



**Workforce Development for Dementia:  
Development of the role, associated  
competence development and proposed  
training required for the new  
“Dementia Pathway Coordinator” in the West  
Midlands to support those with Dementia  
and their intimate carer(s)**

**Anna Tsaroucha, Susan Mary Benbow,  
Rob Merchant, Paul Kingston,  
Centre for Ageing and Mental Health, Staffordshire University**

30<sup>th</sup> June 2010

Published by:  
Centre for Ageing and Mental Health,  
Copyright © 2010 Staffordshire University.

## **Acknowledgements**

This work was commissioned by the Workforce Deanery of the West Midlands Strategic Health Authority.

The work was conducted in collaboration with Kay De Vries, Tom Porter and Dawn Brooker of the Association for Dementia Studies, University of Worcester, and we would like to thank them for working with us and sharing intelligence.

In addition, the project team wish to express their thanks to all the people who have helped in this work, including all the stakeholders who attended meetings, offered their ideas and commented on documents at various stages.

Especial thanks are due to the Alzheimer's Society and Approach, and the users and carers who generously gave their views and time to assist in the project.

Responsibility for the interpretation of stakeholders' views lies with the team, but their thought-provoking contributions were invaluable and often humbling.

# Contents

	Page Number
Executive Summary	5
Introduction	6
Background	6
The West Midlands Dementia Pathway	8
Project Design and Context	10
Methods	11
Literature review	11
Literature search 1	11
Literature search 2	13
Consultation with stakeholders: method	15
Literature Review	16
1) What can be learned from the dementia workforce literature?	16
2) <i>What can be learned from the literature on managing long-term conditions?</i>	25
Findings	31
Feedback from stakeholders	34
The Dementia Pathway Coordinator in the West Midlands:	
Competencies required	38
Illustrative Job Description and Person Specification	46
Construction of Illustrative Person Specification and Job Description	48
Training of the Dementia Pathway Coordinator	54
Discussion	55
Recommendations	57
References	58

## **Executive Summary**

This report firstly summarises the background literature relevant to the new role of Dementia Pathway Coordinator (DPC) in the West Midlands. Secondly, it reports on extensive consultations with a range of stakeholders including people with dementia and their carers, in order to set out the competencies required to fulfil the new DPC role. Thirdly, it sets out the competencies required for the role, together with a job description and person specification.

Our main recommendations are that

- (1) Commissioners and providers should consider how to ensure that the full range of DPC competencies is made available to people with dementia and their families.
- (2) Training for the Dementia Pathway Coordinator should be competency based and include feedback from people with dementia and their families.
- (3) Evaluation of workforce innovations should include feedback from people with dementia and their carers and should address clinical efficiency and service integration.

## **Introduction**

This report was compiled as a collaborative activity between Staffordshire University and the University of Worcester. It is part of two parallel but complementary streams of work: development of the role of (1) a Primary Care Liaison worker by the Association for Dementia Studies, University of Worcester, and (2) a Dementia Pathway Coordinator (DPC) by the Centre for Ageing and Mental Health, Staffordshire University.

The scope of the project was to:

- 1) Develop job descriptions; person specifications;
- 2) Develop competencies;
- 3) Make recommendations for appropriate training/education programmes suitable to enable individuals to fulfil the above new roles in dementia care.

The same project methodology was used by both teams and we present here the work on the DPC.

## **Background**

Dementia has become high profile over recent years, partly in response to the recognition that the older population in the United Kingdom (UK), and globally, is increasing (Alzheimer's Society, 2007), and also because of the associated health and social care costs (Alzheimer's Research Trust, 2010; Lowin, Knapp and McCrone, 2001). It has been acknowledged that dementia will present a challenge for services across the world as the population ages. Alongside this is increasing public awareness of dementia and the expectation that increasing numbers of people will be seeking an early diagnosis (Department of Health (DH), 2009).

The National Dementia Strategy (DH, 2009) has highlighted the need to ensure that the workforce has the correct skills and competencies to deliver services that will inform individuals of the benefits of timely diagnosis, promote the prevention of dementia and support living well with dementia. Workforce development underpins the whole of the

National Dementia Strategy and objective 13 of the Strategy is to develop “*an informed and effective workforce for people with dementia*” (DH, 2009). Improving public and professional awareness and understanding of dementia is the first objective of the National Dementia Strategy (DH, 2009) and is an essential component within healthcare services in moving towards behaviour change and appropriate help-seeking and help provision. The Strategy also recommends that health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training and skill development that is consistent with their roles and responsibilities (NICE–SCIE, 2007).

In this systematic review we have drawn on the literature relating to the dementia workforce and developments in the workforce following the publication of the National Strategy; we have also drawn on relevant literature concerning the community matron role in relation to long-term conditions since dementia can be regarded as a long-term condition (see below).

The Department of Health<sup>1</sup> defines a long term condition as a condition that cannot, at present be cured; but can be controlled by medication and other therapies. Examples of long term conditions include diabetes, heart disease and chronic obstructive pulmonary disease (asthma). The World Health Organisation (WHO, 2005) defines long term conditions (also called chronic diseases) as “*a wide range of health problems that go beyond the conventional definition of chronic illness, such as heart disease, diabetes and asthma*” and require “*ongoing management over a period of years or decades*”. This includes a wide range of health conditions including non-communicable diseases (e.g. cancer and cardiovascular disease), communicable diseases (e.g. HIV/AIDS), certain mental disorders (e.g. schizophrenia, depression), and ongoing impairments in structure (e.g. blindness, joint disorders). Alongside these definitions, the National Service Framework (NSF) for Long-term Conditions (DH, 2005a) specifically includes dementia within its definitions as a progressive long-term neurological condition, but then proceeds to exclude it from the remit of NSF for Long-term Conditions by noting that dementia is covered in the NSF for Older People (DH, 2001). The definition used: ‘*a ‘longterm neurological condition’ results from disease of, injury or damage to the body’s nervous system (ie the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life*’ (DH, 2005b, p9) is clearly applicable to the dementias.

---

<sup>1</sup> Department of Health, The National Archives; This snapshot taken on **06/05/2010**

*“We need to look at dementia care within the broader context of the long-term conditions agenda and ensure that people with dementia have access to the holistic care provided by specialist older people’s nurses. All parts of the jigsaw need to be joined together.... We can no longer ignore dementia, or pretend that it is just an inevitable consequence of the ageing process. A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society”* (Jonathan Webster, Nurse Consultant for older people at University College London Hospital, quoted in Nursing Times, 2008).

