Key principles of person-centred dementia care
Introduction: promoting person-centred care

The primary purpose of the National Care Forum (NCF) is to promote quality outcomes for people who receive care and support through the not-for-profit sector. NCF members make a formal commitment through the chief executives to adhere to NCF’s underpinning values and promote quality for all people receiving care services.

This Statement of Best Practice has been prepared by the NCF Older People and Dementia Care Committee to specify indicators of quality in relation to person-centred dementia care services. It is not intended to be definitive or to provide detailed information on dementia. The Statement will be periodically reviewed. It is expected that a person-centred approach will be evidenced in the Statement of Purpose and Service User Guides produced by NCF members.

Dementia is defined by the Mental Health Foundation (2006) as:

“... a decline in mental ability which affects memory, thinking, problem solving, concentration and perception... Dementia is almost invariably a disease of ageing.”

A person-centred approach to providing care and support is as important for people who receive services (and their family or significant others) as it is to staff. The emphasis should always be on the person as an individual. In a person-centred approach the unique qualities of the individual as determined by their life history and experiences, likes and dislikes, are their defining characteristics. People with dementia have the same rights as citizens. This includes the right to be treated with dignity and respect. Care and support services should build on individual strengths and abilities to maximise and promote independence. Services should enable people to feel valued and safe. The inherent risks of life should be recognised. However, given the potential vulnerability of some people with dementia there is a need for a good understanding of adult protection requirements. Each of the principles contained in this Best Practice Statement is supported by example key indicators.

Assessment, care planning and review

Assessment, care planning and reviewing are key aspects of best practice. Documenting the service received by individuals is vital. The way in which care services are documented will evidence what is occurring for the individual as well as demonstrating whether person-centred care is integral to the service provided.

Key indicators of best practice:
- a full assessment is undertaken prior to a service being provided
- evaluation and reassessment is ongoing
- all relevant documentation used by the organisation demonstrates that
- the individual is fully involved
- cultural needs are appropriately considered
- well-being for the individual is actively promoted
- the language used will be acceptable to the person receiving care
- care plans are used as communication tools - evaluation is meaningless in the absence of well documented care
- a key worker system matches individuals and staff
- relatives (and significant others) feel involved and supported

Valuing communication

Effective communication improves the quality of life of people with dementia. It is essential that efforts are made to enhance communication, make time to listen and to understand.
Key indicators of best practice:

- staff are aware of the different communication needs of different individuals including taking account of any hearing or visual problems or where English is a second language
- staff are trained to understand the importance of verbal and non-verbal communication and barriers to effective communication
- a multi-disciplinary approach is used to implement communication strategies
- staff are able to access specialist advice and information
- advocacy services are utilised

Access to services

People with dementia are entitled to full access to other services. The coordination of health and social care services to meet the needs of people with dementia is essential. This should include a joint approach to assessment and joint planning of local services.

Key indicators of best practice:

- each person has a full assessment of their need. This should include diagnosis and access, where necessary, to specialist professional advice and support.
- specific services are accessed promptly in response to the person’s assessed need, including for example, health care, physiotherapy and nutrition
- mental health needs are acknowledged and appropriate services are provided
- medication is taken as intended
- a palliative care approach to end of life care is adopted including appropriate pain management
- advocacy services are made available where necessary

Well-being and fulfilment

Fulfilment means different things to different people. Enjoyment of, and engagement in life, is crucial to well-being and fulfilment. Activity can give meaning and purpose to life. Self respect and self esteem arise from day to day activities. Life should be fun in whatever way is meaningful to the individual, irrespective of disability or impairment.

The key principle to achieving well-being and fulfilment for people with dementia is that activities should lead to a sense of feeling enabled and empowered.

Key indicators of best practice:

- the relationship between staff and service users is empowering and gives meaning to everyday events which can otherwise be taken for granted
- it is never too late to learn new skills
- life stories are used to ensure a good understanding of individuals
- a balance between stimulating and calming activities
- staff recognise individuals’ styles of participation through observation and assessment
- measurements of well-being and satisfaction are regularly reviewed
- risk is accepted as an integral part of enjoying life.

Staff support and development

Staff are any organisation’s most valuable asset. The organisation is responsible for creating a culture that enables staff to reflect, to learn and to develop. It is essential that a person-centred approach to dementia care is consistently applied throughout the whole organisation.

Key indicators of best practice:

- recruitment procedures and practices reflect a culture and style of the organisation which supports a person-centred approach.
- as much importance is given to staff retention as to staff recruitment.
Promoting quality care through the not-for-profit sector

Key principles of person-centred dementia

- a focus on abilities, promoting appropriate attitudes and enabling staff to contribute fully to the provision of care
- valuing diversity
- staff have a non-judgmental approach and a positive regard for each other and for those they care for
- systems are in place for professional supervision and support
- appropriate learning and training opportunities are provided

Embedding a person-centred approach

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 they choose
- 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

The care setting

The care setting can have a significant effect on the ability of a person with dementia to be independent or to be appropriately supported. Receiving care and support in a care home can bring additional challenges. The design of the building can impact on the creation of a homely environment.

