

Impact case study (REF3)

Institution: University of Aberdeen		
Unit of Assessment: UoA31 (Theology and Religious Studies)		
Title of case study: The spiritual lives of people living with dementia		
Period when the underpinning research was undertaken: 2012-2014		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): John Swinton	Role(s) (e.g. job title): Professor	Period(s) employed by submitting HEI: 07/1997- present
Period when the claimed impact occurred: 2014-2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>The care and support of people living with dementia is one of the key medical, social and spiritual issues of our day. Whilst most of the focus and the majority of the funding goes into the thus far illusive search for cure, the most pressing need within society is for authentic understanding and effective communal care. This case study relates to Swinton's work on dementia care, which has succeeded in the re-framing of dementia as part of the spiritual life of the community and has had impact on local government, caring agencies, third sector organisations, dementia care providers and religious communities in the United Kingdom and internationally.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>The research that underpins this case study relates to Swinton's book <i>Dementia: Living in the Memories of God</i> and the subsequent Arts & Humanities Research Council (AHRC)-funded research arising from the publication of this text. In this book, Swinton uses practical theology to reframe and reconceive the nature of dementia itself and offers innovative proposals regarding our understanding and care for people living with this condition. The book aims to inform and enhance the care practices of ministers of religion, hospital chaplains, care professionals, and medical practitioners more generally. It serves to provide insight and resources to those actually living with dementia such that they can understand their situation more positively. Our cultural discourse about dementia has been framed in a reductive and profoundly negative way, concentrating almost exclusively upon the condition as a biological disease marked by neurological decline and the loss of the self. The book fundamentally challenges this assumption. It argues that dementia must properly be conceived and confronted as a social, cultural and spiritual phenomenon rather than merely as a narrowly biological one. In fact, even at the biological level there is strong evidence that psychology, culture, and spirituality can and do have an impact upon neurological processes. Dementia is best approached as a phenomenon which raises profound questions of <i>meaning</i>. Understood in this way, the complex human experience of dementia is seen to be one that occurs <i>within a community</i>. As such, it becomes clear that the fundamental questions of identity, memory, hope, and knowledge of God raised by our experience of dementia are, in reality questions whose very nature and significance can only be pursued in a properly social register—i.e., in ways that take seriously how the experience of dementia occurs in and through interpersonal relationships, rather than as something that 'happens' only within the confines of an individual brain. Dementia is not simply a medical condition because the experience of dementia is fundamentally a matter of the radical transformation of relations between an individual and communities. If that is so, then attention much be given to the particular kinds of communities within which dementia unfolds. With specific reference to the Christian community, the book argues that this involves reconceiving of human identity and personhood as realities that are fundamentally grounded in God's memory rather than merely preserved by the fragility of human memory as such. In this way, Swinton redefines dementia in a specifically theological light,</p>		

drawing its experience into contact with the story of the Christian gospel wherein believers discover their identities as they relate to one another but also to God, rather than achieving and sustaining them only on the basis of what we can or cannot remember or can and cannot do. Undertaken at a time when more than 850,000 people in the UK are living with dementia, this research offers deep hope and alternatives for care for a situation where hope is often absent.

Follow on research: AHRC Project—Exploring the spiritual lives of people with advanced dementia.

Based on the research and arguments set forth in the monograph, Swinton was subsequently awarded an AHRC follow-on grant in the value of GBP65,000. The aim of this award was to support actions by which the ideas developed in the study could be put into action within the context of advanced dementia. The follow-on project developed and tested a pathway to impact from Swinton's research which was designed to access and meet the spiritual needs of people with advanced dementia, and to allow fresh understandings and new modes of spiritual care for families, carers and people living with dementia. The process that emerged came to be called 'The Purple Bicycle Project' (PBP).

3. References to the research (indicative maximum of six references)

John Swinton: *Dementia: Living in the Memories of God* (2012) Grand Rapids: Eerdmans. The book won The Michael Ramsey Prize for Theological Excellence in 2016. This prize is awarded every three years by the Archbishop of Canterbury and celebrates the most promising contemporary theological writing from the global Church. The book was also shortlisted for the 2018 Grawemeyer prize in religion and played a significant role in Prof Swinton being awarded the 2018 American Psychiatric Association's Oskar Pfister award for an outstanding contribution to religion and psychiatry. The text has been translated into Finnish and Filipino.

