**Creating Dementia Friendly Churches –**

**A Livability Project**

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**Introduction**

At present there are over 700,000 people with dementia in the United Kingdom and it is expected that by the year 2038 there will be 1.4 million. Dementia is a progressive, degenerative and largely irreversible syndrome, characterised by the widespread impairment in mental functioning (NICE 2007). People with dementia often become increasingly dependent and can place considerable physical, emotional and economic strain on their family.

Recent health and social policy towards people with dementia is outlined in the National Dementia Strategy, *‘Living with Dementia’* (DH 2009), and is further developed in directives, such as the Prime Minister’s *‘Dementia Challenge’* (DH 2012) *a*nd ‘*Caring for our future: reforming care and support’* (DH 2012a)*.*  This policy highlights the need to maintain respect and dignity in people with dementia, promote personalised support offering optimal choice and control, and create dementia friendly communities.

Livabilty is the largest Christian disability charity in the United Kingdom which includes community mission work that seeks to make communities a better place to live. Livability started in 2007 as a merger between John Groom’s and the Shaftsbury Society. Within the context of this paper on people with dementia, it is noteworthy that Lord Shaftsbury was a leading mental health reformer. Livability seeks to put the Christian faith into action by demonstrating the unique value of every individual and challenging the systems which deny people justice. Livability therefore is concerned with and has a commitment to people with dementia and ensuring that conditions surrounding their support promote respect and dignity, enables their independence, and facilitates the ability of people with dementia to make their views known and make worthwhile choices.

Churches are an important focus and source of support within the local community. This paper looks at recent developments within health and social policy and develops the idea of ‘dementia friendly churches’ which are churches that are inclusive and welcoming to people with dementia and their family carers, and provides them with a sense of belonging.

**Developments within Dementia**

Dementia is a clinical syndrome that includes Alzheimer’s disease, Multi-infarct dementia and Lewy Body Dementia and may include one of the following features: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, and out-of-character behaviour. The likelihood of developing dementia increases with age, and it is estimated that about 20% people have moderate to severe dementia by the age of 85.

Since the 1980s, limitations within the medical approach towards dementia have been recognised, notably that it leads to marginalisation and depersonalisation. Recent writers have highlighted how neurological ***and*** psycho/social factors affect people’s experience of dementia. This latter approach, called ‘person centred care’ highlights personhood which arises through relationships between the person with dementia and ‘*others, in the context of relationship, and social being’* [my italics]’ (Kitwood 1997, p. 8). The implication is that dementia occurs within the context of human relationships which are themselves constitutive of communities (Swinton 2012). The relational and communal nature of dementia is further articulated by Sabat (2001), Nolan et *al.* (2004), and O’Connor and Bartlett (2010). Brody (1971) sees people with dementia as having ‘excess disability’ which arises out of the structures, language and practices within a community and gives rise to more disability than can be explained by the disease alone. Social isolation, anxiety and depression are therefore often a consequence of dementia. Taylor (2004) highlights the importance of the community as a network of relationships that gives rise to self-identity and allows people with dementia to be recognised as people. As Swinton (2012) notes ‘any diminution of the self is first and foremost a diminution of community (p. 107)’. Therefore when a person develops dementia their experience not only depends on neurological pathology and interpersonal relationships, but also the community in which they live and the engagement between person with dementia and the community.

**Health and Social Policy**

Until recently people with dementia were not specifically addressed within health and social care policy. Prior to the mid-1970s, the dominant approach towards people with dementia was based on statutory support within large mental hospitals. This policy came into disfavour partly because of the difficulty maintaining the selfhood of patients and ensuring their personalised support. Thus recent policy draws on a community orientated model of mental health and a relational understanding of dementia.

Within recent policy, ‘the community’ is now seen as the primary source of support for people with dementia, through family, friends and neighbours. However, it was found that family members often experienced emotional stress supporting relatives with dementia and it was difficult to secure continued support from friends and neighbours. As health and social policy developed through the 1990s and 2000s, the idea that the local community constitutes ‘social capital’ was developed and consideration occurred on how it could be utilised. Thus a convergence occurred between theoretical developments in dementia studies and health and social policy, regarding the significance of local communities.

The longstanding disinterest in people with dementia within health and social policy has now been reversed and a swift succession of Government directives has emerged starting with the National Strategy for Dementia, *‘Living Well with Dementia’* (DH 1999) and gave rise to four priority objectives comprising (DH 2010):

• good-quality early diagnosis and intervention for all

• improved quality of care in general hospitals

• living well with dementia in care homes, and

• reduced use of antipsychotic medication.

More recently, health and social policy in general and to people with dementia specifically, has sought to highlight the need for personalised support and the development of supportive communities. In March 2012, David Cameron launched ‘*Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015’* which comprised four key commitments comprising:

* Dementia-friendly communities across the country
* Support from leading businesses for the *Prime Minister’s Challenge on Dementia*
* Awareness-raising campaign
* A major event over the summer 2012, bringing together UK leaders from industry, academia and the public sector.

