

# Person-centred care in the community

Prepared by Prof. Murna Downs  
Head of School,  
School of Dementia Studies  
University of Bradford

On behalf of Genio  
March 2015



## Foreword

This paper is part of a series of Learning Papers commissioned by Genio to explore learnings in practice on specific topics within Dementia. This paper results from a workshop titled Person Centred Care in the community, facilitated by Prof. Murna Downs and attended by representatives of dementia projects supported by Genio.

Person centred care is widely recognised as the preferred approach to care. How it is understood reflects on its implementation in practice across a variety of settings. The purpose of this workshop was to revisit the theory behind the practice and to consider its applicability across the community setting.

Understanding the key aspects of personhood, psychological needs, social psychology and the person's perspective provides the foundations of best practice as we navigate the implementation of this approach in practice. The key elements to providing a person centred approach to care in the community are explored in this paper and include impacting negative imagery; supporting family members; managing risk; and measuring effectiveness.

We would like to acknowledge the work of Prof. Murna Downs in producing this paper and to thank representatives from dementia projects supported by Genio\* for their valuable reflections and contributions to the Person Centred Care in the community workshop.

I would also like to acknowledge the support of the Atlantic Philanthropies in funding this paper.

**Elaine Howard**  
**Genio Programme Manager - Dementia**

\*Projects supported by the HSE & Genio Dementia Programme:

Kinsale Community Response to Dementia (K-CORD)	Cork Integrated Dementia Care Across Settings (Cork - IDEAS)	Memory Matters Community Component
Living Well with Dementia (LWwD)	Connolly Hospital Integrated Care Pathways for People with Dementia	Community Outreach Dementia Project Leitrim (CODPL)
Community Action on Dementia in Mayo	Development of an Integrated Care Pathway for People with Dementia (DemPath)	Flourishing with Dementia (FwD)
The 5 Steps to Living Well with Dementia in South Tipperary		The Crystal Project
		There's No Place Like Home!

# Contents

1. Purpose	4
2. Introduction	4
3. Key concepts of person-centred care	4
3.1 Personhood	5
3.2 Psychological needs	5
3.3 The bio-psychosocial model of dementia	6
3.4 The importance of understanding the person's perspective	8
4. Person-centred care in the community	8
4.1 Tackling the impact of negative imagery and language	9
4.2 Supporting family members	9
4.3 Managing risk	11
4.4 Measuring effectiveness in the community	11
Conclusion	12
References	13

## 1. Purpose

The purpose of this paper is to describe the key concepts of person-centred dementia care and to identify the areas which should be addressed to ensure its successful application in the community.

## 2. Introduction

The person-centred approach to care, pioneered by Kitwood and his colleague Bredin in the early 1990's, is now universally accepted as synonymous with best practice in care for people with dementia (Downs 2013; World Health Organization 2012). The strap line for this approach to care is: *'the Person Comes First'*. The focus on the person is central to England's *Living well with dementia: A National Dementia Strategy* (Department of Health 2009), which has on its cover the words *Putting People First*.

This emphasis on placing the *person* first was in response to the dominant perception – somewhat true to this day – that because someone had dementia they were therefore viewed as less the person they had been, indeed less like a person at all. From a person-centred perspective the key challenge facing people living with dementia is the threat of no longer being considered a person, a human being with needs, rights and entitlements (Kitwood 1997). Kitwood's (1997) person-centred approach sought to reinstate the person living with dementia as a valued human and social being with not only moral worth but also entitlement to human rights (Morton 1999). It emphasises 4 key aspects of living with dementia:

1. Personhood: that people living with dementia are first and foremost people;
2. Psychological needs: that as people, they have the same needs as other

people – be it for physical comfort, psychological, emotional, social and spiritual well-being;

3. Social psychology: that our supports and services need to provide a supportive social psychology i.e. interactions and relationships which affirm the person's personhood (sense of person-ness) and address their psychological needs;
4. Person's perspective: the importance of engaging directly with the person's experience and understanding how the world looks from their perspective.