'Developing an approach for meeting the spiritual needs of people with advanced dementia.' Grant awarded to Swinton: Arts and Humanities (AHRC) Follow On Fund. Commenced March 2013 - March 2014 (GBP61,635).

4. Details of the impact (indicative maximum 750 words)

Swinton's research has had transformative effects upon care for those with dementia in three principal ways.

1. Social care policy and practice

The research has had a clear impact on health and social care practice nationally and internationally. Alongside of the initiatives highlighted in section 2 (below), as a direct result of his work on dementia, Swinton was commissioned by Aberdeen's Health and Social Care Partnership to review dementia services in Aberdeen and to develop new innovative modes of practice. His report was accepted by the Partnership in 2016. They described it as 'excellent.' Tom Cowan, then head of joint operations for Aberdeen City Health and Social Care Partnership's (ACHSCP) states: '*Professor Swinton was invaluable ... in all matters relating to the care of older people – particularly those affected by dementia. He was an invaluable resource and strongly influenced my thinking both in Aberdeen, but also here in Edinburgh where we are undergoing a whole-system transformation – based on the Three-Conversations Approach – which reshapes our whole approach to support around the individual. This was very much influenced by John Swinton's work with us.*' (1) The report was formally launched by the Partnership at a select meeting of health and social care professionals in Aberdeen on December 13th 2017. It is now hosted and signposted on the website of Aberdeen Council of Voluntary Organisations (ACVO). (2) ACVO offers a wide range of services to support third sector organisations operating in Aberdeen. Policy and practice in Aberdeen and Edinburgh City Health and Social Care Services has been, therefore, changed by Swinton's work which has brought about systematic transformation in provision.

This impact on healthcare policy and practice has been extended internationally, particularly in Australia. As a direct result of his research, Swinton was invited to work alongside HammondCare,

a major care provider in Sydney which provides innovative care for people living with dementia. This work has included Swinton undertaking a nine-month residential role with the provider in Sydney. In that context, Swinton worked to explore the implications of his research for the organisation, including impactful changes to and reform of the management policy, practice, and organisational culture of HammondCare. (3) As a result of Swinton's involvement, three significant impacts have occurred within the organisation in relation to policy and practice:

1. HammondCare's main policy document, *Future Directions-2018-2022*, (4) now includes theological perspectives that were not considered previously, accounting for the spiritual dimensions of patients. This change is directly linked with Swinton's work with the Board and the Executive and has had a significant impact on the way the organisation's identity and controlling philosophy is shaping its ongoing operations.
2. The organisation now has pastoral and spiritual care guidelines which relate to all care staff. These were developed by Swinton and previously there were no formal guidelines for spiritual care.
3. Swinton has submitted a report suggesting that, in the light of his previous and current research, key changes to policy and practice are required within care staff approaches to people with dementia. The organisation has indicated that it intends to implement the findings of the report which will mean making significant changes to the ways in which staff are organised and care is provided.

2. *The Purple Bicycle Project (PBP)*

The PBP was developed so as to create a direct avenue to impact care provision with the findings from Swinton's research, converting research into action and impact. The PBP is a six-step process, arising from Swinton's research, that can be utilised by families and care providers to access the spiritual needs of people with advanced dementia. The approach involves creating an intentional 'community of communication' the individual – family, friends, carers and professionals. Through a process of narrating the person with dementia's spiritual needs, a spiritual care plan is developed which is then put into action and regularly reviewed. The plan outlines concrete strategies to enhance the person's spiritual life. The plan is laid out in a document shared by the various participants in the group, with each participant being given specific responsibility for a particular aspect of spiritual care. All of this is undertaken in a way in which the spiritual needs of people who have become non-verbal can be recognised and acted upon. For example, a person might be helped to participate in a gardening club; or to find meaningful and quiet places (often church buildings) where the person can be still; or to articulate their spirituality through art or music. PBP's unique contribution is the way in which the process presents these kinds of practices as a linked and coherent expression of care and concern for the spiritual lives of people with advanced dementia.

