Common Core Principles for Supporting People with Dementia

A guide to training the social care and health workforce

skillsforcare

Skills for Health

DH Department of Health

Ministerial foreword

Dementia is one of the most important issues we face as the population ages. The coalition Government is committed to implementing *Living well with dementia: A National Dementia Strategy* in full. The Strategy sets out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

Last September the Government published a new outcomes-focused implementation plan, *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*, with a greater focus on accelerating the pace of improvement in dementia care, through local delivery and local accountability.

The quality of the workforce is critical to the successful implementation of the Strategy. To support the delivery of improved education and training on dementia, the Department of Health has established a Workforce Advisory Group, chaired by Professor Alistair Burns, National Clinical Director for Dementia.

To support this work the Department has asked Skills for Care and Skills for Health to develop this set of Common Core Principles for Supporting People with Dementia. The principles have been devised by working with employers, people with dementia, carers and provider organisations.

I hope these principles will be used to support workforce development by any health or social care provider and for anyone working with people at any stage of dementia.

I encourage all those involved in providing vital care and support for people with dementia to embed the principles in their culture, their agreements with partner agencies and their own policies and practices.

Paul Burstow MP
Minister of State for Care Services

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Purpose and structure of the guide

This guide presents eight Common Core Principles for Supporting People with Dementia. They can be used to enable workforce development for any member of staff working in health or social care with people at any stage of dementia, from the earliest signs to the fully diagnosed condition. The common core principles are relevant to every setting and provide a basis for a general understanding of the condition. They aim to build workers' confidence in adapting their actions and communication in order to respond appropriately to the person with dementia. Signposting to resources and further reading has been included at the end of the guide.

Although the guide is written primarily for the health and social care sectors, the principles and supporting information will also be of interest to those working in any situation where people interact with those with dementia. The principles can be applied to any customer-focused provision, with equal relevance to those working in settings such as shops and banks, as well as public sector settings such as library, education and housing services.

The principles have been written on the assumption that the workforce supporting people in the later stages of dementia will have received specialist training and support.

Section 1 Introduction

Describes the rationale for developing the principles, presents background information on dementia and suggestions for using the guide.

Section 2 Common core principles

Sets out the common core principles and the indicative behaviours expected in a skilled workforce.

Section 3 Embedding the common core principles

Provides guidance for leaders and managers, commissioners and training and education leads to develop a workforce that can create dementia friendly settings. These settings are able to demonstrate that people with dementia are supported appropriately, with staff who are confident in adapting their behaviour to provide care that enables people to 'live well with dementia'.

Section 4 Planning training and development

Provides guidance on planning and delivering education for the wider workforce that is tailored to local contexts. This includes signposting to the national occupational standards and qualifications that support training and education but does not provide a prescriptive list of competences.

The Common Core Principles for Supporting People with Dementia

Principle 1 Know the early signs of dementia.

Principle 2 Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.

Principle 3 Communicate sensitively to support meaningful interaction.

Principle 4 Promote independence and encourage activity.

Principle 5 Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.

Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

Principle 7 Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.

Principle 8 Work as part of a multi-agency team to support the person with dementia.

1. Introduction

"As their dementia progresses, people may be less able to enter our world – we may need to enter theirs and enjoy it with them."

Barbara Pointon, Carer

These common core principles will help to develop a workforce that responds confidently to the person with dementia, understanding how to enter their world and support the life they are leading.

Rationale for developing the common core principles

Dementia refers to a collection of symptoms characterised by a progressive loss of cognitive abilities affecting reasoning, communication and the ability to carry out routine activities associated with daily living. It is a complex condition that can be linked with a number of medical difficulties and therefore requires a careful diagnosis. The condition is likely to deteriorate over time and carries significant implications for everyone involved. However, careful advice can provide reassurance to families and enable people to adapt their lifestyles to accommodate the changes that are taking place and 'live well with dementia'. It is becoming increasingly common with one in six people over the age of 80 having a form of dementia. (*Dementia UK The full report*, Alzheimer's Society, 2007). See www.scie.org.uk/publications/dementia/about.asp for a full explanation of dementia.

Recognising the early signs of dementia can be difficult and it takes time to make a diagnosis. An assessment requires a good knowledge of the person affected as well as a careful consideration of physical factors to ensure that underlying medical changes are identified (National Institute of Clinical Excellence and Social Care Institute of Excellence Guidelines 2007). The process of diagnosis must be accompanied by sensitive support and compassion as people affected and their families start to understand the longer-term implications of the condition.

Every person with dementia should have the support of people who are confident in adapting their interaction to reduce the stress and anxiety that dementia can bring. It is essential that support is tailored to the person and their personal interests and specific needs, encouraging independence and choice in the decisions they make. The purpose of the principles set out here is to enable health and social care settings to become 'dementia friendly', with a workforce who are confident in supporting dementia, whether in community, hospital or specialist settings. We have included references to resources that can be used informally or as part of a specific training programme to implement the common core principles in the workplace.

Training and development has a key role in the implementation of the National Dementia Strategy (DH 2009) and these common core principles will support development of the wider workforce. The best way to create a workforce that completely understands and responds positively to people with dementia is for workers, students and trainees to have these principles embedded in their practice. The common core principles should be used as a general framework, which can be adapted and used flexibly according to the specific needs of the setting. They can provide the basis of training and development for individual workers, teams and for wider corporate training programmes. They have been mapped to generic national occupational standards and agreed units of learning available through the Qualifications and Credit Framework (QCF). Employers are encouraged to use these resources as a foundation for their development plans for specific local settings. Section 3 gives the opportunity to contextualise the principles and national occupational standards to specific situations.

How to use the common core principles

The common core principles will enable health and social care practitioners to respond in a timely and appropriate way to the needs of people with emerging signs of dementia as well as to those with a confirmed diagnosis of the condition. They have been developed using current policy and guidance – particularly *Living Well with Dementia: A National Dementia Strategy* (DH 2009) and the National Dementia Declaration for England (DAA 2010) – and advice from carers and practitioners. The common core principles will be a central element in supporting organisations to implement their local dementia strategies and plans as indicated in diagram 1. They will support developments which take place locally to improve the experience of people with dementia and their carers using health and social care services, along with other guidance such as the *Core Competences for End of Life Care* (SfC/SfH/DH/NHS 2009) and *Carers Matter – Everybody's Business* (SfC/SfH 2011). In addition it may also be helpful to consider the Department of Health document *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy* (DH, 2010).

