the children acting as teachers for the older people!

> "Seeing children. We have a close relationship with the local primary school. They come in and sing. That brightens people up. They like to see children. The primary school children were bringing in iPads. It was the Activities Coordinator who was doing that with them. They were showing the residents what you do with them."

7.15 This intergenerational dimension was quoted in several interviews. A particular place was reserved for the grandparent / grandchild relationship. In this case, daughter of a resident with dementia highlighted the special relationship between her mother and her daughter.

> "But also I think with [great granddaughter], it's not maybe what she does for you, but what you do for her. Because you're still teaching her things. So she goes away very happy to have learnt something new."

> "They love it if young people come in. They both benefit from it. The young person because they're getting a history, and things they've never experienced. Young people now - it's all computers and phones and things like that, but these people know what it was like not to have a phone, not to have a colour TV."

Families

7.16 The next generation - children of residents - were frequently responsible for placing their parent with dementia in care. Inevitably this gave rise to conflicting feelings.

> "If the resident is happy, it lifts their spirit, there's a knock-on effect for families. I do think quite often it's a horrible situation for families. They've had to put them into care. It's one of those things where they're 'failing' at one level."

7.17 Grandchildren, by contrast, were free of these kinds of contradictory emotions. One resident clearly enjoyed her contact with her grandchildren.

> "It's the same with the youngsters. I have a good time with the kids. They come in and see me, which is lovely because sometimes the youngsters don't want to do

that with grandparents, but mine do. They know they don’t have to phone me up. They just arrive at the door and if I’m here, I’m here. ”

Animals

7.18 Animals were described as often being able to draw out emotions in people living with dementia. The delightful chaos that sometimes ensued when animals were brought into the care home served as an attraction both for residents and visitors alike.

> “It's done wonders for the residents it calms them down. The staff will call out 'bring the dog!'. One family brings in the granddaughter because of the dog.'

7.19 Examples were given where the use of animals was more structured, verging on a form of therapy.

> "She comes in once a fortnight and she goes round all the units with her dog. (therapet) It's good she goes round the units because everyone gets involved."

7.20 One senior care worker brought together several of the above elements which contributed to lifting people's spirits.

> "If we filled the home with music, children, and animals, they wouldn't need us!"

Physical contact

7.21 As residents progressed to the later stages of dementia, verbal communication became more difficult, and they often became more socially isolated. In these circumstances, physical contact became proportionately more important as a way fo asserting a common humanity. Several examples were given of spontaneous, informal physical contact.

> “Every time I take mum out and she comes back, the person who opens the door usually gives mum a hug.”

7.22 This Activity Coordinator highlighted the tension between what you want to do as a human being, and the potential constraints of the ‘system’.

> “Physical contact's a great thing as well. You're probably not mean to do it, but you just sit and stroke somebody's hand. When I come in in the morning the arms are up for a cuddle.”

7.23 The head of a dementia unit had experienced something similar.

> “There was a man in one of the units, and he was a wee grumpy man. He'd never married, he'd been a loner all his life. He was in the dining room one day, and I can't even remember what was wrong with him, and I hugged him from behind. I don't know what possessed me, because I'd never hugged this man - ever - but he was in such a bad mood and I wanted to cheer him up. And you felt him just relax, and he actually said 'You don't know how long it has been since somebody has kind of ...' - just to feel loved, nurtured.”

7.24 Sometimes the contact was a planned part of a therapy programme. One interviewee described the value of touch.

> “And also touch is a big one. You have to know your residents because some people don't want you near them. Personal space is very important. I always touch on the arm, it's natural, it's not that I'm testing anything, it's just what I would do. But as the relationship develops, and you're getting to know them, and the trust is there a bit more, you get to know.”

Relationships with staff

7.25 The quality of the relationships developed by residents with the staff in the care home was a significant factor in their lives. Good relationships had the effect of raising the morale of residents. Where this worked well, a genuine sense of community was developed. As the daughter of a resident said:

> "The people who work here have a feeling of belonging ... it's not just a job. They belong here. Everybody belongs here. When I come to visit you I feel like I'm part of a family too.... If you talk about keeping the spirits up I think that it's really important that there's a feeling of belonging - not just living."

