

A Social Model of Dementia Care

The Social Model definition of disability: *‘the loss or limitation of opportunities to take part in the community on an equal level with others because of physical and social barriers’* and refers to being disabled as having an impairment defined as *‘the loss or limitation of physical, mental or sensory function on a long-term or permanent basis’*.

Application of the Social Model to dementia care: In contrast to a medical model the social model regards dementia as an impairment, where a marked difference can be made to quality of life by the way people with dementia are supported, and through their built and social environment.

The Dementia Journey: The social model needs to be applied within the context of the dementia care pathway, including memory assessment and diagnosis and multi-agency specialist support for the person and their carer(s). The model requires support to accommodate social, physical, spiritual and psychological aspects of dementia throughout a person’s journey with:

- Focus on the remaining abilities, skills and capacities of the person
- Recognition of the discrimination and marginalisation experienced by people with dementia.
- Importance of listening to the personal experience of dementia and how interactions either impact positively or negatively on the identity of the person.
- Awareness of the influence of the social and built environment in enabling or disabling people with dementia

Focus on the Person: By understanding how dementia affects functions such as memory, orientation, understanding, judgement, learning, language it is possible to focus on the person rather than the illness. This calls for greater understanding of how ‘difficult’ behaviours in people with dementia should be understood as a means of communicating and may reflect strong emotional reactions rather than pathology.

Appropriate interventions can have a significant impact on the quality of life of the person with dementia enabling the person to live more contentedly, be supported to make choices, have optimal control and enjoy increased participation in activities. There are a number of tools that can contribute to personalised and person-centred care and which help to

- Understand what is important to the person
- Understand the person’s life history
- Understand how the person communicates
- Know and act on what matters to the person
- Know what is working/ not working for the person and make changes

A social model of dementia requires a culture that both supports this way of working through a framework of core values and principles described below.

Core Values

- Maximising personal control
- Enabling choice
- Respecting dignity
- Preserving continuity (of lived experience and care provision)
- Promoting equity

Principles

- Treating the person as an individual, respecting their rights and wishes
- Ensuring individual's privacy and dignity
- Tailoring care to individual and changing needs
- Knowing the history of the person and what is important to and for them
- Maximising abilities and independence
- Recognising the importance of relatives and friends
- Managing risk appropriately
- Promoting choice
- Empowering residents, relatives and staff
- Valuing and trusting staff
- Open-mindedness
- Honesty
- Love
- Homeliness
- Friendliness
- Calmness and peacefulness
- Harmony
- Trust

Empowerment of people with dementia

- Physical environment that supports social interaction, a sense of self and enables people with dementia
- The management team adopt a visionary leadership approach, embracing creativity and collaborative approaches to care
- Ensure good levels of nutrition
- Reduce stigmatisation and marginalisation
- Promote confidence, allowing people to contribute to daily activities such as deciding menus / helping prepare meals
- Focus on remaining abilities instead of losses
- Listening to people's personal experience of dementia
- Help to remain active and feel involved in life
- Staff always seeking valid consent from individuals
- All staff trained in dementia care to a level that is consistent with their responsibilities
- Encourage supportive family relationships

- Facilitate inclusion in the wider community
- Ethnically and culturally appropriate
- Appropriate language to reduce stigmatisation, i.e. 'assisting with meals' as opposed to 'feeding'
- Regularly review person-centred support plans.

Specific factors of care provision

- Maintenance of individuality and **a sense of self**
- High quality, flexible, responsive and person-centred care
- Choice (particularly in personal routines)
- Meals and food – having a choice of food and opportunities to make snacks and drinks
- Care from kind and knowledgeable staff
- Continuity of staffing
- Support service availability
- Personal safety
- Ability to come and go at will (safety dependent)
- Staff using preferred manner of address
- Choice of gender of staff for intimate care
- Control over money

Respite care objectives

- Maintenance or improvements in the functioning of the person with dementia
- Maintenance of routines as to prevent distress and to preserve continuity of care
- Improved quality of life for the person with dementia
- Regular breaks for carers to help them keep someone with dementia at home
- Direct support services for carers
- Emergency care, for example, in cases of carer illness
- Temporary placements until permanent arrangements can be made
- Opportunities for people with dementia to get to know the home with a view to eventual placement

