



**North Yorkshire**  
County Council

Health and Adult Services

# **DEMENTIA**

**GUIDANCE FOR PROVIDERS OF RESIDENTIAL AND  
DOMICILARY CARE  
IN MEETING  
WORKFORCE DEVELOPMENT STANDARDS**

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## **Foreword by Richard Webb**

I am very pleased to introduce this North Yorkshire County Council (NYCC) Dementia Guidance, which focuses on developing the skills of the social care workforce across residential and domiciliary care.

It is well known that with people living longer the number of people with dementia is rising. In North Yorkshire levels of dementia are predicted to rise from 8,264 in 2008, to 13,876 in 2025. Alongside this, demand for public services is growing. Last year, a national report by the Alzheimer's Society stated that up to 80% of people in care homes have some form of dementia. There are also an increasing number of people living with dementia being supported in their own homes. As the number of people affected by dementia increases it is important that the adult social care workforce has the necessary skills and knowledge to provide the required standard of care.

Building on the reputation NYCC already has of commissioning and providing high quality support and services - wherever people choose to live - it is essential that the workforce is equipped to deliver person-centred quality support, now and into the future. This will be backed by a more integrated health and care system with a focus on areas like supported self-management and community-based support. All of this activity is aligned with our 2020 vision for health and social care in North Yorkshire, which puts people in control of their care and support and protects those who are most vulnerable. A key focus is to promote independence, dignity and choice, and the quality of care is key to this.

This Dementia Guidance is an important resource in meeting this aim. It is targeted at managers and staff working in residential and domiciliary services, both internal and external, including Extracare environments. It will help providers not only to meet their contractual obligations to NYCC relating to care and support for people living with dementia, but will also help agencies to meet Care Quality Commission requirements and standards. More important than this, it will help to ensure that people can live well with dementia - with dignity and respect - to sustain them in their accommodation of choice for as long as possible.

Richard Webb

Director of Health and Adult Services

## How to use this guide

This is a practical guide for providers of residential and domiciliary care services for people with dementia, to help build workforce competencies.

It also acts as a reference guide for links to local and national information on dementia and dementia related support/good practice

- [Section 1](#) provides a general overview of the aims and functions of the guide
- [Section 2](#) outlines national policy and why dementia is a priority
- [Section 3](#) outlines the relationship to North Yorkshire and York's dementia strategy and contractual obligations
- [Section 4](#) sets out broad principles of good practice in relation to dementia and workforce development
- [Section 5](#) sets out national dementia competencies and qualifications
- [Section 6](#) describes North Yorkshire and York's dementia competency framework and expectations
- [Section 7](#) is a reference guide to relevant local information/services
- [Section 8](#) is a reference guide to relevant national information/services/good practice guidance and tools
- [Appendix 1](#) includes the National Dementia Declaration full set of outcomes

## 1. INTRODUCTION

This Dementia Guidance is for providers of residential and domiciliary care which are provided by, or commissioned by, NYCC. It is also available for non-council commissioned provider services, with the aim of promoting good practice across the county.

The Guidance focuses on **workforce development**, which is only one aspect - albeit a very important one - of providing quality, individualised care and support to people living with dementia. Other aspects of care, such as the environment, personalised activities, safeguarding, end of life care, mental capacity and deprivation of liberty safeguards etc. are not dealt with here, but this guide does include **signposting information** to good practice in these areas

The Guidance includes general points in terms of best practice in workforce development and dementia, plus more detailed information on related policy, occupational standards, and where provider organisations can go to find additional information. These elements are key to delivering the joint North Yorkshire and York Dementia Strategy.

The North Yorkshire **dementia self assessment template** for providers has also been revised. Providers can use this Dementia Guidance to help to complete this template; it will help organisations to take stock against nationally agreed standards of competency, and the directory of information in sections 7 and 8 can help providers explore how ongoing improvements can be made.

Workforce development is a key component of the National Dementia Strategy *Living Well with Dementia* (2009), and of the local *Joint North Yorkshire and York Dementia Strategy*. Objective 13 of the national strategy relates to **An informed and effective workforce for people with dementia**, where the importance of this is emphasised:

*“The need for improved training is a priority that runs across all the themes in the Strategy.”*

## 2. DEMENTIA AS A PRIORITY

### What is dementia?

Dementia is an 'umbrella' term used to describe the symptoms that occur when the brain is affected by a range of specific diseases and conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding. There are many different types of dementia although some are far more common than others, for example Alzheimer's, vascular dementia, dementia with Lewy Bodies, etc. More information on types of dementia is signposted in section 8 of this guide. Whilst it more commonly affects older people, and the risk of certain types of dementia increases with age, it is important to remember that younger people can be affected by dementia as well.

### A growing issue

As people are living longer, the number of people living with dementia is increasing.

A recent report by the national Alzheimer's Society<sup>1</sup> calculated a 40% increase in the number of people with dementia over the next 12 years. For North Yorkshire County Council this means that the population of people living with dementia is predicted to rise from 9721 in 2013, to 13609 in 2025.

### National policy

The importance of an informed and effective workforce is evidenced and underlined in a number of national policies:

- The National Dementia Strategy [Living Well with Dementia](#) (2009) sets out 17 objectives.
- Objective 13 focuses attention on workforce development.

#### **Objective 13: an informed and effective workforce for people with dementia**

All health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia

Further to this, in 2010, a revised implementation plan was published: ['Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy'](#) (2011). This includes a focus on four objectives:

- Good quality early diagnosis and intervention for all
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of anti-psychotic medication

In 2012, the ['The Prime Minister's Challenge on Dementia – Delivering Major Improvements in Dementia Care and Research by 2015'](#), set out the imperatives for the Coalition Government in terms of dementia, highlighting:

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<sup>1</sup> Alzheimer's Society 'Dementia UK; second edition', September 2014

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

[NICE social care quality standards](#) and guidance for dementia were published in April 2013 (QS30), building on the NICE Dementia Quality Standard (QS1). It applies to all social care settings and services working with and caring for people living with dementia.

### **Ensuring outcomes for individuals - The National Dementia Declaration**

The National Dementia Declaration has been created by people living with dementia, carers of people with dementia and a large number of organisations who seek radical change in the way that our society responds to dementia. People with dementia and their family carers have described seven outcomes they would like to see in their lives. These outcomes are described in more detail in Appendix 1.

- 1. I have personal choice and control or influence over decisions about me**
- 2. I know that services are designed around me and my needs**
- 3. I have support that helps me live my life**
- 4. I have the knowledge and know-how to get what I need**
- 5. I live in an enabling and supportive environment where I feel valued and understood**
- 6. I have a sense of belonging and of being a valued part of family, community and civic life**
- 7. I know there is research going on which delivers a better life for me now and hope for the future**

There are tools listed in this guide that will help you to work towards these outcomes, and to provide evidence of this. As mentioned previously, workforce development is **ONE** aspect of providing positive outcomes for people living with dementia. Tools that you may find of particular interest to help you take a broad view of how you are supporting people with dementia include, for example:

[\*\*\*Progress for Providers \(Helen Sanderson Associates\)\*\*\*](#) – free self assessment tools specifically targeted at providers to help support good practice in personalised care and support . There are several self assessment tools - both for dementia care specifically and for a range of related issues, such as reablement, supporting people living at home, and end of life care.

### **National Monitoring and inspection**

Dementia is an increasingly high profile issue. The CQC Report Position Statement and Action Plan for Older People, including People with Dementia 2010- 2015 highlighted workforce training and leadership as ‘fundamental’. Further to this, in its recent report ‘[A Fresh Start for the Regulation and Inspection of Adult Social Care](#)’ (2013) the CQC is now placing more of a spotlight on inspecting the quality of dementia care.

This workforce development guidance - combined with a holistic approach to dementia care as signposted in this document – will help you to provide quality support and to evidence this to the CQC.