7.26 Care staff were seen as integral to this process.

> “They like to share a joke or a laugh with you, and you talk about things that you've done or when we've been away on holiday, They love to hear where we've been.”

7.27 Domestic staff contributed as well.

> “A domestic coming into the room and saying 'Mary - how are you?' it's an act of care.”

7.28 Only one of the four care homes visited made use of volunteers, but in this setting they were seen as playing an important role in creating diversified community that helped to maintain morale among residents.

Surprises and spontaneous activity

7.29 Normal life is full of surprises, but this element can be lost when you are placed in an institution with its own rhythms and routines. In this context, spontaneous activity and events that 'come out of the blue' can carry a disproportionately positive value. The daughter of a resident described how this applied for her mother.

> “We only had an hour, but we went down on the harbour, we sat on the wall, had an ice cream, and you said that’s made a difference to the day because it wasn’t planned, it was impromptu. The element of surprise is quite important. Having little surprises every day!”

7.30 Another resident spoke of the value of family members arriving spontaneously to visit her.

> “Suddenly one or two of them will come in the door one day and it’s lovely. But you never chase them and say it’s time to go and see Granny. I think that’s a mistake. It’s got to come from them. It’s lovely when they want to come – even if they just stick their head round the door.”

Identifying and meeting spiritual care needs

7.31 Staff who were interviewed agreed that the quality of relationships with both residents and with their families was an essential pre-requisite for understanding and responding appropriately to residents' spiritual care needs.

7.32 Staff would get to know the resident - building up trust, becoming acquainted with their past life, and becoming confident to 'read' what they were wanting. Sometimes this would mean learning to read their body language.

> "You've got to have time for each person. You can't fob them off. You have to imagine, if that was your mum or dad, how you would want someone spending time with them or treating them. They are all individuals - you can't presume that because one would like to do something that they all would."

7.33 The family is also a vital source of information about the spiritual care needs of residents,.

> "But we do rely on families telling us what they were like before the dementia and how it presents now."

7.34 Sometimes, however, this is not necessarily straightforward.

> "You have residents come in with information that the social worker has compiled that sometimes is more accurate than others. So the family is vital in giving you as much information as they can. Most families we have great relationships with. There are certain families where for whatever reason.... I'm thinking of one family, it's quite a big family, and they all have different opinions about what's best for their mum. So you can be stuck in the middle sometimes."

7.35 Interviewees referred to a range of specific processes and approaches which helped build up the picture of the resident. The care planning process was the overarching mechanism that identified the residents needs and aspirations and how these should be addressed.

> "The first page (of the care plan) should give you a good feel for the person, what the family think of this person. What we're trying to get families to do is what inspires you about this person, not about what the problems are. That whole approach helps you get a good picture of the person in a positive sense.

7.36 Creating 'life stories' or completing 'Getting to know me' forms made an important contribution.

> "That's where their families are important and their history... We do a 'getting to know me' sheet in the care plan. We ask the families to fill that in."

7.37 Other specific techniques employed by staff included 'Talking mats' where the resident used pictures to indicate preferences.

7.38 Several staff mentioned the challenge of residents being admitted at an increasingly late stage of their dementia.

> "Years ago we would have quite a lot of new clients coming in and we would have a brief history and it would tell you how they were brought up, siblings, family, life, where they lived and how they came to that position. (Now) you don't get a lot of that. It depends on the worker... But we do rely on families telling us what they were like before the dementia and how it presents now."

Specific spiritual care needs of people living with dementia

7.39 We explored with care home staff the extent to which the spiritual care needs of a person living with dementia differed from those of someone who was elderly but not experiencing dementia. There was a strong sense that the difference lay not in what you did, but how you did it.

