



# Dementia Services: Supplementary Guidance for Specialist Providers

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The Ensuring Quality standards expect a demonstration of quality which is proportionate to the type of service that it delivers. This document provides guidance on the sort of information we expect from a provider who wishes to advertise their service as appropriate to supporting individuals with dementia.

In order to do so all your answer must show that your organisation values 'the importance of seeing the PERSON with dementia as opposed to the person with DEMENTIA'<sup>1</sup>

## Standard 1: I have support that is right for me

### • I am at the centre of the service

Are you committed to providing person-centred support for people with Dementia? For example, how do you embed the [Common Core Principles for Supporting People with Dementia](#) into working practices?<sup>2</sup>

How do you plan your service for people with dementia? For example:

- Are your activities designed to maximise quality of life for people with dementia?
  - Person centred and focused on the individuals likes/hobbies/interests
  - Activities that are relevant to the individuals life ie; career, family life, relationships, etc.
  - Activities that were important to the individual before developing dementia
- Does your environment (if relevant) meet the following standards:
  - Uncluttered
  - Use of colour/landmarks and signage to assist with way-finding
  - Appropriate levels of lighting
  - Avoidance of heavily patterned furnishings
  - Access to outside space or large enough amount of inside space to walk about.
  - Access to pressure relieving cushions and beds?
- Who is your service aimed at and how do you tailor your service to meet this?

Considerations should include:

  - Mild / Moderate /Severe stage of dementia
  - Various types of dementia, e.g. Alzheimer's Disease, Dementia with Lewy Bodies, Vascular Dementia etc.
  - How is the progression of the disease managed within the service?<sup>3</sup>

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<sup>1</sup> Kitwood, t. Dementia Reconsidered: The Person Comes First (Rethining Aging), 1997

<sup>2</sup> <https://www.gov.uk/government/publications/common-core-principles-for-supporting-people-with-dementia>



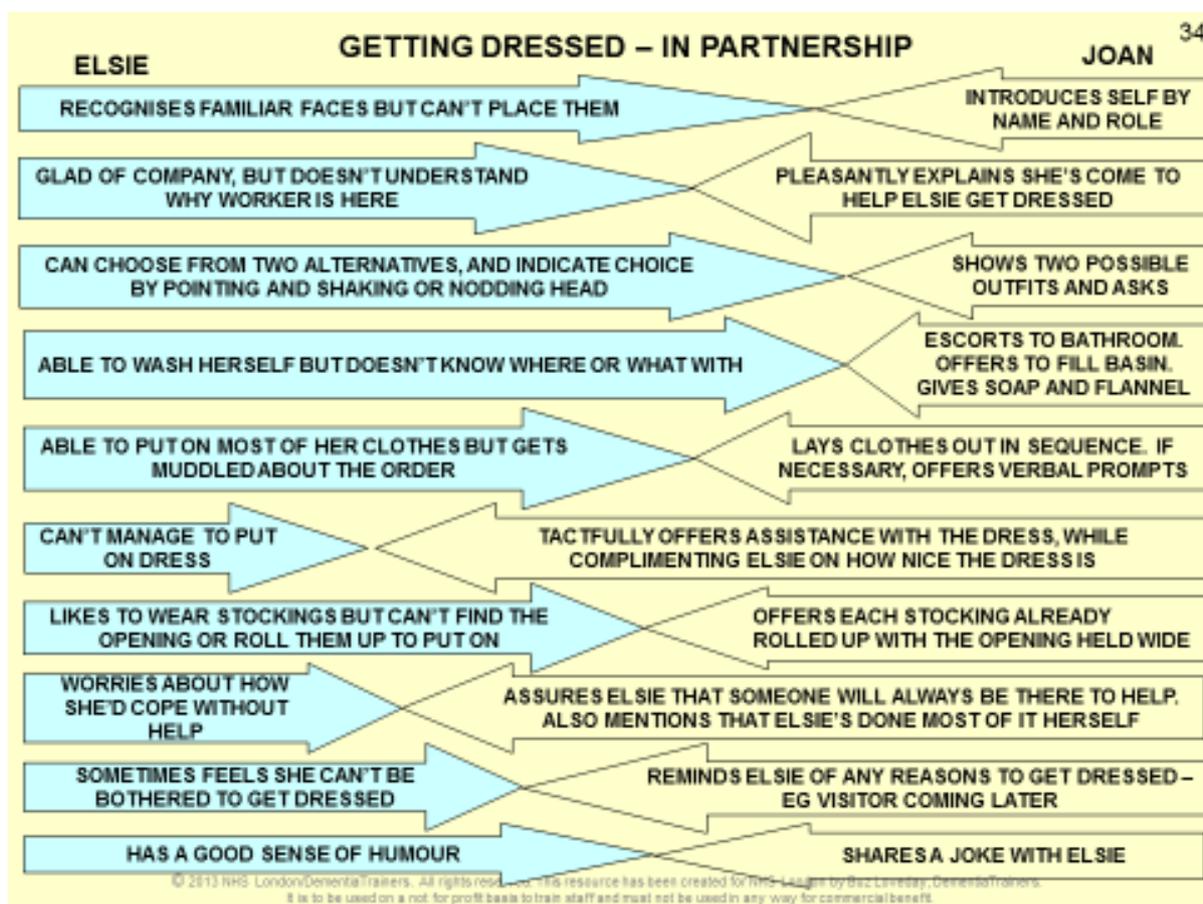
- How do you focus on the whole person including their additional health needs other than dementia?