### **Working with others**

Growing out of the National Dementia Declaration is the **Dementia Action Alliance**. This is a growing body of organisations committed to delivering the seven outcomes stated above. If you are an organisation that would like to improve the lives of people with dementia, you might consider joining the Alliance, as it could be a useful vehicle for promoting partnership working with others. The Alliance is split into different groups and there is a Yorkshire & Humber Dementia Action Alliance. To sign up follow the link through: [www.dementiaaction.org.uk/](http://www.dementiaaction.org.uk/)

### 3. NYCC CONTEXT

The Joint North Yorkshire & York Dementia Strategy is a multi-agency strategy setting out how partners in North Yorkshire and York will respond to the National Dementia Strategy and how they will deliver services to meet local need. The strategic aim is to develop services for people with dementia that:

- are sensitive to each person's individual circumstances;
- support people to live individual, productive, fulfilling and active lives for as long as possible;
- encourages people and their carers to be actively involved in decisions about their care;
- support people in negotiating along the care pathway as and when they choose as appropriate;
- provide information that is supplied in a way that is understood and helps to support the person and their carers in the options available from diagnosis until the end of life, and
- are in line with best practice and wherever possible good evidenced based practice and are cost effective.

People living with dementia and families/carers need to be confident that they can receive quality, personalised care and support in a range of settings, and it is important that agencies across North Yorkshire are well prepared to deliver this into the future.

Dementia is 'everybody's business', not just health and social care agencies. It is important that people with dementia are enabled to feel part of the wider community, as well as receiving quality care and support in whatever setting they happen to live in. Part of this means that there are shared understandings and approaches to decision making, risk-taking and safeguarding, and it is key that staff understand and develop this in partnership.

A local Dementia Workforce Development Group has been established, with the aim of improving standards, and building skills, awareness and knowledge amongst those working with people with dementia. This group is multi-agency and includes representation from the Independent Care Group. Any suggestions from providers are welcomed via this route.

#### **A new contract with providers**

Given the anticipated increase in the numbers of people living with dementia the Council expects providers to have a general awareness of dementia so that they can understand how to recognise changes in people's behaviour and how to support people effectively.

Providers who state they have a specialism of dementia are required to demonstrate that staff have been trained to a level which exceeds level 1 dementia awareness (see section 6).

A **dementia self assessment template** has been developed by the Council to enable providers to assess their dementia workforce development. This template can be used to identify areas which could be improved or developed and this should form the basis of an action plan, against which the provider can monitor their ongoing improvement. It is a contractual requirement that providers complete self assessments, such as the dementia template, and this information will be used to inform commissioners of the standard of care in the market and for quality assurance purposes.

## 4. DEVELOPING THE WORKFORCE

Providers are responsible for creating a culture that enables staff to reflect, to learn and to develop. The National Care Forum<sup>2</sup> set out some key indicators of person-centred dementia care, including:

- 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;
- 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, and
- appropriate learning and training opportunities are provided.

The recruitment and selection processes of provider organisations should identify the values and attributes that staff will need when working with people living with dementia, including the ability to empathise and understand the complexities around the condition and appreciate the difficulties faced by people who are living with it, and of their family members/informal carers.

### **A comprehensive approach**

It is recommended that a comprehensive training plan is put in place, and reviewed regularly. Staff also need to have a good understanding of issues which may need particular approaches for or have a particular impact for people with dementia, including:

- Safeguarding
- Appropriate decision-making
- Responding to health problems
- The impact of co-morbidities
- End of life care

Resources/good practice links related to these issues are provided in section 8.

To support providers at a general level, **Skills for Care** have a suite of dementia specific guidance:

- *The common core principles for supporting people with dementia.*
- *Supporting dementia workers*
- *Supporting people in the advanced stages of dementia*
- *Resources to support workers and carers of people with dementia*

These documents can all be found on:

[www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx](http://www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx)

The **National Dementia Declaration** outcomes profiled in full in Appendix 1 should also be used as a guide to assess workforce needs and competencies.

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<sup>2</sup> National Care Forum *Key principles of person-centred dementia care* (2012)

NYCC have re-designed their **dementia self-assessment template** to help providers consider where they need to focus their efforts. This is available as a separate document and can be obtained through <http://www.northyorks.gov.uk/article/26212/General-procedures-and-guidelines-for-adult-social-care-services-providers>

### **Types of learning**

As noted above, workforce development is not just about training, but training is an essential component. It can be delivered through a range of formats, including:

#### *Face-to-face learning*

Lectures, classroom based discussions, seminars, tutorials, workshops and clinical/practical/work-based learning. It also includes e-learning.

#### *Online-learning*

Refers to any electronically assisted instruction. It is an approach to facilitate and enhance learning through the use of computers and communications technology. It involves education offered using any electronic delivery methods such as CD ROM's, video conferencing, digital television, websites, discussion forums and email.

#### *Blended learning*

Includes face-to-face and online-learning, used together to deliver instruction.

#### *Development opportunities*

Such as coaching, mentoring, and research opportunities

### **Leadership**

Managers of provider services play a key role in workforce development. The Skills For Care publication [Supporting dementia workers](#) is particularly valuable in setting out the ways in which they can develop the skills and confidence of staff, in supporting and caring for people with dementia. The **NYCC dementia self-assessment template** will also be a useful tool to aid managers to take stock and monitor progress.

## 5. NATIONAL QUALITY STANDARDS AND QUALIFICATIONS

This section sets out key standards and qualifications related to dementia and general information on learning resources.

### NATIONAL QUALITY STANDARDS AND QUALIFICATIONS

#### [NICE QS1 Dementia Quality Standard \(2010\)](#)

This quality standard (QS1) covers the care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. Quality statement 1 relates to “Appropriately trained staff”. This quality standard should be considered in conjunction with [NICE Quality Standard 30 on supporting people to live well with dementia](#) (QS30, issued 2013). These quality standards aim to promote quality of provision such that:

- **Service providers** ensure that all health and social care workers are appropriately trained in dementia care according to their roles and responsibilities
- **Health and social care professionals** who work with people with dementia ensure they receive training in dementia care consistent with their roles and responsibilities.
- **Commissioners** ensure service providers have arrangements for training health and social care professionals in dementia care.
- **People with dementia** can expect that the health and social care professionals who care for them will have dementia care training.

#### [Common Core Principles for Supporting People with Dementia. A guide to training the social care and health workforce \(Department of Health, Skills for Health, Skills for Care, 2011\)](#)

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. They aim to build workers’ confidence in responding appropriately to the person with dementia. Signposting to resources and further reading has been included at the end of the guide.

The common core principles should be used as a general framework, which can be adapted 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 (NOS) and agreed units of learning available through the Qualifications and Credit Framework (QCF).

#### [Care Certificate](#)

The Care Certificate has replaced the Common Induction Standards and is an identified set of standards for people working in health and social care to adhere to in their daily working life. There are 15 standards covering a variety of areas, with Standard 9 ensuring that the staff member has an awareness and understanding of people with a mental health condition, dementia or a learning disability.

#### [Management Induction Standards \(MIS\)](#)

The Skills for Care adult social care MIS were initially launched in 2008 and were refreshed in 2012. They are aimed at those new to management as well as those new in post who have previously managed other care services, and can be used in a wide range of settings. MIS are a measure of good practice and Skills for Care highly recommends that new

managers should normally have demonstrated all the knowledge requirements of the recommended core standards within six months of taking up a management role. MIS standard 4.1.4 requires understanding of how compliance with policy helps to implement person-centred and outcomes-based practice; 'policy' would widely be expected to include the *Common Core Principles for Supporting People with Dementia* highlighted above.

