

Changing the conversation: from suffering with dementia through dementia as a disability rights issue, to a deeper theological perspective.

Introduction

As an invited key note speaker at a conference on dementia I was intrigued to receive an email attachment alongside the details of the conference. The attachment outlined specific dos and don'ts of addressing an audience of people who might have dementia or who might be caring for people with dementia. In particular speakers were given specific direction on the acceptability or not of language used in relation to dementia. Of note speakers were asked to talk of people 'living with' rather than 'suffering from' dementia. However, this attachment was far from being a nod to a 'snowflake generation', a generation that might take easy offence. Indeed it parallels the kinds of delicate conversation over language that have been going on for some time in disability studies. Instead, as with conversations around disability, this attachment was part of a sustained project to change perceptions about dementia. While there can be no objection to conversations that call out unjust discriminatory attitudes, the move to oust suffering from the conversation and replace it with a focus on living well is an interesting one, especially where living well appears to be equated with being empowered to make choices, exercise rights and self-representation. These abilities associated with living well with dementia are precisely what are lost as dementia takes its course. In this paper I explore how the impetus to change the conversation on dementia has been influenced by disability studies. I then question the wisdom of a focus on rights and choice and the avoidance of suffering through theology and especially the writing of Pope John Paul II, who takes both human rights and the significance of suffering seriously.

Trajectory of the conversation

The project to challenge discriminatory attitudes to dementia can be traced from the work of the Alzheimer's Society to policy discussion papers and subsequent projects that listened to the lived experience of people living with dementia. The Alzheimer's Society, set up in the UK in 1979, has a clear and simple vision: 'a world without dementia'. In the meantime the Society has a mission to 'transform the landscape of dementia forever'. According to the Society's mission statement, 'until the day we find a cure we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice' (Alzheimer's Society, *Vision, mission, values*). Without pulling any punches the Society recognises that 'dementia can devastate lives' however one of its main strategies is to 'change the conversation on dementia' (Alzheimer's Society, *Strategy*).

The urge to change the conversation has come about through the growing realisation that dementia is 'one of the greatest challenges facing our ageing society' and it is a challenge that demands 'concerted action' (*National Dementia Declaration*, 2010, p.2). Notably, dementia organisations now stress that dementia is not only associated with ageing. In 2009 the UK government had published a five year National Dementia Strategy in the light of the rising costs of dementia care. Although organisations involved in dementia welcomed the strategy they were concerned about what would happen when the strategy came to an end in 2014. Moreover they also pointed out that the government 'can only do so much': what was required was 'radical and sustainable change' in the way in which society responds to dementia (*National Dementia Declaration*, 2010, pp.2, 3). To kick-start this change in 2010 some 44 dementia organisations, people with dementia and their carers got together to create the *National Dementia Declaration*. The Declaration describes 7 'desired outcomes' or Statements that people with dementia and their carers would like to see in their lives. The Statements each begin with a bold 'I' and reflect the desire to have control or influence over decision-making, to exercise choice including choice of support, to have access to relevant

information, to live in an enabling and supportive environment, to have a sense of value and belonging, and to be aware of research to improve the lives of people with dementia.

Alongside the publication of the Declaration the Dementia Action Alliance was launched to field a ‘major plan of action to change the experience of living with dementia in England for good’ (*National Dementia Declaration*, 2010, p.2).

Following this sustained project to change the conversation a policy discussion paper was published in August 2015 by the Mental Health Foundation entitled *Dementia, rights, and the social model of disability: a new direction for policy and practice?* This paper explicitly linked dementia with disability. Publication of the policy paper was supported by the Joseph Rowntree Foundation whose aim is to build a more inclusive society.

Acknowledging that its starting point is novel (Mental Health Foundation, p.6), though how novel it is remains contentious, the policy paper directly uses the success of disability rights movements to challenge what it sees as the prevailing medical model of disability as applied to dementia. In the medical model the person’s disability or condition is considered to be the problem, thus the ‘problem’ tends to be in the individual. This is contrasted to the social model of disability which locates problems in discriminatory social structures. It is noteworthy that the policy paper only makes reference to these two models.

From the outset the policy paper unreservedly endorses the social model of disability as the way forward for interpreting dementia care and it cites the development of dementia-friendly communities as a successful example of the model in practice (Mental Health Foundation, p.1). Undoubtedly the ground-breaking work of Tom Kitwood provides a foundation for the shift towards the social model and in Appendix C the policy paper draws attention to Kitwood’s term ‘malignant social psychology’ that describes pervasive negative attitudes and abusive behaviours and practices towards people with dementia. Kitwood himself observes that this malignant social psychology not only undermines personhood but it

also directly affects the well-being of the person with dementia and the possibilities of living well with the condition (Kitwood, 1997). In its urge to create a new dialogue and to view dementia as primarily a human rights issue (Mental Health Foundation, p.4) framed within social experience the policy paper stresses the right for people living with dementia to be protected from discrimination and the right to be supported in their own decision-making. This is clear in its section on relevant legislation where the policy report names not only the Equality Act 2010, Mental Capacity legislation and the Care Act 2014 but also the UN Convention on the Rights of Persons with Disabilities (CRPD), the Human Rights Act 1998 and the European Convention on Human Rights (Mental Health Foundation, pp.7-11).

