

The relevance of the person for living well with dementia

Statement 5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Statement 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Evidence for improved outcomes for people with dementia through provision of person-centred care had been largely observational. However, Chenoweth and colleagues have recently reported (Chenoweth *et al.*, 2009) a cluster randomised controlled trial, where urban residential sites were randomly assigned to person-centred care, Dementia Care Mapping (DCM), or usual care. The authors found that person-centred care and DCM both seem to reduce agitation in people with dementia in residential care. A brief description of DCM is provided later in this chapter.

Nonetheless, what has been striking is that relationships are important in wellbeing of individuals with dementia, and this is a recurrent theme indeed throughout this book. In general, 'social trust' (trust in other people) is strongly associated with high life satisfaction and happiness (e.g. Helliwell, 2003), and the number and strength of social connections are among the largest and most robust predictors of subjective wellbeing, including life satisfaction, overall happiness and decrease in depressive symptoms (e.g. Dolan, Peasgood and White, 2008; Helliwell and Putnam, 2004; Pichler, 2006).

Research traditionally focuses on how disease affects the brain of an individual with dementia, and it is hoped that results from animal models will inform on the neurobiology of health and disease. Through 'translational

research', the ideal is that animal models, where medical and surgical interventions can be investigated, will lead to better treatments in human beings. However, with animal models, while we arguably have a good understanding of what happens in the brains of these animals – for example, through cellular or histochemical, electrophysiological or neuroimaging techniques – we really are unable to understand what is going on in the *minds* of non-human primates and other non-human species. The focus in contemporary English health policy has been, however, to take the concept of a 'person' seriously, and a subtle appreciation has been recently that the mind and body are possibly not as dissociable as previously thought. Notwithstanding the precise way in which cognition, emotion and the body interact is as yet poorly understood, there is certainly a wish to understand the 'whole person', and to think how aspects of the wellbeing are particularly important to wellbeing and its counterpart, ill-being. This approach is critical if we are to make sense of how carers can help to enhance the wellbeing of individuals with dementia, where possible, and the importance of constructive social relationships in the environment of an individual with dementia. Physical health can clearly affect mental wellbeing, as well, and therefore it is essential that the 'needs' of pain management and nutrition for any individual with dementia are addressed in full.

AN OVERVIEW OF THE IMPORTANCE OF PHYSICAL AND MENTAL HEALTH FOR LIVING WELL IN DEMENTIA

Treating an individual living well with dementia is a critical plank of policy.

Chapter 5 of the National Dementia Strategy (Department of Health, 2009) explains early on that this is to be taken in the context of an individual living well with dementia as part of a wider community, and that individuals including immediates need access to high-quality services.

Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

The starting point is that individuals with dementia are not always in a position to seek help or advice about other issues that could be affecting their health and wellbeing. Therefore, it is important that they are enabled to access services where further help can be given. People with dementia should be empowered, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Chapter 5 of the National Dementia Strategy (Department of Health, 2009) provides a helpful overview as follows.

A comprehensive community personal support service would provide:

- home care that is reliable, with staff who have basic training in dementia care;
- flexibility to respond to changing needs, not determined by rigid time slots that prevent staff from working alongside people rather than doing things for them;
- access to personalised social activity, short breaks and day services;
- access to peer support networks;
- access to expert patient and carer programmes;
- responsiveness to crisis services;
- access to supported housing that is inclusive of people with dementia;
- respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers;
- flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia;
- independent advocacy services; and
- assistive technologies such as telecare.

SERVICES THAT HELP MAINTAIN PHYSICAL AND MENTAL HEALTH AND WELLBEING

The National Institute for Health and Clinical Excellence (NICE) Quality Standard 30 quality statement 6 on the importance of physical and mental health for living well with dementia is relevant to different stakeholders.

- **People with dementia** can have routine check-ups of their physical and mental health and can see healthcare professionals when they have concerns.
- **Carers of people with dementia** are involved in helping the person they support have routine physical and mental health check-ups and see healthcare professionals when they have concerns. The Department of Health defines a 'carer' as someone who provides unpaid support to family or friends who couldn't manage without this help, whether they are caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.
- **Local authorities and others commissioning services** work with providers to ensure the services they commission enable people with dementia, with the involvement of their carers, to have routine check-ups of their physical and mental health and see healthcare professionals when they have concerns.
- **Organisations** providing care and support ensure people with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

- **Social care and healthcare staff** enable people with dementia, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

THE IMPORTANCE OF CARERS

Family carers are possibly the most important 'resource' available for people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important rôle they play in the care of the person with dementia. This clearly requires joined-up thinking in the benefits system, thinking what support carers might be entitled to on a statutory basis.