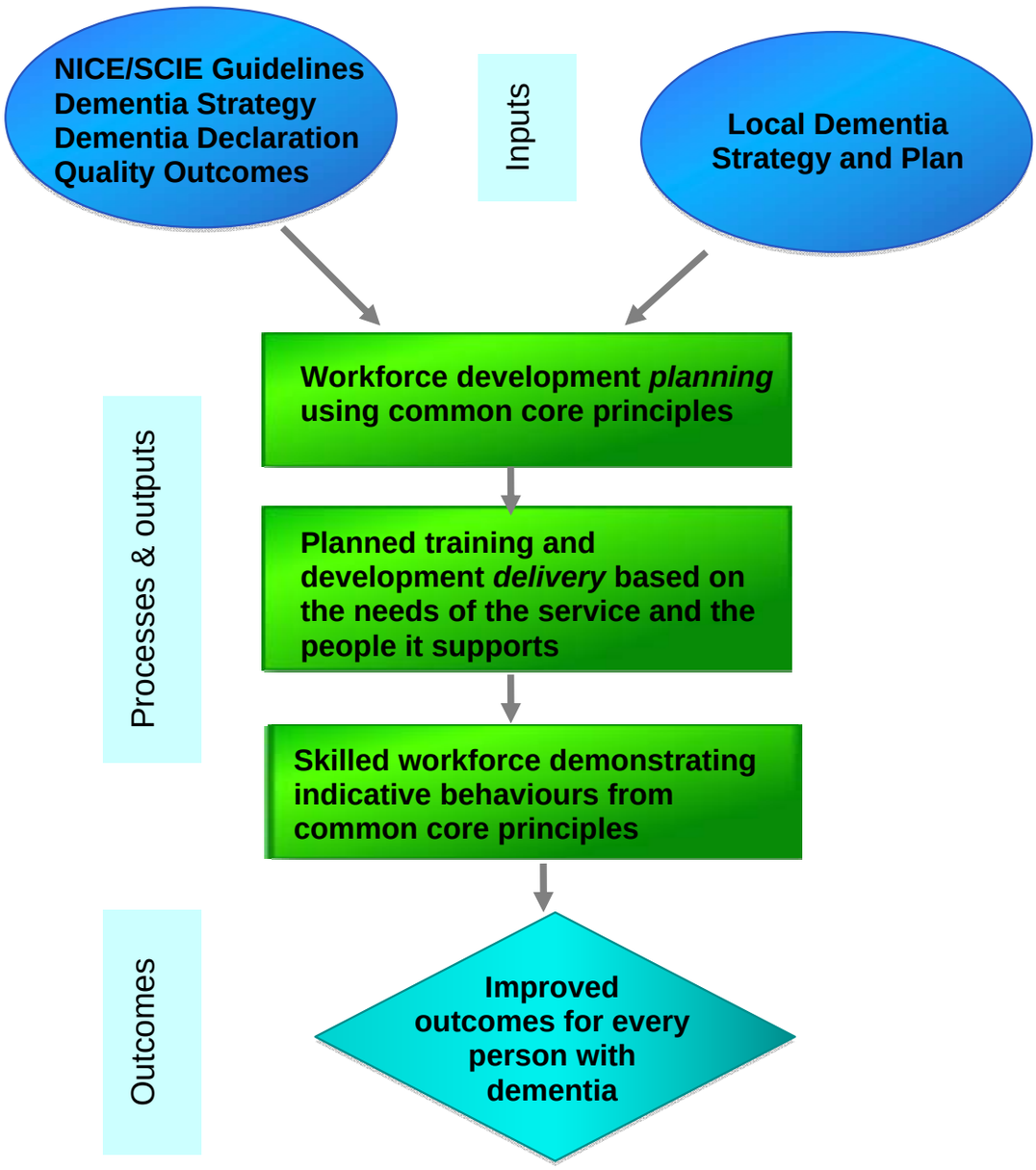


Diagram 1 The role of the common core principles in implementing the Dementia Strategy at a local level.

2. The Common Core Principles for Supporting People with Dementia

In this section, we describe the common core principles together with the indicative behaviours that the workforce should demonstrate to show that the principles have been embedded in the way they respond to the person with dementia.

Principle 1 Know the early signs of dementia

- Loss or lapses of recent memory
- Mood changes or uncharacteristic behaviour (in later stages this will become more pronounced)
- Poor concentration
- Problems communicating
- Getting lost in familiar places
- Making mistakes in a previously learned skill (e.g. cookery)
- Problems telling the time or using money
- Changes in sleep patterns and appetite
- Personality changes
- Visio-spatial perception issues (i.e. the brain does not process images as normal)

In later stages these signs will be more pronounced, and it can become more difficult for people to live well with dementia.

Context

The signs of early dementia can include loss of memory, mood changes, loss of concentration and problems communicating. It is important that people working in health and social care have some understanding of these signs so they can identify if people they are caring for may have dementia and need adjustments to the care they receive. Health and social care workers should understand that when people with dementia show challenging behaviour they are not being challenging on purpose, but that this is part of the condition (see principle 5).

Indicative behaviours demonstrated by the workforce:

- You should be able to identify the signs listed above and always be aware of their existence in people you are working with. It is important that you understand that these signs are associated with dementia – but they can also be associated with other conditions that may need investigation.

- Understand that dementia is a progressive condition, which means the damage to the brain and its effects become more pronounced over time. It is likely that different approaches may be needed at different points to support people with dementia.
- You should be aware of the implications of other disabilities or illnesses that may show the signs of dementia.
- Ensure that you support people affected and their main carers* in their own homes. You also need to be able to recognise if the situation is deteriorating – and ensure appropriate support is in place.
- Think about the whole person when assessing for signs of dementia, taking into account their usual interests, behaviour and home support.

Principle 2 Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage

Context

Early diagnosis ensures that every individual with initial signs of dementia is able to plan for their short, medium and long term health and well-being needs.

A medical diagnosis will help to rule out other conditions that may have similar symptoms to dementia.

Specialists can make an early diagnosis, through a referral by the GP. It is a supportive process rather than a negative experience providing reassurance for the person affected and their family, friends and carers.

Dementia is identified through a process of evaluating diagnostic evidence from different sources by a consultant. The person's health and emotional well-being should be assessed in the context of their usual pattern of skills and behaviour.

Finally it is important to remember that the diagnosis of dementia can have an effect on the person's emotions.

Indicative behaviours demonstrated by the workforce:

- If you are concerned that a person you are supporting has any change in their physical or mental health then you can suggest that they seek GP advice and support, and possibly obtain a referral to a consultant.