### **The West Midlands Dementia Pathway**

The vision of the West Midlands *“Dementia Care Pathway”* (Saad, Smith and Rochfort, 2008) is to ensure by 2012 that: *“... all people with a suspected or confirmed diagnosis of Dementia will access an integrated, seamless, proactive and high quality locality based service that encompasses all the expertise to meet needs of the people with Dementia and those of their carers. The emphasis will be on personalisation and choice”* (p5).

The report identified eight standards that are expected to help achieve the vision for the West Midlands. These are: jointly planned health and social care commissioning for people with dementia and their caregivers which provides seamless, integrated and proactive care; services for dementia interfaced with services available for all other long term conditions and those for older people; home as the base starting point for interventions; a competent workforce; resourced intimate caregiver service; a Dementia Pathway Co-ordinator; use of GP practices to trigger preventative and therapeutic actions for defined types of dementia; and minimum core standards of competency for dementia care used to underpin all education programmes for staff working with these people (Saad *et al*, 2008).

Saad *et al* (2008) base the principles applicable across the whole dementia pathway on the document *“Putting People First”* (HM Government, 2007). This work sets out clearly what needs to be achieved, stressing the need for improved information and advocacy and more control and personalisation of services. *“Features of a good care pathway”* (Figure 1) was developed by Saad *et al* (2008) and identifies where the role of a Primary Care Liaison Worker and Dementia Pathway Coordinator (see below) could be positioned in relation to the pathway for persons with dementia, including the pre-diagnosis period.

# Features of a good care pathway

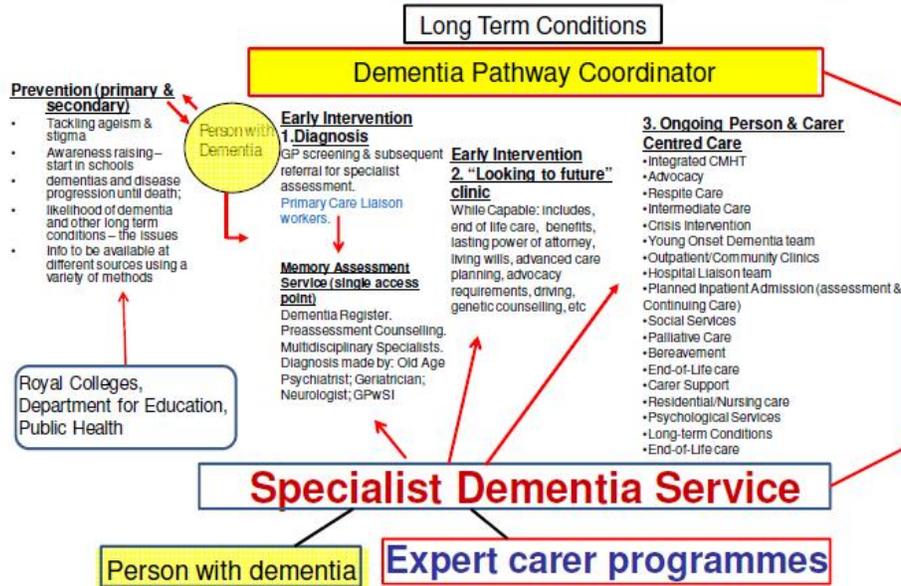


Figure 1 The West Midlands Dementia Care Pathway (Saad et al, 2008)

## Project design and context

A project team was established and work-plan and time frame were agreed with the commissioning organisation. Comprehensive literature and policy reviews were conducted relating to both roles. This report deals with the work on the Dementia Pathway Coordinator alone and should be read in conjunction with the report on the Primary Care Liaison worker.

### Context

The role of Dementia Pathway Coordinator (DPC) has been identified by NHS West Midlands and outlined in the Dementia Clinical Pathway Group Report, West Midlands SHA (Saad et al, 2008). As part of the Pathway Group's report, a model titled "Features of a good care pathway" was developed identifying the points at which the DPC would operate after the person had received their diagnosis of dementia and had interacted with the Primary Care Liaison Workers.

The Dementia Pathway Role Tender document issued by NHS West Midlands, and drawing on the Clinical Pathway Group Report, has provided the context for this literature review observing: *"The service coordinator will be responsible for coordinating the involvement of other agencies with their client e.g. that any advanced care planning decision are recorded. As the condition of the person with Dementia changes, the Service Coordinator will steer the person with the Dementia in and out of the most appropriate services... Accordingly, the West Midlands Strategic Health Authority (SHA)... is looking to commission the development of a job description, person specification, required competence and suggested training pathway for a new "Dementia Pathway Coordinator" role that will provide a point of contact for all those with dementia and their carers on an ongoing basis and help to signpost the additional help and support."* (NHS West Midlands, 2009, p2). The document acknowledges the context of long term conditions (DH, 2005a) and that many people with dementia will have other co-morbidities.

Using this outline, key words were identified to explore the role and nature of the proposed workforce development by NHS West Midlands as it plans for the current and future needs of an ageing population and increased prevalence of dementia. Inclusion and exclusion criteria were agreed and databases identified to search for literature to inform and support the development of the Dementia Pathway Coordinator.

## Methods

### Literature Review

The aim of the literature review was as follows: to identify pre-existing literature that evidences National Dementia Strategy objective 13 “*an informed and effective workforce for people with dementia*”. In order to do this we carried out two literature reviews: search 1 aimed to identify relevant learning from the literature on the dementia workforce and search 2 to identify relevant learning from the literature on community matrons/ management of long-term conditions.

#### **1) Literature Search 1: what can be learned from the dementia workforce literature?**

In order to construct a literature review protocol for search 1, the tender document for this study was examined to identify key words to be utilised in a search of databases. The identified key words were then placed into search strings to construct a phrase or descriptor to be placed within a database search engine: these were then reviewed by project team members prior to use. Searches took place during January 2010.

The search terms identified were:

- Dementia *and* Liaison *and* Community
- Dementia *and* Community *and* Support
- Dementia *and* Primary Care *and* Workforce
- Dementia *and* Workforce *and* (Training *or* Recruitment *or* Education *or* Skills)
- Dementia *and* Service *and* Signposting
- Dementia *and* Advisor *and* Services
- Dementia *and* Competencies (Competency) *and* Skills
- Dementia *and* (Navigator *or* Agent)

The following inclusion/exclusion criteria were agreed to enable the sifting of resulting data.