One of the main objectives of the social model of disability is to bring about a rethink of the language used to describe disability and, for the policy paper, dementia. As the policy paper explains and drawing attention to the way in which the person with dementia is called 'the sufferer', 'language is critical as it is one of the ways in which barriers are created in communities and exclusion and oppression are maintained' (Mental Health Foundation, p.23). This concern over language has been very much honed through the experience of those working in disability where 'language guidelines' have become standard (see for instance, the UK government Department for Work and Pensions, 2014).

To some people the link between dementia and disability may not seem immediately obvious. As the sociologist and disability rights advocate Professor Tom Shakespeare and his colleagues put it, dementia and disability seem like 'planets spinning on different axes'. Nevertheless Shakespeare et al also point out that these planets are aligning (Shakespeare et al, 2017) as perhaps demonstrated by the work of the Mental Health Foundation. However once it is seen that the change in conversation is in part propelled by the desire to change attitudes, in particular discriminatory attitudes, then the connection becomes clear. Following the guidance on the Equality Act 2010 as set out by the Office of Disability Issues disability

is a protected characteristic and the Act prohibits discrimination not only against people who are disabled but also against others who are treated less favourably because of another person's disability (Office for Disability Issues, 2011 p. 6). A person is considered to have a disability if the person has a physical or mental impairment that has a substantial and a long-term negative effect on that person's ability to do normal daily activities, for example the person takes longer to complete tasks such as dressing (Office for Disability Issues, 2011 p. 5). Although the Act is concerned with the effects of disability rather than the disability itself, it is noteworthy that in the guidance forms of dementia are named among disabilities that are progressive, that get worse over time (Office for Disability Issues, 2011 p. 7, 8). By making a connection between dementia and disability not only is there added protection against discrimination under the Equality Act, but also advantage can be taken of the CRPD. Again, the United Nations Economic Commission for Europe notes that dementia can be considered a disability and so be linked to the rights set out in the CRPD (UNECE 2015). Moreover the person with dementia and those caring for them may be able to qualify for a range of services, schemes and benefits. As the dementia activist Helga Rohra explains, dementia, and in her case Lewy Body dementia is a disability. However, she adds if a person can come to terms with the disability then they can live a fulfilling life (Rohra, 2016, p.9). In her book *Dementia Activist: Fighting for Our Rights* she reminds people with dementia that life is still ahead of them: 'don't let yourself be shunted off into the sidelines. Stand up for your rights, and remember "Nothing about us without us!"' (Rohra, 2016, p.137).

In tandem with the work of the Mental Health Foundation and also supported by the Joseph Rowntree Foundation, reflections from people with dementia were collected and collated into two reports to form the backbone of a website, *Dementia without walls*. The project ran from June 2012 to the end of 2015 and one of its spin-offs is the Dementia Engagement and Empowerment Programme (DEEP), a national user movement of people

with dementia. DEEP aims to raise awareness about dementia, influence policies and strategies, and ‘challenge the existing narrative about what it is like to live with dementia’ (DEEP, 2015a). As with the Mental Health Foundation policy paper, one area of concern for both the *Dementia without walls* project and for DEEP is the way in which language is used.

This concern is powerfully expressed by Jo Bennett who has early onset dementia and was one of the contributors to the *Dementia without walls* project. As Bennett explains in a radio interview, ‘there is no such word as suffering with dementia, we are living with it’. Crystally clear on this change in language, Bennett points out that ‘suffering’ has now been ‘erased’ in favour of ‘living with’ dementia. For Bennett the focus must now be on learning to think in the present and on developing ways of adapting to a life with dementia. As a language guide produced by DEEP notes, ‘the language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves’: ‘dementia sufferer’, a phrase that makes people with dementia want to ‘curl up and die’ is one of the phrases to avoid (DEEP, 2015b). The reasoning behind this challenge to the language is not primarily to deny suffering, after all people do at times suffer. Rather people with dementia do not want suffering to define them. As another dementia voice Tommy Dunne explains, they do not want to be seen as ‘shells of their former selves’. For many the word ‘suffering’ implies being a victim, someone who requires pity or someone who bears the burden of impairment, passivity or a person who does not live a full and personal life.