7.40 The priority was to help the resident feel safe and secure

> "We have a lady with mid stage dementia. She's always enjoyed painting and drawing, but her needs are changing as her cognitive function changes. She appreciates a quiet space and enjoys sorting out her pencils into colours. Before, she would have drawn. Now she likes a quiet supportive environment with one or two people."

7.41 Progressively many become less able to communicate or express their desires.

> "With communication declining, the families are at a loss to know what to do, how to spend time with their loved one."

7.42 They often prefer quiet spaces and 1:1 activities.

> "People living with dementia are more easily distracted, so that's why we do 1:1 work. Touch is important. You sit and hold their hand. You're looking for more non-verbal things. If they're not reacting, you maybe do a hand massage."

7.43 They value physical contact and sensory experiences.

> "Some of the residents are quite hard to reach, so they could touch the herbs and smell them. There was the mint - 'Oh that was the Sunday roast'."

> "[The Namaste session] is really quite rewarding because you're doing something for your mum.... One lady - her appearance is very important to her - so her daughter would comb her hair or just sit and read to her. She likes her nails painted. It's nice for the families to feel they're doing something."

7.44 In consequence, staff need to be more creative in their responses and skilled in communicating with the person living with dementia.

Who plays a role in meeting these spiritual care needs

7.45 There is a large group of what we might term ''Insiders' who play a central role in supporting residents needs once they have entered a care home. These include staff (managers, care staff, domestic staff, activity coordinators) and other residents. As we have seen (above), a particular skill set is required to do this effectively.

7.46 By contrast, there are a number of 'outsiders' (including family and friends, outside professionals such as admiral nurses, and faith group members who visit the care home) who also play a role. Their 'outsideness' is simply a function of their not being with the resident in such a permanent way in the care home.

7.47 A slightly different category of 'bridge builders' would include people in various voluntary roles who act as a link between the local community and the care home. Here we would include young people completing their Duke of Edinburgh award, and volunteers undertaking practical tasks around the care home such as the gardening.

Potential improvements

7.48 We asked interviewees how spiritual care for people living with dementia in care homes could be made better. There was a strong sense that the term ‘spiritual care’ was in itself not without problems. Staff {as well as residents and family members) found the term confusing. There was a tendency to associate it with faith based activity. While most acknowledged the importance of care that extended to the deeper parts of the psyche, this term often felt restrictive.

> "We need to de-mystify the word 'spiritual'. People say 'Oh I don't believe in this'. It's a broader and wider thing.”

7.49 Staff in particular felt that improved training and capacity building would be the most effective way of bringing about a change of awareness and improved skills in the workforce.

7.50 In parallel to this, interviewees pointed out that training could usefully be made available to faith groups and the wider community, with a view to them understanding more effectively what they contribute to residents in a care home.

7.51 This made a lot of sense in the context of another suggestion for improving the overall quality of care. Increasing the ‘traffic’ between care home and community was mentioned by several people.

> “[Local churches] is still an area where relationships are still not as good as we would like sometimes.”

> “If people were prepared to visit, and develop voluntary relationships with the residents like elders in the church. But it's sadly lacking. Maybe because people feel uncomfortable with dementia.”

8 Qualitative findings: national stakeholder seminar

8.1 Following the completion of the research, a number of national stakeholders were invited to a seminar to hear the research findings and to discuss their implications for policy and practice. This chapter outlines the main issues raised at the seminar.

Participant profile

8.2 The following organisations were represented at the seminar:

Edinburgh Interfaith Association
Ahlul Bayt Society
Alzheimer's Scotland
Scottish Care
National Dementia Carers Network (NDCAN)
SSSC
AGE Scotland
Scottish Government
Interfaith Scotland
Evaluation Support Scotland
Faith in Older People

8.3 The Care Inspectorate, the Scottish Dementia Working Group, and NHS Education for Scotland were invited but were unable to attend. A follow-up meeting was subsequently held with the Care Inspectorate.