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
English speaking article	Non-English speaking article
United Kingdom located	Non-UK
Dementia based	Secondary Care located
	Non-dementia

#### Databases searched

- PubMed
- AgeInfo
- CINAHL
- Social Care Online

The database OVID was also utilised but by this time substantial literature duplication had been noted within the search responses. Finally a search of Google Scholar was carried out to uncover any further sources of information.

Searching on broad search terms using international databases (e.g. PubMed) resulted in 3005 responses on one single search (*Dementia and Community and Support*), other search criteria provided either no or few responses e.g. *Dementia and Competencies and Skills* provided 3 responses from PubMed. The search terms *Dementia and Advisor(er) and Services* produced no response from key databases including PubMed and CINAHL. Similarly the search terms *Dementia and Service and Signposting* brought no response in any of the databases used.

The resulting literature from each search in each database was collated into a single Endnote library; this was then filtered for duplication and non-UK articles. A resulting Endnote Library of 150 pieces of literature resulted from this process. This dataset was reviewed to ensure articles included met the inclusion/exclusion criteria. Following this final review a reporting structure was introduced identifying five specific areas for the literature review:

- (1) What has been tried before
- (2) Carers
- (3) Context
- (4) Skills
- (5) Job Role

**2) Literature Search 2: what can be learned from the literature on long-term conditions?**

The objective of search 2 was to identify as many potentially relevant studies, reports, and sources of literature as possible to review the role of the community matron in the context of long term conditions. A systematic search was undertaken (see NHS Centre for Reviews and Dissemination, 2008) involving comprehensive searches of electronic databases, journals, books, citation tracking and internet searches (following links when appropriate) for articles from 1995 to date (June 16, 2010). The following terms were entered when searching the electronic resources listed below:

- Long Term Conditions and Coordinator
- Long Term Conditions and Community Matron

PubMed (hits: a=0; b=5)

CINAHL (hits: a=1; b=8)

Social Care Online (hits: a=0; b=6)

Age Info (hits: a=27; b=24)

Ovid Nursing Collection (hits: a=5; b=0)

ProQuest Nursing and Allied Health Source (hits: a=4; b=19)

ISI Web of Knowledge (hits: a=5; b=19)

NHS Health and Social Care (hits: a=22; b=7)

Google Scholar (hits: a=696; b=297)

Zetoc (hits: a=0; b=3)

Cochrane Library (hits: 0)

DARE (hits: 0)

Grey literature was identified through Google Scholar.

The inclusion and exclusion criteria that were originally agreed were also used for this second review. The only difference was that non-dementia specific papers were also included (i.e. long term conditions).

This additional part of the literature search took place in June 2010. The relevant identified literature was inserted into the Endnote library where it was filtered for duplication. As a result, 78 pieces of literature were obtained that met the inclusion/exclusion criteria.

## **Consultation with stakeholders: Method**

The consultations with stakeholders fell into two main areas of work:

### 1. Consultations with professional stakeholders

This consultation involved:

- i. Stakeholder meetings at Staffordshire University and the University of Worcester
- ii. Widespread circulation of documents as the project proceeded to allow for stakeholders to respond electronically
- iii. Telephone conversations and meetings with interested parties
- iv. Responses were collated and shared within the team in order to develop the work.

### 2. Consultations with users and carers

This aspect of consultation involved attending Approach cafés, a carers group, a memory group (made up of people living with a dementia), and informal meetings with other users and carers. The Staffordshire University consultation with users and carers included formal feedback from 47 café attenders (both users and carers), 11 carer group members and 11 memory group members (all users), plus informal feedback from other user and carer sources and cross-over feedback from the consultations carried out by colleagues at Worcester University. Responses were collated and shared within the team in order to develop the work.

## Literature Review

### **1) *What can be learned from the dementia workforce literature?***

The wider UK context for this literature review is the recently launched National Dementia Strategy (DH, 2009) which has resulted in investment and policy development requirements particularly affecting workforce provision. The All Party Parliamentary Group on Dementia (APPG, 2009) report, NICE-SCIE Dementia guidance (2007) and the House of Commons Committee of Public Accounts (2008) have led to a policy environment that has provided impetus and shape for current workforce developments to meet the needs of people with dementia and their carers.

#### **(1) What has been tried before?**

The proposed development of Dementia Pathway Coordinators (DPC) within the West Midlands workforce is a new initiative. A number of studies were identified that mapped existing dementia services and/or pilot services to gain insight from previous experience.

Dementia services have been developing in the UK for a number of years but this development has been marked by differing models and no strategy to share good practice between areas. In a comparison of services between England and the Netherlands, Kumpers and colleagues (2005) identified key structural and cultural barriers to achieving recommended standards at the time (Kumpers, Mur, Maarse and van Raak, 2005); these provide a helpful reminder of the pre-existing challenges for any service development in the area of dementia care:

- a professional biomedical culture, often unresponsive to more comprehensive non-medical care needs, and incorporated in organisational structures;
- traditional care models in social care, focusing on basic physical care;
- efficiency pressures in health and social care related to a market environment; and
- difficulties in setting up complex interdisciplinary and interagency processes.

However the various services reviewed in this report do share common themes of innovation in response to need, quantifiable success, clear learning, and evaluated benefit to service users and carers. A number of individual services have been identified in this review process. Where appropriate the services are identified; others are listed below (McMillan,

2009; Greaves, 2008; Bender, Constance and Williams, 2007; Heathcote, Newton and Hong, 2007; Coombes, Colligan and Keenan, 2004). A recent development has been the Alzheimer's Society Dementia Advisor service, providing a signposting service for people with dementia, carers and families (Chidgey, 2009). The service offers a structure of support that can be commissioned by local providers from the Alzheimer's Society. In the development of the report in which this literature review is contained, it was found that the Alzheimer's Society model for Dementia Advisor recruitment and appointment had been employed by some Demonstrator sites as part of the National Dementia Strategy. The four main aims of the service identified are; (1) Quality information and signposting service tailored to individual need; (2) Focus on the individual – empowering them; (3) Collaboration with other health and care professionals; (4) Accessibility – seeking hard to reach people (Alzheimer's Society, 2009). The Mental Health Foundation and partners launched a Dementia Advice and Support Service (DASS), with similar characteristics to the current Alzheimer's Society model, in 2001. Project aims were to improve the availability of information, promote user and carer well-being, extend the network of available services, and develop supporting evidence. However this service sought further impact than the current Dementia Advisor model by seeking to increase the involvement of GPs in diagnosing and treating dementia in its early stages and extending the period of community based living for people with dementia.