* 'Carer' is used throughout to indicate family and friends who provide social care support, as distinct from social care workers and volunteers.

- You should identify the most appropriate other professionals and/or carers to work with you and share how best to support a person with ongoing assessment.
- Explain the need for an investigation of early signs of dementia in a way that is appropriate to the person.
- Able to adapt your behaviour to support the person and offer person-centred care (see principles 3 and 4).
- You must ensure family carers are involved in the diagnosis as they have a right to be involved. In addition, they can be a useful source of important information to assist the process. They will also need support (see principle 6).

Principle 3 Communicate sensitively to support meaningful interaction

Context

Dementia may affect a person's ability to understand and use language accurately and appropriately. This is often seen as difficulty with remembering words or using them accurately, repetition of thoughts and lack of coherence. As the condition progresses communication can become increasingly difficult.

This is likely to vary from day to day and requires the health and social care workforce, family and friends to respond and adapt their communication with the person. It is important to remember that other conditions and disabilities may also affect people's ability to communicate (e.g. learning disability).

Indicative behaviours demonstrated by the workforce:

- Always make time for people with dementia and remain patient in every situation.
- You should make use of the person's past experiences and life story to support communicating with them.
- You should take into account a person's usual communication skills and background culture.
- Try to keep the environment calm and as quiet as possible when communicating, allowing plenty of time to have conversations.
- Always face the person in conversation and be reassuring in your expressions, tone of voice and words, to reduce frustration.

When speaking:

- speak clearly using short sentences—don't give too much information or ask too many questions
- use simple vocabulary and avoid jargon
- remember that it takes time for people with dementia to take in a question, find the right words and frame the reply; don't use more explanations as this will cause more confusion—just wait
- try not to finish a person's sentence unless you are asked to do so
- try to avoid negative statements such as "Don't…", instead try to reinforce positive behaviour
- remember to monitor your tone of voice carefully
- enjoy interacting together and use humour to communicate this pleasure.

- Repetitive questions from people with dementia can be challenging—try to respond as though it is the first time you have heard the question.
- Whatever is said to you, it is best to accept this and not argue.
- You may need to frame any questions so the person can answer 'yes' or 'no' in specific situations, but avoid using this technique extensively.
- Listen carefully to grasp the meaning and tone of the person's conversation.
- You should use non verbal communication such as gesture, facial expression and written communication.
- Take account of any hearing or visual problems or second language difficulties.
- You can use images, pictures, symbols or music to enhance communication and facilitate understanding.
- If the person is already receiving other services, communication should be undertaken according to any communication guidelines that have been already developed to support the person (e.g. in their care plan).

Principle 4 Promote independence and encourage activity

Context

It is important that people with dementia are encouraged to maintain the activities they enjoy and continue to be active. However, you should be sensitive to any activities that may cause frustration.

The care received by people who have dementia must take into account each person's individual needs and preferences and be delivered with patience, dignity and respect at all times, that is, it must be person-centred.

It is important to recognise when people with dementia become more dependent, and support this appropriately.

Indicative behaviours demonstrated by the workforce:

- You should be able to respond with consideration and respect for the needs of the person you are working with.
- Ensure that you support people with dementia in making their own choices, including what to eat and drink.
- You should to do things together with the person rather than for them, supporting their own choices even if you regard this as risky. Risk-taking is part of everyday life—a person with dementia is no different. (See the Department of Health's guidance, *Nothing ventured, nothing gained: risk guidance for people with dementia*, DH 2010).
- It is important to do everything possible to support someone with dementia who is undergoing memory loss, e.g. by demonstrating how things can be done and using signage to support this.
- Always try and support people with dementia to self care including using the toilet for as long as possible. However, in home care settings it is important to be mindful of the established roles of family or friends who are carers.
- You should be able to support people with dementia to access mainstream services, such as shops and banks, wherever possible.
- Ensure that people with dementia have access to appropriate means of nutrition and hydration. This should be supported in line with individual care plans (if available)
- It is essential to presume a person has the capacity to make decisions for themselves unless it is proved otherwise.
- You should support and enable individuals to use technology to support self care which is Principle 5 of the *Common Core Principles to Support Self Care* – (DH/SfC/SfH - *Common Core Principles to support self care: a guide to support implementation*, 2008).
- You should assess the person's capacity to make decisions in accordance with the Mental Capacity Act. See NHS Choices for a summary: www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/MentalCapacityAct.aspx

You should identify an appropriate person to work with you. You may need to know about the process of devising advanced statements, which outline how the person would like decisions to be taken on their behalf should they lose capacity, including advance decisions about refusing treatment, and about 'lasting power of attorney' and preferred place of care.

Principle 5 Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience

Context

People with dementia can find that unfamiliar situations become very confusing and often they struggle with changes to their environment and routines. They may not perceive the environment or other people's actions in the same way as we do. This may lead to uncharacteristic behaviour that is difficult to understand and manage.

Access to structured activities and personal interaction will support people to participate socially and reduce frustration that may lead to challenging behaviour.

The guidance from the National Institute for Health and Clinical Excellence (NICE/SCIE 2006, 2007; NICE 2008) states that medication to reduce challenging behaviour should be given only in exceptional circumstances and should be reviewed on a regular basis (at least monthly). At review, reduction or cessation of the medication should be actively considered. While prescription of antipsychotics is appropriate for a certain small cohort of people who will derive some benefit from the treatment, evidence shows that for the majority of people with dementia these drugs can be counterproductive.

Person-centred care is key to supporting people with dementia and any challenging behaviour. This approach recognises that behaviours often have underlying causes. To support this, health and social care staff should try to understand the personal history of the person and their life story in order to address the causes of challenging behaviour.

Indicative behaviours demonstrated by the workforce:

- Be aware that challenging behaviour can be managed and supported in a variety of different ways, not just through the use of anti-psychotic drugs.
- You should be able to support people with dementia in a person-centred way which should help you identify any triggers that cause challenging behaviour. Always consider whether there is an unmet need that is causing the challenging behaviour.
- You should be able to identify the cause of confusion or any unmet needs that may be causing challenging behaviour.
- Try to remember that all behaviour is a reaction to a feeling—try to understand why someone may feel the way they do.

- You should be aware that the following could cause challenging behaviour:
  - misunderstanding their environment
  - feeling frustrated at being unable to understand others or make themselves understood
  - feeling frightened
  - loss of inhibitions, self control and decreased awareness of rules about appropriate behaviour
  - responding to what they feel to be over-controlling care
  - past history and experiences
  - being in pain, including chronic pain
  - your or others' responses to their actions.