8.4 The main areas of consensus were as follows.

Spiritual care

8.5 Spiritual care needs to be understood in the broader context of care for the whole person (rather than a narrower definition related to religion). There is a risk that spiritual care 'activities' are delegated to the Activities Coordinator 'because it's about church', as opposed to seeing it as everyone's responsibility.

8.6 The involvement of family and friends in understanding a resident's spiritual care needs is important, but they need to feel confident that the information is used well.

Data sharing

8.7 There is a need for a common 'ownership' (among staff and family members) of the data that describes what is important to the resident. However, this can present challenges and risks for confidentiality.

8.8 There is value in the integration of data sharing, with the person's notes 'following' them, and potentially being available via ICT rather than just paper based formats.

Staff capacity building

8.9 There is a need to instil confidence, and to build the capacity, of staff so that they feel more able to have conversations with residents, family members and colleagues about spiritual care (FiOP has developed an on-line course – 'Spiritual Care Matters' - which aims to do this).

8.10 There are both risks and benefits to addressing spiritual care issues, and sometimes there are 'myths' about the special 'permissions' required to embark on more in-depth discussions with residents. Many of these issues can be addressed through formal and informal training.

8.11 Spiritual care needs to become embedded in SVQs. Training around holistic care should have spiritual care built in, but be more inclusive than simply a knowledge of when different religious festivals are held.

8.12 It is sometimes difficult to implement an individual's learning as it can get lost in the requirement to fulfil a range of other tasks. We need a stronger understanding of the spiritual care needs of staff. (see *Trees that Bend in the Wind – Scottish Care Report).* Staff whose support needs are poorly addressed will be less capable of providing effective care for residents.

Human rights

8.13 People often assume all spiritual care work is based on this, but it is not always clear exactly what this means. The Scottish National Care Standards are human rights based, but tend to focus on 'I' rather than 'We'. There needs to be a reciprocity in enabling spiritual care. A key focus of spiritual care is around relationships, and being able to understand how this applies to individuals.

8.14 In general, we need to recognise the importance of 'honest conversations'.

The role of churches and other faith communities

8.15 There are an elaborate range of functions that faith communities could perform for a care home. These include: 'adopt a care home', regular contact with residents (both in and outside of the care home), acting as a 'conduit' to the local community.

8.16 Faith communities would need training to enable an understanding of dementia and other issues affecting older people in care homes (as well as appreciating how a care home is run) in order to offer support effectively. This would involve the normal requirements for supporting volunteers - training / capacity building, regulation (eg PVGs), risk assessments.

8.17 It would be important to stress the need for reciprocity between the faith community and the care home - it should not be 'one- way traffic'.

8.18 Transport is sometimes an issue in enabling a resident to retain faith or community connections.

Policy implications

8.19 There are potential policy implications for, at least, the following policy areas

- Spiritual care strategy (NES)
- Commissioning – should this include a requirement to demonstrate the incorporation of spiritual care
- Self- Directed Support – how could this be used in care homes to support spiritual care
- How the Care Inspectorate could include spiritual care in its inspection of care homes eg what questions they ask and how would this relate to the new National Care Standards
- The new dementia strategy and charter
- The palliative care delivery strategy – ensuring that the implementation is inclusive of spiritual care

9 Discussion and conclusions

9.1 This chapter explores and synthesises the main issues and implications arising from the various components of the research – the online survey, the telephone interviews, the case study visits, and the two seminars.

Understanding spiritual care

9.2 Spiritual care is already being offered to people living with dementia in care homes. There are many practical examples of care addressing needs that go well beyond the physical realm. However, most staff would describe this as 'holistic', 'person centred' care, or care that addresses the mind, body, and spirit.

9.3 The term 'spiritual care' still tends to be associated with religious faith and practice. Currently there appears to be disjuncture between what people in care homes term spiritual care (providing for explicitly faith related needs, such as regular services of worship), and the practice of care that engages residents at a deeper level. This tension was apparent in the online survey, with respondents generally stating that spiritual care was an important element of their work, and available to residents. But, when asked for examples of practice, it was 'religious' activity that was quoted.