The current state of the conversation

Disability rights movements have long recognised the power of presenting the lived experience of people in order to change attitudes. Moving on from the *Dementia without walls* project, in 2017 the Alzheimer’s Society in partnership with Ipsos MORI produced a report entitled *Turning Up The Volume: unheard voices of people with dementia*. The aim of

Turning Up The Volume was to let the voice of people living with dementia and the voice of their carers come through. One interesting outcome from the findings of *Turning Up The Volume* is a reformulation of the *National Dementia Declaration*. The Declaration had set out a list of 7 Statements of what life should be like for people with dementia. As *Turning Up The Volume* explains, the Dementia Action Alliance, now consisting of some 150 organisations and groups, puts the person with dementia ‘at the centre’ of the refreshed statements. However, significantly, whereas the 2010 Statements focused on the ‘I’ of the person, the revised 2017 Statements speak of ‘we’ to encompass ‘people with dementia, their carers, their families, and everyone else affected by dementia’ (Alzheimer’s Society, 2017, p.25). Certainly the language of *Turning Up The Volume* is more rights-based than the previous Declaration. Nevertheless, the emphasis is on recognising the person’s right to contribute to society, to be included in communities, to be respected as ‘partners in care’ (Alzheimer’s Society, 2017, p.27). *Turning Up The Volume* confidently asserts that with ‘the right level of support from government, professional care providers and society’ people with dementia can be enabled to live well (Alzheimer’s Society, 2017, p.29). Moreover, *Turning Up The Volume* is adamant that ‘people affected by dementia still have an incredible amount to offer to their community. If appropriately supported they can continue to play an active and valuable role even years after diagnosis’ (Alzheimer’s Society, 2017, p.35). It would seem that the shift towards relationships may indicate at least implicitly a move away from the social model to a relational model of disability. The more nuanced relational model may reflect better both the personal experiences of people with dementia and the complexity of a condition that is not simply made a problem by the environment or social attitudes (see Shakespeare et al, 2017). As Rohra says, ‘not having our disability written all over our faces is a blessing and a curse in equal parts’: on the one hand Rohra enjoys walking down the street without being instantly recognised as a person with dementia, on the other hand she has

to explain her need for extra support (Rohra, 2016, p.139). Rohra notes that dementia deprived her of the ability to write long pieces, especially about her own experiences and so she had a partner writer for her book *Dementia Activist: Fighting for Our Rights*.

However the problems over language and getting it right remain. This is illustrated by those like Shakespeare, Zeiling and Mittler who question phrases commonly used by people with dementia, their carers and organisations themselves. Shakespeare et al point out that phrases such as ‘dementia friendly’ to describe communities have been seen as ‘patronizing and inappropriate’ since they seem to buy into the idea that people without dementia should be kind rather than viewing dementia as a human rights issue (Shakespeare et al, 2017, p.9).

These deeply held views about the use of language have been respectfully called into question by Associate Professor Ruth Bartlett, Lore Windemuth-Wolfson, Keith Oliver, and Tom Denning in their guest editorial ‘Suffering with dementia: the other side of “living well”’ published in 2017 in the journal *International Psychogeriatrics*. Bartlett et al are keen to broaden the dementia debate and in their editorial they wish to ‘redress the balance that is disturbed by a relentlessly positive view of living with the condition’.

Bartlett et al critique the emphasis on living well with dementia because of what they see as its corollary, that there is the possibility of living badly with dementia. They suggest that suffering in itself is hard to define since suffering is intensely personal and they accept that ‘dementia sufferer’ is a demeaning label. Nevertheless they say that even though people do live well with dementia, the condition always involves suffering at some point whether it be at the onset of the condition when a person begins to realise all is not well, or when the person undergoes fearful experiences or lack of control over life, or social suffering in the way the person is treated. Although the authors acknowledge that the intention to move the conversation away from ‘suffering from dementia’ to ‘living with dementia’ is intended to promote personhood, they argue that this in fact risks a denial of suffering. Instead they claim

that there is a need to recognise the suffering aspect to satisfy two important areas: first from a legal viewpoint so that people with dementia can be identified as disabled for the purposes of the Equality Act and so that reasonable adjustments can be made, and second from a humanitarian point of view. Under the humanitarian view the person and the family or carers are recognised as suffering in different ways and to varying degrees in the realms of the physical, emotional and existential. This recognition of stress and suffering calls for social action. Certainly the authors accept that the turn to living well is important, however it cannot be simply an aspiration or the concern of people with dementia themselves. In recognising that people with dementia do indeed suffer the authors believe that they are promoting ‘a more realistic understanding of the dementia experience’ (Bartlett et al, 2017, pp.177-179).

Although Bartlett et al do not address the medical versus social model of disability debate, their critique is precisely that of those who point out that disability cannot be reduced to the outcome of social barriers alone and that impairment, and suffering, are realities (Matthews, 2013, pp.25-27). However it seems to me that this debate between those who demand to speak about either ‘living with dementia’ or ‘suffering with dementia’ is not about the experiences of dementia per se. After all, both sides accept that dementia is a devastating and debilitating condition, and the move towards a change of language is a call to a change in attitudes and to an acknowledgment of human rights. Rather it seems that the debate turns on understandings of suffering. For both sides it is suffering that carries all the negative connotations. On the one hand the difficult realities of dementia, its ‘sufferings’, need to be acknowledged; on the other hand these ‘sufferings’ are implicitly associated with what demeans the person, and in particular with what diminishes personhood. As the Department of Work and Pensions says, suffering suggests discomfort, constant pain, passivity and a sense of hopelessness (2014, 1.2). Recall, to be called a ‘sufferer’ makes people with dementia want to ‘curl up and die’ (DEEP, 2015).

