

Creating Dementia Friendly Churches – A Livability Project

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 a 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’* and *‘Caring for our future: reforming care and support’* (DH 2012).’ This policy highlights the need to maintain respect and dignity in people with dementia, promote personalised support that offers optimal choice and control, and create dementia friendly communities.

Churches are an important focus and source of support within the local community, and historically contributed to the development and reform of provision to people with mental health conditions. This document reviews recent developments in social policy and proposes an empirical study supporting the development of ‘dementia friendly churches’. This term describes churches in local community that are inclusive and welcoming to people with dementia and their family carers, and offers them a sense of belonging.

Review of Literature

Developments within Dementia

Numerous conditions display dementia, including 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 years.

Since the 1980s, the limitations of the medical approach towards dementia has been recognised, notably that it leads to marginalisation and depersonalisation. Recent writers have highlighted how neurological **and** psycho/social factors affects people’s experience of dementia. This latter approach, called ‘person centred care’ highlights personhood which is seen to arise 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 human relationships which are constitutive of communities (Swinton 2012). The relational and communal nature of dementia is further articulated by Sabat (2004), Nolan et al. (2004) and O’Connor and Bartlett (2012). Taylor (2004) highlights

the importance of community as a network of relationships that allow 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 their engagement with it.

Policy

Until recently people with dementia were not specifically addressed within policy on health and social care. 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, together with a relational understanding of dementia.

Within recent policy, ‘the community’ is now increasingly seen as the main source of support for people with dementia, namely 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, these are:

- 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'*(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. We see 'dementia friendly churches' building on the idea that people's experience arises in part through local communities of which they are a part, and facilitating present social policy regarding dementia friendly communities.

Church

While Christians have historically influenced conditions for people with mental health problems, the dominant way people with dementia have been seen has been secular, notably bio-medical, and more recently with respect to person-centred care, humanistic (Morse and Hitchings 2008) *Could it be Dementia?* Monach Books, Oxford.

Hurtley, R. (2010).

Various writers have sought to develop a Christian perspective on people with dementia though has often tended to be prescriptive and uncritical of ideology, organisations and practices within society. Swinton (2012) develops a more critical perspective of dementia that

'... offers a radical redescription of the world, turning it from a place of individualism and competitiveness, 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 as not only 'a product of damaged neurons' but also as 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 to 'redescribe' people's experience of dementia such as the Trinity, creation, the Kingdom of God and the incarnation. Following thorough analysis, 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 reciprocity 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 that have developed within the Church. McFadden and McFadden (2011) sees hospitality as fulfilling the command 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. They also see it as fulfilling the command in Hebrews 13, 2 to welcome strangers for by doing so some have entertained angels without knowing it. McFadden and McFadden (2011) see examples of hospitality in the work of Mother Teresa and Jean Vanier as people who open their life to the poor, and saw the presence of Christ in all they met. Swinton (2000, p. 9) calls upon the church to develop a radical friendship with people who have mental health conditions ‘and 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 are an innovative idea and describe churches that welcome people with dementia and their family carers, and offers them a sense of belonging. While dementia friendly churches seek to support people with dementia and provide a source of empowerment, they are 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 lost and extending the Kingdom by developing new ways of addressing the needs of the poor, through 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 also with establishing peace, justice and reconciliation.

Method

This study draws on two approaches to methodology that sees knowledge as socially constructed and giving rise to the organisation of society, the development of social networks, and leading to the inclusion and empowerment.

Practical Theology

The dominant approach towards dementia within the Church has tended to apply theological principles to inform and support people with dementia and their family carers. While this approach may be helpful and offer comfort to people with dementia and their family carers, it has tended to be uncritical of mental health provision and socio-political structures within society. Swinton (2000) argues that ‘Doing practical theology involves a process of critical reflection on the actions of the church, in the light of gospel and tradition, and in constructive dialogue with other disciplines (p. 11).’ The approach seeks first to identify and elaborate the views of participants within social networks, and then moves to theory and then returns to practice with a revised understanding.

Action Research

Carr and Kemmis (1986) says that action research is concerned with improving and understanding of practice and the situation in which it takes place. Other writers have a broader understanding of action research, and see its focus going beyond practice and concerned with society and its development (Bogdan and Biklen 1992: p. 223). Action research sees its practitioners marshalling data and through a systematic process of reflection to expose unjust practices, while recommending actions requiring change. As with practical theology, action research starts with practice and practitioners, actively involved in the cause for which the research is conducted.

Aims

The aims of the research are

To identify

- what dementia friendly communities could/should do,
- difficulties in developing a dementia friendly community and how they are addressed,
- activities and their benefits to people with dementia and their families,
- the impact of developing dementia friendly church practices within the church congregation,
- theological issues relating to people with dementia and their support through dementia friendly churches.

Stage 1

The following tools will be prepared prior to collecting data in Stage 2 and Stage 3 of the study

- i. Interview schedule regarding respondents views on desired activities that dementia friendly churches should do
- ii. Written account of the study for participants and Consent Form.

Stage 2

Ten people comprising people with dementia and family carers (including those with a relative living in a care home or hospital) will be chosen from people who are active in a church. They will be invited to attend an open ended interview using the Questionnaire developed in Stage 1 of the study and will be led by the researcher. A second person will attend the interview and record all significant and relevant comments made by the respondents.

Stage 3

Five churches seeking to develop a dementia friendly church will be selected comprising a range of traditions and denominations. The researcher will attend a series of meetings with the Dementia Friendly Church Planning Team, prior to and following the introduction of dementia friendly practices, policies and activities. The Team will be led by a church leader and will comprise at least one person who has dementia, or who is a family carer. The

researcher will introduce the idea of dementia friendly churches to the Team and outline the findings of Stage 2 of this study. While overall leadership of the meetings will be undertaken by the church leader, the researcher will guide certain areas of discussion, particularly those relating to difficulties that have emerged concerning the promotion of dementia friendliness and their resolution. In addition stories of success and achievement will be discussed in the meetings, and lessons learnt from these examples. The researcher will make notes immediately following the meeting. The researcher's attendance at the meeting will be for six months commencing at the start of the project with a particular church.

A full report of the study will be written giving an account of its progress, findings and implications for the future development of dementia friendly churches. This document will be sent to Senior Staff within Livability, and other interested groups and organisations, including participating churches. Smaller versions, this document together with examples of good practice and stories of success and achievement will be written for journals and web sites. The findings of the study will be disseminated at conferences.

Ethical Implications

All participants in the study will be given a written outline and verbal description of what the study involves. All participants' questions will be clearly and fully answered. Following this, each participant will be invited to sign a consent form relating to their participation within the study. Should any participant wish to leave the study at any time they will be free to do so within any adverse implications.

The names of each participant and participating churches/and other place names will not be revealed in any account of the study, and pseudonyms will always be used. Data collected in the study will be kept by the research. A password will be used to protect data contained on a lap top and written data will be kept in a locked drawer.

Should any person become distressed by the study they will be referred to a health care professional or church leader; whoever is the most appropriate. All people talking to people with dementia and their family carers will be asked not to share private and confidential information with others who are not part of the Team.

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