9.4 There is a need to clarify (and secure widespread support for) the concept of spiritual care, ensuring that 'quality of care' translates into genuine 'quality of life'.

Delivering spiritual care

9.5 Most care homes, when asked to give practical examples of when they had provided understanding and support for the less tangible and 'higher' level needs of residents, were able to do so - especially those involved in the case studies. These ranged from small acts of kindness (such as a spontaneous hug) to more systematic approaches (developing small community choirs, running a 'Namaste' session).

9.6 There is a high degree of consensus about what lifts the spirits of residents in care homes. These include: music and singing; interaction with children and intergenerational activity; the presence of animals and pets; physical touch; contact with family members; enduring relationships with staff; access to religious or faith-related activity both in the care home and in the community.

9.7 Spiritual care draws people out of themselves, and into relationship with others and the world around them. It has implications for staff inter-personal skills, and community building.

Spiritual care for those living with advanced dementia

9.8 The spiritual care of people living with dementia can continue right to the end of life. Despite an apparently reduced ability to communicate among many of those with advanced dementia, numerous examples were given of staff and family members being able to maintain communication and to address the higher level needs of their loved one. At the same time, it important to recognise the considerable practical and emotional challenges to doing this effectively.

9.9 Significantly, it is the 'how' rather than the 'what' which needs to change. A greater focus on 1:1 care in an environment that is safe and secure will become increasingly

required for people living with dementia. As verbal communication diminishes, there will be a growing reliance on other non-verbal means. Music and singing has an important role to play here.

The potential role of faith communities

9.10 There is potential for faith communities to play a significantly more active role in the lives of people living with dementia in care homes – both in the care home and in the local community. The current picture is mixed, 75% of care homes having arrangements in place for the provision of religious services and pastoral support for individual residents. At the same time, many report that it is difficult to set up regular visits by the priest of minister, and some say it is hard to get people from the churches to visit.

9.11 The Church of Scotland has 1500 parishes, (and 1.7m members) and there are 873 care homes for older people in Scotland. Although neither network has an even distribution throughout the country, a rather crude numerical analysis would give us almost two churches for every care home. It would theoretically be possible for each care home to be ‘adopted’ by a church. This would give access to human capital (for example the members of the congregations as potential ‘befrienders’), social capital (for example the ability to maintain links and relationships within local communities), and a measure of economic capital (with these links providing access, for example, to skills and employment opportunities).

9.12 Underpinning yjis, there would appear to be considerable scope for the training and development of volunteers from faith communities to become involved in the life of local care homes. This could offer mutual benefit - opportunities for faith communities to participate in local community activity, and increased capacity for the overall 'team' within the care home.

9.13 If the other churches and faith communities were to become involved, there would clearly be significant scales of economy.

9.14 In order to launch anything of this nature, there would be implications for awareness raising, training, and capacity building.

Non-Christian faith communities

9.15 There are very few examples of non-Christian faith communities taking part in the life of care homes in a structured way. This reflects a national demographic, with non-Christian religions engaging 2.5% of the Scottish population.

9.16 However, informal discussion with some of these communities during the qualitative fieldwork phase of the research gave some indications that groups (such as the Muslim and Sikh communities) are now facing up to the challenge of changing patterns of social behaviour in third generation 'immigrant' families. In short, there is some evidence that communities which would previously have provided care for the elders within the home setting, are now looking at alternative modes of care, including care homes.

9.17 it is worth exploring how these communities can contribute to the spiritual care of people living with dementia in care homes.

Training, capacity building, and sharing practice

9.18 For any substantial change of practice to become rooted within a sector, there are always implications for the training of staff and for organisational capacity building. Evidence from the online survey and the qualitative discussions suggested that care homes would be open to appropriate training on how to address spiritual care issues. Only 3% of managers said that no training was required.