In this discourse theology, and especially the theology of Pope John Paul II can perhaps help because this theology does take both rights and suffering seriously, and in doing so it maintains to the utmost the full human dignity of being a person. Moreover it can bear the tension between the reality of suffering and living life well. Certainly the voices of other theologians who talk about human dignity are relevant in this discourse. John Swinton in particular has developed a theological understanding of personhood that grounds personhood and the dignity of being human in the knowledge and memory of God (Swinton, 2012) and thus Swinton gives due priority to the action of God in the lives of human beings. Swinton emphasises that ‘persons exist independently of their relations. They are to be valued, loved, and cared for as persons simply because they are human beings’ (Swinton, 2012, p.159). In this way Swinton moves beyond a purely relational model of disability, though relation remains vital. According to Swinton ‘affliction’, the particular suffering that dementia brings, can be overcome by love and the ‘hospitality’ of others (Swinton, pp.264-268). Notably, for any discussion on autonomy and rights Swinton tends towards the idea that ‘autonomy is a human idea that functions to separate human beings from one another and mark them out as “individuals.” It is, however, an illusory idea’ (Swinton, p.162). Swinton takes the view that ‘we are not the authors of our own stories’ because, he says, ‘we have no option other than to participate in the story that God has written into creation’ (Swinton, p.163). Theologically speaking this is of course true, at least in one sense. God is the Creator and Sustainer of our lives and we are his gifts. Nevertheless, we are asked to participate freely in our life’s story and this is why autonomy has an important place in human life: we can make, break and shape our own lives.

The connection between self-representation, rights, disability and the language of suffering is perhaps made explicit in disability theologies where the disabled suffer because of social injustice (Eiseland, 1994, p.62): they are disabled by discriminatory attitudes and

inaccessible environments. These theologies often take their inspiration from liberation theologies. Nancy Eiseland's iconic re-imaging of God as physically disabled yet also as a new model of wholeness (Eiseland, 1994) is a good example of how lived experiences of disability can take up a social model of disability to challenge not only societal attitudes but also more traditional theology. However it is perhaps more difficult to re-image God as cognitively impaired, though Peter Kevern asks us to consider the possibility that Christ 'demented' on the Cross (Kevern, 2010). Indeed, Eiseland herself says that an exploration of the experiences of people with intellectual disabilities lies outside the scope of her work and her theological argument (Eiseland, 1994, pp.37-38). Moreover there is a tendency for some liberation based theologies to claim that theology promotes disability simply as virtuous suffering and this is one reason why Eiseland seeks to change the 'symbol of Christ, from that of suffering servant, model of virtuous suffering, or conquering lord, toward a formulation of Jesus Christ as disabled God' (Eiseland, 1994, p.94). There is also a tendency to view a person's disability as defining both identity and character, hence Eiseland's focus on God as disabled and her comment that she does not want to be 'fixed' in heaven (1994, pp.73-74). These liberation approaches seem to be unhelpful both for a recognition of the reality of suffering and for those with dementia who do not want to be defined by their condition.

Of course it is important to avoid the twin dangers of seeing suffering as somehow virtuous or that in speaking about living well with dementia society simply celebrates those who seem to overcome tragedy in much the same way as Sharon Betcher says people with disabilities have been used in a culture that relies on a 'norm' of how people should be (2010, p.109). Nevertheless a reflection on Pope John Paul II's theology of suffering can go beyond making public opinion simply sensitive to people who are suffering and even beyond a call to action. This is because Pope John Paul focuses on Christ, on the person who suffers

themselves and how the person remains a principal actor in his or her life, and on the way in which a life of suffering has not only meaning but also a deep significance. Moreover, and in contrast to thinkers like Eiseland for whom Jesus is a model for the disabled, Pope John Paul II sees both similarity in the suffering of Jesus and every human being, yet also radical dissimilarity that can only be understood in part. This is because the suffering of Jesus is unique: it is the suffering of the God-man (Matthews, 2013, pp.142-143).

On human rights, dementia and disability

In *Dignitatis humanae*, the Second Vatican Council Declaration on Religious Liberty the Catholic Church expressed a positive stance towards the promotion of human dignity and the ‘rightful freedom’ of people (*Dignitatis humanae* n.1). To underscore this, Pope John Paul II acknowledged that the growing number of human rights declarations demonstrate ‘a growing moral sensitivity, more alert to acknowledging the value and dignity of every individual as a human being’ (Pope John Paul II, 1995, n.18). These rights and corresponding duties are not the result of the will of states or legislatures but are universal, inviolable, inalienable, and an expression of ‘personal dignity’ that flows directly from being a human being (Pope John XXIII, 1963, n.9, 44). Of course Pope John Paul II recognises that human rights have often been violated or distorted. Nevertheless he calls on the Church and ‘all people of good will’ to ensure that ‘the acceptance of their “letter” mean everywhere also the actualization of their “spirit”’ (1979, n.17).