Independence is a pervasive critical feature in wellbeing in dementia. Most people want to remain living in their own homes for as long as possible. That message appears to be consistently communicated by the public, by older people generally and by people with dementia specifically, whether they young or old. Indeed, while the effects of cholinesterase inhibitors in improving memory symptoms in **dementia of the Alzheimer type** are considered to be modest at best, the argument was advanced that even such modest effects might be beneficial in delaying the institutionalisation of individuals with dementia (e.g. Fillit and Hill, 2004). According to the National Dementia Strategy (Department of Health, 2009), most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance than is currently routinely available. Residential care may be the most appropriate and effective way of meeting someone's needs and providing a service of choice.

Examples of services that help maintain physical and mental health and wellbeing include:

- general practice
- occupational therapy services
- Admiral Nurses
- community palliative care
- health promotion services, including smoking cessation
- mental health teams
- opticians
- hearing therapists
- dentists
- chiropodists
- physiotherapy services.

A PERSON-CENTRED CARE APPROACH

'Person-centred care' principles are a good starting point for high-quality care, laid out in the National Service Framework (Department of Health, 2001). These principles reflect the increasing evidence that individuals with dementia are able to continue with their emotional lives and experience pleasure and distress in response to things they enjoy or dislike (Kitwood, 1997).

Christine Bryden (2005), in her powerful story of her journey with dementia, talks of her fear of ceasing to be:

We all believe the toxic lie of dementia; that the mind is absent and the body is an empty shell. Our sense of self is shattered with this new label of dementia. Who am I, if I can no longer be a valued member of society? What if I don't know who I am and who I was?

Loss of self is a persistent philosophy in everyday thinking about dementia, although increasingly, carers, practitioners, philosophers and academics are turning away from this view of 'identity', towards one in which interdependence and relationships contribute towards maintenance of self.

Person-centred care principles include:

- valuing the person and their family
- treating the person as an individual
- taking the perspective of the person when planning and providing care
- ensuring that a positive social environment exists in which the person can experience relative wellbeing.

For the late Tom Kitwood, an essential part of person-centred care was a focus on the *uniqueness* of individuals. This follows from his position that personhood is relational, in that each of our relationships is unique. Focusing on uniqueness requires us to focus on the differences between us (for, by definition, similarity is not unique). Kitwood's (1997) work was pivotal in implicating the interactions of caregivers in contributing to 'depersonalisation' and illbeing of people with dementia. He has been instrumental in calling for recognition of an enduring personhood and arguing for the centrality of the person within person-centred care. Kitwood, therefore arguing against the determinism of the biomedical model, proposed that the symptoms and behavioural changes associated with dementia do not arise purely from neuropathology, but from a dialectical interplay between neuropathology and the person's psychosocial environment.

Kitwood, who developed the Bradford Dementia Group at the University of Bradford in the UK, was the initial developer of person-centred care. Kitwood argued that viewing people with dementia only in medical terms leads them to be seen as objects and as having no subjectivity or personhood. Kitwood

argued that people's experience of dementia not only arises from biomedical phenomena such as their degree of neurological impairment and their physical health but also from social and psychological factors such as their personal biography and day-to-day interaction with other people. Kitwood described the mutual contribution of biomedical and social/psychological on the development of dementia as a 'dialectical process' and expressed it as an equation:

$$D = NI + PH + B + MSP$$

D = dementia
NI = neurological impairment
PH = physical health
B = biography
MSP = malignant social psychology

Kitwood's approach is usually known as 'person-centred care', although his approach needs to be differentiated from '**person-centred approaches**' that merely highlight the need for individualised care. Kitwood's approach is more conceptually and theoretically developed, and it highlights the importance of the person with dementia rather than the disease process itself. Kitwood argued that people with dementia do not lose their personhood, but rather it can be maintained through relationships with other people. Thus, Kitwood defines personhood as 'a standing or a status that is bestowed on one human being, by another in the context of relationship and social being' (Kitwood, 1997). Within person-centred care therefore, the personal and social identity of a person with dementia arises out of what is said and done with them.

According to *Tom Kitwood on Dementia: A Reader and Critical Commentary* (2007), edited by Clive Baldwin and Andrea Capstick, Kitwood's work on illbeing and wellbeing in dementia appears to have unfolded in three main phases. In the earliest of these (from around 1987–1990), the emphasis is entirely on illbeing, which is considered to be an inevitable consequence of dementia and is frequently suggested by him as a precondition for its onset. In the mid-phase (1991–95), the emphasis shifts from both illbeing and wellbeing in the context of the interpersonal interaction with the person with dementia, largely in formal care settings. In the latest phase of Kitwood's work (1995–98), the focus moves again from a binary distinction between illbeing and wellbeing to a more detailed consideration of the psychological needs of people with dementia and the challenges of the equipping caregivers to meet these needs.