The Croydon Memory Service Model (CMSM) developed to identify and support people in the early stages of dementia has received considerable attention both in variety of journals (Banerjee, Willis, Matthews, Contell, Chan, *et al*, 2007; Duffin, 2009; Garwood, 2009) and in national policy. A recently published report examining the CMSM has created seven quality indicators to evaluate services for people with dementia (Willis, Chan, Murray, Matthews and Banerjee, 2009). These quality indicators are:

- i. Provision of broad-based care as well as assessment
- ii. Clear communication about diagnosis and care
- iii. Continuing peer support groups
- iv. Easy availability of staff
- v. Professional staff behaviour
- vi. The service working for people with young-onset dementia and their carers
- vii. Strategies to manage those with subjective memory important but no objective deficits.

Work by Banerjee and Wittenberg (2009) has suggested, through the extrapolation of the CMSM to a national English context, that the service need only achieve a modest increase in the average quality of life of the person with dementia combined with a 10% diversion of people with dementia from residential care in order to be cost-effective. However, in order to achieve positive outcomes, such services require specific and appropriate commissioning to nurture their existence and potential success (Gladman, Jones, Radford, Walker and Rothera, 2007; Pool, 2006). This theme is repeated in the National Dementia Strategy's (DH, 2009) Objective 14: commissioning of services should be informed by the World Class Commissioning guidance. Mountain (2006), exploring self-management for people with early dementia, recommends education improvements for professional staff and service users and carers to enable self-management. Furthermore Mountain identifies a "whole-systems" approach in which concepts of self-management are "*drawn together into a seamless service system that is capable of providing timely interventions for treatment, care and support*" (p440).

Incorporating a multi-agency approach within community located service delivery has been assessed as demonstrating greater flexibility and responsiveness, reducing carer stress and preventing crises through the sharing of responsibilities and continuous assessment of need (Rothera, Jones, Harwood, Avery, Fisher, *et al*, 2008). Furthermore the community location can potentially reduce the requirement for centralised hospital based services (Stevenson, Ewing, Herschell and Keith, 2007). A multi agency (or multi disciplinary) team has also been demonstrated to provide a more integrated, targeted and person-centred approach (Abendstern, Reilly, Hughes, Venables and Challis, 2006). Pool (2006) identifies the key difference between person-centred and non-person-centred services, providing a summary for managers of services to conduct audits of provision.

In considering service provision, thought needs to be given to the person with dementia who lives alone. Price (2007) considers the use of movement sensors providing data about the person's daily life that is utilised to devise an appropriate care package.

Reviewing services for people with dementia in rural areas, McDonald and Heath (2008) found that the needs of people with a learning difficulty who face a greater risk of developing dementia, and the needs of people from minority ethnic groups need to be integrated into service planning, particularly in the distinctiveness of rural settings to service delivery (MacDonald and Heath, 2008). However Iliffe and Manthorpe (2004a) have critiqued an approach that seeks to develop separate services to meet the needs of people from differing ethnicities, arguing that cultural competency in service provision should be available to all

service users: *“Ethnicity is a general concept that subsumes and conceals the impact of migration, education, health beliefs and socio-economic status on health, and is therefore problematic.... .the experiences of people with dementia and their carers show that the important issues for service providers to consider are language, religious belief and observance, cultural practices (including food and personal care practices) and social support and coping mechanisms”* (Illife and Manthorpe, 2004a, p282). The need for dementia services to encompass people from a wide range of backgrounds and need remains. Reviewing services for people from marginalised groups, Beattie et al (2005) found that people with dementia and their carers not only have problems in finding services, but also in fitting into those services once they have been located. Awareness of the promotion of cultural competency and the identification of need and factors that block access to care and support (St. John, 2004; Bowes and Wilkinson, 2003) will be important factors in establishing a DPC workforce.

Nurses have traditionally played a vital role in the delivery of services to people with dementia (Bryans and Wilcock, 2001; Armstrong, 1997). The Admiral Nurse service, first piloted by the charity “fordementia” in 1990, provided a redirection of care, as the Admiral Nurse focuses on the carer as client, aiming to facilitate the best quality of care for the person with dementia (Armstrong, 2001).

## **(2) Carers**

The importance of carers in the care of the person with dementia is well documented, together with the desire of carers for improved communication (Nolan and Keady, 1995) and workforce training (Nurock and Wojciechowska, 2007). The approach by the charity “fordementia” (now called Dementia UK) which has informed the development of the charity’s Admiral Nurse program has been the view of the carer as client (Armstrong, 2001), enabling the carer to remain in their critical role of caring for the person with dementia. Butterworth in 1995 presented a 15 year account of caring for a relative with dementia. Amongst the observations were the vital role of GPs and the need for caregivers to know how to obtain services (Butterworth, 1995), the need for information regarding available services, the diagnosis of dementia, and the legal and financial aspects of caring (Cascioli, Al-Madfai, Osborne and Phelps, 2008). Howcroft (2004) recommends that carers should be involved in the assessment, diagnosis and management of Alzheimer’s disease. Additionally, Moriarty (2001) has identified the need to monitor carers’ ability and willingness to provide care. Care-givers who are enabled to develop communication competence can experience positive psychological health outcomes and decreases in depression (Query and

Kreps, 1997). Alongside this, it is important that carers of people with dementia receive support in the provision of personal/physical and healthcare tasks (Pickard and Glendinning, 2001).

The full recognition of the role that carers play in service provision has significance for effective outcomes. A multi-agency approach in service delivery for home support, which included service users and carers in routine decision making, found that their inclusion prevented crises and reduced carer stress (Rothera et al, 2008). Hoskins, Coleman and McNeely (2005), in an assessment for Community Mental Health Teams supporting carers of people with dementia, recommend the use of the Caregiver Strain Index as an effective means of monitoring caregiver well-being and service effectiveness. Effective and person-centred service provision also requires assessment of demographic factors such as ethnic diversity and language need (Snayde and Moriarty, 2009). The Alzheimer's Scotland report "Action on Dementia" (2003) explored the needs of carers and identified specific groups to be supported within service provision, including; young carers; minority ethnic carers; lesbian, gay, bisexual and transgender carers; carers of people with Downs Syndrome and dementia; carers of younger people with dementia; and carers living in rural areas. Carers face a risk of isolation, which is compounded by geographical context, particularly in rural areas (McDonald and Heath, 2008). Furthermore the report "Action on Dementia" highlighted the importance of factors including; carers' health and coping skills, the characteristics of the person with dementia, the relationship to the cared for person, and the availability of other informal support and formal care. Pickard and Glendinning (2001) have identified the age of the carer as a further factor for consideration, as older people with dementia in the community were found to be most likely cared for by other older people. Identifying this combination of factors will be important for a Dementia Pathway Co-ordinator to ensure the prevention of crises through the effective support of carers.