Undoubtedly, in stressing dementia as a ‘human rights issue’ advocates are drawing attention to some of the violations and distortions that concern Pope John Paul II. However there is a difficulty in seeing dementia and disability as principally human rights issues. One major distortion that impacts explicitly on dementia and on disability is especially prevalent in today’s field of healthcare, and this is the tendency to conflate rights and human dignity

with autonomy (see Macklin, 2003). The problem is exacerbated by the tendency to interpret autonomy simply as the freedom to choose where an autonomous decision becomes merely a matter of capacity with no necessary link to either reason or moral thinking. This is not to say that the freedom to make choice is utterly suspect. As Saint Augustine confirms the good of free will is indeed a great good, but the difficulty is that this freedom is a captivated freedom, *liberum arbitrium captivatum*, a freedom of indifferent choice, a freedom of pure autonomy, ‘freedom which makes men think they are free when they have no masters’ (Augustine, *Free Choice of the Will*, 1.15, 32). This freedom is a lesser good than the good of graced free will. Free choice freed *liberum arbitrium liberatum* is the freedom to make the right choice and it is freedom enabled by the gift of God’s grace (Augustine, *Grace and Free Will*, 31). Pope John Paul II similarly explains that while freedom and autonomy are significant, human beings do not have unlimited autonomy and a correct interpretation of autonomy is not so much total self-rule as harmonising freedom with the will of God through grace (Pope John Paul II, 1982, pp.27, 84). In terms of autonomy as empowerment, human dignity and freedom are not derivatives of power. Rather the dignity of being human, of relationality, by analogy with the relations in the Trinity, and of self-gift, following the model of Christ are truly part of human nature.

The conflation of dignity and the ability to exercise free choice raises two problems in particular: firstly it feeds into demands to make autonomy an absolute principle in healthcare, thus reducing the work of healthcare professionals to merely the delivering of choice. Certainly choice is highly significant in people’s lives, as demonstrated by the 7 Statements of the *National Dementia Declaration*. However, the issue of enabling choice becomes much more complex especially when the stakes are high, as evidenced by the debates surrounding legislation that seeks to make death a healthcare choice through assisted dying. Secondly, it fosters a hierarchy of disability which favours the autonomous person over the non-

autonomous human being where the intellectually disabled person or the person with dementia who no longer has capacity for decision-making inevitably ends up at the lower end of the hierarchy and so risks further marginalisation. Rather than setting individuals against each other as where the autonomies of patients and doctors collide or where there is a hierarchy of disability, Pope John Paul II reminds us that ‘God entrusts every human being to each and every other human being’ (Pope John Paul II, 1988a, n.30).

And on suffering

In his encyclical letter *Evangelium vitae, The Gospel of Life* Pope John Paul II observes that people find it difficult to face and accept suffering. It is important to note that the Pope does think that suffering should be alleviated where possible and it should always be met with ‘companionship, sympathy and support’ (Pope John Paul II, 1995, n.67). However he is concerned that people may easily become overwhelmed by their frailties or that a ‘misguided pity’ or an ‘understandable even if misplaced compassion’ may lead to eliminating suffering by eliminating the sufferer. Pope John Paul II is especially troubled by a current mentality that has replaced the criterion of personal dignity with the criteria of ‘efficiency, functionality and usefulness’ or simply the exercise of autonomy (Pope John Paul II, 1995, n.23). Indeed the Pope argues that where people ‘are considered not for what they “are”, but for what they “have, do and produce”’ then this is ‘the supremacy of the strong over the weak’ (Pope John Paul II, 1995, n.23). This concern seems to be precisely the concern articulated by DEEP in its call to move to a language not of suffering but of living with dementia. However rather than abandoning the language of suffering the Pope suggests that ‘a religious outlook’ could help to provide ‘a positive understanding of the mystery of suffering’ (Pope John Paul II, 1995, n.15). This appears to go beyond Bartlett et al’s challenge to acknowledge the reality of suffering by including it in the discourse around dementia since the Pope here is stressing

suffering as both mystery and as having positive value when seen from a theological perspective. To be sure the Pope does think that suffering is ‘an evil’ and ‘a trial’ yet through God’s action it can be transformed into a source for good (Pope John Paul II, 1995, n.67). Theology speaks about suffering in terms of witness to the love and mercy of God and to the call to discipleship, to follow Christ (Pope John Paul II, 1992a).

Theology has long recognised that human suffering is not a subject for easy answers. Moreover suffering challenges faith (Pope John Paul II, 1995, n.31). In order to reflect and pray about the complexity and perplexity of suffering Pope John Paul established the World Day for the Sick, starting in 1992, to be celebrated on 11 February. Central to his concern to promote the personal dignity of every human being, the Pope used these world days to speak not only to carers and healthcare workers but also to people who were sick and suffering, and he specifically designates people who are sick and disabled as ‘the main actors’ of these world days (Pope John Paul II, 1992b, n.5).