The process has been tried and tested in a variety of caring contexts: when it was originally piloted as part of the original AHRC grant itself (see Section 3), it received positive acclaim. Following this pilot, an extensive Scotland-wide project was undertaken in 2019 by a consortium of four organisations (Faith in Older People, Aberdeen University, Mowat Research, and Simon Jaquet Consultancy Services Ltd). The project was funded by the Life Changes Trust (a major funder for dementia care and research in Scotland) and has involved the introduction and application of the PBP process to provide spiritual care in care homes (5). The project was action oriented, bringing about change to policy and practice in dementia care by using Swinton's PBP as the chief educational directive around which the project and its impacts were built. Where previously spiritual care had not been an aspect of dementia care, it is now firmly on the agenda for policy and practice as a result of Swinton's research, and this training for care providers offered the means for this aspect of dementia care to be fulfilled. The project delivered PBP to 860 care homes and various regulatory bodies, including Alzheimer's Scotland and Age Scotland. Following this delivery, a report assessing this provision and its impact was published and disseminated to 900 individuals and organisations to inform and influence subsequent policy and practice around spiritual care provision, changing practice to include spiritual care provision holistically alongside other dementia care. (6) These changes in dementia provision in the area of spiritual care, resulting from Swinton's research through this project, have been rolled out as a result across care homes in Scotland and beyond, impacting provision in care of those with dementia, and making

this part of the Care Inspectorate's focus on person centred provision in terms of the whole human's experience. (7)

The project worked with five groups who could be impacted from the research: people with dementia, families and carers, faith communities, residential care home staff and policy makers. The project has five foci in terms of its impact on care provision:

1. Contrary to assumptions that people become less spiritual as they enter into dementia, Swinton's research clearly showed that the spiritual needs of people with advanced dementia can be elicited and acted upon through story. The process involves family, friends, professionals, ministers, etc., who know the person in different contexts telling stories relating to the individual's spirituality. These stories are recorded and represented in written and picture form and are used to inform the concrete strategies for care and to allocate responsibility to people within that group to work towards meeting the recognised needs. As a result, care provider's assumptions and practices have changed throughout Scotland to include spiritual care in provision.
2. Through a series of workshops and further engagement with staff the PBP has trained people in the practices and in new ways of understanding and acting upon the spiritual needs of people with dementia, creating spiritual capital and influencing provision and policy for individual providers who are now aware of, and required to consider, spiritual care provision.
3. The project has shown that the PBP training helps people in church organisations to understand dementia and the idea of spiritual care and has encouraged faith communities to become more active within care home situations, impacting church communities and pastoral provision. 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. The PBP process works to identify relatives, established volunteers, and local church pastoral carers who were already interested in this kind of care and inclined to engagement, and through its process creates a coherent centre around previously disparate and *ad hoc* approaches and provision can be reconceived and reorganised to better effect.
4. It is clear from feedback, that through PBP training, care home staff have changed and developed their thinking and practice around dementia and spiritual care: at the end of the process, they were able to identify clearly the nature of spiritual care and the relationship of this to the spiritual care of people with dementia. For example, one care worker in the report stated: *'I wasn't really sure what to expect of the two days but have definitely been inspired by the insight into a way into spiritual care.'* Another said: *'The subject of faith in older people was clearly addressed. The 6 steps were very helpful.'*
5. The report has encouraged further emphasis on spiritual care alongside of the human rights approach already evidence within Scottish Government policy, shaping government practice and policy. For example, this component of provision directly drawn from Swinton's research is now found in the Scottish Government's *Standards of Care for Dementia in Scotland: Action to support the change programme*, *Scotland's National Dementia Strategy*, and in the Life Changes Trust's *Human Rights and Dementia: A resource for creating better lives*.