A report investigating the needs of people with dementia and their carers carried out by a local Alzheimer's Society organisation and Senior Citizens Forum in the Shropshire and Telford and Wrekin area, made a number of recommendations including; "*that from the point of diagnosis a key point of contact is identified who is known to the sufferer and where appropriate their carer(s) and who is able to rapidly mobilise support appropriate support*", and, "*that all professionals working in the health and care sector are actively encouraged to ensure that their communication arrangements with colleagues are appropriate and rapid*" (Shropshire and Telford branch of the Alzheimer's Society and Telford and Wrekin Senior Citizens Forum, 2008, p17).

### **(3) Context or place for role**

Reflecting on the needs and expectations of carers, the location and context in which the DPC role is set will be important in enabling effective communication between a range of services and to meet the needs and expectations of people with dementia and their carers. Exploring the theme of sustaining a community-based service workforce, Ryan, Nolan, Enderby and Reid (2004) observed that job satisfaction was enhanced by factors including good organisational support. The interface of the DPC within multi-disciplinary teams will require clear job role and management expectations. It also raises a vital question: where is the DPC to be located and within which service? In their assessment of the CMSM, Willis et al (2009) identified themes concerning satisfaction that included service experience, clear communication and gaps in service.

Commissioners should consider the importance of localities when commissioning new services. Localities are entities with particular institutional contexts and histories that can have specific impacts on the processes of policy implementation (Kumpers, Mur, Hardy, van Raak, Maarse, 2006). Rural localities can provide the context for challenge and innovation (Innes, Cox, Smith and Mason, 2006). In their research focused on dementia service provision in rural localities, McDonald and Heath (2008) observed *“this piece of research revealed the importance of locality in meeting need flexibly and empathetically”* (pxii).

### **(4) Skills**

In calling for an informed and effective workforce for people with Dementia the All Party Parliamentary Group (APPG, 2009) observed: *“solutions must be based on an acceptance of the level of skill required to provide good quality dementia care,”* and, *“in order to overcome organisational barriers, all staff involved in providing services for people with dementia need to understand good person-centred care and be determined to implement it”* (APPG, 2009, pxii-xiii).

In assessing skills required within a dementia workforce, the APPG (2009) acknowledged the importance of personal qualities including empathy and warmth. The need to acknowledge personal qualities (attitude) was emphasised by Herbert (1997): *“in recruiting new people, achieving the overall balance in both skills and attitudes should be the aim”* (p115). Iliffe, Wilcock and Haworth (2004) identified 12 competencies needed by

professionals across the dementia care pathway. In the post-diagnosis phase, where the prospective DPC workforce will operate, the competencies identified by Iliffe et al include:

- Integrating different perspectives: “...it is a complex task of mixing different viewpoints into a workable plan that all can implement.”
- Networking: “knowing what resources are available locally is key to supportive dementia care in the community.”
- Case management: “...the systematic monitoring and response to dementia over time...”
- Disability perspectives: “emphasise...[disability] and you are more likely to identify remaining capabilities and strengths, and find ways to offset losses.”
- Problem analysis: “without stepping back for a longer view of behaviour problems in dementia it is easy to reach for the prescription pad.” (Iliffe et al, 2004, p17).

Increasing the basic knowledge base care home workers hold about dementia, including person-centred care, communication, working with carers and relatives, and behaviours that challenge, has been demonstrated to improve staff skills and the quality of care (Lombard, 2009; Conroy, 2008; Ward, Vass and Aggarwal, 2008; Bhaduri and Sutcliffe, 2007; Done and Thomas, 2001; Morris, 1999). Similar basic knowledge will be important to the development of a DPC workforce. In the development of a Dementia Pathway Workforce, skill level may need to take into account specialist skills in order to determine pay grade/banding. In the case of up-skilling a pre-existing workforce member, they may already hold significant skills, e.g. Mental Capacity Act awareness and utilisation, which will be relevant to the support of someone with dementia (Griffith, 2006). Additionally consideration will need to be given to the support of people living with a learning disability who develop dementia (Wilkinson, Kerr and Cunningham, 2005; Hussein and Manthorpe, 2005) as effective service provision will require skilled care co-ordination in order to meet their needs.

The communication skills of staff are highly significant when working with people with dementia and their carers (Bryans and Wilcock, 2001; Biernacki, 2000; Jenkins, 1998). In a review of professional development amongst 774 community-based professionals, Iliffe and Manthorpe (2004b) argued that professional development needed to be widened to include capacities around diagnosis: and particularly communication and support. Within communication, advocacy requires attention (Wells, 2007), as a DPC communicates on behalf of a particular client to enable service provision: thus the boundary between dementia advocacy and information provision may become blurred (Cantley and Steven, 2004).

Service planners and commissioners need to be clear as to how advocacy provision fits with the DPC system (Cantley and Steven, 2004).

A Scottish training scheme equipping community nurses working with people diagnosed with dementia with counselling skills found that participating nurses identified their language as more person-centred with improved listening skills bringing potential benefit to service users (Trueland, 2008). Keady and Williams (1998) had previously used case illustrations to demonstrate core skills of listening, understanding, empathy, non-judgemental acceptance, or unconditional positive regard, and genuineness or congruence when considering the needs of people with dementia and their caregivers. Hope (2009) has identified the importance of ongoing education and support to equip professionals involved in the care of people with dementia to respond to key ethical questions that arise when supporting a person with dementia and their carer in the setting of person-centred care (Lorentzon and Bryan, 2007).

In the context of the DPC holding a nursing qualification, the Admiral Nurse Core Competencies developed by Dewing and Traynor (2005), developed as a response to Agenda for Change requirements within the NHS, provide a helpful short framework of 8 core competencies:

- (1) Therapeutic work
- (2) Sharing information about dementia and carer issues
- (3) Advanced assessment skills
- (4) Prioritising work load
- (5) Preventative and health promotion
- (6) Ethical and person centre care
- (7) Balancing the needs of the carer and the person with dementia
- (8) Promoting best practice

Ho (2000) investigated the role of community mental health nurses as recognised by family carers of people with dementia, and reported four main themes: (1) emotional support and advice, (2) liaison and networking, (3) training and information giving and, (4) isolation and loneliness.