For Pope John Paul II the phrase ‘main actors’ is highly significant. Although written some 15 years before *Turning Up The Volume*, like the report the Pope is not casting people who are sick and disabled in a ‘sick role’ that points to vulnerability or calls for pity. Nor is the Pope simply endorsing the kind of person-centred care that tends to equate good care merely with empowering patient autonomy. Instead he explains that people with disabilities, and here we can include people with dementia, are ‘main actors’ in two principle spheres: first they are, like all other people, ‘also sent out as labourers in the vineyard’ (Pope John Paul II, 1988b, n.53; 2000, n.7); and second, Christians honour God ‘in the human body, both under the captivating aspects of strength, vitality and beauty and under those of fragility and decline’ (Pope John Paul II, 1998, n.9). Moreover every person has a part to play in community life.

One much neglected way of being a ‘labourer in the vineyard’ is that of being a prophet. A prophet proclaims a truth that others may not see, a truth that in fact saves. Generally, most people live very narrow lives, lives that are centred on cognitive abilities and the exercise of choice and control. This is why people fear disability and dementia in particular: people fear being robbed of their cognitive faculties and therefore being seen as a ‘shell’ of their former selves. One response to this fear is to focus on ‘living well’ with dementia in terms of enabling choice and fostering autonomy for as long as possible, though always in the knowledge that the losses cannot be staved off forever. In contrast the prophetic voice of dementia and profound disability asks us to ‘live well’ not cognitively but ‘by the heart’. ‘By the heart’ is a phrase used by Jean Vanier the founder of the L’Arche communities where people with intellectual disabilities live alongside and supported by others. Certainly Vanier understands living ‘by the heart’ to encompass vulnerability and interdependence (Vanier, 1998, p.63) and it also includes suffering because all loss entails suffering. For Vanier in living by the heart we recognise that ‘we human beings are all fundamentally the same. We all belong to a common, broken humanity’ (Vanier, 1998, p.37). For Vanier suffering is not useless, indeed the wound that we all carry by virtue of being human is inherent in the human condition: ‘what we have to do is walk with it instead of fleeing from it’. Indeed ‘it is only through the pain of the cross that we discover what the resurrection means’ (Vanier, 1998, p.140). Similarly, as Pope John Paul II explains ‘suffering and illness belong to the condition of man, a fragile, limited creature’ (Pope John Paul II, 1997, n.4). However this way of living can be immediately recognised by anyone who lives with dementia and by those who share their lives. By focussing on rights and enabling choice the prophetic role of people with dementia and with disabilities risks becoming lost. By showing people that we can all live life to the full in a creative and rich way, that we all live in a network of supporting relationships where no person is abandoned

or redundant, we can give witness to what gives authentic value to life. As the third century theologian Irenaeus says, ‘the glory of God is a human being fully alive’ (Irenaeus, *Against heresies*, Book IV.20.7). This does not mean that it is only the rational cognitive part of human beings that matters. It is the whole human being that matters.

Another misinterpretation of suffering sees it as purely passive or virtuous. However again the experience of people living with dementia demonstrates that both the person with dementia and those with whom they interact minister to each other: suffering alongside each other provides many opportunities to ‘release love’ and to show solidarity (Pope John Paul II, 1984, n.30; 2002, n.2). Moreover by living well with suffering the person actively gives witness to the profound dignity and preciousness of human life (Pope John Paul II, 2000, n.12). The solidarity between people who suffer together for each other shows both the gift of self and the refusal to become isolated or alienated from others or from God (Pope John Paul II, 1997, n.5). And not least, by living well with suffering a person can witness greatly to trust in God. After all, since Christ, as God and man, has taken upon himself the sufferings of all humanity, no person is beyond the reach of God (Pope John Paul II, 2002, n.2).

Theology also offers models of community that do not risk falling into the trap identified by Shakespeare of being ‘friendly’ but at the same time patronising. Vanier’s L’Arche communities are good examples that a way of supportive living, living by the heart, is a real possibility and perhaps this could be a useful model for those seeking to live well with dementia. Implicit in Vanier’s approach to community are some of the principles of Catholic social teaching and applying the principles of Catholic social teaching to social interactions can be a source of real hope for everyone (see Pontifical Council for Justice and Peace, 2005). In Catholic social teaching communities are called to take account of the common good that is the complete development of all people where every person is enabled to live fully. Dignity is central to any vision of the human person and suffering in no way