The person-centred approach introduced optimism to a field more familiar with pessimism and despair. It posed a direct challenge to the prevailing belief that a poor quality of life was an inevitable feature of living with dementia. In particular, it led to a focus on the potential of communication and relationships to promote well-being for people with dementia. While Kitwood stressed that the concept of person-centred care applied to all settings, person-centred care has received most attention in formal care settings, most notably care homes. There have been several demonstrations of its effectiveness in these settings (e.g. Fossey et al. 2006; Sloane et al. 2004). It is now being applied across the journey of living with dementia, from diagnosis to death.

## 3. Key concepts of person-centred care

The person-centred approach is a philosophy of care which aims to enhance well-being for people with dementia (Downs et al. 2006). It achieves this by addressing the following key concepts: personhood, psychological needs, the

bio-psychosocial model and the person's perspective. Each is now described in detail.

### 3.1 Personhood

Personhood is a pivotal concept in person-centred care (Brooker 2004). It sets a value base that people living with dementia have moral worth and entitlement to social standing, regardless of the degree of cognitive impairment (Kitwood 1997). 'Putting the person first' is one of Kitwood's key contributions to the field. The person-centred approach has been credited with reinstating the person as a valued human and social being with moral worth and human rights (Morton 1999).

For Kitwood and his colleague, Kathleen Bredin (Kitwood and Bredin 1992a), personhood was seen as being constructed in relationship with others. It is something 'bestowed' by the other. In Kitwood and Bredin's (1992a) view the greatest threat to a person living with dementia is the loss of personhood – no longer being seen as fully human in the eyes of others. In this relational approach to personhood, a person is a person among others. What other people do, or fail to do, will enhance or diminish that person's personhood or standing as an individual.

Such an approach to personhood is in contrast to the cognitive approach which characterises personhood in terms of rationality. A person is a person because they have the capacity to think and engage in intellectual processes. This view emphasising rationality leads to concluding that people living with dementia, especially those living with advanced dementia, are in some ways no longer human (Post 2000) or no longer alive. We are all familiar with the following sentiments, in this case from a wife of someone living with dementia:

*I just don't know what to think or feel. It's like he's not even there anymore, and it distresses me something awful. He doesn't know me. He thinks I'm a strange woman in the house. He shouts and he tries to slap me away from him. It's not like him at all.*

(Gubrium 2005, p.314)

Bartlett and O'Connor (2007) have critiqued the notion of personhood; promoting instead the importance of citizenship. They argue that people with dementia are first and foremost citizens with the rights and entitlements of all citizens. Without an equal emphasis on upholding citizenship and community participation, no amount of health and social care reform will lead to people living well with dementia (Bartlett & O'Connor 2007). Increasing emphasis is being placed in people with dementia and their family members as being members of community (Bartlett & O'Connor 2007). There is now growing emphasis on upholding their rights to citizenship and participation to the extent they wish in community life. For example, the theme of Alzheimer Europe 2014 conference was *Dementia, a rights-based approach*.

### 3.2 Psychological needs

Another key concept underlying Kitwood's (1997) approach to person-centred dementia care is the importance of ensuring well-being by meeting people with dementia's psychological needs. Kitwood (1997) proposed that people living with dementia had needs for:

- Attachment – the need for secure bonds with carers;
- Comfort – relief of pain, closeness and tenderness;
- Identity – to be known by others;

- Occupation – being involved in the process of life;
- Inclusion – need to have our social standing as persons recognised.

These needs culminated in an overarching need for love and interconnectedness. Addressing psychological, emotional, social and spiritual needs is at the heart of person-centred care.