As the result of the impact of this new mode of provision which arises from Swinton's research, the following recommendations were identified in a joint policy seminar on PBP with national stake holders and third sector users: 1) The need for the Scottish Government to 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. 2) The need for Scottish Social Services Council (SSSC) and NHS Education for Scotland now to highlight the importance of spiritual care to colleges which offer SVQs and nursing qualifications. 3) The need for the third sector organisation 'Faith in Older People' (FIOP) to 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), and to disseminate further its on-line courses ('Spiritual Care Matters') to care homes, hospitals, and faith communities, making use of these research

findings. The further need for FIOP now to work with the Scottish Dementia Working Group to explore methods of incorporating an individual's story more effectively into the care plan. 3) The need for the Care Inspectorate to inspect around the enablement of spiritual care as an integrated element within the new national health and social care standards, and to disseminate practical examples of spiritual care from within the care home sector. The further need for the Care Inspectorate to encourage a stronger focus on spiritual care in the care planning process, linking it to the concept to person centred planning. 4) The need for Scottish Care to encourage care homes to consider the value of volunteers and befrienders as a way of strengthening the scale and scope of their work, as well as to explore how spiritual care might be a part of the commissioning process. 5) The need for the Life Changes Trust to develop good practice case studies of collaboration between faith communities and care homes at a local level, as well as to build capacity in faith communities to enable them better to understand the needs of people living with dementia. (6)

3. *New Spiritual Capital among Churches, Care Providers and Religious Communities*

Since the publication of the research, Swinton has given over 150 lectures on issues around dementia and dementia care in the UK, Sweden, France, Switzerland, Canada, USA, Australia and New Zealand, reaching c. 8-10,000 with his research. This has not only created significant new spiritual capital, but also had concrete impacts especially on ecclesial policy and provision. As the Archbishop of Canterbury has noted regarding the significance of the impact of this global dissemination of Swinton's research: *'His work on dementia ... has informed my own response as well as enabled countless local church leaders and volunteers to reflect on their practice and relationships in this area. John's work has much wider impact. He regularly contributes to strategic work on vital issues for the church. Last year, he collaborated with my office in shaping a major piece of work on church and disability, which has yielded theological reflection, but also significant practical work on questions of access to buildings, on enabling local churches to gain confidence in becoming more inclusive, and in examining the Church of England's practice in discerning vocation. ... John's contribution to both thought and practice is invaluable, and reaches far beyond the church, in shaping how ordinary Christians relate to all those around them and participate in essential community care and wellbeing.'* (8) As a direct result of the global impact of his contribution to education and provision for those with disabilities and dementia, Swinton was awarded the Lanfranc award for Education by the Archbishop of Canterbury in 2020. Swinton was also invited to front a series on spiritual care for elderly people produced by AgeCare TV in Australia. This comprises of a series of ten television programmes exploring different dimensions of age care and dementia care. The series has had significant usage in Australia and in UK, Hong Kong and Canada, shaping the culture around spirituality and dementia and age care globally. Over 1,500 work booklets associated with the TV series have been purchased, and the uptake on the series has ranged through care workers and providers, policy writers, volunteers and church ministers. (9)

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. Email from Aberdeen City Health and Social Care Partnership on 24/09/2019
2. <http://acvo.org.uk/wp-content/uploads/2018/02/Swinton-dementia-report-14-12-2017-2.pdf>
3. Email from CEO HammondCare, Sydney, on 27/09/2019
4. HammondCare Policy Documents: *Future Directions 2018-2022 & Guidelines for Spiritual Care within HammondCare* (pdf)
5. Purple Bicycle Project Review Report: *Spiritual Care for People with Dementia in Care Homes* (pdf)
6. Life Changes Trust funded report: *De-Mystifying Spiritual Care*
7. Email from Scottish Care Inspectorate on 04/11/2019 and survey announcement: <https://www.careinspectorate.com/index.php/news/3706-spiritual-care-of-people-living-with-dementia-in-care-homes-survey-now-open>
8. Email from The Most Revd Archbishop of Canterbury on 24/09/2019
9. Email from Agecare TV, Sydney on 02/10/2019