9.19 Key to any training will be establishing a clear and shared understanding of what is meant by 'spiritual care'. Also, the varied roles played by the different actors (residents themselves, family members and friends, staff, volunteers) could usefully be explored. Given the time constraints and pressure of work, it would be important to develop flexible learning opportunities that can fit round the working day, and be seen to have a relevance for day-to-day practice (rather than, for example, requiring college attendance),

9.20 We came across many examples of interesting and creative practice in the course of the research, ranging from small but effective ways of meeting an individual's spiritual care needs through to larger scale programmes. There would be value in creating ways of sharing practical approaches to spiritual care across the sector – especially through the use of ICT.

9.21 There is an important role for both residents and family members to play in the training process.

The current funding environment

9.22 Current pressure on care homes, due to reducing budgets and unfilled posts, 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 outside and making unreasonable demands on staff time and energies.

9.23 Two factors may be helpful in this regard. Firstly, the starting point for supporting the further development of spiritual care is the reality that it is already happening in many settings. This would argue in favour of an 'appreciative inquiry' approach, where current strengths are recognised, celebrated, and built on. Secondly, the potential for the use of volunteers means that, with sensitive management, there is scope to involve a wider set of stakeholders in this work.

Achievement of LCT remit

People living with dementia in care homes

9.24 The research process has begun to open up a focused debate about the reality of providing spiritual care for people living with dementia in care homes. If built on, especially through the work of the Purple Bicycle Project, residents in care homes will be more likely to have their spiritual needs and aspirations acknowledged and actively pursued. Residents themselves are central to this. They need to be supported to articulate what is important for them.

Families and carers

9.25 Families and carers of people living with dementia in care homes are a vital constituency to keep on board. Of all the stakeholder groups, they have the greatest

investment in the well-being of their loved ones, including their spiritual care in its widest sense. It will be important to engage them in any work related to spiritual care. They could contribute at a number of levels, including sharing experiences with others, and assisting with informal training.

Faith communities

9.26 The research has demonstrated some of the actual and potential roles for faith communities in engaging with the care home sector to provide spiritual support to people living with dementia. There is scope to expand this, particularly in relation to forging new, broader ranging relationships between care homes and their local faith communities. This needs to include non Christian faith communities.

Residential care home staff

9.27 Although some would not use the term, residential care home staff already play a vital role in providing spiritual care for residents. Staff acknowledge the importance of addressing the full range of human needs in a holistic manner. It will be important to have the debate about what constitutes 'spiritual care', and to clarify terminology. Staff would benefit from opportunities to share good practice and learn from the experience of others in this field.

Policy makers

9.28 The research has contributed to an embryonic debate about how best to address the deepest needs of older people as they come to the end of their lives - in particular those living with dementia. Policy makers will be better able to develop appropriate policy responses that takes account of the spiritual needs and aspirations of people living with dementia. Policy needs to be informed by the reality of good work 'on the ground', combining aspiration for quality improvement with a practical acknowledgment of current constraining factors.

10 Recommendations

10.1

Scottish Government

10.2 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.

Scottish Social Services Council (SSSC) and NHS Education for Scotland (NES)

10.3 The SSSC and NES should highlight the importance of spiritual care to colleges which offer SVQs and nursing qualifications. This could include access to the FIOP on-line course.

Faith in Older People (FIOP)

10.4 FIOP should play a major role in ensuring that faith communities have a good understanding of spiritual care in the context of dementia, alongside other conditions affecting older people.

10.5 FIOP should further promote its on-line courses ('Spiritual Care Matters') to care homes, hospitals, and faith communities, making use of these research findings.

10.6 FIOP should actively encourage and promote the use of volunteers in the care home sector.

10.7 FIOP should work with [full name] NDCAM and the Scottish Dementia Working Group to explore methods of incorporating an individual's story more effectively into the care plan.

10.8 FIOP should consider how best to build up the confidence and capacity of faith communities, so they are able to offer support to care homes – for both faith-based and more general activity.

10.9 FIOP should explore and disseminate examples of good practice of care homes and faith communities working together at local level (including any examples of faith communities 'adopting a care home'), so that the learning can inform and encourage similar ventures elsewhere.