Respite and day care

- Clarity of purpose
- A homely, welcoming environment
- Individualised care based on knowing the person with dementia
- Good quality care including occupation and stimulation
- Choice of stimulating and activities appropriate to individual need
- Staff skilled and experienced in dementia care
- Good communication between carers, staff and the person with dementia
- Staff recognition of carer's knowledge and expertise
- Staff able to work in partnership with carers
- Flexibility in the availability of the service
- Continuity of staff
- Good links with other services
- Accessibility

- Good preparation of the person with dementia and carers prior to the stay

Environment

- Provide reasonable freedom of access to all low-risk areas, including gardens, ensuring that routes which may be used by inquisitive residents contain interesting features or suitable furniture (pictures on wall, rummage boxes, easy chairs)
- Provide a number of small, semi-public sitting areas
- Incorporate special points of interest to aid cueing for residents
- Include features which enable opportunities for purposeful activities
- Preclude situations which would allow invasive noise
- Residents rooms to have personalised display on door or to side of door to aid recognition, e.g. 3D memory box
- Appropriate use of technology to maximise independence and to minimise risk

Activities

- Match activities with the needs, abilities and interests (both past and present) of the person with dementia
- A combination of restful and active activities, i.e.
 - Music, dance, movement
 - Art sessions
 - Poetry and local stories
 - Gardening or spending time in the garden
 - Domestic tasks
 - Reminiscence
- Planning structured, individualised activities that involve and interest the person with dementia and may reduce many of their behavioural and psychological symptoms
- Involvement in activities of daily living
- Involvement in special occasions – birthdays / anniversaries
- Staff know and respect the past skills and experiences of the person with dementia
- Staff do not make assumptions about the likes and dislikes of the person with dementia
- Links with the community

Food and nutrition / mealtimes

- Find out about residents likes and dislikes and respond accordingly
- Offer choice and variety
- Consideration given to crockery and cutlery to suit individual needs
- Finger food for those prone to wandering
- Flexible breakfast and supper times to suit individual residents
- Good quality, varied and well presented food
- Special food for celebrations
- Welcoming friends and relatives to join meals
- Avoiding the dining room being set up too early before the meal is served
- Making kitchen facilities available for relatives to use to make drinks and snacks
- Encouraging residents with dementia to assist with meals, e.g. in preparing some food, setting or clearing tables or washing up
- Making mealtimes a social occasion by having staff eat with residents

- Considering how best to arrange mealtimes to meet the needs of people who retain good social and manual skills as well as those who require more assistance
- Ensuring that staff are trained in how best to assist people with dementia to eat

Physical health

- Physical health problems will be identified and appropriately treated
- Good links with general and specialist health services
- Maintain and promote physical health for the residents through the well recognised principles of good diet, appropriate exercise, accident prevention and preventative care from chiropodists to dentists etc.
- Recognition of comorbidities – i.e. depression/anxiety and tailoring interventions

Managing medication

- Minimising the use of anti-psychotic medication by implementing good practice in terms of behaviour management by understanding the personal history of the person with dementia and recognising possible conflicts in the environment
- Prevention of escalation of problem behaviours by means of early intervention and recognition of triggers
- Access to specialist input into decision-making concerning the initiation, review and cessation of anti-psychotic medication

End of life care

- Privacy, space and familiarity are important components of the physical environment in the end of life experience (Kaysor-Jones et al, 2003)
- A private quiet environment in which family can stay and spend time with the person dying
- Recognition of cultural rituals
- Recognition of social death and the impact this has on relatives and friends (Cox, Gilhooly & McLennan, 1997)
- Provision of support for advance care planning, expert symptom management, care for psychological and spiritual suffering and bereavement services for family and staff caregivers (Hanson & Ersek 2006)
- Health and social care professionals ensure that people who are in the later stages of dementia have their palliative care needs met in accordance with the Department of Health's End of Life Care Strategy (2008).