- **I am part of the community**

How do you support people to stay part of the community?

- **I am independent**

How do you help people do as much as they can for themselves? Elsie's example below is a good illustration of task division which is not just limited to care needs. How do you apply this principle to all their needs?



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- **I can make decisions about my support**

<sup>3</sup> [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1772](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1772)



- How you enable people with dementia to make decisions and choice about their lifestyle?
- How you ensure the MCA is implemented – discuss how you work in line with the 5 key principles of the Mental Capacity Act (2005) and the Deprivation of Liberty Safeguards.
- If relevant how do you support people with capacity to access support from the Independent Mental Capacity Advocate (IMCA)?

## Standard 2: I get what I want out of the service

- The organisation knows what I want to achieve
- They support me to do this safely
- We make sure it is happening

In order to meet standard 2 and deliver person centred care you must first demonstrate how you find out about everyone as an individual and what their needs are by creating a support plan which:

- Finds out about people as individuals
- draws on their needs, interests, hobbies and life stories
- Works with their family and friends

You must then demonstrate how you then meet the person's individual health and care needs, for example by:

- Promoting a physically healthier life style, if relevant, by including nutritional requirements, falls, continence, sexual health, pressure relief
- Promoting well-being by supporting people to be happy and to live well, through maintaining and developing relationships and social connections, for example, though meeting the needs identified in Kittwoods' Flower:

1. **Comfort:** provision of warmth and closeness to others
2. **Identity:** to know who you are both in how you feel about yourself and how you think
3. **Attachment:** the need to feel attached to others particularly at times of anxiety – nurturing & trust
4. **Occupation:** being involved in the process of life
5. **Inclusion:** being part of the 'group', and

**Love:** central to all needs<sup>5</sup>

## Standard 3: I am supported to take risks and stay safe

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<sup>5</sup> Kittwood, T. (1997) *Dementia Reconsidered: The Person Comes First* (Rethinking Aging), 81



*“Each day brings its own catalogue of risks, some minor and some dangerous. But over time and with forgetting, there is the risk of being put on the sidelines, of being seen as a hindrance, and having control taken away from you, under the guise of it being for your own good. So, while we can, we must challenge the risks... People living with a dementia must be allowed to take risks, because if we don’t, we are in danger of relaxing into the disease. At times we feel hopeless. At times the hurt we feel is indescribable and we can let it be a barrier to life. But there is a life for us, if we risk it.”*  
(Personal account of living with dementia, Morgan, 2009, 28)<sup>6</sup>

In order to demonstrate that you meet the standards you must show that you support people to have as much control as possible. The Department of Health said “one of the biggest barriers to enabling people with dementia have more control over their lives is an overly cautious approach to risk”<sup>7</sup> How do you use risk enablement plans and risk assessment tools to give people the right amount of autonomy and control?