[The Guide to Qualifications and Standards in Adult Social Care 2014/15](#) sets out the types of qualifications on the Qualifications and Credit Framework (QCF) - including awards, certificates and diplomas available at different levels. Each one is made up of units, some mandatory and some optional, so that the qualification can be built to include the areas of knowledge and skill that will be specifically relevant to a person's role.

Principal qualifications of competence for those working in social care include the level 2 and level 3 Health and Social Care (HSC) diplomas. Within the diplomas it is also possible to take a specialist dementia pathway which will allow learners to further tailor their learning where they are asked to demonstrate both knowledge and competence of working with individuals with dementia.

There are four specific dementia QCF qualifications available for learners:

➤ **Level 2 Award in Awareness of Dementia**

A knowledge-only qualification consisting of four level 2 units on awareness, person-centred support, communication and equality and diversity.

➤ **Level 2 Certificate in Dementia Care**

A competence qualification requiring learners to build on the learning from the award to demonstrate their skills in working with individuals with dementia (though learners do not necessarily have to take the level 2 award before embarking upon the certificate).

➤ **Level 3 Award in Awareness of Dementia**

A higher level knowledge-only qualification covering the experience of dementia, administration of medication, communication and the importance of equality and inclusion .

➤ **Level 3 Certificate in Dementia Care**

A higher level competence qualification for learners who have a more advanced specialist role in working with individuals with dementia.

The certificates provide the opportunity for contextualised continuing professional development (CPD) for workers with experience in social care to develop knowledge and skills around supporting individuals with dementia so that they can provide high quality person centred support. It is not intended that the certificates confirm competence in the social care role as this can only be truly achieved through the Health and Social Care diplomas.

[Skills for Care 'Skills Selector' for dementia](#)

Through their 'Skills Selector' Skills for Care have set out units and qualifications around the care and support of people with dementia, linked to specific areas of skills and knowledge. This framework also includes a breakdown of rules of combination for specific dementia qualifications.

## **INFORMATION ON LEARNING RESOURCES**

**Note:** Provider organisations are responsible for making appropriate checks and seeking relevant assurances in relation to any external links.

### **Training providers**

NYCC is not in a position to recommend particular training providers. Information on local and national learning resources can be obtained through some of the links listed in sections 7 and 8. The [Royal College of Nursing website](#) also lists a large number of learning resources in relation to dementia, many of which are relevant across all sectors of care/professional groups:

### **Online-learning**

Online-learning can be a very useful way of delivering training to staff, but it should be recognised that staff will benefit significantly from the opportunity to explore the issues together, with the opportunity to ask questions, solve problems and share good practice. As well as supporting individual learning, online-learning tools can be used creatively in pairs or groups to allow this opportunity.

**Skills for Care** have published guidance for employers on employing learning technologies in workforce development: [Learning Technologies; a Guide for Employers](#)

**SCIE Dementia Care Gateway** provides the [Open Dementia Programme](#): and this is used by NYCC through its Learning Zone. The programme communicates information in a variety of ways, and includes videos filmed by SCIE and the Alzheimer's Society. It has seven modules:

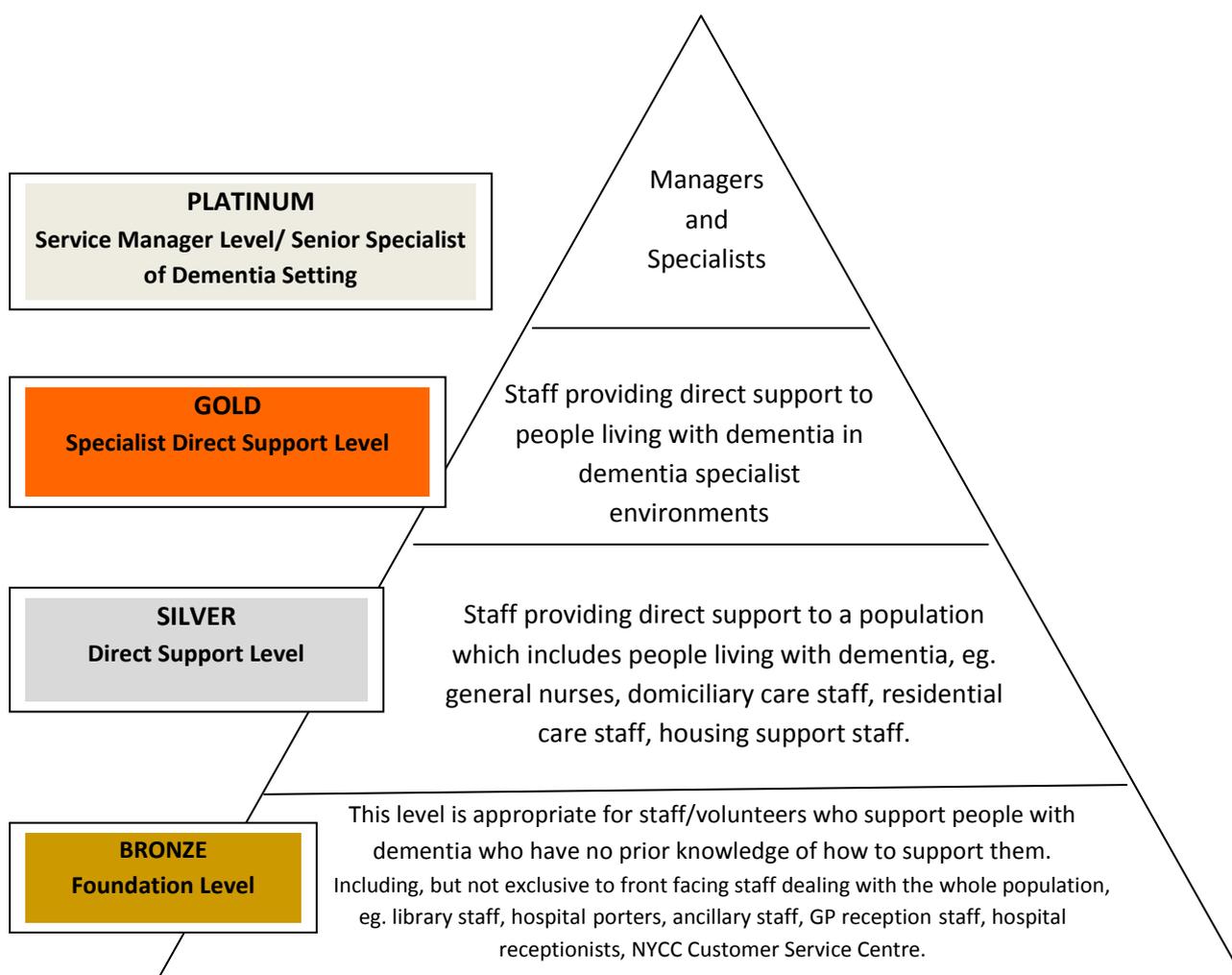
- What it is and what it isn't
- Living with dementia
- What causes dementia
- Diagnosis and who can help
- Common difficulties and how to help
- The emotional impact of dementia
- Positive communications.

The SCIE [Open Dementia Programme](#) is completely free and open to everyone.

## 6. NORTH YORKSHIRE DEMENTIA COMPETENCIES FRAMEWORK

As part of the North Yorkshire and York Dementia Strategy, a baseline of dementia competencies has been developed, based on the National Declaration Dementia outcomes. The baseline framework with the levels of competency is featured below.

Providers are advised to use this framework when planning and evaluating workforce development in relation to dementia. The **dementia self assessment template** will help providers to set a baseline and can be used for ongoing monitoring purposes.



The competencies are described in more detail below, with suggested levels of attainment:

### **BRONZE level competency**

**All staff who might come into contact with people with dementia (including ancillary staff) should have at least basic dementia awareness training.**

The **SCIE [Open Dementia Programme](#)** modules 1-3 are a suggested level of attainment to meet this standard (see section 5 'online learning' in this guidance).