- You can support a person with challenging behaviour by following the approach suggested by the Alzheimer's Society:

1) find ways to react calmly if challenging behaviour has occurred
2) work out what triggers the aggressive behaviour
3) tackle the triggers
4) take time to manage your own feelings
5) be creative in finding alternative activities to help an individual move on from feelings of anxiety.

"As their dementia progresses, people may be less able to enter our world – we may need to enter theirs and enjoy it with them" as campaigner Barbara Pointon puts it.

Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

Context

Dementia can be a distressing condition as the person's cognitive abilities deteriorate, causing upset, frustration and/or embarrassment for the person with dementia and for their family, friends and carers.

Family, friends and carers need to maintain their own health and well-being as well as care for the person with dementia. Family members need to have support with developing their own coping strategies.

Planning for the future and making arrangements to manage financial needs will be essential for the person and their family—possibly including 'lasting power of attorney'.

It is very important that the main carer is shown how to access forms of respite care and that their own support needs are assessed. Respite care can be provided in the person's home (through a domiciliary care agency or personal assistant). See *Carers Matter – Everybody's Business* (SfC/SfH 2011).

Indicative behaviours demonstrated by the workforce:

- Understand that dementia is also distressing for the main carer and families.
- You should be able to encourage family and friends to participate in shared activities with the person with dementia. It is essential to respect the choices made by family and friends.
- Signposting people to information to help them understand the impact of dementia or to refer them to colleagues/other sources of advice who can help them with this.
- Support for family and friends to express their concerns, acknowledge their worries and find ways of responding positively to the difficulties presented.
- Encourage people with dementia to maintain their social contacts, as this provides essential support for the family as well as for the person with dementia.
- You must involve the family or main carer in all planning and discussions on care and welfare. It should not be assumed that the family can offer daily care.
- Understand how to support the assessment of carers' needs—intervention should occur before breaking point.

Principle 7 Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia

Context

Managers working in health and social care have a responsibility to ensure their teams are adequately trained and supported to be able to meet the needs of people with dementia. Different members of the team may require different levels of support and training depending on their specific job role, the nature of their work and the support needs of the people they are working with.

Indicative behaviours demonstrated by the workforce:

- Managers should identify the most appropriate communication channels for staff teams to ensure people with dementia have appropriate support.
- Managers need to ensure all team members receive basic awareness training and education together with regular updates. This should be supported by the personal development plans of team members.
- Managers should ensure staff induction programmes for new staff include dementia awareness.
- Managers should consider inviting specially trained dementia specialists to support the wider team to improve the quality of care provided by every team member (including consideration of supporting this with dementia-specific qualifications such as the QCF awards and certificates in awareness of dementia and dementia care, and the dementia pathways through the QCF diplomas in Health and Social Care at levels 2 and 3).
- Managers should ensure their team are trained to devise, deliver and review joint care plans prepared with the person with dementia and their family or carer.
- Managers should try to ensure continuity of staff providing care where possible—this is reassuring to people with dementia.
- Managers should encourage staff to see the person and not the condition.
- Managers need to ensure health and social care staff are aware that dementia can complicate the treatment, care and support for people with other conditions and disabilities.

Principle 8 Work as part of a multi-agency team to support the person with dementia

Context

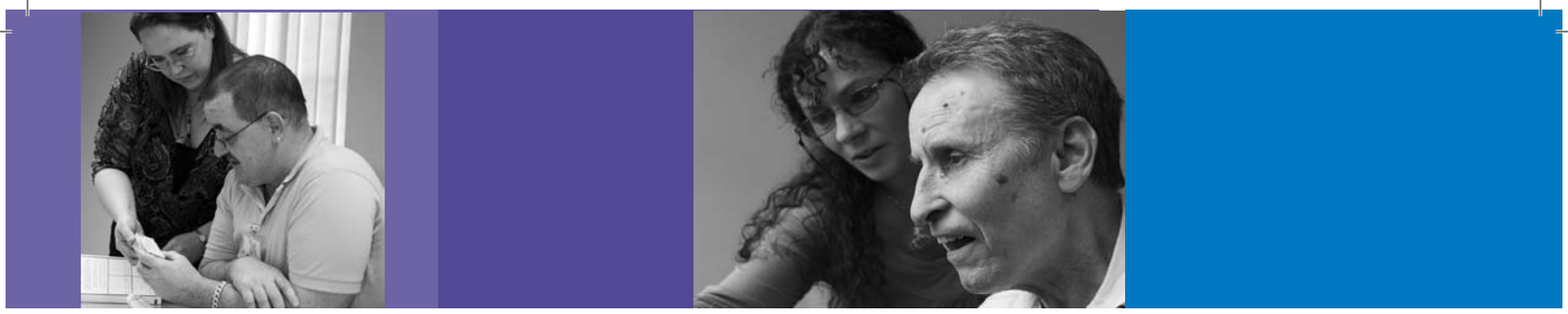
Care provided should be designed specifically for the person affected with all practitioners liaising together to support personalised care.

Many practitioners will contribute to the care of a person with dementia over the course of the condition. It is essential that the person with dementia is not confused unnecessarily by a succession of professionals and clinical or care procedures.

Coordinated support must include sharing of relevant information (when appropriate) with other practitioners when people's circumstances change. Informed consent is an essential element of this.

Indicative behaviours demonstrated by the workforce:

- You should contribute to consistency of support in your workplace so that the person can get to know the people caring for them.
- Aim to have a seamless approach between different teams and agencies to support people with dementia.
- Ensure that information is provided for other people who may need to care for the person affected, especially when they move from one place to another, e.g. from home care to a residential setting.
- You should be able to explain to the person with dementia that sharing important information with carers and family will improve the support and treatment they receive. You must be able to decide if the person has the capacity to consent to this.
- You should ensure that appropriate processes are in place for information sharing between agencies. There may need to be an overall coordinator to do this.
- It may sometimes be appropriate for family carers to receive confidential information about the person they are caring for on a need to know basis.



3. Embedding the common core principles

Using the common core principles to build a confident workforce

The principles are based on current policy and information provided by people who use services, and by practitioners in different health and social care settings. They therefore provide a framework for learning and development and form the foundation for good practice in any setting.

The indicative behaviours demonstrate how the attitudes and actions of individual staff support people with dementia and they can be used for setting appraisal objectives for individual workers and designing learning programmes for groups of staff. It is important that the indicative behaviours are applied to specific work contexts and roles, in order to support the development of good practice across an organisation. Section 4 on the next page is useful for identifying the national occupational standards and qualifications that may match requirements for learning programmes to develop workforce skills. It is not an exhaustive list, however, and managers will need to assess their workforce needs based on the requirements of the people using their service.