In Kitwood's (1997) view, well-being was achievable for people with dementia if their needs were met, including, and perhaps most importantly, their need for love. It was through human interaction and engagement that personhood and feelings of well-being were to be attained and maintained. Behavioural expressions of ill-being (for example, crying, shouting and hitting) were seen as responses to assaults on personhood, rather than as part of the disease process. Thus, by changing the nature of the interaction one could directly affect the individual's personhood and well-being.

Closely related to the recognition of these needs is the recognition that people will actively strive to meet these needs. Kitwood (1997) stressed that people with dementia were active agents, actively seeking meaning in their lives. Indeed it was his thesis that the so called 'behavioural and psychological symptoms of dementia' were in fact rational responses to having one's needs denied or personhood diminished. This argument was not unique to Kitwood, indeed in the US, Rader had written about 'agenda behaviour' as early as 1987 and Algase and colleagues (Algase et al.1996) proposed the concept of need driven compromised behaviour. Stokes (2000) and others argue that many of the 'behavioural symptoms' viewed as inevitable aspects of living with dementia are attempts to meet needs.

### 3.3 The bio-psychosocial model of dementia

Kitwood argued that the effects of living with dementia were not solely the effects of a neurological condition but the result of a dynamic interplay between biological, social and psychological factors. In this way dementia is a process – a dynamic interplay, in Kitwood's words 'a dialectic' – not a given end point. Much of his interest in proposing an alternative paradigm for understanding dementia (reflected in the title of his book, *Dementia Reconsidered*) was spurred by his disillusionment with the standard medical understanding of, and response to, people with dementia, which in his view neglected these psychological and social aspects. He forcibly argued that much of the poor quality of life experienced by people with dementia could be attributable to the psychosocial context. One such social context is that people with dementia are the most vulnerable, stigmatised and socially excluded members of society (Alzheimer's Disease International 2012; Graham et al. 2003). Dementia carries a stigma that exacerbates the challenges of living with dementia throughout its course, from diagnosis to death, both for the person with dementia and their family carers (Alzheimer's Disease International 2012; Katsuno 2005). A recent report published by the UK's International Longevity Centre (2014) concludes that the stigma of dementia leads to social withdrawal and distancing and that this social exclusion impacts negatively on a person's quality of life (International Longevity Centre 2014).

For Kitwood, the dominance of biological determinism had at least two interrelated, unfavourable consequences for people with dementia:

- A neglect of the important influences of the social context, life history, personality, physical health and social psychology on quality of life;
- A sense of therapeutic nihilism, i.e. that nothing can be done to help people with dementia.

This proposed dynamic interplay between psycho-social aspects and neurological impairment provided the rationale for the person-centred approach to care that looked to human and psychosocial rather than exclusively pharmacological approaches to care. It stressed that the goal of care should be to affirm the person's value as a human being (personhood) and to facilitate their agency by:

- knowing the person's biography and life history;
- being attuned to the person's subjective experience of living with dementia;
- addressing the person's psychological needs;
- ensuring interpersonal interactions and care processes enable and affirm, rather than demean or diminish, the person.

In a similar vein Spector and Orrell (2010), in their paper discussing a bio-psychosocial approach to dementia, distinguish between 'tractable factors' or aspects of a person's life which are amenable to change; and 'fixed' or 'intractable factors,' which are not amenable to change. Examples of tractable factors include stimulation, mood, coping strategies, personal psychology and the social environment; whereas fixed psychosocial factors include personality traits, previous life events and education. Adopting a bio-psychosocial approach introduces therapeutic potential to dementia care where 'change, adaptation and

improvement is possible' (Spector & Orrell 2010, p. 959). The quality of life of people with dementia is something about which a lot can be done.