entails its loss. There are two aspects to dignity: a natural aspect that every human being has no matter what his or her condition. Theologically this dignity is based on the image of God and it is a dignity that a person can never lose. This understanding of intrinsic dignity is not the same as the narrow view of dignity that comes and goes depending on the person's situation or indeed their ability to exercise their rights. All human beings always have human dignity. And this dignity is raised even higher in theological terms because we are called to be friends with God. This means that we have unconditional respect for all human beings because each is unique and irreplaceable. Made in the image of God reminds us that no one can fully grasp the being of another person. The person, however much we know and love them, remains a mystery for us yet that person is wanted by God for his or her own sake. The option for the poor and the marginalised indicates that we all have to help others to live life to the full. In Catholic social teaching this option is not a kind of looking down on or charity or pity for those less fortunate than ourselves. Instead it is also a recognition that the poor and the marginalised are in fact closer to God precisely because of their own dependence and vulnerability. They know they need help, unlike those who have a narrow cognitive view. Subsidiarity is a significant principle for people with dementia and with disabilities and it plays very much an enabling role. Subsidiarity means allowing the individual to do what he or she can and then the family help and if more help is needed the next layer of society comes to help. This is enabling help not taking over help. Solidarity is a very important concept because it reminds us all that we are brothers and sisters together and all in this world together. Justice reminds us that all human beings have the same needs and same dignity and, as a matter of justice we must act ethically towards all human beings. Acting ethically towards people with dementia is both a matter of rights and human dignity. Finally, care of creation is included because people with the narrow cognitive view are often too busy or too

wrapped up in themselves to think about creation. Those who live by the heart are more open to the beauty and joy of simply being with creation and with others.

In addition to principles for just social interaction Pope John Paul II explains that wherever communities are being built up, whether they are family communities or wider social groupings, they should be set on a spirituality of communion. For the Pope this spirituality of communion is profoundly linked to the mystery of the Trinity and the light from the Trinity shining on the faces of ‘our brothers and sisters’, the people around us, each of whom bears the image of the triune God. In realising this powerful connection between us, there can be no ‘us’ and ‘them’. Indeed this spirituality of communion makes us able to share each other’s joys and sufferings, to sense the desires of others and attend to their needs, ‘to offer them deep and genuine friendship’ and to see the person as ‘a gift for me’ (Pope John Paul II, 2001, n.43).

Conclusion

The project to change the conversation on dementia, to emphasise living well, to highlight the significance of human rights and dignity, including the great good of autonomy is surely an important step forward. With a focus on rights, on challenging discriminatory attitudes and on adapting environments the influence of the discourse on disability seems undeniable. Similarly the move away from seeing dementia simply as a medical issue and people with dementia as the problem towards creating enabling communities seems to tap into the social model of disability. Undoubtedly the linking of dementia with disability can be fruitful and the lessons learnt from disability studies can be helpful especially where language is concerned. Nevertheless, theology remains a vital resource to check and enrich a dialogue that can benefit us all. In particular theology can rescue the concept of suffering from those who interpret it solely in terms of victimhood, pity, being a burden, lacking in autonomy,

passivity and a negative version of dependence. Put in a theological context suffering does not demean the person by somehow making the person less human. Instead suffering is an unavoidable part of the human condition and living well with suffering deepens our being human. This is not about extolling suffering as if it is a virtue or something to be pursued as a good. Rather it is to recognise that suffering is a human reality that calls for a mutual response of love, compassion and solidarity. Such a response does not diminish the person. Rather it builds up people into a diverse community of persons.

References

Alzheimer's Society. nd. *Vision, mission, values*. <https://www.alzheimers.org.uk/about-us/vision-mission-and-values>

Alzheimer's Society. nd. *Strategy 2017-2022*. <https://www.alzheimers.org.uk/about-us/our-strategy-2017-2022>

Alzheimer's Society. (2017). *Turning Up The Volume: unheard voices of people with dementia*.

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning_up_the_volume_unheard_voices_of_people_with_dementia.pdf

Augustine. 354-430. (1968). Free Choice of the Will. *The Teacher; The Free Choice of the Will; Grace and Free Will (The Fathers of the Church)* Vol.59 trans. R. Russell, 72-242. Washington: Catholic University of America Press.

Bartlett, R., Windemuth-Wolfson, L., Oliver, K., Denning, T. (2017). Suffering with dementia: the other side of “living well”. *International Psychogeriatrics* 29:2 pp.177-179

Bennett, J. nd. <http://dementiawithoutwalls.org.uk/voices/there-is-no-such-word-as-suffering-with-dementia-we-are-living-with-it-jo-bennett/>

Betcher, S. (2010). Becoming Flesh of My Flesh: Feminist and Disability Theologies on the Edge of Posthumanist Discourse. *Journal of Feminist Studies in Religion* 26/2 pp.107-139.

Dementia Engagement and Empowerment programme, DEEP. (2015a). *Report*.