Alternatively, the **[Alzheimer's Society Dementia Friends](#)** training could be considered. There is online training with information specifically for customer facing staff, or face to face sessions can be arranged at no cost.

### **SILVER level competency**

**Front line staff working with adults/older people, some of which have dementia (including Senior Health Care Assistants, Senior Care Workers, Team Leaders, Supervisory Staff and Nurses):**

Consider undertaking the Level 2 Dementia Award, or equivalent learning and development based on these standards.

### **GOLD level competency**

**Front line staff working with adults/older people, in specific dementia settings or primarily with people who have dementia:**

Consider undertaking the Level 2 Dementia Certificate, or equivalent learning and development based on these standards.

Alternatively, the Level 2 Health and Social Care Diploma has a dementia route, which covers all of the dementia award competencies and some of the certificate competencies.

**Senior Health Care Assistants, Senior Care Workers and Supervisory Staff and Nurses working in specific dementia settings or primarily with people who have dementia:**

Consider undertaking the Level 3 Dementia Award, or equivalent learning and development based on these standards.

Ideally, staff at this level should achieve the Level 3 Dementia Certificate.

Alternatively the Level 3 Health and Social Care Diploma has a dementia route, which covers all of the dementia award competencies and some of the certificate competencies.

### **PLATINUM level competency**

**Managers of Dementia Specific Care Settings**

Managers of dementia specific settings need to have the skills and knowledge to manage the environment and staff practice to ensure the individual living with dementia and their carers receive support of sufficient quality to meet the National Dementia Strategy Outcomes.

There are no specifically designed competencies to address this level of manager, however the following needs to be considered when commissioning learning and development for these managers:-

- Awareness, knowledge and understanding of dementia
- Design and management of dementia care services
- Management of risk and minimising restraint – best practice when supporting someone with dementia
- Leadership in person centred dementia care
- Business leadership in dementia care

Sections 7 and 8 outline the support available to help providers deliver these standards.

**The above are guidelines only and should not be used as a prescriptive list when commissioning training, it is important managers and commissioners consider the dementia outcomes and ensure any learning and development is scheduled to meet these outcomes.**

## **7. LOCAL ORGANISATIONS/INFORMATION**

This section lists local organisations that can provide support and information related to dementia/workforce development. This list is not exhaustive and NYCC can take no responsibility for the quality of any support/information provided through any external links. Provider organisations are responsible for making appropriate checks and seeking relevant assurances.

**Please note that this list is not exhaustive; it focuses on services that are available across the county and does not include all locally based dementia support. Contact your local Dementia Support Service for further information on local availability.**

### **NORTH YORKSHIRE DEMENTIA SUPPORT SERVICE**

NYCC and the local NHS Clinical Commissioning Groups have funded a Dementia Support Service across North Yorkshire.

Two voluntary organisations (Making Space and Dementia Forward) provide a support service that include dementia advisors who provide advice, information and signposting to other relevant services. They also deliver educational programmes so that people understand the condition better and can develop coping strategies to live well with dementia. Anyone can refer into the service, and it is available to people with dementia and to carers. A fuller service description of these organisations is outlined below.

Contact details correspond to each CCG locality:

<b>Locality</b>	<b>Provider</b>	<b>Telephone</b>
Vale of York	<b>DEMENTIA FORWARD</b>	<b>York and the Vale of York 01904 692473 Selby 01757 241054</b>
Harrogate and Rural	<b>DEMENTIA FORWARD</b>	<b>01765 645904</b>
Hambleton, Richmond & Whitby	<b>MAKING SPACE</b>	<b>01609 771089</b>
Scarborough and Ryedale	<b>MAKING SPACE</b>	<b>01723 371958</b>
Craven	<b>MAKING SPACE</b>	<b>01535 609192</b>

### **DEMENTIA SPECIFIC ORGANISATIONS**

#### **Dementia Forward**

**Address:** (Registered Office) Community House, Allhallowgate, Ripon HG4 1LE

**Tel:** 01765 601224

**Email:** [info@dementiaforward.org.uk](mailto:info@dementiaforward.org.uk)

**Website:** [www.dementiaforward.org.uk/](http://www.dementiaforward.org.uk/)

**Information:** Dementia Forward provide a number of services to anyone who is interested in dementia, whether they have received a diagnosis, have concerns about their memory, support someone with memory problems, or work in dementia care. They offer practical advice, support and information to help people make sense of their diagnosis and live well.

They have a team of Dementia Support Advisors, led by an Admiral Nurse (a specialist dementia nurse) who come alongside families and stay with them from the first point of receiving a diagnosis to those needing full time care and for as long as people want support. In addition Dementia Forward provides education for people diagnosed and their family carers and they run a range of social and wellbeing activities. Dementia Forward services cover Vale of York, plus Harrogate and rural CCG localities

### **Making Space**

**Address:** (Local offices)

- Europa House, 20 Esplanade Scarborough YO11 2AQ Tel: 01723 371958
- 7 South Parade Northallerton Tel: 01609 771089
- 147 Skipton Road Keighley West Yorkshire BD21 3BG Tel: 01535 609192

**Generic email address:** NorthYorkshire.DementiaSupport@makingspace.co.uk

**Website:** [www.makingspace.co.uk](http://www.makingspace.co.uk)

**Information:** Making Space provide a local point of contact for people worried about their memory or have a diagnosis of dementia , their carers and family . Their Dementia Navigators aim to empower people with dementia and their carers by providing information, support and signposting enabling a better understanding of the condition. They will help to develop self management skills and to access support in the local community, so promoting independence, well being, choice and control. Staff work alongside other voluntary and specialist services helping individuals to navigate through the system. In addition Making Space provide education sessions for those living with dementia and their carers. Making Space covers Scarborough and Ryedale area; Hambleton, Richmondshire and Whitby; and Craven

### **Alzheimer's Society**

**Address:** Yorkshire and Humber Area Office: IT Centre, Innovation Way, Heslington, York YO10 5NP

**Tel:**

Main Office: 01904 633804

Area offices:

Scarborough, Whitby and Ryedale	01723 500958
Hambleton & Richmondshire	01748 825817
Ripon, Harrogate and Craven	01423 813464
York and Selby	01904 567701

**Email:** [nyo@Alzheimer's.org.uk](mailto:nyo@Alzheimer's.org.uk)

**Website:** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**Information:** Alzheimer's Society provides a range of services and support for people affected by dementia across the North Yorkshire area. Local services differ in each area and might include: Carer information programmes, Dementia Cafes, Befriending, Day Support, Peer Support activities and Singing for the Brain ®. For details contact the local offices above. In addition to providing services they provide information and advice for professionals and campaign for greater public awareness and understanding of dementia.

## **LOCAL ADVOCACY FOR PEOPLE WITH DEMENTIA**

There are a number of local advocacy services, see NYCC website for information: [www.northyorks.gov.uk/article/23955/Advocacy-services-in-North-Yorkshire](http://www.northyorks.gov.uk/article/23955/Advocacy-services-in-North-Yorkshire)

## **CARER ORGANISATIONS**

There are a number of local carer organisations - see the NYCC website for information:  
[www.northyorks.gov.uk/article/23946/Adult-carers](http://www.northyorks.gov.uk/article/23946/Adult-carers)

## **SAFEGUARDING**

NYCC's policy and approach to safeguarding adults and the safeguarding alert form can be accessed on:

[www.northyorks.gov.uk/article/24309/Safeguarding-vulnerable-adults](http://www.northyorks.gov.uk/article/24309/Safeguarding-vulnerable-adults)

There is information on Safeguarding Adults and Mental Capacity Act training for North Yorkshire providers via the NYCC Safeguarding Vulnerable Adults website

[www.northyorks.gov.uk/article/24309/Safeguarding-vulnerable-adults](http://www.northyorks.gov.uk/article/24309/Safeguarding-vulnerable-adults)

It can also be located on the partners workforce development website **Care Alliance for Workforce Development (CAWD)** [www.cawd.org.uk](http://www.cawd.org.uk)

## **ASSESSMENT AND SUPPORT**

For information and guidance, assessment and support for individuals/carers, contact NYCC Customer Services [www.northyorks.gov.uk/article/25905/General-enquiries](http://www.northyorks.gov.uk/article/25905/General-enquiries)

## **FINANCIAL ADVICE/LEGAL ADVICE**

NYCC have introduced a new initiative to advise and help people make decisions about this, called **PAYING FOR CARE**. This includes:

- Information on state benefits you may be entitled to and how to claim;
- Information on the different types of care that is available;
- Guidance on topics such as setting up a Power of Attorney or making a will; and
- Access to specialist advice on the best way to fund your long-term care.