Kitwood (1997) was one of the first writers to emphasise the importance of the social environment in supporting personhood and meeting a person's psychological needs. He described behaviours which bestowed personhood (e.g. validating, celebrating, holding) as 'positive person work' and those which diminished it as 'personal detractors' (e.g. ignoring, outpacing, banishment) constituting a 'malignant social psychology'. Such malignancy was never considered to be intentional on the part of families or care staff but a benign adoption of the dominant culture (Kitwood 1997). Following this line of argument meant that cognitive and behavioural 'symptoms' were as likely to be due to a failure to understand the person's experience and 'malignant' interactions or care practices as to brain failure. Sabat (2003) has gone on to describe 'malignant positioning' as ways of interacting with people living with dementia which not only have a negative effect on how that person is seen by others but also on how that person sees themselves. In the UK the National Institute for Health and Clinical Excellence guidelines pick up on this concept of malignant positioning:

*... respecting the person's autonomy will involve day-to-day interactions and will be achieved if the person with dementia is not positioned in such a way as to impede his or her remaining abilities. Such 'malignant positioning' can be the result of inappropriate psychosocial structures. The fundamental way to combat this tendency, which undermines the person's selfhood, is to encourage good-quality communication (Kitwood 1997; Sabat 2001).*

(NICE SCIE 2007, p.18)

In his work Kitwood emphasised how people with dementia are able to experience joy, comfort, meaning and growth in their lives. He argued that the social environment influenced people's ability to achieve these experiences. For example, a lack of meaningful activity in some institutions can lead people with dementia to feel bored, angry and frustrated. Much of Kitwood's (1997) work focused upon the social environment and, in particular, the ways in which a malignant social psychology disadvantaged people with dementia, barriers well understood in the field of disability.

### 3.4 The importance of understanding the person's perspective

A key tenet of Kitwood's (1997) person-centred care for people with dementia is the importance of engaging directly with the experience of people with dementia and understanding the viewpoint of the person with dementia. Subjective experience is unique to an individual. No two people will share the same subjective experience of an event or situation.

In the last 10 years there has been unprecedented attention paid to the person's perspective and experience. This concern with the person's perspective has grown into a political movement. The slogan from the disability rights movement, 'nothing about us without us,' is receiving widespread acceptance by the dementia community. People with dementia are contributing to policy and debate as experts by experience (see for example the Scottish Dementia Working Group). Most recently, the Dementia Engagement and Empowerment Project in the UK has sought to support groups of people with dementia who are seeking to influence services and policy (Williamson 2012). While not its

primary aim, collective action of this kind has been demonstrated to have positive benefits for the people involved (Clare, Rowlands and Quin 2008). There is an international network for people living with dementia - the Dementia Advocacy and Support Network International (DASNI) ([www.dasninternational.org](http://www.dasninternational.org)).

There is a concern that the 'voice' of people with advanced dementia is not heard (Clare et al. 2008). This means that the experience and perspective of those who lack verbal language or at least fluency, who may have less command over the production of speech, are less well understood. Indeed, there are some who suggest that there is no meaningful experience in the latter phases of dementia. In contrast, person-centred dementia care adds a central concern with a belief in the person's capacity for communication regardless of his/her degree of impairment (Kitwood 1997; Normann et al. 1998, 2002; Norberg 1998, 2001). Kitwood with his colleague Bredin (1992b) developed an observational framework for measuring the quality of care, from the perspective of the person with dementia. This they called Dementia Care Mapping. This is now in its 8th edition (Bradford Dementia Group 2008).

## 4. Person-centred care in the community

The key elements to providing a person-centred approach to care in the community include:

1. Tackling the impact of negative imagery and language
2. Supporting family members



3. Managing risk
4. Measuring effectiveness

#### 4.1 Tackling the impact of negative imagery and language

Approaches to tackling stigma include public awareness and education, as well as community development, most notably dementia-friendly communities. In England the Department of Health's (2012) *Prime Minister's Challenge on Dementia* calls for dementia-friendly communities who understand what the experience of living with dementia is like and know how to support people to live well with dementia. Such communities are now being established in the UK (e.g. Bradford, Plymouth, Sheffield, York) following examples from Belgium (Bruges), Germany (e.g. ACTION) and Japan (Henwood and Downs 2014). Through these initiatives the potential of local social networks and community organisations to support and connect people with dementia to mainstream opportunity is now being realised. For example, in the Scottish dementia plan emphasis is placed on:

*People want to see better use being made of natural supports, peer support and wider community resources, to ensure that people with dementia are enabled to live well with dementia and remain part of their communities. (Scottish Dementia Plan, p.27)*

The English National Dementia Strategy (Department of Health 2009) recognises that public awareness campaigns should stress the retained personhood of people with dementia:

*The content (of the publicity campaign) should inform the public what dementia is, including: its signs and symptoms; what is normal and what is not; that while some abilities are*

*compromised, many remain; and that a person with dementia is no less a person because they have dementia.*

A good example of person-centred public education is the work by Konfetti im Kopf where larger than life size images of people living well with dementia are displayed throughout cities and towns (see for example [www.konfetti-im-kopf.de/konfetti-im-kopf/Aktivierungskampagne.html](http://www.konfetti-im-kopf.de/konfetti-im-kopf/Aktivierungskampagne.html)).

#### 4.2 Supporting family members

Universally, the majority of care for people with Alzheimer's disease and related dementias is carried out in the community by family and friends (World Health Organization 2012).

These so called 'carers' are a heterogeneous group, at a minimum differing according to age and gender (Alzheimer Europe 2000-2001). Person-centred care has sometimes been misunderstood as being concerned only with the welfare of the person with dementia. Yet in *Dementia reconsidered*, Kitwood (Kitwood 1997) emphasised the need to support people with dementia, their families and care staff.

Carers need to be open, flexible, creative, compassionate, responsive and to be inwardly at ease (Kitwood 1997). Fortinsky and Downs (2014) have proposed key transitions in the journey of living with dementia. The Carers Trust (2013) in the UK interviewed family members and identified the following as key transitions in their journey of caring.

### Key transitions in the caring journey

- the diagnosis being made taking on an active caring role
- when their relative's capacity declines
- when they need emotional support
- when their relative loses mobility
- when their relative develops health problems
- when there are changes in their relative's behaviour when the carer changes
- when their relative becomes incontinent when their relative enters residential care when their relative is at the end of life

These points of transition require families to adjust; including re-negotiating their individual identity (Orono 1990), their shared identity as a member of a couple and their family's identity. Hasselkus and Murray (2007) suggest ways that occupational therapists can support families to tailor their everyday occupation both to retain a sense of continuity in their family identities and to construct new identities.

As well as having their own needs for support, family members are keen to be included as partners in care. In order to effectively support their relatives with dementia, they too need an understanding of the concepts of person-centred care. Carer involvement can help to ensure quality care for people with dementia. In the Carers Trust (2013) Triangle of care: Carers included a guide to best practice in dementia care (see [www.rcn.org.uk/data/assets/pdf\\_file/0009/549063/Triangle\\_of\\_Care\\_-\\_Carers\\_Included\\_Sept\\_2013.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0009/549063/Triangle_of_Care_-_Carers_Included_Sept_2013.pdf)) the following key standards are identified as achieving a

### Triangle of Care:

- 1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- 2) Staff are 'carer aware' and trained in carer engagement strategies.
- 3) Policy and practice protocols regarding confidentiality and sharing information are in place.
- 4) Defined post(s) responsible for carers are in place.
- 5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
- 6) A range of carer support services is available.

In an ideal situation the needs of the carer and the person with dementia are both met. It must be noted, however, that these needs are sometimes at odds with one another. The person with dementia and their family may not always hold the same view or seek the same end. These discrepant perspectives will require active management in the community. For example, Reamy and colleagues (2011) explored discrepancies in perceptions of values and care preferences regarding autonomy, burden, control, family, and safety between individuals with dementia and their family caregivers. They interviewed 266 couples and found that carers consistently underestimated their relative's values for all five values. They concluded that many caregivers do not have an accurate depiction of their relative's values. This is of concern as carers may become the surrogate decision makers for their relatives as dementia progresses. They suggest that these findings indicate the need for assessments of values and

preferences and to improve communication within the couple in the early stages of dementia. Baldwin and colleagues (2006) provide a useful guide to the ethical issues facing families when making decisions.