Competency and/or Skill Frameworks have been developed, eg Skills for Care, 2005: however a continuing need is to distinguish the aims and needs of training and education. Downs et al (2009) have observed that, while skills-based workplace training has a place,

the role of Higher Education in dementia studies had a key role in developing specialist knowledge and key skills in critical thinking, reflection and action. The integration of such higher-level skills combined with ethical decision-making may be necessary for the DPC, particularly in the case of the person with dementia who lives alone. Gilmour, Gibson and Campbell (2003) identify the increasing prevalence of people living alone within the population and recommend that resources and support are needed in order that professionals, families and people with dementia achieve a shared responsibility for risk taking in respect of community dwelling persons with dementia.

### **(5) Job role**

Experience from advocacy services suggests that while managers and workers may aim for contact with clients to be limited to case work issues, the nature of dementia often requires a person acting as an advocate to build a relationship with the person with the dementia in order to effectively interact with them and to find out their views and needs (Cantley and Steven, 2004). In building relationships the person may become involved in complex family relationships in order to help and facilitate the caring relationship (Challenger and Hardy, 1998). A key finding by Ryan, Nolan, Reid and Enderby (2008), assessing a Community Dementia Support Service, was the importance of relationships created between support workers, family carers and people with dementia, as they called for “a more explicit recognition of the role of relationships in health and social care” identified in the term “relationship-centred care” (p78). The theme of interpersonal skills in providing effective services for people with dementia has been observed and called for over a number of years (Trueland, 2008; Ho, 2000; Morris, 2000; Herbert, 1997; Watson, 1992).

Staff retention and satisfaction (Ryan *et al*, 2004) will be a continuing need to provide continuity of care (Woods, 1995). Assessing a multi-disciplinary home care project, Snayde and Moriarty (2009) observed: “*one reason for the service’s success in retaining staff is holding regular team meetings in which team members share information, discuss policies, and give each other support. Furthermore, the teams aim to operate in a non-hierarchical way, acknowledging the expertise of the home care workers along with that of other professionals.*” (p151) Integration of multi-disciplinary teams is necessary and requires a significant level of work to achieve successful integration and delivery (Abendstern *et al*, 2006). Evidence suggests that the effective gathering of staff views, as well as the views of service users and carers, may be helpful in the development and planning of quality mechanisms (Manthorpe and Alaszewski, 2002). The integration of the DPC post within existing service delivery structures will require the development of forums in which support

and information can be effectively shared across disciplines supporting the person with dementia and their carer.

Sturdy (2009), observes that people with dementia use every part of the care systems, and identifies the key role of nurses in the delivery of the National Dementia Strategy. Whoever fulfils the DPC role, ongoing training will be an important component of provision and service development for the benefit of people with dementia and their carers.

Finally the role of the DPC will necessarily involve contact with the person with dementia and caregivers as the person with dementia journeys through the late stages of their illness leading to death. However, little consideration has been given to end of life care needs (Kellehear, 2009). Ghiotti (2009), describing the Dementia End of Life Care Project, identified how outcomes centred on improving the well-being of the person with dementia and their caregivers were based on the assumption that principles of palliative care can be applied in the care of the person with dementia and their caregivers.

## ***2) What can be learned from the literature on managing long-term conditions?***

### **(1) The role of a community matron**

The policy document 'The NHS Improvement Plan – Putting People at the Heart of Public Services' (DH, 2004) initiated the role of community matrons in June 2004. An area of particular development was the care and management of the approximately 17.5 million people in the UK who live with 'complex and long-term conditions' (DH, 2005b; DH, 2004) with an estimation that this will increase to 18 million by 2025 (DH, 2008). This cohort of people often receives care that may be reactive and uncoordinated (Bird and Morris, 2006). It has been estimated that 2% of these people account for 30% of unexpected hospital admissions (Murphy, 2004) and that 5% of inpatients, many with long-term conditions, are responsible for 42% of all acute hospital bed days (DH, 2004). When linking these findings, along with the estimate that 78% of all healthcare money is used on long-term conditions, there is clear strain on funds. To address this situation the government had set targets for reducing unplanned hospital admissions by 10-20% and emergency bed days by 5% by 2008 (Mayor, 2005; Murphy, 2004) as well as to treat patients faster and closer to their home (DH, 2005b).

The NHS Improvement Plan viewed community matrons as pivotal in meeting these targets. For this to happen the community matron would become the main practitioner for the patient

with complex needs and take responsibility for the coordination of services in order to meet their patient's needs and improve their well-being (DH, 2005c). In addition, Murphy (2004) suggested that community matrons could work along with other programmes such as the Expert Patient Programme (DH 2001) in order to improve self-care and support better-informed choices for the people with a long-term condition.

Some authors have made attempts to define the role of the community Matron; for example, Bird and Morris (2006) suggested that this is a new type of practitioner who is highly skilled and a specialist in community care and interagency working. Others have described community matrons as highly skilled, autonomous practitioners able to assess, diagnose and prescribe treatment, responsible for coordinating and supporting the care of those with highly complex long-term conditions. (Pollard, 2005; Patrick, Roberts, Hutt, Hewitt, Conelly, *et al*, 2006; Clegg, Hamilton and White, 2007; Rosser and Rickeby, 2007; Masterson, 2007a). According to the DH, community matrons assist people who live with complex long-term condition to remain within their homes not only by coordinating their care packages, but also by educating patient and carer so that they gain better understanding of the condition and can enjoy a better quality of life (DH 2005b). Government Policy documents state that community matrons should provide clinical intervention as well as care coordination (DH, 2005b). The role is specifically defined as; '*...a qualified nurse who can provide advanced nursing and clinical care, as well as effective case management*'. (DH, 2006, p3) However, as Sargent, Pickard, Sheaff and Boaden (2007) suggested in their study, community matrons moved beyond this definition and their care responsibilities influenced: clinical care, care co-ordination, education, advocacy and psychological support with some clinical tasks that were located within the medical paradigm that had previously been provided by the general practitioners (GPs).

According to the NHS Modernisation Agency and Skills for Health (2005), community matrons must be competent in:

- care co-ordination and case management (brokerage and provision);
- physical examination and history taking, diagnosis and treatment planning;
- managing cognitive impairment;
- using population and individual information to support decision making;
- independent and supplementary prescribing and medicines management;
- interagency and partnership working;
- management of long-term conditions (particularly the interplay between multiple diseases);

- working in the home and community settings;
- supporting self managed care;
- managing care at the end of life;
- prevention and health promotion, and
- advanced level professional practice, including self directed learning, managing risk, autonomous practice, higher level communications skills.