Faith communities

10.10 Faith communities should consider how to further strengthen links with local care homes, building on existing work in pastoral care and practical assistance.

10.11 Further links should be developed between the Christian and non-Christian faith communities to share learning about addressing the spiritual care needs of people living with dementia.

Care Inspectorate

10.12 FIOP should discuss with the Care Inspectorate the potential to inspect around the enablement of spiritual care as an integrated element within the new national health & social care standards.

10.13 The Care Inspectorate should actively disseminate practical examples of spiritual care from within the care home sector.

10.14 The Care Inspectorate should promote the importance of addressing the spiritual care needs of staff as a pre-requisite for addressing residents' needs.

10.15 The Care Inspectorate should encourage a stronger focus on spiritual care in the care planning process, linking it to the concept to person centred planning.

Scottish Care

10.16 Scottish Care should actively encourage care homes to consider the value of volunteers and befrienders as a way of strengthening the scale and scope of their work.

10.17 Scottish Care should explore how spiritual care might be a part of the commissioning process.

10.18 Scottish Care should actively encourage care homes to develop a stronger focus on the spiritual care needs of both residents and staff

LCT

10.19 LCT should consider supporting initiatives which focus on:

- The development of good practice case studies of collaboration between faith communities and care homes at a local level
- The further development of online courses in spiritual care
- Capacity building in faith communities to enable them to better understand the needs of people living with dementia

Appendices

1. Scoping interviews topic guide
2. Telephone interview topic guide
3, Online survey

1. Scoping interviews topic guide

1. What are the critical contextual factors that the mapping should take account of (eg Scottish Government policy, individual faith groups policies and plans)?

2. What data is it desirable / possible to gather? This includes: likely number of projects involving people living with dementia; partner organisations; aims and objectives; approaches used; outcomes achieved.

3. What format should the data be collected in, and what is the best balance between quantitative and qualitative data?

4. What are the confidentiality and ethical issues?

5. Who is best able to provide the data, and what are the most effective ways of gathering it?

6. What barriers are there to gathering the data and what are the risks?

7. What are the most effective ways of keeping faith groups and other partners engaged and supportive?

8. What form should the output(s) from the mapping take? How should the results be most effectively shared with stakeholders?

2. Telephone interview topic guide

1. What do you see as the spiritual needs of your residents living with dementia?

2. What do you currently do that you might see as spiritual care for your residents living with dementia? Is this different from the spiritual care for residents who are not living with dementia? What practical examples are there?

3. How is the spiritual care of people living with dementia conceptualised? Is it seen as different to spiritual care for your residents more generally? If so, how?

4. Who is involved in this spiritual care? What roles are played by?
    - The person living with dementia
    - Family and friends
    - Care home staff
    - Care home volunteers
    - Faith community staff (ministers, priests, imams etc)
    - Members of their faith community / group