Managers may find the model below (diagram 2) helpful for planning their workforce's training and development.

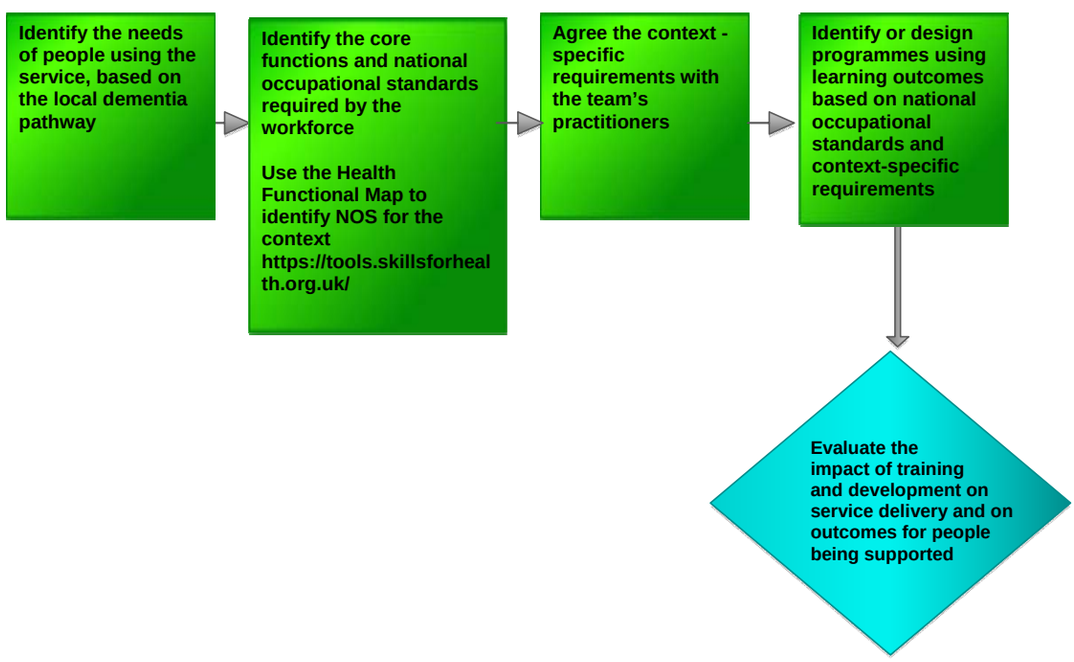


Diagram 2
Framework for planning training and development

Reviewing your workplace

The following questions should help you review your workplace and plan the training and development you need to make your service 'dementia-friendly'. This can be used as a benchmarking record to monitor the improvements and changes that are introduced to the training and development available for the workforce.

Local training and development review	
Describe the services you provide for people with dementia	
Based on the needs of people with dementia who use your service, describe the ambition for the service and for workforce development in your local context	
Who interacts with the person with dementia? ■ Which people? ■ Which teams?	
What skills do they need? ■ Indicative behaviours from common core principles ■ Specialist skills in caring for people with dementia	
What training and development is currently available? Audit: ■ Content ■ Access ■ Resources ■ Qualifications ■ Outcomes—what the person using the service experiences	

What training needs to be accessed, designed and delivered? ■ What kind of learning works best for your workforce? ■ Negotiate with training providers—are the programmes built using national occupational standards? ■ Use Qualifications and Credit Framework units to ensure your workforce achieves a recognised standard of skills ■ Develop your own learning programme—use national occupational standards to inform your context-specific competences	
How will the training and development be delivered? Examples: ■ Corporate induction ■ Local networks ■ Regular staff meetings and training sessions ■ Appraisals ■ Dementia conference for full organisation and partners ■ Others (specify)	

4. Developing a skilled workforce: planning training and development

The following table helps you to describe the detail of training and development for your specific context. The *Common Core Principles for Supporting People with Dementia* have been mapped against suggested national occupational standards, but you will want to validate these standards with your staff groups, ensuring that the needs of the person affected remain central in the planning. You will then be able to devise your learning outcomes accordingly. Appendix 1 provides a table of the units of learning that are available for planning formal education programmes using the Qualifications and Credit Framework.

Table 1

Common Core Principles for Supporting People with Dementia	**Example functions and national occupational standards (NOS)** **Use the Health Functional Map to identify NOS for your context https://tools.skillsforhealth.org.uk/**	**Common core principles indicative behaviours** **Identify the specific indicative behaviours relevant to your operational policies/procedures**
1. Know the early signs of dementia	**Function A Assessment** CHS39 Assess an individual's health status CHS42 Identify individuals with or at risk of developing long term conditions or related ill health	■ You should be able to identify the signs listed above and always be aware of their existence in people you are working with. It is important that you understand that these signs are associated with dementia – but they can also be associated with other conditions that may need investigation. ■ Understand that dementia is a progressive condition, which means the damage to the brain and its effects become more pronounced over time. It is likely that different approaches may be needed at different points to support people with dementia. ■ You should be aware of the implications of other disabilities or illnesses that may show the signs of dementia. ■ Ensure that you support people affected and their main carers* in their own homes. You also need to be able to recognise if the situation is deteriorating – and ensure appropriate support is in place. ■ Think about the whole person when assessing for signs of dementia, taking into account their usual interests, behaviour and home support.

2. Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.	**Function B Health Intervention** HSC26 Support individuals to access and use information CHS99 Refer individuals to specialist sources of assistance in meeting their health care needs	■ If you are concerned that a person you are supporting has any change in their physical or mental health then you can suggest that they seek GP advice and support, and possibly obtain a referral to a consultant. ■ You should identify the most appropriate other professionals and/or carers to work with you and share how best to support a person with ongoing assessment. ■ Explain the need for an investigation of early signs of dementia in a way that is appropriate to the person. ■ Able to adapt your behaviour to support the person and offer person-centred care (see principles 3 and 4). ■ You must ensure family carers are involved in the diagnosis as they have a right to be involved. In addition, they can be a useful source of important information to assist the process. They will also need support (see principle 6).
3. Communicate sensitively to support meaningful interaction	**Function 1 Communication** GEN97 Communicate effectively in a healthcare environment MH1 Promote effective communication and relationships with people who are troubled or distressed HSC369 Support individuals with specific communication needs CHS58 Provide information and support for individuals with long term conditions	■ Always make time for people with dementia and remain patient in every situation. ■ You should make use of the person's past experiences and life story to support communicating with them. ■ You should take into account a person's usual communication skills and background culture. ■ Try to keep the environment calm and as quiet as possible when communicating, allowing plenty of time to have conversations. ■ Always face the person in conversation and be reassuring in your expressions, tone of voice and words, to reduce frustration. ■ When speaking: - speak clearly using short sentences—don't give too much information or ask too many questions - use simple vocabulary and avoid jargon - remember that it takes time for people with dementia to take in a question, find the right words and frame the reply; don't use more explanations as this will cause more confusion—just wait