FACTORS CONTRIBUTING TO, AND INDICATORS OF, WELLBEING

In the *Brighter Futures* report by Kitwood, Buckland and Petre (1995), the authors set out factors contributing to 'wellbeing' (and illbeing). The **factors contributing to wellbeing** are summarised in Table 6.1.

TABLE 6.1 The factors contributing to wellbeing

Social setting	A measure of importance is engagement. This represents an active and conscious link with the outside world. There has been a great deal of work to show that providing a structure and opportunity for interaction does create engagement in people with dementia of all levels of activity.
Cognitive ability	There are many examples of people 'faring well', despite having impaired cognitive function. Wellbeing can be expressed in different ways, according to level of cognitive activity; wellbeing is never taken away simply because of cognitive decline. However, there is a strong link between cognitive impairment and lower wellbeing.
Dependency	For those who have forms of physical dependency that isolate (e.g. visual impairment), there is an especial need for help in maintaining contact with the outside world. A person who is isolated from social contact is deprived of nourishment for their wellbeing. A person who is open to new experiences is better able to fare well with their changing and confusing circumstances.
Quality of social contact	People who have any social contact, regardless of its quality, fare better than those who are isolated and ignored. In short, where there is wellbeing present, it should be promoted as far as possible. Keeping the person engaged will help promote wellbeing a great deal. Moreover, if this can include good quality social interaction, there is a strong chance that the person will maintain or improve in their level of wellbeing.
Staff	Most staff describe themselves as being motivated by caring, and pay is rarely cited as a cause of satisfaction or dissatisfaction. Homes that have staff who have a personal concern for their work have residents with higher levels of wellbeing.
Physical setting	The data suggest that measures of physical environment have little relationship with wellbeing. However, there is a very mild effect relating to the physical amenities measure. The inference is that homes that have facilities such as adequate or accessible toilets and a decent laundry are more able to enhance the wellbeing of residents.

Source: Kitwood, Buckland and Petre (1995).

Source: Kitwood, Buckland and Petre (1995).

Likewise, the **factors contributing to illbeing** are shown in **Table 6.2**. In Kitwood and Bredin (1992), the authors identified 12 indicators of wellbeing that are operationally defined. In *Towards a Theory of Dementia Care: The Interpersonal Process* (1993), Kitwood summarised it as follows:

Behind this, we postulated 'four global states', grounded in the life of emotion and feeling rather than that of elaborate cognition. The states are self-esteem, agency, social confidence and hope. ... A communicative act was carried through successfully. The dementia sufferer felt recognized [sic] as a person: self-esteem was enhanced. A gesture was transmuted into action: agency was confirmed. The dementia sufferer moved towards the Other

and was welcomed: social confidence increased. Confusion and disorder within the psyche were met with order and stability in the social world: hope was sustained. It is the repetition of the experience, we may hypothesize [sic], that can establish wellbeing even in the face of severe cognitive impairment.

TABLE 6.2 The factors contributing to illbeing

Social setting	One of the most important factors that lead to increased illbeing are for people to be left unattended, showing signs of illbeing, for long periods of time. The lack of attention, once over 30 minutes, very significantly contributes towards to a high state of illbeing. Apathy and loneliness are the most common forms of illbeing observable in those who are left unattended.
Dependency	Individual dependency varies greatly, and has a direct effect on the extent to which people can generate their own quality of life. Physical dependency can be extremely crippling, and loss of sight, hearing and language places the individual at risk of isolation, potentially leading to extreme anger, or withdrawal and despair.
Personality	Neuroticism, agreeableness and conscientiousness are three important dimensions of personality that discriminate between high and low illbeing.
Relationships	The data concerning this are not conclusive.
Staff	Higher levels of illbeing are observable where there is an emphasis of staff routines and procedures.

PERSONHOOD AS CENTRAL TO PERSON-CENTRED CARE

At the heart of Kitwood's conception of person-centred care was a sense of 'personhood', meaning 'what it is like to be a person'. Kitwood argued that personhood depended not on ability or capacity, but it is a 'standing or status that is bestowed upon one human being, by others, in the context of relationship and social being.' It implies recognition, respect and trust (1997) and that personhood was the right of every human being regardless of capacity.

Kitwood drew attention to personhood as:

- **an essentially relational concept** – that is, one did not 'possess' personhood but personhood exists in the way one is treated
- **essentially dynamic** – that it could ebb and flow
- **to some extent situational** – the social and physical environment could support and uphold or undermine personhood
- **a unique encounter** between two individuals that could not be legislated for without using uniqueness.