### 4.3 Managing risk

It is increasingly acknowledged that risk assessment and management is an essential aspect of ensuring person-centred care in the community. As family members and professionals we tend towards being risk averse. Being risk averse can have a detrimental effect on a person's well-being. Charlotte Clarke and colleagues (2011) in their practice guide entitled *Risk and Dementia Care: Approaches to Everyday Living* discuss a person-centred approach to managing risk for people with dementia. The book argues that

*"Focussing only on the physical safety of someone with dementia can result in the person's psychological and social wellbeing being neglected or 'silently harmed'"* (p.197).

The authors promote a person-centred approach to risk which promotes choice for people with dementia, while recognising the challenges carers face. See her talking about this work here [www.nutshell-videos.ed.ac.uk/charlotte-clarke-dementia-risk/](http://www.nutshell-videos.ed.ac.uk/charlotte-clarke-dementia-risk/).

### 4.4 Measuring effectiveness in the community

Measuring effectiveness of any intervention or service is more complex than it may at first appear. Different stakeholders may have different aims in mind for a service. For example, up until relatively recently, services designed to give a family member a break, paid insufficient attention to ensuring they adopted approaches which

enhanced the quality of life of people living with dementia. This has resulted in family members, in need of a break, being reluctant to use services as they lacked confidence that their relative would have a positive experience.

In England, the Department of Health (2010) published the quality outcomes they sought to achieve. Written as 'I statements' these can be easily described as person-centred (Department of Health 2010).

They include:

- I can enjoy life
- I feel a part of a community
- I know what I can do to help myself
- I was diagnosed early
- I get treatment and support best for me and my family
- Those around me are well supported
- I am treated with dignity and respect
- I understand so I can make good decisions
- I am confident my end of life wishes will be respected

These resonate with Scotland's rights-based approach to standards of care ([www.scotland.gov.uk/Publications/2011/05/31085414/0](http://www.scotland.gov.uk/Publications/2011/05/31085414/0)):

- I have the right to a diagnosis.
- I have the right to be regarded as a unique individual and to be treated with dignity and respect.
- I have the right to access a range of treatment, care and supports.
- I have the right to be as independent as possible and be included in my community.

- I have the right to have carers who are well supported and educated about dementia.
- I have the right to end of life care that respects my wishes.

Assessing the extent to which people affected by dementia – both people living with dementia and their family members - say yes to these can be used as indicators or measures as to whether supports and services in the community are achieving their desired aim.

## Conclusion

Person-centred care is a well established universally embraced approach to care for people with dementia. It was first pioneered by Kitwood at the University of Bradford in the 1980's. Its defining feature was to put the person first. It has since been refined by many other academics and professionals and embedded in a range of dementia care settings. While developed largely in response to disenfranchisement of people with advanced dementia living in care homes, it is equally applicable across the journey with dementia. This approach is increasingly being adopted by national strategies – the scope of which includes care in the community.