	CHS151 Develop strategies to optimise individuals communication skills and abilities	- try not to finish a person's sentence unless you are asked to do so - try to avoid negative statements such as "Don't…", instead try to reinforce positive behaviour - remember to monitor your tone of voice carefully - enjoy interacting together and use humour to communicate this pleasure. ■ Repetitive questions from people with dementia can be challenging—try to respond as though it is the first time you have heard the question. ■ Whatever is said to you, it is best to accept this and not argue. ■ You may need to frame any questions so the person can answer 'yes' or 'no' in specific situations, but avoid using this technique extensively. ■ Listen carefully to grasp the meaning and tone of the person's conversation. ■ You should use non verbal communication such as gesture, facial expression and written communication. ■ Take account of any hearing or visual problems or second language difficulties. ■ You can use images, pictures, symbols or music to enhance communication and facilitate understanding. ■ If the person is already receiving other services, communication should be undertaken according to any communication guidelines that have been already developed to support the person (e.g. in their care plan).
4. Promote independence and encourage activity	**Function B Health Intervention** CMC3 Enable individuals with long term conditions to make informed choices concerning their health and well-being HSC3112 Support individuals to identify and promote their own health and social well-being	■ You should be able to respond with consideration and respect for the needs of the person you are working with. ■ Ensure that you support people with dementia in making their own choices, including what to eat and drink. ■ You should to do things together with the person rather than for them, supporting their own choices even if you regard this as risky. Risk-taking is part of everyday life—a person with dementia is no different. (See the Department of Health's guidance, *Nothing ventured, nothing gained: risk guidance for people with dementia*, DH 2010).

	HSC45 Develop practices which promote choice, well-being and protection of all individuals HSC366 Support individuals to represent their own needs and wishes at decision making forums HSC330 Support individuals to access and use services and facilities CME4 Provide information and advice to support individuals in undertaking desired occupational and non-occupational activities OP12 Enable older people to cope with changes to their health and wellbeing	■ It is important to do everything possible to support someone with dementia who is undergoing memory loss, e.g. by demonstrating how things can be done and using signage to support this. ■ Always try and support people with dementia to self care including using the toilet for as long as possible. However, in home care settings it is important to be mindful of the established roles of family or friends who are carers. ■ You should be able to support people with dementia to access mainstream services, such as shops and banks, wherever possible. ■ Ensure that people with dementia have access to appropriate means of nutrition and hydration. This should be supported in line with individual care plans (if available) ■ It is essential to presume a person has the capacity to make decisions for themselves unless it is proved otherwise. ■ You should support and enable individuals to use technology to support self care which is Principle 5 of the *Common Core Principles to Support Self Care* – (DH/SfC/SfH - *Common Core Principles to support self care: a guide to support implementation*, 2008). ■ You should assess the person's capacity to make decisions in accordance with the Mental Capacity Act. See NHS Choices for a summary: www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/MentalCapacityAct.aspx You should identify an appropriate person to work with you. You may need to know about the process of devising advanced statements, which outline how the person would like decisions to be taken on their behalf should they lose capacity, including advance decisions about refusing treatment, and about 'lasting power of attorney' and preferred place of care.

5. Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.	HSC382 Support individuals to prepare for, adapt to and manage change MH11 Enable families to address issues with individuals' behaviour HSC227 Contribute to working in collaboration with carers in the caring role HSC319 Support families in their own home	■ Be aware that challenging behaviour can be managed and supported in a variety of different ways, not just through the use of anti-psychotic drugs. ■ You should be able to support people with dementia in a person-centred way which should help you identify any triggers that cause challenging behaviour. Always consider whether there is an unmet need that is causing the challenging behaviour. ■ You should be able to identify the cause of confusion or any unmet needs that may be causing challenging behaviour. ■ Try to remember that all behaviour is a reaction to a feeling—try to understand why someone may feel the way they do. ■ You should be aware that the following could cause challenging behaviour: - misunderstanding their environment - feeling frustrated at being unable to understand others or make themselves understood - feeling frightened - loss of inhibitions, self control and decreased awareness of rules about appropriate behaviour - responding to what they feel to be over-controlling care - past history and experiences - being in pain, including chronic pain - your or others' responses to their actions. You can support a person with challenging behaviour by following the approach suggested by the Alzheimer's Society: 1) find ways to react calmly if challenging behaviour has occurred 2) work out what triggers the aggressive behaviour 3) tackle the triggers 4) take time to manage your own feelings 5) be creative in finding alternative activities to help an individual move on from feelings of anxiety. *"As their dementia progresses, people may be less able to enter our world – we may need to enter theirs and enjoy it with them"* as campaigner Barbara Pointon puts it.

6. Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.	HN3 Enable carers to access and assess support networks and respite services HSC387 Work in collaboration with carers in the caring role HSC319 Support families in their own home	■ Understand that dementia is also distressing for the main carer and families. ■ You should be able to encourage family and friends to participate in shared activities with the person with dementia. It is essential to respect the choices made by family and friends. ■ Signposting people to information to help them understand the impact of dementia or to refer them to colleagues/other sources of advice who can help them with this. ■ Support for family and friends to express their concerns, acknowledge their worries and find ways of responding positively to the difficulties presented. ■ Encourage people with dementia to maintain their social contacts, as this provides essential support for the family as well as for the person with dementia. ■ You must involve the family or main carer in all planning and discussions on care and welfare. It should not be assumed that the family can offer daily care. ■ Understand how to support the assessment of carers' needs—intervention should occur before breaking point
7. Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia	**Function 2 Personal and People Development** HCS43 Take responsibility for the continuing professional development of self and others GEN35 Provide supervision to other individuals **Function H Management and Administration** LMCA1 Manage and develop yourself and your workforce within care services H133 Manage multiagency collaborative working	■ Managers should identify the most appropriate communication channels for staff teams to ensure people with dementia have appropriate support. ■ Managers need to ensure all team members receive basic awareness training and education together with regular updates. This should be supported by the personal development plans of team members. ■ Managers should ensure staff induction programmes for new staff include dementia awareness. ■ Managers should consider inviting specially trained dementia specialists to support the wider team to improve the quality of care provided by every team member (including consideration of supporting this with dementia-specific qualifications such as the QCF awards and certificates in awareness of dementia and dementia care, and the dementia pathways through the QCF diplomas in Health and Social Care at levels 2 and 3).