Person-centred care for Kitwood thus flowed from a concept of personhood. Such care was to be aimed at upholding the personhood of the individual threatened by the onset and progression of dementia (the dementia itself not

being the factor that undermined personhood, but the individual and social responses to the dementia). Since Kitwood wrote, there has been much work that has demonstrated that, contrary to the popular perception, for those people with dementia, **the Self remains** (see, for example, Sabat and Harré, 1992; Klein *et al.*, 2003; Surr, 2006). Such a Self may be vulnerable that is nevertheless retained in the face of dementia and the response of others to dementia.

MAINTAINING PERSONHOOD IN DEMENTIA CARE

As reviewed by the National Care Forum (2007) in their *Key Principles of Person-Centred Dementia Care*, in order for a person-centred approach to be embedded in an organisation, appropriate relationships have to be established.

This will be evidenced in areas such as:

- the philosophy of care
- the person with dementia being at the heart of all services
- the person with dementia being enabled to maintain the relationships with significant others as he or she chooses
- respect and value for human life
- communication will be open and honest, and presented in a way that is understood
- staff presenting a positive attitude.

PERSON-CENTRED CARE AND 'DEMENTIA CARE MAPPING'

As argued by Aveyard (2001), the concept of person-centred care, developed by Kitwood, has become a driving force in the philosophy of care for people with dementia, and could provide a valuable framework on which to base educational programmes. Person-centred care puts the needs of the person with dementia at the very heart of care provision. If those needs are also at the heart of education for people working in the field, then, arguably, the contents of an educational programme will reflect the needs of the person with dementia.

Person-centred care has been identified as a key factor for upholding dignity in health and social care (SCIE Guide 9), and DCM is a method that has been specifically developed to improve person-centred care (Young and Sturdy, 2004; Bradford Dementia Group, 2005). Although other person-centred care tools exist (Nolan *et al.*, 2004; McCormack, 2004; McCormack and McCance, 2006), few are as well developed or as widely used as DCM.

DCM is a complex care improvement process whereby five to eight individuals within a care setting are continuously observed over 4–6 hours by a trained DCM practitioner (a 'mapper'). At 5-minute intervals, a record is made of what has happened to each individual being observed using two coding frameworks. *Behaviour Category Codes* capture the type of activity engaged in, and *Mood/Engagement Values* are a judgement of the state of affect and engagement

experienced using a 6-point scale ranging from +5 (very positive mood or deep engagement) to -5 (very negative mood). Mood/Engagement Values are averaged over the mapping period to provide a summary Well/Illbeing score for an individual or group. A detailed set of operational coding rules informs decision-making.

Observations are undertaken, with the knowledge of patients, in communal places. The observation style is unobtrusive, and if it is seen to be increasing feelings of illbeing in patients, then the mapping is stopped. Observations are analysed and summarised, then fed back to the care team, and action plans for change can be developed at an individual, group or organisational level. After a suitable time period, the care setting is mapped again to evaluate whether the action arising from the initial evaluation has had any impact on the lived experience of care. A cycle of mapping, action planning and evaluation is therefore established.

DCM has face validity (Brooker *et al.*, 1998; Younger and Martin, 2000; Brooker, 2005), and there is some evidence to support its efficacy in long-term care (Martin and Younger, 2001). The latest version (DCM8) has been validated in psychiatric services (Brooker and Surr, 2006). Using the DCM method to develop person-centred care practice could apply equally well to people who have health conditions other than dementia (Jaycock, Persaud and Johnson, 2006), including older people receiving general hospital care.

WHOLE PERSON CARE

Whole person care is becoming an increasingly important policy strand. The Royal College of Psychiatrists in March 2013 produced a report, *Whole-Person Care: From Rhetoric to Reality; Achieving parity between mental and physical health*, and introduced this by explaining the need for the 'parity' between physical and mental health:

The long-standing and continuing lack of parity between mental and physical health evidenced in this report is inequitable and socially unjust. This 'mental health treatment gap', exemplified by lower treatment rates for mental health conditions, premature mortality of people with mental health problems and underfunding of mental healthcare relative to the scale and impact of mental health problems, falls short of government commitments to international human rights conventions which recognise the rights of people with mental health problems to the highest attainable standard of health; yet it can be argued that this lack of parity is so embedded in healthcare and in society that it is tolerated and hardly remarked upon. It also affects people with physical health problems who also have mental health needs that may not be recognised in more physically healthcare-orientated settings. The poorer outcomes that result are considered by many, both within and outside mental healthcare, as all that can be expected.