<https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia>

Dementia Engagement and Empowerment Programme, DEEP. (2015b) *Language Guide*

<http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

Dementia Action Alliance. (2017). *Review of the Dementia Statements Companion Paper*.

https://www.dementiaaction.org.uk/assets/0003/3965/Companion_document_August_2017_banded_final.pdf

Dementia without walls. (2012-2015). <https://www.jrf.org.uk/report/dementia-without-walls-%E2%80%93-reflections-people-dementia>

Department for Work and Pensions. (2014). *Guidance, Inclusive language: words to use and avoid when writing about disability*. <https://www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability>

Dunne, T. nd. *The Elder Magazine* <https://www.elder.org/the-elder/an-interview-with-tommy-dunne-living-with-dementia-not-suffering-from-it/>

Eiesland, N. (1994). *The Disabled God: Towards a Liberatory Theology of Disability*. Nashville: Abingdon Press.

Irenaeus. c.135-2000. (1985). *Against heresies. Ante-Nicene Fathers Vol.1*. Ed Roberts and Donaldson. Grand Rapids: Eerdmans.

John XXIII (Pope). (1963). *Pacem in Terris*. http://w2.vatican.va/content/john-xxiii/en/encyclicals/documents/hf_j-xxiii_enc_11041963_pacem.html

John Paul II (Pope). (1979). *Redemptor hominis*. http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_04031979_redemptor-hominis.html

John Paul II (Pope). (1982). *Love and Responsibility*. New York: Collins.

John Paul II (Pope). (1984). *Salvifici doloris*. http://w2.vatican.va/content/john-paul-ii/en/apost_letters/1984/documents/hf_jp-ii_apl_11021984_salvifici-doloris.html

John Paul II (Pope). (1988a). *Mulieris Dignitatem*. http://w2.vatican.va/content/john-paul-ii/en/apost_letters/1988/documents/hf_jp-ii_apl_19880815_mulieris-dignitatem.html

John Paul II (Pope). (1988b). *Christifideles Laici* http://w2.vatican.va/content/john-paul-ii/en/apost_exhortations/documents/hf_jp-ii_exh_30121988_christifideles-laici.html

John Paul II (Pope). (1992a). *Letter Instituting the World Day of the Sick* (13 May 1992). https://w2.vatican.va/content/john-paul-ii/it/letters/1992/documents/hf_jp-ii LET_13051992_world-day-sick.html

John Paul II (Pope). (1992b). *World Day of the Sick I*. https://w2.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_21101992_world-day-of-the-sick-1993.html

John Paul II (Pope). (1995). *Evangelium vitae*. http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html

John Paul II (Pope). (1997). *World Day of the Sick V*. https://w2.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_16101996_world-day-of-the-sick-1997.html

John Paul II (Pope). (1998). *World Day of the Sick VI*. https://w2.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_29061997_world-day-of-the-sick-1998.html

John Paul II (Pope). (2000). *World Day of the Sick VIII*. https://w2.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_19990806_world-day-of-the-sick-2000.html

John Paul II (Pope). (2001). *Novo Millennio Ineunte*. http://w2.vatican.va/content/john-paul-ii/en/apost_letters/2001/documents/hf_jp-ii_apl_20010106_novo-millennio-ineunte.html

John Paul II (Pope). (2002). *World Day of the Sick X*. https://w2.vatican.va/content/john-paul-ii/en/messages/sick/documents/hf_jp-ii_mes_20010813_world-day-of-the-sick-2002.html

Kevern, P. (2010). Sharing the mind of Christ: preliminary thoughts on dementia and the Cross. *New Blackfriars* 91/1034 pp.408-422.

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

National Dementia Declaration for England. (2010). <https://dementiapartnerships.com/wp-content/uploads/sites/2/dementia-declaration.pdf>

Macklin, R. (2003). Dignity is a useless concept. *BMJ* 327: 1419.

Matthews, P. (2013). *Pope John Paul II and the Apparently 'Non-acting' Person*. Leominster: Gracewing.

Mental health Foundation. (2015). *Dementia, rights, and the social model of disability: a new direction for policy and practice?*

<https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-policy-discussion.pdf>

Office for Disability Issues. (2011). *Equality Act 2010, Guidance*.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/570382/Equality_Act_2010-disability_definition.pdf

Pontifical Council for Justice and Peace. (2005). *Compendium of the Social Doctrine of the Church*. Washington: USCCB Publishing.

Rohra, H. (2016). *Dementia Activist: Fighting for Our Rights*. London: Jessica Kingsley.

Second Vatican Council. (1965). *Dignitatis humanae*.

http://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_decl_19651207_dignitatis-humanae_en.html

Shakespeare, T., Zeiling, H., Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia*

https://www.researchgate.net/publication/315826543_Rights_in_mind_Thinking_differently_about_dementia_and_disability

Swinton, J. (2012). *Dementia: Living in the Memories of God*. London: SCM Press.

UN Economic Commission for Europe (UNECE). (2015). *Policy Brief: Dignity and non-discrimination for persons with dementia*.

https://www.unece.org/fileadmin/DAM/pau/age/Policy_briefs/ECE-WG.1-23.pdf

Vanier, J. (1998). *Becoming Human*. London: Darton, Longman and Todd.