Quantitative data on the perceptions of the role of 119 community nurses (Armour, 2007) revealed that key competencies, aims and responsibilities identified were the same as those outlined by the above competency framework for community matrons.

According to the NHS Improvement Plan (DH, 2004) the community matron service will:

- help to prevent unnecessary admissions to hospital
- reduce length of stay of necessary hospital admissions
- improve outcomes for patients
- integrate all elements of care
- improve patients' ability to function and their quality of life
- help patients and their families plan for the future
- increase choice for patients
- enable patients to remain in their homes and communities
- improve end of life care

When introducing a new role, the implementation of a 'whole systems approach' to workforce development is vital rather than the introduction of a new role in isolation (Rosser and Rickaby, 2007).

Bird and Morris (2006) commented that if the community matron is to reduce unplanned hospital admissions then there must be close partnership between the primary care setting, the secondary care setting and social services. The community matron will coordinate inter-agency cooperation. The authors also suggest that the role will be highly evident and available for both the patient and the other members of the team. This is not just a coordination role but expands to undertaking clinical interventions, making referrals, prescribing medicines and requesting investigations (Bird and Morris, 2006). In addition, a person-centred approach is central to the community matron role (Masterson, 2007b) and a core element of the government's strategy for long term conditions. Person centred care puts the individual literally at the centre of their care and encourages self management of

care (Arigho and Straham, 2006). Hence, the success of the community matron is ultimately dependent on ensuring the delivery of person centred care (Masterson, 2007b).

## **(2) Education/ training of community matrons**

The educational needs of community matrons are complicated as the necessary skills range from generic to advanced level (Pateman, 2005). The literature demonstrates a consensus that community matrons are advanced level practitioners (Rosser and Rickaby, 2007; Ball, 2006; Banning, 2006; Woodend, 2006; Pateman, 2005). In the US these practitioners are trained to degree level (Murphy, 2004) whereas successful models in the UK to date utilise postgraduate practitioners who have had further training. Banning (2006) suggested that training should be at masters level but not necessarily a full masters programme. Others have suggested that a programme of preparation for the community matron role should continue to be delivered at Masters Level (Rosser and Rickaby, 2007).

In addition, Rosser and Rickaby's (2007) evaluation of the national pilot education programme preparing community matrons to perform their role suggests that fast and efficient education commissioning is feasible on a national basis. It is vital to build on existing educational frameworks and collaborations to maximise the possibility of success. Hence, to take full advantage of learning from past experience, new role development requires training that is service and patient centred and built on a competency framework which allows clear direction and outcome. Their evaluation (Rosser and Rickaby, 2007) has been regarded by the DH as an exemplar of transparent communication between Service Organisations and Education Providers when developing a programme to support a new practice role.

Advanced nursing practice involves extending role boundaries by taking on skills which may previously have been regarded as medical (Woodend, 2006). Community matrons should also identify their personal needs and commission suitable education and training (DH 2005b). In a study of advanced practitioners, the majority suggested that the best preparation for these roles is an amalgamation of the right experience and appropriate educational training (Ball, 2006). The importance of partnership between higher education organisations and workforce needs was also emphasised in the preparation of these programmes (Casey and Mackereth, 2006). The significance of responding swiftly to changes and improvements in health policy was also noted by the authors. Pooler and Campbell (2006) emphasised the importance of ensuring that Primary Care Trusts

guarantee that community matrons' educational needs are assessed in the workplace to allow for appropriate development.

### **(3) Evidence of the effectiveness of the community matron role**

Many studies have suggested that the introduction of the community matron has made a big impact in terms of reduction in hospital admissions, in hospital bed days and GP visits, along the lines of government targets (Bowler, 2009; Chapman, et al, 2009; Russell, et al, 2009; Derbyshire PCT, 2008; Leighton, Clegg and Bee, 2008; Armour, 2007; Barnet PCT, 2007; Lyndon, 2007; Rosser and Rickaby, 2007; Sadler, 2006; Agnew, 2005) as well as value for money (Barnet PCT, 2007). Similar results were also reported by the Castlefields Health Centre in Runcorn (Castlefields, 2004) which was promoted by the DH as an example of successful provision of a proactive service, reduction of hospital admissions and improvement in patient outcomes (Tovey, 2005). According to Armour (2007) the strongest impact of the new community matron role was that it enabled patients to stay in their own homes and communities, and to develop better disease management. In contrast, the Evercare programme reported no changes in hospital admission rates, hospital bed days or mortality in nine PCTs studied between 2003 and 2004 (Sheaff, Boaden, Sargent, Pickard, Gravelle, *et al*, 2009; Gravelle, Dusheiko, Sheaff, Sargent, Boaden, *et al*, 2006; UnitedHealthGroup, 2004).

There is also evidence that the introduction of the community matron role improved the quality of life of the patients (Cubby and Bowler, 2010; Russell, et al, 2009; Derbyshire PCT, 2008; Armour, 2007; Barnet PCT, 2007; Wright, Ryder and Gousy, 2007), increasing patient psychosocial support and improving communication between patients and health professionals (Cubby and Bowler, 2010; Russell, Roe, Bee and Russell, 2009; Sheaff et al, 2009; Armour, 2007; Rosser and Rickaby, 2007; Sargent et al, 2007;); increasing the confidence of patients in managing their long-term conditions.(Wright, Ryder and Gousy, 2007); as well as providing more holistic/patient centred care (Cubby and Bowler, 2010; Gravelle et al, 2006; Sargent and Boaden, 2006).

Bowler (2009) collected 124 patients' views of the community matron service (Gateshead PCT, South Tyne Side PCT and Sunderland Teaching PCT). Results suggested that the community matron service was well regarded and beneficial with high levels of patient satisfaction. The most important factors for patients included: an assurance of the service

being there; reliable and supportive staff; effective communication skills; and matron availability. The data confirmed that the service helped to reduce the number of hospital admissions. Patient education and the development of patients' self management may be essential for the effectiveness of the community matron role in meeting the medical and social needs of the patients (Chapman et al, 2009; Russell, et al, 2009; Derbyshire PCT, 2007). High levels of patient and carer satisfaction with the community matron service/role have been reported in numerous studies (Bowler, 2009; Sheaff et al, 2009; Lyndon, 2007; Staines, 2007, Leighton et al, 2007; Gravelle, et al, 2006).