Leadership and Management

- Ensure staff induction emphasises the core values and principles
- Ensure core values and principles are reinforced through staff training and development
- Ensure management and systems support staff in day to day implementation of the values and principles
- Provide good leadership that demonstrates the values and principles
- Ensure staff management (for example shift patterns, cover arrangements) provides residents with consistency of care.
- A strong commitment to providing relationship-centred dementia care.

- A commitment to a culture in which staff communication and interaction with residents are valued as core work.
- Good multi-disciplinary links maintained with a wide range of health services, social care services and other community groups.
- A commitment to involving relatives and residents with dementia in influencing care practice and the management of the home.
- Able to address the ethical dilemmas that arise in dementia care, for example, in balancing the promotion of autonomy for people with dementia against decisions being made by others in the 'best interests' of people with dementia.
- Recognition that dementia care is particularly demanding of staff and respond to their needs by, for example: ensuring good communication and a sense of staff involvement and ownership; by handling staff emotions and inter-relationships well; and, by providing support through good staff supervision

Staff

- Care and support staff will be appropriately trained and skilled to work with people living with dementia and their carers
- Staff will enable social interactions and focus on bringing out the best in someone and on how an individual is feeling
- Staff will understand the world from the perspective and experiences of the individual experiencing a dementia and demonstrate empathy through actions and support
- Staff will value people experiencing dementia and be inclusive of the family and friends who care and support them
- Flexible worker role – span day services, home care and respite services to enable increased continuity, flexibility and improve responsiveness
- Care staff feel valued as individuals, supported and appropriately rewarded; working with people with dementia is very demanding of staff.
- The contribution of domestic, catering, laundry, maintenance and administrative staff should be valued.

Equality and diversity

- Do not make stereotypical assumptions about people based on their ethnic or cultural backgrounds; recognise the diversity that exists within communities and respond accordingly.
- Be clear about the minority ethnic and cultural groups for which the service is to be provided.
- Ensure that the perspectives of the relevant communities are addressed in all policies and practices.
- Ensure that staff can communicate with residents and their families in ways and in languages that are appropriate.
- Person-centred care must be ethnically and culturally appropriate, so the home should:
 - respond appropriately to any particular physical needs of the residents, relating, for example, to diet, health, skin care;
 - ensure that the residents' social needs are addressed including appropriate occupation and leisure activities, and maintenance of family and community links;
 - use 'life story' work to develop the staff's understanding of all people with dementia whilst ensuring regard to the ethnic and cultural background of the resident;

- respect residents' spiritual backgrounds and make the necessary arrangements for them to fulfil the practices of their faith.
- Ensure that the staff group includes people who know and understand the past social world of the resident and the implications of the past for current needs
- Ensure that staff supervision addresses racism and broader race and cultural issues.
- Develop good links with key people and organisations within the relevant ethnic and cultural communities.

Risk enablement and safeguarding

Risk enablement (Department of Health, 2010) is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether. It involves:

- The development of systems for enabling and managing risk which allow people with dementia to retain as much control over their lives as possible.
- Recognising the strengths that each person with dementia possesses and builds on the abilities that he or she has retained.
- Taking a tailored approach to risk by acknowledging that dementia affects different people in different ways. A more person-centred approach to risk and dementia concentrates upon identifying risky situations for individuals with dementia rather than viewing every person with dementia as being at equal risk.
- Identifying less restrictive alternatives – those interventions that cause less disruption or change in the circumstances of the person with dementia and which maximize their independence and freedom, with due attention to the safety of others.
- The recognition that people with dementia's perceptions of risk are likely to be influenced by events and decisions that have occurred during the course of their lives, as well as by the impact of any changes that can be attributed to the effects of dementia.
- Acknowledgement that a shared *agreement* about risk will not always be possible but it is important that everyone involved in reaching decisions about risk reaches a shared *understanding* of the viewpoints of all those who are affected by decisions involving risk.
- Strike a good balance between the protection of residents and the quality of life gains that come from taking some risks.
- Risk assessments need to consider the impact on people with dementia's wellbeing and autonomy as well as the possible risks to their physical safety.
- Effective practice to combat and prevent abuse
- Monitoring, anticipating and addressing environmental, physical health and psychosocial factors that may increase the likelihood of behaviour that challenges, especially violence and aggression and the risk of harm to self or others, i.e.
 - overcrowding
 - lack of privacy
 - lack of activities
 - inadequate staff attention
 - poor communication between the person with dementia and staff
 - conflicts between staff and carers