Key indicators of best practice:
- the environment supports a person-centred approach to care
- there is a sense of ease and freedom where people can be themselves
- the building does not rely on a person having a memory – people should be able to find their way around easily
- changes in colours in different areas assist with orientation
- culture/ethnic needs are acknowledged
- the design maximises independence, compensates for disabilities and impairments and is safe for all who work or visit the building
- The outside garden space is an extension of the environment providing accessible and usable space.

The use of technology to support person-centred care

Technology and telecare should complement the services provided by staff. It should be used to enable individuals to function safely and to maximise independence.

Key indicators of best practice:
- technology enables people with dementia to conduct their daily lives and retain their integrity
- technology enables staff to maintain high standards of care
- technology is a discrete component of an individual’s assessed need and subsequent care plan
- technology is used to support person-centred care and not to reduce the need for human contact

Disseminating best practice

Disseminating best practice is vital if perceptions regarding dementia and dementia care services are to change. This includes both public and professional attitudes. Success needs to be shared and celebrated e.g. demonstrating from the individual’s perspective the benefits of joint health and social care, or how a specific therapy has helped.
Key organisations for resources

There is a growing literature, knowledge and resource base in dementia care provision. In addition there are a number of important organisations which offer information, guidance and advice. This listing is not intended to be exhaustive.

The **Alzheimer’s Society** ([http://www.alzheimers.org.uk/](http://www.alzheimers.org.uk/)) is the UK’s leading care and research charity for people with dementia, their families and carers. The organisation produces a range of publications and practice guides promoting quality care services including:
- Quality dementia care in care homes: person centred standards
- A guide to implementing good practice in care homes
- Home care standards for the care of people with dementia
- A package for providers of home care service to plan and deliver care to people with dementia
- Food for Thought practice guides
- Raising awareness of the challenges experienced by people with dementia concerning food, eating and drinking. It has practical suggestions to help support the knowledge and experience of health and social care staff.

The **Bradford Dementia Group** was established in 1992 at the University of Bradford to develop teaching, education and research in the field of dementia care. Their mission is to improve the quality of life and quality of care for people with dementia and their families. The Group offers training in person-centred care and Dementia Care Mapping and has an international reputation. The Group edits the Jessica Kingsley series of Good Practice Guides on Dementia Care. The series is a set of accessible, jargon-free good practice guides for practitioners and professionals. [www.brad.ac.uk/acad/health/bdg/](http://www.brad.ac.uk/acad/health/bdg/)

**Dementia Services Development Centres** ([www.dsdcengland.org.uk](http://www.dsdcengland.org.uk)) are regional centres providing service development support on all aspects of dementia care services. They include:
- The Dementia North Centre is a partnership between the Dementia North Trust and Northumbria University covering the North and Yorkshire region. Dementia North helps service providers to use this knowledge to develop their services through information, education and training, research and evaluation. [www.dementianorth.org.uk](http://www.dementianorth.org.uk)

The **North West Dementia Centre (NWDC)** based within the Personal Social Services Research Unit (PSSRU) at the University of Manchester. The aim of the centre is to promote awareness of dementia, its consequences and effective management to professionals and the general public through information and service development. [www.medicine.manchester.ac.uk/pssru/nwdc/](http://www.medicine.manchester.ac.uk/pssru/nwdc/)

The **Dementia Services Development Centre**, at the University of Stirling, was established in 1989 through the Dementia Services Development Trust and the University to provide extensive information about dementia services and is involved in developing and disseminating research and good practice about services for people with dementia. The centre, based in the Iris Murdoch Building which is an exemplar of dementia-friendly design, offers organisations access to consultancy, training and specialist services. [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)

The **National Institute for Mental Health in England (NIMHE)**, a part of the Care Services Improvement Partnership (CSIP), is responsible for supporting the implementation of positive change in mental health services. [www.nimhe.csip.org.uk](http://www.nimhe.csip.org.uk)
The Social Care Institute for Excellence (SCIE) has produced a series of Research Briefings on aspects of dementia care which can be downloaded from www.scie.org.uk

SCIE also hosts a website disseminating good practice materials. www.scie-socialcareonline.org.uk

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The NCF members are not-for-profit care providers. They are united by a common social purpose in which a commercial business approach to the provision of services enables reinvestment in services and development. By bringing together the entrepreneurial drive of a business approach with the ethos of public service, not-for-profit organisations offer an innovative model of service delivery to the care sector. In this way NCF members are already making a significant contribution to communities and local economies through the full range of social care services.

The NCF embraces the diversity of the care sector and includes within membership a wide range of services. This includes: home care, housing with care, day care, intermediate care, outreach, residential and nursing care, and specialist provision for all adults and older people receiving care and support services through the not-for-profit sector.

If you are interested in joining the NCF and would like more information please contact the NCF office on 024 7624 3619 or visit our website www.nationalcareforum.org.uk

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