There has been much consideration regarding what ‘whole person care’, a growing trend in healthcare, might be about. Tom Hutchinson (2011) writes as follows:

So, what does the ‘whole person’ in whole person care really mean? It is perhaps easiest to start with what it does not mean. Whole person care is now knowing all about the patient in all dimensions (biological, psychological, social, spiritual and many others that could probably be listed) and taking responsibility for taking care of all of them. Such an undertaking would be doomed to failure and would probably be perceived by patients as overstepping the bounds of the medical mandate and even seen as invasive. When a patient comes to see a doctor he does not expect a combination biological scientist, psychologist, social worker and spiritual guidance counselor [sic], all of them working full out at the same time. Within the context of the clinical interaction, he/she wants someone who will provide competent medical care and treat him/her seriously as a person, usually no more and no less. It sounds simple, and yet, there is more to it than first apparent. While not everything needs to be dealt with at the same time, nothing that comes up can necessarily be ruled out of bounds as a potential avenue for addressing the problem.

PHYSICAL HEALTH: NUTRITION AND ‘DIGNITY IN CARE’

Social Care Institute for Excellence **Guide 15 on ‘dignity in care’** describes also general principles regarding importance of nutrition and pain management.

Good nutrition, good hydration and enjoyable mealtimes can dramatically improve the health and wellbeing of older people. Mealtimes, therefore, should be considered a priority in terms of importance and dedication of staff time; systems within organisations should support this. Protected mealtimes have been introduced in many hospitals: this means that non-acute clinical activity stops, the ward is tidied and patients are made ready for their meals. It gives patients ‘space’ to eat and enjoy their meals. It also gives nurses time to give assistance to those who need it and raises staff awareness on the importance of good nutrition.

Water is vital to life, and there is increasing evidence of the benefits of good hydration in the promotion of health and wellbeing in older people. The evidence suggests that good hydration can help prevent falls, constipation, pressure sores, kidney stones, blood pressure problems and headaches. Furthermore, poor hydration has been shown to contribute to obesity, depression, inactivity and fatigue and to prolong healing and recovery.

It is interesting to note the perspective of a real ‘#dementiachallenger’ (Beth Britton) on types of drinks that individuals with dementia might like. Beth writes passionately, based on her real experiences. Her blogs are very inspiring to read. This is a very short extract from a popular blogpost dated 8th May 2013.

First of all consider the sort of drinks being offered. Have you tasted them personally? Are they pleasant? It may seem obvious, but it's easy to ignore the fact that if what we are offering someone doesn't taste nice it is unlikely to be welcomed. When a person has dementia they may not be able to articulate their dislike for something, so they will just leave it or spit it out, causing immense frustration for them and their carer(s).

Many care providers are hooked on giving their residents squash – water flavoured with concentrated and often additive-packed so-called 'fruit'. This is about as far from real fruit juice as you can get – it is synthetic, can be metallic tasting and is full of preservatives that should be avoided. I certainly wouldn't want to drink it and we banned squash from being given to my dad, favouring real fruit smoothies that were a perfect consistency and a delicious taste.

EQUALITY AND DIVERSITY CONSIDERATIONS

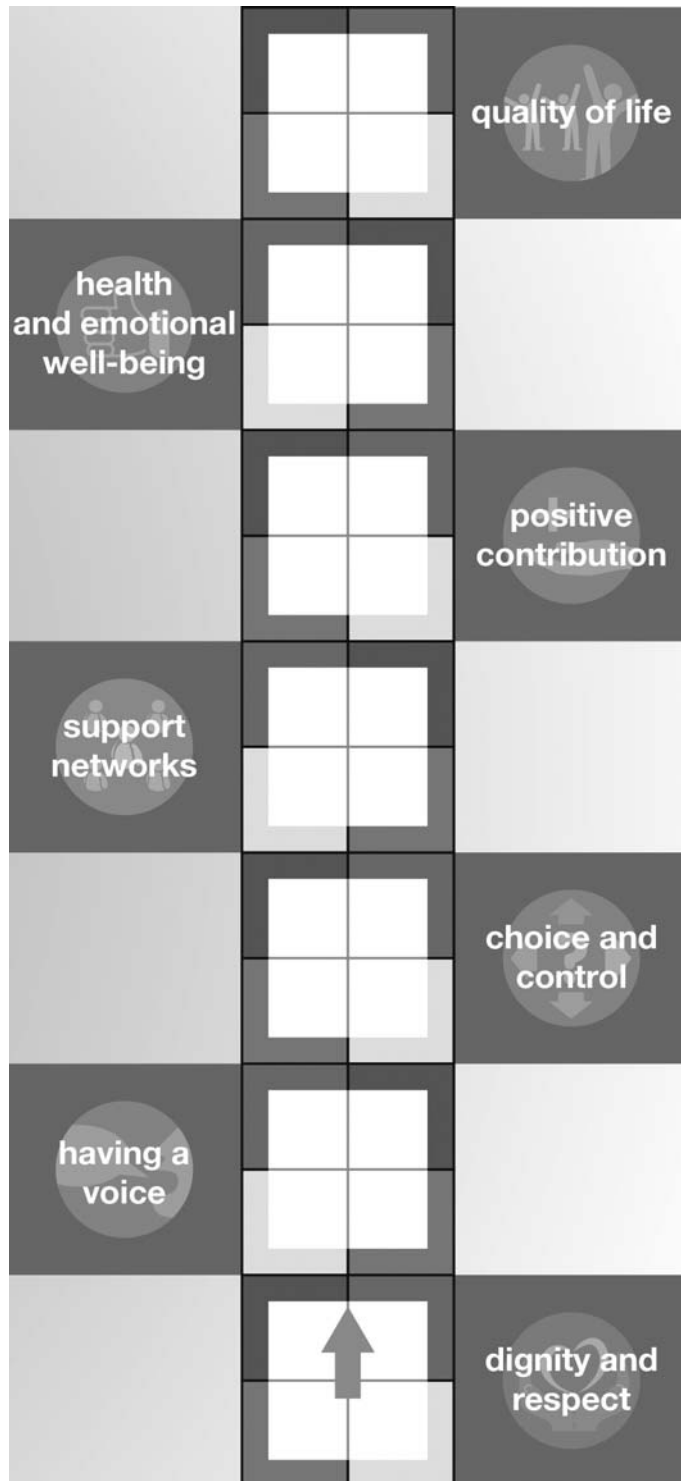
NICE clinical guideline 42 recommendation 1.1.1.7 lists alternative and additional support that may be needed if language or acquired language impairment is a barrier to accessing or understanding support.