## Standard 4: I have all the information I need to make the service work for me

In order to be a quality provider it is important that you can communicate clearly with people with dementia and their carers in a way that they understand.

It is also helpful to be able to sign post and support people to access:

1. basic information on dementia e.g. fact sheets available on the Alzheimer’s Society website<sup>8</sup>
2. guidance on management of the condition and circumstances to support them to live well and to cope with changes to their health and wellbeing<sup>9</sup>
3. clear guidance on how to access local services that can support them now and in the future if needs change. This includes health and social care contacts, as well as voluntary sector services that can offer support and help people to live well.

## Standards important for the organisation

### Standard 5: The organisation listens to people and makes changes

In order to meet standard 5 you must demonstrate that people and their carers have the opportunity to influence the design, plan and evaluation and delivery of your service. To do this you must show

<sup>6</sup> Morgan, K. (2009) ‘Risks of living with Alzheimer’s disease: a personal view’, *Journal of Adult Protection*, 11(3): 26-29.

<sup>7</sup> DH (2010) Nothing ventured, nothing gained: risk guidance for people with dementia, <https://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia>

<sup>8</sup> <http://www.alzheimers.org.uk/site/scripts/downloads.php?categoryID=200465>

<sup>9</sup> Providers may use this Alzheimer’s Society Dementia guide [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2239](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2239)



- how you interpret messages that people with dementia may be struggling to communicate, through understanding non-verbal communication and using aids such as talking mats
- how do you ensure your staff understand that some people with dementia may not be able to communicate that they are in pain and proactively look for other cues, such as non-verbal communication, and administer pain relief accordingly.
- How do you manage behaviour that is described as challenging?

Please discuss how you satisfy the following Communication Standards:

Standard 1: There is a detailed description of how best to communicate with individuals.

Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

Standard 3: Staff value and use competently the best approaches to communication with each individual they support.

Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate.

Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing.

## **Standard 6: The organisation treats everyone as equally important and respects everyone's needs**

People with dementia continue to have other support needs, especially those common amongst older people such as sensory loss.<sup>10</sup> What do you do to recognise and support this?

Older people are sexual beings and not all older people are heterosexual. How do you support your staff to have awareness and understanding of lesbian, gay, bisexual and transgender issues, to ensure that they do not make judgments concerning a person's sexuality or gender identity, and that individual preferences are respected?

## **Standard 7: Staff have the right qualities, skills and experience**

In order to demonstrate that you are a specialist dementia provider all members of staff, including both clinical and non-clinical staff in contact with service users, have training equivalent to the following:

- Social Care Institute of Excellence's free 'open dementia e-learning programme'<sup>11</sup>
- Dementia Awareness training as delivered by any of the Councils. E.g. Dementia Friends
- Tier 1 dementia awareness training, as defined by NHS England; London Clinical Network for dementia<sup>12</sup>.

<sup>10</sup> <http://www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/files/sight-loss.pdf>

<sup>11</sup> <http://www.scie.org.uk/publications/dementia/open-dementia-e-learning-programme/index.asp>



Staff who work regularly with people with dementia receive more specialist training such as:

- Social Care level 2 training in NVQ or QCF with units specific to dementia
- Tier 2 training, as defined by NHS England<sup>13</sup>

## **Standard 8: The organisation has every thing in place to deliver a safe service**

Behaviour which is seen as challenging is often a way of communicating an unmet need. In order to safely manage the behaviours it is important to identify the unmet need. People are offered an assessment at an early opportunity to establish underlying causes and aggravating factors, such as unmet psychological needs and unidentified pain. Interventions to improve such behaviour or distress should respond to identified factors and be recorded in their care plan.

In order to meet standard 8 you must commit to using Antipsychotic medication only as a last resort, and if used, minimised both in dosage and time prescribed, in line with NICE guidance.

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<sup>12</sup> NHS England(June, 2014) *Guide to Dementia Training for Health and Social Care Staff in London, Improving quality of care.*

<sup>13</sup> Ibid.