Anyone access the Paying for Care website should go to the "Arrange a call" page of the Paying for Care website, which can be found at: [www.payingforcare.org/information](http://www.payingforcare.org/information)

## **ASSISTIVE TECHNOLOGY AND EQUIPMENT FOR PEOPLE WITH DEMENTIA**

For a self assessment with links to local/national information on assistive technology and equipment, see NYCC's website and go to ASKSARA:

[www.northyorks.gov.uk/article/28938/AskSARA-for-advice-and-support-to-help-daily-living](http://www.northyorks.gov.uk/article/28938/AskSARA-for-advice-and-support-to-help-daily-living)

## **GENERAL ADVICE AND INFORMATION FOR PROVIDERS**

### **Independent Care Group (ICG)**

**Address:** Independent Care Group , 5 Beechwood Grove, Harrogate, HG2 8QP

**Tel:** 01423 816 582 / 07766 714157

**E-mail:** [keren.wilson@indcaregroup.plus.com](mailto:keren.wilson@indcaregroup.plus.com)

**Website:** <http://www.independentcaregroup.co.uk>

**Information:** ICG is the recognised representative body for independent care providers (private and voluntary) in York and North Yorkshire. They work on behalf of care providers for all client groups including care homes, domiciliary care agencies, supported living and extra care housing providers, and day care centres in the private and voluntary parts of the independent sector. The ICG provide members with a range of information, including workforce development issues and training opportunities.

## **8. NATIONAL ORGANISATIONS/INFORMATION**

**Note: Provider organisations are responsible for making appropriate checks and seeking relevant assurances in relation to any external links provided here.**

Useful national information/good practice is listed here, in the following sections:

- General information about dementia
- Delivering high quality dementia care
- Safeguarding/ risk assessment / legal matters
- Healthcare and dementia
- Incontinence and dementia
- Sensory impairment and dementia
- The environment
- Telecare and Information & Communication Technology
- Advanced stages /end of life care
- Dementia Care Mapping
- Managing behaviours that challenge / behaviours that are unpredictable
- Activities / creative arts and dementia
- Supporting carers
- Early onset dementia/younger people with dementia
- Equality and diversity
- Consulting and involving people with dementia who use services
- Promoting peer support
- National dementia specific organisations
- National workforce development agencies

### **General information about dementia**

The national **Alzheimer's Society** [www.alzheimers.org.uk](http://www.alzheimers.org.uk) has a range of factsheets such as: *What is Dementia?*; *What is Alzheimer's Disease?*; *What is Vascular Disease?*; *What is Dementia with Lewy Bodies?*; *The Later Stages of Dementia* and so on. These factsheets are available in a number of different languages and can be saved, printed or purchased. To access the factsheets go to:

[www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137](http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137)

**Dementia UK** [www.dementiauk.org/](http://www.dementiauk.org/) has a Q&A on dementia and related support on its website, and some factsheets are available.

The **NHS website** has a section called *About Dementia*. Aimed primarily at the public it provides useful information, including information on risk factors for dementia and knowing the symptoms of dementia. Go to: [www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx](http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx)

## **Department of Health Dementia Information Portal [www.dementia.dh.gov.uk](http://www.dementia.dh.gov.uk)**

A DH website 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 (archive material only from March 2013)

## **Delivering high quality dementia care**

More information on tools for delivering high quality dementia care is included in NYCC's 'Dementia Care and Support in Extra Care Housing Guide' which is pertinent to all sectors of care.

## **Dementia Partnerships [www.dementiapartnerships.com](http://www.dementiapartnerships.com)**

Dementia Partnerships is an innovation hub bringing together people, partnerships and networks to share knowledge and learning to improve the quality of life for people with dementia.

## **Skills for Care**

*Supporting dementia workers* A case study-based manager's guide to good practice in learning and development for social care workers supporting people with dementia (Skills for Care Spring 2012)

[www.skillsforcare.org.uk/Document-library/Skills/Dementia/Supporting-Dementia-workers-online-copy\(revised\).pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Supporting-Dementia-workers-online-copy(revised).pdf)

## **Royal College of Nursing**

*Supporting people to Live Well with Dementia; A guide to implementing the National Strategy* (2009) This guide highlights key issues from the National Dementia Strategy for care homes, and implications for providers and care home managers

[www.rcnpublishing.com/userimages/ContentEditor/1373368465648/Living-well-with-dementia-in-a-care-home.pdf](http://www.rcnpublishing.com/userimages/ContentEditor/1373368465648/Living-well-with-dementia-in-a-care-home.pdf)

## **Social Care Institute for Excellence (SCIE)**

The SCIE website ([www.scie.org.uk](http://www.scie.org.uk)) has a section called *Dementia Gateway*. The website provides information including resources on understanding dementia. The SCIE website also has a number of videos in which people share their experiences of dementia.

To access the information go to: [www.scie.org.uk/publications/dementia/index.asp](http://www.scie.org.uk/publications/dementia/index.asp)

The *SCIE Research briefing 3: Aiding communication with people with dementia* (April 2004 Updated April 2005) is also a useful publication for provider staff

[www.scie.org.uk/publications/briefings/briefing03/](http://www.scie.org.uk/publications/briefings/briefing03/)

## **Helen Sanderson Associates**

*Progress for Providers; Checking your progress in delivering personalised support for people living with dementia* (2012) This guidance is specifically targeted at care homes and provides a number of useful checklists for supporting good practice.

[www.progressforproviders.org/checklists/delivering-personalised-support-for-people-living-with-dementia/](http://www.progressforproviders.org/checklists/delivering-personalised-support-for-people-living-with-dementia/)

## **My Health Skills + Dementia Skills Network**

<http://www.myhealthskills.com/groups/3/show>

My Health Skills is the first tool of its type for healthcare employees, though it is relevant to workers in the social care sector. Its focus is on workforce transformation, learning and skills,

and aims to enable people in the sector to network, to share best practice, expertise and resources. Co-invested and supported by The UK Commission for Employment and Skills (UKCES) and Skills for Health (SfH), My Health Skills, has an online system that offers members a platform to voice opinion, access relevant information, build capability and seek advice from fellow colleagues within the healthcare sector.

The **Dementia Skills Network** <https://www.myhealthskills.com/groups/3/show> is part of MyHealthSkills and is aimed at anyone who wants to improve the education and skills of the workforce caring for those living with dementia and their families.

### **My Home Life**

*My Home Life* [www.myhomelife.org.uk](http://www.myhomelife.org.uk) is an initiative aimed at improving the quality of life of people who are living, dying, visiting or working in care homes for older people. Although not focused specifically on caring for people with dementia this website provides useful guidance on eight best practice themes: managing transitions; maintaining identity; creating community; sharing decision making; improving health and healthcare; supporting good end of life; keeping workforce fit for purpose and promoting a positive culture.