Consent and decision making

- People with dementia should have the opportunity to make informed decisions about their care and treatment in partnership with health and social care professionals
- It is vital to treat each person with dementia as an individual and to assume that they have the capacity to make decisions for themselves unless proved otherwise.
- All people with dementia must be given full support in making their own decisions for as long as possible.
- Individuals must retain the right to make what might be seen as eccentric or unwise decisions
- Anything done for or on behalf of individuals without capacity must be in their best interests
- Anything done on or on behalf of individuals without capacity should restrict their rights and basic freedoms as little as possible.
- Valid consent should be sought, informing the person of options and checking that the person with dementia understands, that there is no coercion and that he or she continues to consent over time.
- If the person lacks capacity to make a decision, the provisions of the Mental Capacity Act (2005) must be followed.

Engagement with staff and relatives

- Involve relatives in ways that are appropriate to the needs and circumstances of individual residents and their families.
- Provide support for relatives either individually or through support groups.
- A commitment to involving relatives and residents in influencing care practice and the management of the home.
- Staff able to work in partnership with relatives and carers

Quality Assurance

- Quality Standards (NICE, 2010)
- Care Quality Commission
- Dementia Care Mapping
<http://www.brad.ac.uk/health/dementia/DementiaCareMapping/>
<http://www.dementiacarematters.com/>
- My Home Life (NCF & NCHRDF 2006)
- Senses Framework (residents, staff and relatives/carers) (Ryan et al, 2008)
- Progress in Personalisation for People with Dementia (Trevor Adams, Martin Routledge and Helen Sanderson)
- Client and carer satisfaction
- Outcome measurement

Key publications and guidance

All-Party Parliamentary Group on Dementia (2009). *Prepared to Care*. London: APPGD
http://alzheimers.org.uk/site/scripts/download_info.php?fileID=735

Alzheimer's Society (2007). *Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes*. London: Alzheimer's Society.
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http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf

Cantley, C & Wilson R.C. (2002) *Put yourself in my place; Designing and managing care homes for people with dementia*. Bristol: Policy Press / Joseph Rowntree Foundation.
<http://www.jrf.org.uk/publications/designing-and-managing-care-homes-people-with-dementia>

Department of Health (2010). *Nothing ventured, nothing gained: risk guidance for dementia*.
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Department of Health (2008). *End of Life Care Strategy – promoting high quality care for all adults at the end of life*. http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf

Department of Health, (2009). *Living well with dementia: a national dementia strategy*.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

Helen Sanderson Associates (2012). *Progress for Providers: Checking your progress in delivering personalised support for people living with dementia*
<http://www.in-control.org.uk/media/114740/progressforprovidersdementia.pdf>

NCF Older People and Dementia Care Committee (2007). *Key Principles of Person-centred Dementia Care*. <http://www.nationalcareforum.org.uk/content/Key%20principles%20of%20person-centred%20dementia%20care.pdf>

SCIE (2005). *Aiding communication with people with dementia*. SCIE research briefing No 3.
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NICE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/English>

National Care Forum and the National Care Homes Research and Development Forum (2006). *My Home Life – Quality of life in care homes*. London: Help the Aged.
http://www.dignityincare.org.uk/library/Resources/Dignity/OtherOrganisation/My_Home_Life.pdf

Mental Capacity Act (2005). London: HMSO

NICE (2010). Implementation Directorate. Quality Standards Programme. *Dementia Quality Standard*.
<http://www.nice.org.uk/aboutnice/qualitystandards/dementia/?domedia=1&mid=7EF3AFC7-19B9-E0B5-D4504471A4FD758E>