Social care and healthcare staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexuality, ethnicity, age and religion. These needs should be recorded in care plans and addressed (**NICE clinical guideline 42, recommendations 1.1.1.3 and 1.1.1.5**).

NICE clinical guideline 42 recommendation 1.1.1.1 highlights that people should not be excluded from services because of diagnosis, age or coexisting learning disabilities.

'THINK LOCAL, ACT PERSONAL'

The real challenge with the person-led initiatives is that such initiatives must be accessible for the wider public for them to succeed. Gill Phillips in her 'Whose Shoes' movement (*see* the Case Study later in this chapter) has made an outstanding contribution in this area. This idea embodies true innovation at its best, with a clear focus in user-adoption, protected in law by registered trademark and registered design right. It is striking that no one session using the 'Whose Shoes' board game or the electronic format can ever be the same, because there are different participants, different questions/themes, and different perspectives (e.g. person, carer, provider). One of the most important aspects also is that it gently encourages participants to question their own assumptions, as this is essential for 'unfreezing' from a particular cultural set of beliefs (Lewin, 1951). This ultimately will be one of the biggest challenges as healthcare becomes integrated with social care in English health policy



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with time. The Foreword to this book written by Sally-Ann Marciano is a good example of how a medical model in its purest form, with all its rigid funding applications, can fail dismally wellbeing of the person with dementia.

Phillips' '**path to personalisation**' was included in the original board game version 'Whose Shoes? Putting People First' to reflect the seven outcomes of *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. You will see that they match very closely some main themes of my thesis: quality of life (**whole book**), health and emotional wellbeing (some health aspects are discussed in **Chapters 6 and 8**), support networks (and dementia-friendly communities, **Chapter 17**), choice and control (decision-making, **Chapter 11**), having a voice (advocacy, **Chapter 11**, and communication, **Chapter 12**). It brings alive the collaborative nature of the tool as people add tiles to the board, representing contributions from all the key stakeholders. In the electronic tool, the wording on the pathway has been updated to align more closely with Think Local Act Personal's 'Making It Real' markers: the cross-cutting themes 'marking progress towards personalised, community based support', derived from work led by members of the National Co-Production Advisory Group, which is made up of people who use services and carers.

Gill has recently also collaborated with the **Think Local Act Personal** initiative, a sector-wide commitment to transform adult social care through personalisation and community-based support.

Case Study: The Whose Shoes? story

GILL PHILLIPS, 22 JUNE 2012

www.thinklocalactpersonal.org.uk/Blog/WhoseShoes/

'Whose Shoes?', like so many ideas that turn out to be successful, was born out of frustration. I was passionate about the possibilities offered by the emerging personalisation agenda. I had originally heard Caroline Tomlinson talking about the amazing differences a personalised approach had made to her disabled son Joseph and indeed to the whole family. Caroline had explained how Joseph became able to exercise choice and control over his support needs, assisted by his 'circle of support'. They moved away from a life of impersonal 'services' to one where Joe had a good quality of life – something that most of us take for granted. I had been totally inspired but asked 'But what if you don't have a Caroline? ...'. I didn't expand but people knew what I meant – a wonderful, dedicated mother, able and willing to take on the system, to fight tooth and nail for what her son needed. I started to see the challenges and barriers that lay ahead in trying to 'make personalisation real' for everyone.