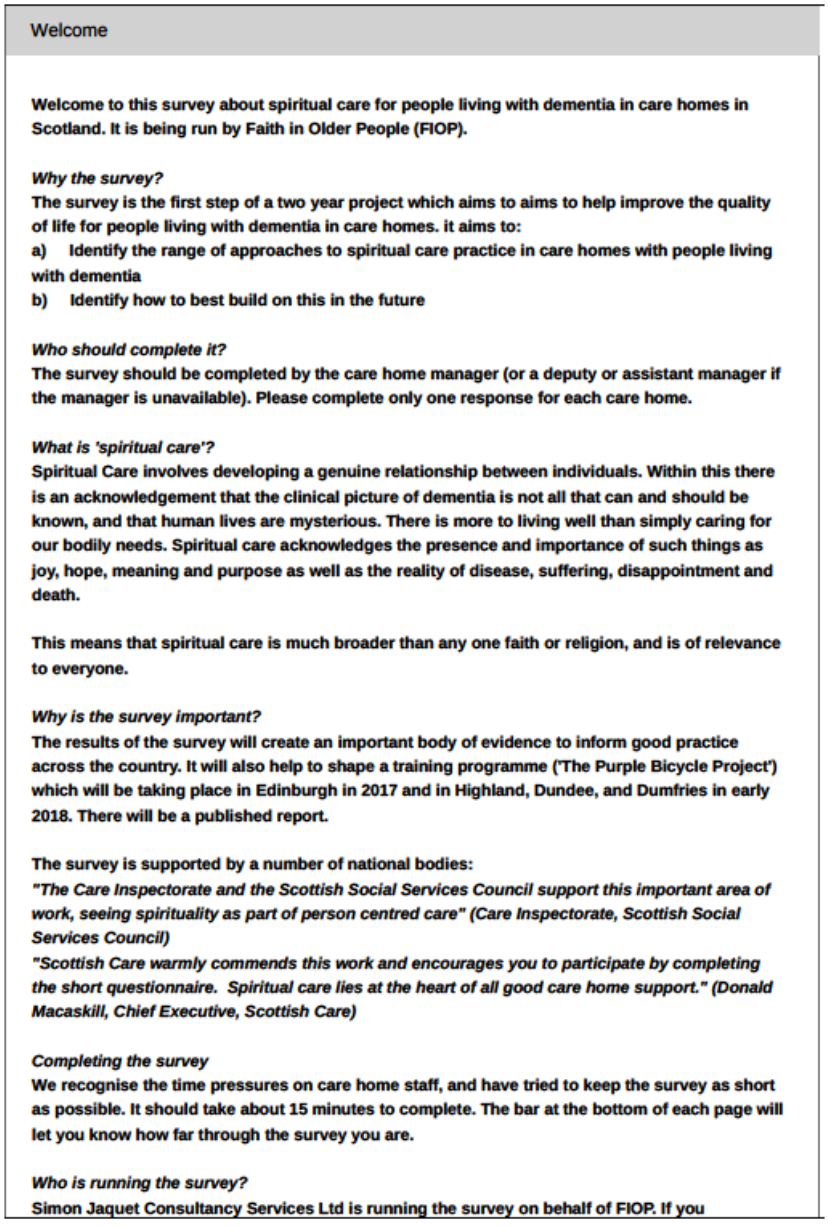
5. What would you like to see more of in the way spiritual care is provided? How could spiritual care for people living with dementia be improved?

6. Are there any spiritual care issues particular to your sector?

7. Is there anything else you would like to add?

3. Online survey

Double click on text to open survey.



Welcome

Welcome to this survey about spiritual care for people living with dementia in care homes in Scotland. It is being run by Faith in Older People (FIOP).

Why the survey?
The survey is the first step of a two year project which aims to aims to help improve the quality of life for people living with dementia in care homes. it aims to:
a) Identify the range of approaches to spiritual care practice in care homes with people living with dementia
b) Identify how to best build on this in the future

Who should complete it?
The survey should be completed by the care home manager (or a deputy or assistant manager if the manager is unavailable). Please complete only one response for each care home.

What is 'spiritual care'?
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.

Why is the survey important?
The results of the survey will create an important body of evidence to inform good practice across the country. It will also help to shape a training programme ('The Purple Bicycle Project') which will be taking place in Edinburgh in 2017 and in Highland, Dundee, and Dumfries in early 2018. There will be a published report.

The survey is supported by a number of national bodies:
"The Care Inspectorate and the Scottish Social Services Council support this important area of work, seeing spirituality as part of person centred care" (Care Inspectorate, Scottish Social Services Council)
"Scottish Care warmly commends this work and encourages you to participate by completing the short questionnaire. Spiritual care lies at the heart of all good care home support." (Donald Macaskill, Chief Executive, Scottish Care)

Completing the survey
We recognise the time pressures on care home staff, and have tried to keep the survey as short as possible. It should take about 15 minutes to complete. The bar at the bottom of each page will let you know how far through the survey you are.

Who is running the survey?
Simon Jaquet Consultancy Services Ltd is running the survey on behalf of FIOP. If you