## References

- Algase, D.L., Beck, C., Kolanowski, A., Whall, A., Berent, S., and Richards, K. (1996) 'Need-driven dementia-compromised behavior: an alternative view of disruptive behavior', *American Journal of Alzheimer's Disease*, 11(6), 10.
- Alzheimer's Disease International (2012) *World Alzheimer Report 2012: Overcoming the stigma of dementia*, London: Alzheimer's Disease International.
- Alzheimer Europe (2000-2001) *Equality in the provision of care at home* [online], available: <http://www.alzheimer-europe.org/Alzheimer-Europe/Our-work/Completed-projects/2000-2001-Equality-in-home-care-provision> [accessed 8th Oct 2015].
- Bartlett, R. and O'Connor, D. (2007) 'From personhood to citizenship: Broadening the lens for dementia practice and research', *Journal of Aging Studies*, 21(2), 107-118.
- Baldwin, C., Hope, T., Hughes, J. et al. (2005) *Making difficult decisions: The experience of caring for someone with dementia*, London: Alzheimer's Society.
- Bradford Dementia Group (2008) *Dementia Care Mapping 8th edition*, Bradford: University of Bradford.
- Brooker, D. (2004) 'What is person-centred care for people with dementia?', *Reviews in Clinical Psychology*, 13, 215-222.
- Carers Trust (2013) *A road less rocky: Supporting carers of people with dementia* [online], available: [https://www.carers.org/sites/default/files/dementia\\_report\\_road\\_less\\_rocky\\_final\\_low.pdf](https://www.carers.org/sites/default/files/dementia_report_road_less_rocky_final_low.pdf) [accessed 8th Oct 2015].
- Clare, L., Rowlands, J.M. and Quin, R. (2008) 'Collective strength: The impact of developing a shared social identity in early-stage dementia', *Dementia: The International Journal of Social Research and Practice*, 7(1), 9-30.
- Clarke, C.L., Keady, J., Wilkinson, H., Gibb, C.E., Luce, A., Cook, A. and Williams, L. (2009) 'Dementia and risk: Contested territories of everyday life', *Journal of Nursing and Healthcare of Chronic Illness*, 2(2), 102-112.
- Clarke, C.L., Wilkinson H., Keady, J. and Gibb, C.E. (2011) *Risk and dementia care: Approaches to everyday living*, London: Jessica Kingsley.
- Department of Health (2009) *Living well with dementia: A national dementia strategy*, London: Department of Health Publications.
- Department of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*, London: Department of Health Publications.
- Department of Health (2012) *Prime Minister's challenge on dementia*, London: Department of Health Publications.
- Downs, M. (2013) 'Putting people – and compassion – first: the UK's approach to person-centred care for individuals with dementia', *Generations, Journal of the American Society on Ageing*, 37(3) 53-59.
- Downs, M., Clare, L. and Mackenzie, J. (2006) 'Understandings of dementia: Explanatory models and their implications for the person with dementia and therapeutic effort', in Hughes, J.C., Louw, S.J. and Sabat, S.R., eds., *Dementia: Mind, meaning and person*, Oxford: Oxford University Press.