I subsequently led the Research and Evaluation work of the Individual Budgets pilot in Coventry. In a booklet called 'Our stories' we collected the experiences of service users who received individual budgets. Great stories they were too, in many cases transforming lives. But again I was worried how people would fare outside and beyond the spotlight of the 'pilots' ...

I attended conferences. I listened to what people were saying – service users, carers, care providers as well as the keynote speakers. I had a growing sense of unease as I heard presenters saying how 'vital' it was that people made progress with personalisation, often focusing on graphs and charts and targets. They said it was 'imperative' for people to engage with the agenda ... but often seemed to miss the point that 'engagement' is a matter of hearts and minds, not sector leaders saying things a bit louder!

I became frustrated that people didn't seem to 'get' the fact that the new approach meant total transformation. It needed to evolve from grass-roots level. Nobody knew all the answers. People needed time to think things through, to work together and take ownership – all the different interest groups dropping their sometimes entrenched 'silo' positions. They needed to listen to 'people with lived experience', experts in their own lives and support needs. They needed to co-produce sustainable solutions, especially in the context of rapidly dwindling funds. The Whose Shoes? concept was born and much midnight oil was burned on R&D.

As the Whose Shoes? network grew, I adopted a very personalised approach, putting customers in touch with each other, co-producing and sharing facilitation ideas. We experimented together, pushing the boundaries. To begin with, people tended to use the tool to explore personalisation with their own staff. But then, as confidence grew, it became a genuine co-production tool to work with service users and carers; everyone contributing as equals.

Think Local Act Personal committed over 30 national organisations to work together and to develop, as one of the key priorities, a set of markers. These markers are being used to support all those working towards personalisation. This will help organisations check their progress and decide what they need to do to keep moving forward to deliver real change and positive outcomes with people.

Making It Real highlights the issues most important to the quality of people's lives. It helps the sector take responsibility for change and publicly share the progress being made.

Making It Real is built around 'I' statements. These express what people want to see and experience; and what they would expect to find if personalisation is really working well. I statements are an assertion about the feelings, beliefs and values of the person speaking. In the case of 'Making it Real', the I statements are what older and disabled people, carers and citizens expect to feel and

experience when it comes to personalised care and support. They are grouped around six key themes:

1. information and advice
2. active and supportive communities
3. flexible integrated care and support
4. workforce
5. risk enablement *and*
6. personal budgets and self-funding.

There are in total twenty-six statements. Some examples of these statements are:

'I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it is my own money, direct payment, or a council managed personal budget).'

'I feel that my community is a safe place to live and local people look out for me and each other.'

'I have good information and advice on the range of options for choosing my support staff.'

CONCLUSION

There has been a recent shift from thinking about a 'patient' with a series of 'itemised problems' to be management to a 'person' with his or her own individual issues. The past and present of that individual will shape that person's future, and approaches of person-centred care are pervasive in thinking about an individual may 'live well' with dementia. This book now progresses how elements of the physical environment can affect people with dementia – for example, assistive technologies and similar innovations (such as ambient assisted living devices) – as well as how parts of the home or ward can best be designed with an individual in mind. However, not all individuals with a clinical diagnosis of dementia will experience the same problems as result of their illness, and specific problems (such as in social dealings or wayfinding) may come to the fore as a result of the unique dementia process. Furthermore, it is clear that the community at large needs to be a welcoming one for an individual with dementia to live well in, and that will be the focus of the penultimate chapter of this book.