		■ Managers should ensure their team are trained to devise, deliver and review joint care plans prepared with the person with dementia and their family or carer. ■ Managers should try to ensure continuity of staff providing care where possible—this is reassuring to people with dementia. ■ Managers should encourage staff to see the person and not the condition. ■ Managers need to ensure health and social care staff are aware that dementia can complicate the treatment, care and support for people with other conditions and disabilities
8. Work as part of a multi-agency team to support the person with dementia	CHS85 Review and evaluate care management plans with individuals diagnosed with long term conditions AG3 Assist in the transfer of individuals between agencies and services	■ You should contribute to consistency of support in your workplace so that the person can get to know the people caring for them. ■ Aim to have a seamless approach between different teams and agencies to support people with dementia. ■ Ensure that information is provided for other people who may need to care for the person affected, especially when they move from one place to another, e.g. from home care to a residential setting. ■ You should be able to explain to the person with dementia that sharing important information with carers and family will improve the support and treatment they receive. You must be able to decide if the person has the capacity to consent to this. ■ You should ensure that appropriate processes are in place for information sharing between agencies. There may need to be an overall coordinator to do this. ■ It may sometimes be appropriate for family carers to receive confidential information about the person they are caring for on a need to know basis.

Resources

The following resources are included as examples of tools that may be useful in improving the way your service works and for developing learning programmes for your workforce. There are a links to video clips that provide powerful stories illustrating how people can be supported. The list below is not exhaustive and we would strongly recommend that you apply your own criteria to evaluating any resources before incorporating into them your plans.

Alzheimer's Society

Alzheimer's Society (2009). *Counting the cost caring for people with dementia on hospital wards*, London.

Alzheimer's Society (2009). *Dementia: What every commissioner needs to know Guidance on delivering the National Dementia Strategy for England*, London.

Fact sheets
http://www.alzheimers.org.uk/factsheets

Memory problems guidance
http://www.youtube.com/watch?v=bZJ92WVsxOo&feature=channel

Personal stories
http://www.youtube.com/watch?v=TBcoMkTD5F4&feature=channel

Remember the person poster
Example of posters that can be used to improve general understanding of dementia
http://www.southwestdementiapartnership.org.uk/wp-content/uploads/daw.jpg

Bradford Dementia Group
Education programmes and good practice guides
http://www.jkp.com/catalogue/ser/bradford
http://www.brad.ac.uk/health/dementia/

Butterfly scheme
The Butterfly Scheme allows people whose memory is permanently affected by dementia to make this clear to hospital staff and provides a simple, practical strategy for meeting their needs. The patients receive more effective and appropriate care, reducing their stress levels and increasing their safety and well-being.
barbara.hodkinson@ntlworld.com

Credit card reminders
Prompt cards to help embed knowledge and understanding of dementia in the wider workforce. These can be tailored for your specific workforce

Dementia Advisers
Dementia advisers provide a point of contact for people requiring information on issues and services related to dementia. They provide personalised information to people with dementia and their carers. This includes appropriate signposting to alternative organisations, giving advice on matters such as finance, incontinence and services for carers. It is shared role across health and social care and in collaboration with a wide range of stakeholders.
http://www.skillsforhealth.org.uk/sitesearch.html?q=national+transferable+&option=com_artofgm&filter=0

Department of Health Dementia Information Portal
DH website which follows the implementation of the National Dementia Strategy and offers information and support to anyone with an interest in improving services for people with dementia.
http://www.dementia.dh.gov.uk

Dementia conferences for local communities
Events designed specifically for the wider local community in order to improve the knowledge and understanding of dementia.

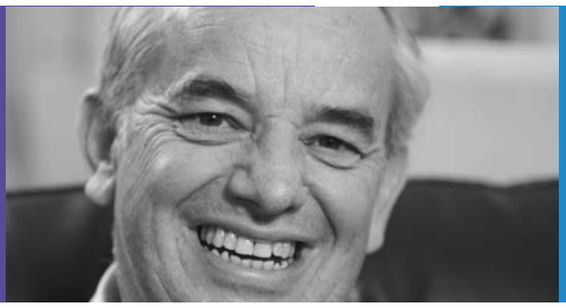
Hospital Discharge Plans

These plans provide an easy format to ensure a good handover of information back to carers and community services. This will improve the experience of any vulnerable person and decrease the likelihood of unnecessary repeat admissions. For more information contact Ruth.Bell@oldham.gov.uk

Discharge/Information Plan Part A
http://www.ldhealthnetwork.org.uk/docs/cispa.pdf

Discharge/Information Plan Part B
http://www.ldhealthnetwork.org.uk/docs/cispb.pdf

Hospital Passports
A leaflet that has been designed to support vulnerable people when they are in hospital. It provides essential information such as how the person prefers to take medications, the support they need at meal times and their personal preferences. It can be filled in by the person or their carer and should be taken into hospital and kept by the bedside so that is always available for hospital staff to read.
www.salford.nhs.uk



Gloucestershire local health and social care workforce strategy
An example of how local needs and the national strategy have been used to develop a training and education strategy for Gloucestershire
www.gloucestershire.gov.uk/dementiatraining

Lets Respect Toolkit for Care Homes
A guide for staff working in care homes to help improve the care of older people with mental health needs.
http://www.nmhdu.org.uk/news/lets-respect-toolkit-for-care-homes-published/

National Audit Office
Improving services and support for people with dementia. National Audit Office, London. 2007
http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx

NHS Choices
Identifying dementia
http://www.youtube.com/watch?v=-72pnJXzSqk&feature=related

Respect for Dementia
Suffolk Mental Health Partnership NHS Trust
http://www.youtube.com/watch?v=lhV2jAZYIrQ

Skills for Health
Nationally Transferable Roles
A named cluster of competences and related activities that is applicable, relevant and replicable across different geographic locations in the UK. A nationally transferable role may be either a whole job levelled to the Career Framework, e.g. advanced orthopaedic practitioner, or a subset of various jobs at different levels of the Career Framework, e.g. point of care testing. It has been used to develop Dementia Adviser roles.
http://www.skillsforhealth.org.uk/site-search.html?q=national+transferable+&option=com_artofgm&filter=0