- Fortinsky, R. and Downs, M. (2014) 'Optimising person-centred transitions in the dementia journey: A comparison of national dementia strategies', *Health Affairs*, 33(4), 566-573.
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N. and Jacoby, R. (2006) 'Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial', *British Medical Journal (Clinical Research ed.)*, 332(7544), 756-761.
- Graham, N., Lindsay, J., Katona, C., Bertolote, J.M. et al. (2003) 'Reducing stigma and discrimination against older people with mental disorders: a technical consensus statement', *International Journal of Geriatric Psychiatry*, 18, 670-678.
- Hasselkus, B.R. and Murray, B.J. (2007) 'Everyday occupation, well-being and identity: The experience of caregivers in families with dementia', *American Journal of Occupational Therapy*, 61, 9-20.
- Henwood, C. and Downs, M. (2014) 'Dementia-friendly communities', in Downs, M. and Bowers, B., eds., *Excellence in dementia care: Research into practice* (2nd ed.), Maidenhead, Berkshire: Open University Press/McGraw-Hill.
- International Longevity Centre (2014) *New perspectives and approaches to understanding dementia and stigma* [online], available: [http://www.ilcuk.org.uk/index.php/publications/publication\\_details/new\\_perspectives\\_and\\_approaches\\_to\\_understanding\\_dementia\\_and\\_stigma](http://www.ilcuk.org.uk/index.php/publications/publication_details/new_perspectives_and_approaches_to_understanding_dementia_and_stigma) [accessed 8th Oct 2015].
- Katsuno, T. (2005) 'Dementia from the inside: How people with early-stage dementia evaluate their quality of life', *Ageing & Society*, 25(2), 197-214.
- Kitwood, T. (1997) *Dementia reconsidered: the person comes first*, Buckingham: Open University Press.
- Kitwood, T. and Bredin, K. (1992a) 'Towards a theory of dementia care: Personhood and well-being', *Ageing and Society*, 12, 269-287.
- Kitwood, T. and Bredin, K. (1992b) 'A new approach to the evaluation of dementia care', *Journal of Advances in Health and Nursing Care*, 1(5), 41-60.
- Morton, I. (1999) *Person-centred approaches to dementia care*, Bicester, Oxon: Winslow Press.
- National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (NICE SCIE) (2007) *Dementia: A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care*, London: NICE SCIE Publications.
- Norberg, A. (1998) 'Interaction with people suffering from severe dementia', in Wimo, A., Jonsson, B., Karlsson, G. and Wingblad, B., eds., *Health economics of dementia*, Chichester: John Wiley and Sons.
- Normann, H.K., Asplund, K. and Norberg, A. (1998) 'Episodes of lucidity in people with severe dementia as narrated by formal carers', *Journal of Advanced Nursing*, 28(6), 1295-1300.
- Normann, H.K., Norberg, A. and Asplund, K. (2002) 'Confirmation and lucidity during conversations with a woman with severe dementia', *Journal of Advanced Nursing*, 39(4), 370-376.
- Orono, C.J. (1990) 'Temporality and identity loss due to Alzheimer's disease', *Social Science and Medicine*, 30, 1247-1256.

Post, S. (2000) *The moral challenge of Alzheimer's disease: Ethical issues from diagnosis to dying*, London: Johns Hopkins University Press.

Reamy, A., Kyungmin, K., Zarit, S. and Whitlatch, C. (2011) 'Understanding discrepancy in perceptions of values: Individuals with mild to moderate dementia and their family caregivers', *The Gerontologist*, 51(4), 473-483.

Sabat, S. (2001) *The experience of Alzheimer's disease: Life through a tangled veil*, Oxford: Blackwell.

Sabat, S. (2003) 'Malignant positioning and the predicament of Alzheimer's disease', in Harre, R. and Moghaddam, F.M., eds., *The self and others: positioning individuals and groups in personal, political and cultural contexts*, Westport, Connecticut: Greenwood Publishing Group.

Scotland's National Dementia Strategy 2013-2016 (2013) [online], available: (<http://www.gov.scot/Resource/0042/00423472.pdf>) [accessed 8th Oct 2015].

Sloane, P.D., Hoefffer, B., Mitchell, C.M., McKenzie, D.A., Barrick, A.L., Rader, J. et al. (2004) 'Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial', *Journal of the American Geriatrics Society*, 52(11), 1795-1804.

Spector, A. and Orrell, M. (2010) 'Using a biopsychosocial model of dementia as a tool to guide clinical practice', *International Psychogeriatrics*, 22(6), 967-965.

Stokes, G. (2000) *Challenging behaviour: A person-centred approach*, Bicester, Oxon: Winslow Press.

Williamson, T. (2012) *A stronger collective voice for people with dementia* [online], available: <http://www.jrf.org.uk/publications/stronger-collective-voice> [accessed 8th Oct 2015].

World Health Organization (2012) *Dementia, a public health priority* [online], available: [http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/) [accessed 8th Oct 2015].

**Genio**

Marlinstown Office Park  
Mullingar  
Co. Westmeath  
Ireland

T: 044 9385940  
E: info@genio.ie

[www.genio.ie](http://www.genio.ie)



Established in March 2008, Genio Limited is an Irish Registered Company  
(Reg no. 454839). Genio Trust is a registered charity (CHY 19312).