WEBSITE

- Think Local Act Personal: www.thinklocalactpersonal.org.uk

REFERENCES

- Aveyard, B. (2001) Education and person-centred approaches to dementia care, *Nurs Older People*, 12(10), pp. 17–19.
- Baldwin, C., and Capstick, A. (eds) (2007) *Tom Kitwood on Dementia: A Reader and Critical Commentary*. Maidenhead: Open University Press.
- Bradford Dementia Group (2005) *DCM 8 User's Manual*. Bradford: University of Bradford.
- Brooker, D. (2005) Dementia Care Mapping (DCM): a review of the research literature, *Gerontologist*, 45 Spec No 1(1), pp. 11–18.
- Brooker, D., Foster, N., Banner, A., et al. (1998) The efficacy of Dementia Care Mapping as an audit tool: report of a 3-year British NHS evaluation, *Aging Ment Health*, 2(1), 60–70.
- Brooker D.J., and Surr C. (2006) Dementia Care Mapping (DCM): initial validation of DCM 8 in UK field trials, *Int J Geriatr Psychiatry*, 21(11), pp. 1018–25.
- Bryden, C. (2005) *Dancing with Dementia: My Story of Living Positively with Dementia*. London: Jessica Kinsley.
- Chenoweth, L., King, M.T., Jeon, Y.H., et al. (2009) Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial, *Lancet Neurol*, 8(4), pp. 317–25.
- Department of Health (2001) *National Service Framework for Older People*. London: Department of Health.
- Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy; Putting people first*. London: The Stationery Office, available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/168221/dh_094052.pdf
- Dolan, P., Peasgood, T., and White, M. (2008) Do we really know what makes us happy? A review of the economic literature on the factors associated with subjective wellbeing, *J Econ Psychol*, 29(1), pp. 94–122.
- Fillit, H., and Hill, J. (2004) The economic benefits of acetylcholinesterase inhibitors for patients with Alzheimer disease and associated dementias, *Alzheimer Dis Assoc Disord*, 18(Suppl. 1), pp. S24–9.
- Helliwell, J.F. (2003) How's life? Combining individual and national variables to explain subjective well-being, *Econ Model*, 20, pp. 331–60.
- Helliwell, J.F., and Putnam, R. (2004) The social context of well-being, *Philos Trans R Soc Lond B Biol Sci*, 359(1449), pp. 1435–46.
- Hutchinson, T.A. (2011) *The challenge of medical dichotomies and the congruent physician-patient relationship*, chapter 4 (pp. 31–44) in: Hutchinson, T.A. (ed.) *Whole Person Care: A New Paradigm for the 21st Century*. New York, NY: Springer-Verlag.
- Jaycock, S., Persaud M., and Johnson, R. (2006) The effectiveness of Dementia Care Mapping in intellectual disability residential services: a follow-up study, *J Intellect Disabil*, 10(4), pp. 365–75.
- Kitwood, T. (1993) Towards a theory of dementia care: the interpersonal process, *Ageing Soc*, 13(1), pp. 51–67.
- Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

- Kitwood, T., and Bredin, K. (1992) Towards a theory of dementia care: personhood and wellbeing, *Ageing Soc*, **12**, pp. 269–87.
- Kitwood, T., Buckland, S., and Petre, T. (1995) Findings relating to wellbeing, and findings relating to illbeing'. In: *Brighter Futures: A report into provision for persons with dementia in residential homes, nursing homes and sheltered housing*, London: Anchor Housing Association.
- Klein, S.B., Cosmides, L., Costabile, K.A. (2003) Preserved knowledge of self in a case of Alzheimer's disease, *Soc Cogn*, **21**(2), pp. 157–63.
- Lewin, K. (1951) *Field Theory in Social Science: Selected Theoretical Papers*. Edited by Cartwright, D., New York, NY: Harper & Row.
- Martin, G.W., and Younger, D. (2001) Person-centred care for people with dementia: a quality audit approach, *J Psychiatr Ment Health Nurs*, **8**(5), pp. 443–8.
- McCormack, B. (2004) Person-centredness in gerontological nursing: an overview of the literature, *J Clin Nurs*, **13**(3a), pp. 31–8.
- McCormack, B., and McCance, T.V. (2006) Development of a framework for person-centred nursing, *J Adv Nurs*, **56**(5), pp. 472–9.
- National Care Forum (2007) *Key Principles of Person-Centred Dementia Care*. Coventry: National Care Forum, available at: www.guidepoststrust.org.uk/wp-content/uploads/2012/05/Key-principles-of-person-centred-dementia-care.pdf
- National Institute for Health and Care Excellence (2013) *NICE Quality Standard 30. Quality standard for supporting people to live well with dementia?* available at: <http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30/>
- Nolan, M.R., Davies, S., Brown, J., et al. (2004) Beyond person-centred care: a new vision for gerontological nursing, *J Clin Nurs*, **13**(13a), pp. 45–53.
- Pichler, F. (2006) Subjective quality of life of young Europeans: feeling happy but who knows why? *Soc Indicat Res*, **75**, pp. 419–44.
- Royal College of Psychiatrists (2013) *Whole-Person Care: From Rhetoric to Reality; Achieving parity between mental and physical health*. London: Royal College of Psychiatrists.
- Sabat, S.R., and Harré, R. (1992) The construction and deconstruction of self and Alzheimer's disease, *Ageing Soc*, **12**(4), pp. 443–61.
- Social Care Institute for Excellence (SCIE) (2009) *Guidance 15: Dignity in Care*. London: SCIE, available at: www.scie.org.uk/publications/guides/guide15/
- Surr, C.A. (2006) Preservation of self in people with dementia living in residential care: a socio-biographical approach, *Soc Sci Med Care*, **62**(7), pp. 1720–30.
- Young, J., and Sturdy, D. (2004) Senior moments, *Health Serv J*, **114**(5909), pp. 26–7.
- Younger, D., and Martin, G. (2000) Dementia Care Mapping: an approach to quality audit of services for people with dementia in two health districts, *J Adv Nurs*, **32**(5), pp. 1206–12.