The newness of dementia friendly communities and lack of research has meant they are difficult to define, though through conversations and interviews *‘Knowing the Foundations of Dementia Friendly Communities for the North East’*(Prior 2012)identifies the following aims of dementia friendly communities are to

* reduce stigma
* increase understanding and awareness about dementia and how to support people with dementia
* support people with dementia to remain active and included members of their communities
* support people with dementia maintain their independence for as long as possible

The Joseph Rowntree Foundation Report, *‘Creating a Dementia Friendly York’* (Joseph Rowntree Foundation 2012)developed the ‘The Four Cornerstone Model’ of dementia-friendly communities. This model asserts that people with dementia are at the heart of dementia-friendly communities, and sets out four constituent ‘cornerstones’ comprising place, people, resources and networks. The Report also heard a range of views about the role of different faith groups in York, and while some offered constant support and encouragement, others failed to recognise the changing needs of people with dementia in their congregations. One man commented,

*‘My wife was a regular attendee at church; she played the organ form many years. Now she doesn’t go because she is humiliated that she can’t remember when to stand up or sit down* (p. 39).’

We see ‘dementia friendly churches’ as a positive response by Christians and the Church to the anticipated rise in the number of people with dementia. We see this recognises not only the significance of the church in people’s life but also the important role of the church within the local community. In addition we see dementia friendly churches as a way of addressing mission to people with dementia and facilitating a means of support within the local community.

**The Church**

While Christians have historically influenced conditions for people with mental health problems, the dominant approach to people with dementia has been secular, notably bio-medical, and more recently with respect to person-centred care, humanistic.

Various writers have sought to develop a Christian perspective on people with dementia though it has often tended to be prescriptive and uncritical of ideology, organisations and practices within society. Other writers, Swinton (2012) notes adopt a broad approach towards spirituality which they claim is ‘generic and neutral’ (p. 6). Swinton (2012) develops an alternative to each of these approaches and puts forward a more critical perspective on dementia that

‘… offers a radical redescription of the world, turning it from a place of individualism and competiveness, a place where autonomy, freedom, and choice reign supreme, into a place where we discover the sovereignty and majesty of God, who has created all things’ (p.18).

Swinton sees dementia not only as ‘a product of damaged neurons’ but also arising through particular forms of relationship and *community* [my italics]’ (p. 107). He argues for a multidisciplinary approach towards dementia that draws not only bio-medical and psycho-social discourses’ but that the starting point should be theological as ‘it is impossible to understand the full meaning of being a human person without first understanding who God is and where human beings stand in relation to God’ (p. 160). Swinton thus brings to bear a range of theological ideas such as the Trinitarian nature of God, creation, the incarnation and the Kingdom of God to ‘redescribe’ dementia. Swinton puts forward different ways healing can arise in people with dementia that includes (1) critical thinking and redescription, (2) care as a reflection of Godly action, (3) recognition of holiness in the other remembering well, (4) lament, (5) visitation, and (6) hospitality amongst strangers.

Reynolds (2008) defines hospitality as ‘a radical form of reciprocosity that creates space for identifying and receiving the stranger as oneself (p. 142)’. The idea of hospitality draws on theological discourses throughout the Old and New Testaments, together with those developed within the Church. McFadden and McFadden (2011) see hospitality as fulfilling the obligation in Leviticus 25, 23 to welcome strangers and sojourners into their household, feeding them and providing them with their needs, as if they were part of their own family and also the reminder in Hebrews 13, 2 that by welcoming strangers some have entertained angels without knowing it. McFadden and McFadden (2011) see Mother Teresa and Jean Vanier as people who have opened their life to the poor, and have seen the presence of Christ in all they met. Swinton (2000) calls upon the church to display radical friendship to people with mental health conditions and to ‘rediscover its prophetic roots in the life, death and resurrection of Jesus Christ and to reclaim its identity as a friend and protector of the poor, the outcaste and the stranger’ (p. 9).

Dementia friendly churches draw on the idea of friendship and hospitality and describe churches that welcome people with dementia and their family carers, and offer them a sense of belonging. While dementia friendly churches seek to support people with dementia and offer a source of empowerment, they are also personal spaces that are modelled on God’s love for all and revealed through Jesus Christ.

Underpinning dementia friendly churches is the idea that God is seeking the outsider and stranger, and extending the Kingdom through new ways of addressing the needs of the poor, and giving rise to personal change and social and political development. Dementia friendly churches therefore correspond with the overall mission of the Church which Bosch (1991) sees as not only concerned with proclaiming personal salvation, but with also establishing peace, justice and reconciliation.

Livability are now developing a project concerned with the creating dementia friendliness which fits in well with support for dementia friendly communities in recent health and social policy, theoretical developments within dementia care, and concerns within the dementia care community. The project comprises three areas: the first offers dementia friendly training to all managers and staff within Livability care homes; the second, works in partnerships with churches of all denominations to develop dementia friendly practice, and the third to sets up an action research study that identifies what dementia friendly churches look like and identifies different challenges and their resolution within the creation of dementia friendliness. We believe our work is important, innovative and will address an issue that is concerning many people at this time. Underpinning our work is that belief that people with dementia are no less a person because they have dementia, and that the mission of the Church is to all people, not least people with dementia.

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