### **This Is Me**

'This Is Me' is a tool that has been developed to support personalised care for people with dementia who are receiving professional care in any setting – at home, in hospital, in respite care or a care home. It is a simple and practical tool that people with dementia can use to tell staff about their needs, preferences, likes, dislikes and interests. 'This Is Me' can enable health and social care professionals to see the person as an individual and deliver person-centred care. It can also help to prevent issues with communication, or more serious conditions such as malnutrition and dehydration. It is available to download from: [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1290](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290)

## **Safeguarding /risk assessment /legal matters**

**(see also relevant issues in section 7)**

**SCIE** provides comprehensive general information about safeguarding:

[www.scie.org.uk/adults/safeguarding/](http://www.scie.org.uk/adults/safeguarding/)

**SCIE** also provides comprehensive information and e-learning regarding the Mental Capacity Act and the Deprivation of Liberty Safeguards at

[www.scie.org.uk/publications/elearning/mentalcapacityact/index.asp](http://www.scie.org.uk/publications/elearning/mentalcapacityact/index.asp)

### **Dept of Health**

The Dept of Health produced risk enablement guidance on dementia in 2010, in line with the National Strategy on Dementia. This includes a risk enablement framework.

[www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia](http://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia)

### **Housing Learning and Improvement Network (LIN)**

Housing LIN website provide links to regulation and guidance on dementia/mental capacity and housing issues

[www.housinglin.org.uk/Topics/browse/HousingandDementia/Legislation/](http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Legislation/)

## **Solicitors for the Elderly (SFE)**

Solicitors for the Elderly is an independent, national organisation of lawyers, such as solicitors, barristers, and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers.

[www.solicitorsfortheelderly.com/public/what-is-sfe](http://www.solicitorsfortheelderly.com/public/what-is-sfe)

## **Healthcare and dementia**

People with dementia commonly have additional health problems (such as cancer) and/or long term conditions (such as diabetes). It is sometimes these additional problems that trigger the need for health service inputs. There may be increased risk of these additional health problems being unnoticed or poorly managed. For example:

- a person with diabetes may not be so attentive to what they are eating
- medication for different conditions may have a combined adverse impact
- people with dementia may not understand the need for certain medical interventions
- a person who is in pain may not be able to communicate this very easily
- discomfort or pain could be a reason why people are behaving in a certain way (eg. constantly changing position / not wanting to participate and engage)

It is of key importance that staff are alert to the implications of additional health problems and how to manage this.

## **Nutrition**

For many people with dementia, the changes that are experienced as dementia progresses can have an impact on the whole mealtime experience. These changes can result in weight loss, dehydration or even weight gain. Malnutrition and dehydration can contribute to the risk of developing delirium. Factsheets on nutrition and eating are provided by the Alzheimer's Society: [www.alzheimers.org.uk/Nutrition/](http://www.alzheimers.org.uk/Nutrition/)

## **Exercise/keeping fit**

The Alzheimer's Society has a factsheet on exercise and keeping fit:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1764](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1764)

## **Dentistry**

The Alzheimer's Society provides guidance on dementia and dental care:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=138](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=138)

Information on local community dentistry is available from ??

## **Incontinence and dementia**

Difficulties with using the toilet, accidents and incontinence can all be problems for people with dementia, particularly as the condition progresses. Difficulties can also be linked to the *environment* rather than any personal health issues.

## **Alzheimer's Society**

The Alzheimer's Society provide a factsheet, guidance and tips for carers/support workers on incontinence and toilet problems:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=136)

## Sensory impairment and dementia

People are much more likely to be affected by sight or hearing impairment as they age. Also, people who have had sensory impairments for all/much of their lives may be affected by dementia as they grow older. Sensory impairment combined with dementia can bring an added sense of confusion and disorientation.

**SCIE's Dementia Gateway** has a wide range of resources, including online-learning materials, related to dementia and sensory impairment.

[www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/index.asp](http://www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/index.asp)

## Good Practice in the Design of Homes and Living Spaces for People with Dementia and Sight Loss

The guidelines have been produced by the sight loss charity, Thomas Pocklington Trust and the University of Stirling. They show how good design of living spaces can improve the lives of people who are living with two common conditions - dementia and sight loss.

[www.dementia.stir.ac.uk/design/good-practice-guidelines](http://www.dementia.stir.ac.uk/design/good-practice-guidelines)

## Sight tests at home

To download a free information booklet go to:

[www.visionmatters.org.uk/sight-tests/at-home](http://www.visionmatters.org.uk/sight-tests/at-home)

## The environment

**NYCC's Extracare Team** have produced a Dementia Care and Support in Extra Care Housing Guide [http://www.northyorks.gov.uk/media/29744/Design-and-good-practice-guide--dementia-care/pdf/Design\\_and\\_good\\_practice\\_guide\\_-\\_dementia\\_care\\_\(Nov\\_2014\).pdf](http://www.northyorks.gov.uk/media/29744/Design-and-good-practice-guide--dementia-care/pdf/Design_and_good_practice_guide_-_dementia_care_(Nov_2014).pdf) for providers of Extracare services. This guide has a wide range of information related to the built environment and to good practice in the care and support of people with dementia (including many national links), which will be of interest to all sectors of care. It also includes information on assistive technology and telecare.

## Developing supportive design for people with dementia (Kings Fund)

To support clinical and care staff, managers and estates colleagues, The King's Fund has produced a range of resources to enable hospitals, care homes, primary care premises and specialist housing providers to become more dementia friendly.

[www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia](http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia)

**The King's Fund** has produced a checklist for care homes to check how dementia friendly the environment is:

[www.kingsfund.org.uk/sites/files/kf/field/field\\_pdf/is-your-care-home-dementia-friendly-ehe-tool-kingsfund-mar13.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_pdf/is-your-care-home-dementia-friendly-ehe-tool-kingsfund-mar13.pdf)

**Down's Syndrome Scotland** have produced a practical guide which illustrates how to make the home environment more conducive to supporting someone with both a learning disability and dementia. *'Adapting the home of a person who has Down's Syndrome and Dementia – a guide for carers'*.

<http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/living-with-dementia.pdf>

**Dementia Adventure** is a Community Interest Company which provides training, consultancy and services related to supporting people with dementia to access the outdoors. Research and guides to enabling activities are also available to download.

[www.dementiaadventure.co.uk/](http://www.dementiaadventure.co.uk/)

## Telecare and Information & Communication Technology (ICT)

**AT Dementia** provides information on assistive technology that can help people with dementia [www.atdementia.org.uk/](http://www.atdementia.org.uk/)

The Disabled Living Foundation have produced guidance and a factsheet on equipment and memory loss: [www.dlf.org.uk/factsheets/safety](http://www.dlf.org.uk/factsheets/safety)

**SCIE** have produced guidance on using ICT with people with dementia in a range of ways: [www.scie.org.uk/publications/ictfordementia/index.asp](http://www.scie.org.uk/publications/ictfordementia/index.asp)

### People with dementia using iPads

This technology can enable people to continue to express themselves and interact with others.

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2616&pageNumber=3](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2616&pageNumber=3)

## Advanced stages / End of Life Care and dementia

There are particular factors for people with dementia, such as informed consent, proxy decision making, articulation of basic needs and maintaining dignity. The following good practice resource guides will assist staff:

### Skills for Care

*Supporting People in the Advanced Stages of Dementia; a case study-based manager's guide to good practice in learning and development for social care workers supporting people in the advanced stages of dementia* (May 2013)

[www.skillsforcare.org.uk/Document-library/Skills/Dementia/Advance-stages-of-dementia-guide-%28May-2013%29vfw.pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Advance-stages-of-dementia-guide-%28May-2013%29vfw.pdf)

### Alzheimer's Society

*My Life Until the End; dying well with dementia* (2012)

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2017](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2017)

### National End of Life Care Programme

*Care towards the end of life for people with dementia an online resource guide* (2010)

[www.opaal.org.uk/Libraries/Local/1013/Docs/Dementia\\_resource\\_final\\_20101025.pdf](http://www.opaal.org.uk/Libraries/Local/1013/Docs/Dementia_resource_final_20101025.pdf)

**End of life care in extra care housing - Learning resource pack for housing, care and support staff** (published by the National End of Life Care Programme (NEoLCP) and the Housing LIN, and prepared by the International Longevity Centre)

This end of life learning resource pack (also available as a DVD) is a very useful guide for staff in all settings of care, not just extracare.