Skills for Health and Skills for Care
Carers Matter - Everybody's Business
Set of common core principles intended to encourage organisations to enable carers to be recognised and supported http://www.skillsforhealth.org.uk/service-area/carers/ or http://www.skillsforcare.org.uk/cmeb

Social Care Institute for Excellence and National Institute for Clinical Excellence
Training for all presentation
http://www.scie.org.uk/publications/misc/dementia/dementia-slideset.ppt#453,21,Interventions

Southwest Dementia Partnership
http://www.southwestdementiapartnership.org.uk/

Stirling self study course
A six part self study course in supporting dementia in the care home.
www.dementia.stir.ac.uk

This is me
An easy-to-make personalised leaflet explaining the care and support an individual needs in unfamiliar situations. It should be completed by the person with dementia wherever possible.
http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=399

References

DAA 2010 Dementia Action Alliance (2010). *National Dementia Declaration*, London http://www.dementiaaction.org.uk

DH 2009 Department of Health.(2009). *Living Well with Dementia: A National Dementia Strategy* http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf

DH 2010 Department of Health, (2010). *Nothing ventured, nothing gained: risk guidance for people with dementia*, Leeds. (2010) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

DH 2010 Department of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy* http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

NICE 2010 National Institute for Health and Clinical Excellence (2010) *Dementia quality standards* http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp?domedia=1&mid=7EF3AFC7-19B9-E0B5-D4504471A4FD758E

NICE 2008 *National Institute for Health and Clinical Excellence Public Health Intervention Guidance, Occupational therapy intervention and physical intervention to promote the mental well being of older people in primary care and residential care*, (London 2008)

NICE/SCIE 2006 National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, *Dementia: Supporting people with dementia and their carers in health and social care, Clinical Guidelines* (London 2006)

NICE/SCIE 2007 National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, *Dementia: A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care*. (National Collaborating Centre for Mental Health, London. 2007)

SfC/SfH/DH/NHS 2009 *Common core competences and principles for health and social care workers working with adults at the end of life* (Skills for Care, Skills for Health, Department of Health and NHS End of Life Programme, 2009)
www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx

SfC/SfH/DH/NHS 2010 A framework of National Occupational Standards to support common core competences and principles for health and social care workers working with adults at the end of life. (Skills for Care, Skills for Health, Department of Health and NHS End of Life Programme, 2010)
http://www.skillsforhealth.org.uk/service-area/long-term-conditions/

SfC/SfH (2011) *Carers Matter - Everybody's Business* (Skills for Health & Skills for Care, Leeds 2011)
http://www.skillsforhealth.org.uk/service-area/carers/carers-matter-%11-everybody%27s-business/ or www.skillsforcare.org.uk/cmeb

Appendix 1

Dementia specific Qualification and Credit Framework Units (QCF)

Table 2
The following table provides information on the QCF Units that have been nationally agreed for training programmes developing skills in supporting dementia.
[Key: WBA – work-based assessment; QCF – Qualifications & Credit Framework; NOS – National Occupational Standards; GLH – Guided Learning Hours.]

Dementia specific QCF Units and NOS						
WBA Unit Reference	**Unit Reference**	**Unit Title**	**Level ***	**Credit ***	**GLH**	**NOS**
J/601/2874	DEM 201	Dementia Awareness	2	2	17	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
H/601/2879	DEM 202	The person centred approach to the care and support of individuals with dementia	2	2	17	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
F/601/3683	DEM 204	Understand and implement a person centred approach to the care and support of individuals with dementia	2	3	21	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
T/601/9416	DEM 205	Understand the factors that can influence communication and interaction with individuals who have dementia	2	2	18	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
A/601/2886	DEM 207	Understand equality, diversity and inclusion in dementia care	2	2	20	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
Y/601/9277	DEM 209	Equality, diversity, and inclusion in dementia care practice	2	3	24	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
A/601/9434	DEM 210	Understand and enable interaction and communication with individuals with dementia	2	3	19	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
H/601/9282	DEM 211	Approaches to enable rights and choices for individuals with dementia whilst minimising risks	2	3	25	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
J/601/3538	DEM 301	Understand the process and experience of dementia	3	3	22	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
T/601/9187	DEM 302	Understand and meet the nutritional requirements of individuals with dementia	3	3	26	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
A/601/9191	DEM 304	Enable rights and choices of individuals with dementia whilst minimising risks	3	4	26	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
K/601/9199	DEM 305	Understand the administration of medication to individuals with dementia using a person centred approach	3	2	15	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45

Dementia specific QCF Units and NOS						
WBA Unit Reference	**Unit Reference**	**Unit Title**	**Level ***	**Credit ***	**GLH**	**NOS**
L/601/3539	DEM 308	Understand the role of communication and interactions with individuals who have dementia	3	3	26	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
Y/601/3544	DEM 310	Understand the diversity of individuals with dementia and the importance of inclusion	3	3	23	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
Y/601/4693	DEM 312	Understand and enable interaction and communication with individuals who have dementia	3	4	30	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
F/601/4686	DEM 313	Equality, diversity and inclusion in dementia care practice	3	4	31	HSC21, HSC31, HSC41, HSC24,HSC35, HSC45
M/602/3125	HSS / CHS155	Assist and support individuals to use alternative and augmentative communication systems (AAC)	3	5	35	CHS155
R/602/3943	HSS / GEN014	Advise and inform individuals on managing their condition	3	5	31	GEN14
H/602/3980	HSS / GEN015	Support individuals in undertaking their chosen activities	3	4	24	GEN15
R/602/4011	HSS / GEN020	Support carers to meet the care needs of individuals	3	5	30	GEN20
D/602/1029	HSS / GEN044	Liaise between primary, secondary and community teams	3	2	20	GEN44
D/602/1032	HSS / GEN062	Collate and communicate health information to individuals	3	3	20	GEN62
R/601/8015	HSC 2013	Support Care plan activities	2	2	13	HSC25
A/601/7926	HSC 2011	Support individuals to access and use information about services and facilities	2	3	20	HSC26
M/601/7907	HSC 3033	Support individuals during a period of change	3	4	29	HSC382
H/601/8147	HSC 3038	Work in partnership with families to support individuals	3	4	27	HSC387, HSC388
H/602/3980	HSS / GEN015	Support individuals in undertaking their chosen activities	3	4	24	GEN15

* Every unit and qualification in the QCF has both a ‘credit value’ and a ‘level’. One credit represents 10 hours of average learning time and so the *credit value* shows how much time it takes to complete. The *level* shows how difficult the unit or qualification is on a scale of ‘Entry’ then levels 1–8.

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