[www.housinglin.org.uk/Topics/type/resource/?cid=8615](http://www.housinglin.org.uk/Topics/type/resource/?cid=8615)

## Dementia Care Mapping

Dementia care mapping can be used as an effective method of addressing ongoing workforce development. Although care mapping is a tool that could be transferred to many aspects of care provision, it was developed specifically for people with dementia and dementia-like conditions. It involves sitting at the side of the care area, usually for six hours, observing a person's behaviour, well-being or ill-being and any positive or negative events. Mappers may notice how busy staff can inadvertently upset or disrespect service users, for example, by failing to greet them properly or by talking over their heads. Dementia care mapping evaluates the lived experiences of people with dementia; the tools employed can measure the effectiveness of the transfer of learning into practice and also support managers to lead a positive culture within their organisations. Professor Tom Kitwood first developed dementia care mapping at the University of Bradford; there are several tools now in use which enable dementia care mapping, for example:

### Dementia Care Matters

Dementia Care Matters are an independent training initiative specialising in dementia, and their founder, David Sheard, has developed a Qualitative Observational Tool. This is part of a suite of workforce development tools and training courses offered.

[www.dementiacarematters.com/index.html](http://www.dementiacarematters.com/index.html)

Northern office: 07889 000801

## Managing behaviours that we may find difficult / are unpredictable

**SCIE Dementia Gateway** has a section on difficult situations, and advice on how to manage them including 'aggressive' behaviour, 'a different reality', problems related to using the toilet, repetition, walking, refusing help, sexual expression, being withdrawn, and use of anti-psychotic medication

[www.scie.org.uk/publications/dementia/living-with-dementia/difficult-situations/](http://www.scie.org.uk/publications/dementia/living-with-dementia/difficult-situations/)

### Alzheimer's Society

The Alzheimer's Society host a webpage with a range of resources related to optimising treatment and care for behavioural and psychological symptoms of dementia. This includes a best practice guide based on evidence from clinical research.

[www.alzheimers.org.uk/bpsdguide](http://www.alzheimers.org.uk/bpsdguide)

### Dementia UK

A Dementia UK factsheet: *Maxims for Dealing with Perplexing Behaviour* is a short, user-friendly guide to dealing with behaviours that are hard to understand. This leaflet is written by a family carer, with other carers in mind.

[www.dementiauk.org/assets/files/info\\_and\\_support/docs\\_and\\_reports/MAXIMS FOR DEALING WITH PERPLEXING BEHAVIOURS - updated.pdf](http://www.dementiauk.org/assets/files/info_and_support/docs_and_reports/MAXIMS_FOR_DEALING_WITH_PERPLEXING_BEHAVIOURS_-_updated.pdf)

## Activities / creative arts and dementia

A range of activities, including creative arts, can be a very powerful means through which to enable people with dementia to express themselves. There are a number of resources available to enable staff to develop this in different settings:

### **Alzheimer's Society 'Taking part: activities for people with dementia'**

This publication is an updated version of the original Alzheimer's Society book of activities, first published in 2002. The book includes detailed breakdowns of more than 80 activity ideas that detail precisely 'What you need' and 'How it's done'.

[http://alzheimers.org.uk/site/scripts/news\\_article.php?newsID=1610](http://alzheimers.org.uk/site/scripts/news_article.php?newsID=1610)

**ARTS and Dementia Network** is a forum for the North East Region, founded by **Equal Arts** in 2011, which aims to bring together and support professionals working in the arts, health and social care who are interested in providing opportunities for people with dementia to engage in arts activity. Membership of the network is free and open to professionals working in the arts, health and social care who work with, or have an interest in providing creative opportunities for people with dementia. Tel: 0191 477 5775

[information@equalarts.org.uk](mailto:information@equalarts.org.uk)

[www.equalarts.org.uk/pages/about-us.php](http://www.equalarts.org.uk/pages/about-us.php)

**Arts4Dementia** is a charity helping to develop and co-ordinate high-quality intergenerational arts opportunities for people living with dementia in the community. Their website includes a wide range of resource links useful to all settings of care [www.arts4dementia.org.uk/](http://www.arts4dementia.org.uk/)

**Lost chord** [www.lost-chord.org.uk/index.html](http://www.lost-chord.org.uk/index.html)

Lost Chord began their work in South Yorkshire but are now rolling this out across the country. They provide interactive sessions designed to stimulate responses from people with dementia through the media of music, song and dance.

## Supporting carers

Links to local carer organisations are provided in section 6.

National organisations include:

**Carers Trust** [www.carers.org/](http://www.carers.org/)

Carers Trust is a new charity which was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in 2012. Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

**Carers UK** [www.carersuk.org/](http://www.carersuk.org/)

Carers UK provides information, advice and support for carers. By bringing carers together, we provide a stronger voice which shapes our campaigns to make life better for carers and influences policy makers, employers and service providers, to help them improve carers' lives. They also carry out research and run campaigns.

**Skills for Care/Dementia UK** have produced guidance to highlight the importance of care workers working together with carers: *Dementia; Workers and Carers Together*; *A guide for*

*social care workers on supporting family and friends carers of people with dementia* (Spring 2012)

[www.skillsforcare.org.uk/Document-library/Skills/Dementia/Dandctog-final-versionnidd.pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Dandctog-final-versionnidd.pdf)

## Early onset dementia/ younger people with dementia

People diagnosed with dementia under the age of 65 are often described as 'younger people with dementia' by health and social care professionals. The symptoms of dementia may be similar regardless of a person's age, but younger people may have different needs, and require different forms of support.

The **Alzheimer's Society** has information on early onset dementia:

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=164](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164)

**Alzheimer's Society 'Talking Point'** focuses on a range of issues, including a forum for people with early onset dementia <http://forum.alzheimers.org.uk/forum.php>

## Equality and diversity

**Alzheimer's Society** [www.alzheimers.org.uk](http://www.alzheimers.org.uk) has factsheets related to:

- *Learning Disabilities and Dementia*
- *Supporting lesbian, gay and bisexual people with dementia*

To access the factsheets go to:

[www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137](http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137)

The **'Talking Point'** forum <http://forum.alzheimers.org.uk/forum.php> includes a forum for lesbian and gay people affected by dementia

**The Alzheimer's Society also has publications and factsheets in different languages.**

**The Royal College of Nursing** has a wide range of resources linked to equality and diversity on its website, many of which are relevant across different sectors of care/ professional groups:

[www.rcn.org.uk/development/practice/dementia/supporting\\_people\\_with\\_dementia/cultural\\_diversity](http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia/cultural_diversity)

The **North East Dementia Alliance** have produced a guide: *Support and care for people living with dementia from minority communities* (2013)

[www.nr-foundation.org.uk/wp-content/uploads/2013/05/Attachment-3-Support-and-Care-for-people-living-with-Dementia-from-Minority-Communities-Final.pdf](http://www.nr-foundation.org.uk/wp-content/uploads/2013/05/Attachment-3-Support-and-Care-for-people-living-with-Dementia-from-Minority-Communities-Final.pdf)

**Meriyaadian**, a Bradford based organisation, have produced a guide: *Dementia: Exploring good practice on supporting South Asian carers through access to culturally competent service provision* (2011)

[www.meriyadain.co.uk/pdfs/publications/Dementiaguide2011ENGLISH19may11.pdf](http://www.meriyadain.co.uk/pdfs/publications/Dementiaguide2011ENGLISH19may11.pdf)

## Women and dementia

The dementia women network is funded by Joseph Rowntree Foundation and is run jointly by Innovations in Dementia CIC and the Social Policy Research Unit at the University of York.

They put the spotlight on experiences of women who are disproportionately affected by dementia (as carers, in the workforce, and because women live longer).

[www.dementiawomen.org.uk/index.html](http://www.dementiawomen.org.uk/index.html)

### Promoting Peer Support

People with dementia, and people supporting or caring for someone with dementia, often say that the best decision they made was to meet other people living with the same condition. No-one can support someone with a diagnosis quite like other people with the same diagnosis, and the same goes for carers. There are many opportunities for peer support. Check out local possibilities through your local Dementia Support Service.

On line options are available:

**Dementia Advocacy and Support Network (DASN)** is an internet based international forum [www.dasninternational.org/](http://www.dasninternational.org/)

**Alzheimer's Society 'Talking Point'** is an online forum that enables peer support on a range of issues: <http://forum.alzheimers.org.uk/forum.php>

### Consulting and involving people with dementia who use services

Joseph Rowntree Foundation has produced a report on consulting with people with dementia within settings of care. *Communication and consultation; exploring ways for staff to involve people with dementia in developing services* describes situations and difficulties which will be recognised by all, and demonstrates that meaningful consultation is possible despite the challenges.

[www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services](http://www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services)

## DEMENTIA SPECIFIC ORGANISATIONS (NATIONAL)

### Alzheimer's Society

**Address:** Devon House, 58 St Katharine's Way London E1W 1LB

**Tel:** 020 7423 3500

**E-mail:** [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

**Website:** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**Information:** The Alzheimer's Society is a membership organisation, which works to improve the quality of life of people affected by dementia. They have a number of local affiliated branches across England, Wales and Northern Ireland. They also provide a national telephone helpline and online service, offer training, and fund research programmes.

### Dementia UK

**Address:** 2nd Floor, Resource for London, 356 Holloway Road, London N7 6PA

**Tel:** 020 7697 4160

**E-mail:** [info@dementiauk.org](mailto:info@dementiauk.org)

**Website:** [www.dementiauk.org/](http://www.dementiauk.org/)

**Information:** Dementia UK is a national charity, committed to improving quality of life for all people affected by dementia. They provide mental health nurses specialising in dementia care, called Admiral Nurses. Dementia UK also runs a national helpline and email service Admiral Nursing DIRECT, which is for family and professional carers, people with dementia and those worried about their memory. Call 0845 257 9406 or email [direct@dementiauk.org](mailto:direct@dementiauk.org)

## WORKFORCE DEVELOPMENT AGENCIES (GENERAL)

### Social Care Institute for Excellence (SCIE)

**Address:** 206 Marylebone Road, London, NW1 6AQ

**Tel:** 020 7535 0900

**Email:** [info@scie.org.uk](mailto:info@scie.org.uk)

**Website:** [www.scie.org.uk/index.asp](http://www.scie.org.uk/index.asp)

**Information:** SCIE's aim is to "improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector." Using knowledge gathered from diverse sources and a broad range of people and organisations, SCIE develop resources which they share freely, supporting those working in social care and empowering service users. The website provides links to electronic versions of many books and reports and there are free documents to download. The site also includes up to date research reports on topics relevant to social care.

### Skills For Care

**Address:** West Gate, 6 Grace Street, Leeds, LS1 2RP

**Contact name:** Angela Thompson - Area Officer (York, North Yorkshire)

**Tel:** 0113 245 1716 (Head Office) 07813 031 257 (Angela Thompson)

**Email:** [angela.thompson@skillsforcare.org.uk](mailto:angela.thompson@skillsforcare.org.uk)

**Website:** <http://www.skillsforcare.org.uk/Home.aspx>

**Information:** Skills for Care works with adult social care employers and other partners to develop the skills, knowledge and values of workers in the sector. Their work focuses on four

key areas: understanding the bigger picture; finding and keeping the right staff; setting standards for quality care, and looking ahead.

### **UKHCA (United Kingdom Homecare Association Ltd)**

**Address:** Sutton Business Centre, Restmor Way, Wallington, Surrey, SM6 7AH

**Tel:** 020 8661 8188

**Email:** [enquiries@ukhca.co.uk](mailto:enquiries@ukhca.co.uk)

**Website:** [www.ukhca.co.uk](http://www.ukhca.co.uk)

**Information:** UKHCA is the representative body for organisations that provide personal care – including nursing care - to people in their own homes. The Association represents the views of members with policy makers and promotes training and development of individuals and organisations providing home care. UKHCA produces information on good practice and acts as a focal point for innovation and quality within the care industry. The Association takes an active role in liaison with local and central government on all domiciliary care and related issues. They also have funding resources available for training, some of which is only available to UKHCA members.

### **City & Guilds**

**Address:** 1 Giltspur Street, London EC1A 9DD

**Tel:** 0844 846 0969

**Website:** [www.city-and-guilds.co.uk](http://www.city-and-guilds.co.uk)

**Information:** City & Guilds is the UK's leading vocational awarding body for work related qualifications, awarding over 50% of all National Vocational Qualifications (NVQs). C&G provide a range of office-based qualifications, and a set of management qualifications through the Institute of Leadership & Management . They have also developed a range of new internet and technology products such as Smartscreen.co.uk which provides online support for tutors, assessors and learners of C&G qualifications.

## **APPENDIX 1**

### **Full set of Outcomes within the National Dementia Declaration**

#### **1 I have personal choice and control or influence over decisions about me**

- 1.1 I have control over my life and support to do the things that matter to me.
- 1.2 I have received an early diagnosis which was sensitively communicated.
- 1.3 I have access to adequate resources (private and public) that enable me to choose where and how I live.
- 1.4 I can make decisions now about the care I want in my later life.
- 1.5 I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

#### **2 I know that services are designed around me and my needs**

- 2.1 I feel supported and understood by my GP and get a physical check up regularly without asking for it.
- 2.2 There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
- 2.3 I am treated with dignity and respect whenever I need support from services.
- 2.4 I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.
- 2.5 Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.
- 2.6 My carer can access respite care if and when they want it, along with other services that can help support them in their role.

#### **3 I have support that helps me live my life**

- 3.1 I can choose what support suits me best, so that I don't feel a burden.
- 3.2 I can access a wide range of options and opportunities for support that suits me and my needs.
- 3.3 I know how to get this support and I am confident it will help me.
- 3.4 I have information and support and I can have fun with a network of others, including people in a similar position to me.
- 3.5 My carer also has their own support network that suits their own needs.

#### **4 I have the knowledge and know-how to get what I need**

- 4.1 It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.
- 4.2 I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.
- 4.3 I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.
- 4.4 My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

#### **5 I live in an enabling and supportive environment where I feel valued and understood**

- 5.1 I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.
- 5.2 I am making a contribution which makes me feel valued and valuable.
- 5.3 My neighbours, friends, family and GP keep in touch and are pleased to see me.

- 5.4 I am listened to and have my views considered, from the point I was first worried about my memory.
- 5.5 The importance of helping me to sustain relationships with others is well recognised.
- 5.6 If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.
- 5.7 My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

## **6 I have a sense of belonging and of being a valued part of family, community and civic life**

- 6.1 I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.
- 6.2 Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.
- 6.3 My carer and I continue to have the opportunity to develop new interests and new social networks.
- 6.4 It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

## **7 I know there is research going on which delivers a better life for me now and hope for the future**

- 7.1 I regularly read and hear about new developments in research.
- 7.2 I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.
- 7.3 As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.
- 7.4 I believe that research is key to improving the care I'm receiving now.
- 7.5 I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.
- 7.6 I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.