## Findings

The literature identified in literature review 1 revealed a number of different service models from memory shop/centre/clinic with the bringing together of staff into a single organisational centre, through individual service responses, to locally designed services utilising health visitors and the development of the Admiral Nurse service in the third sector. Despite the variety of models tried key themes can be identified:

- Services are needed that empower and value the person with dementia
- Local need and provision must be mapped so that service response is contextualised to a locality and the DPC has the local knowledge to navigate families through services
- Multi-agency approaches increase flexibility and responsiveness and reduce carer stress
- Collaboration between staff needs to bridge multidisciplinary and professional boundaries to create a “whole-systems” approach: this highlights the need for service integration

The role of carers is critical in meeting the needs of the person with dementia. Carers need to be fully involved and informed in the process of assessment, diagnosis and management to ensure their own well-being is supported and to enable access to relevant information and support. The reduction and/or management of crisis situations will be a key test of how a DPC service enables people with dementia to remain within their normal care environment in their local community.

A key finding from the dementia workforce literature has been that no consensus emerges to identify where to locate a DPC service within an organisational structure. In order to ensure service success the question of role and place within a service structure needs to be resolved. Sustaining a new service workforce will require clear organisational support and management expectations.

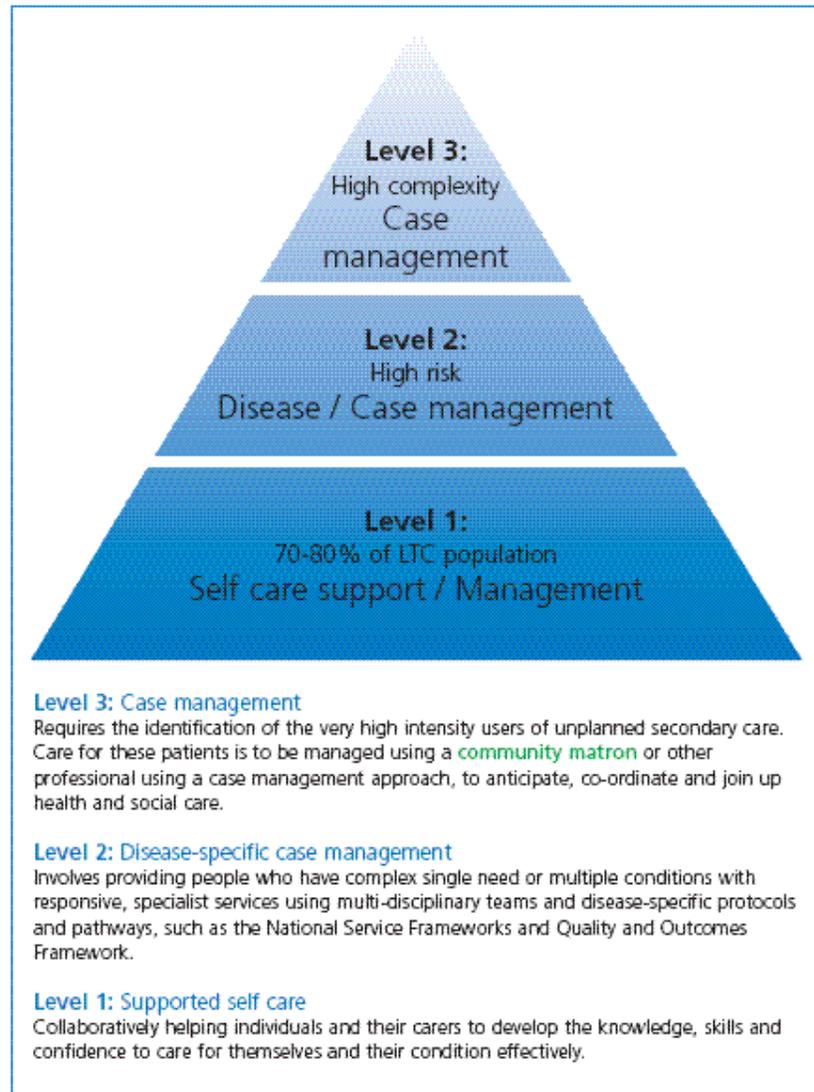
A skill set emerges from the literature that is able to offer a response to complex needs and identify solutions through the use of excellent communication skills. Communication skills appear repeatedly in the literature; communication with the person with dementia,

communication with carers and communication within and between service providers: there should be a clear focus on communication skills as a key competency set within the new workforce. The identification of level or specialisation varies within the literature. What remains vital for a new service and workforce is the expectation and need of people with dementia and their carers to be provided with accurate and timely support throughout the dementia journey.

Literature review 2 takes this further, although much of the evidence supporting the community matron role is qualitative. Community matrons are highly valued on a professional and personal level especially by patients and their carers (Brown et al, 2008), and offer important learning for the new DPC service. The introduction of the community matron role, like that of the DPC, came at a time of evolution and change. Integrating a new role into any existing team can be challenging and, if its full potential is to be reached, role replication and ambiguity must be avoided (Bird and Morris, 2006).

People with long term conditions can be regarded as falling into three broad categories (see Figure 1) (DH, 2005b; DH, 2006): at level one people take an active role in managing themselves and are self-caring with minimum involvement from healthcare workers; at level two there is a need for active intervention as the risk is higher than level one; people at level three are those viewed as highly complex. A large proportion of people in this third category are older people with multiple long term conditions requiring complex intervention and support. The people in this category are the main users of community matron services. We have shown that dementia fits into the context of long term conditions, but, being a progressive condition, it can fluctuate between levels one and three. For this reason, the DPC should be able to target people at all three levels.

Figure 1 Social care model for people with long term conditions (DH, 2005b, p10; DH, 2006, p4).



The DH (2005b; 2006) argues that community matrons should be competent in 12 areas of professional skills, which are presented below. We mapped the role of the Dementia Pathway Coordinator (DPC) against those skills, by placing 'DPC' next to the skill where applicable:

- care co-ordination and case management (brokerage and provision); **DPC**
- physical examination and history taking, diagnosis and treatment planning;
- managing cognitive impairment; **DPC**
- using population and individual information to support decision making; **DPC**

- independent and supplementary prescribing and medicines management;
- interagency and partnership working; **DPC**
- management of long-term conditions (particularly the interplay between multiple diseases); **DPC (Dementia specific)**
- working in the home and community settings; **DPC**
- supporting self managed care; **DPC**
- managing care at the end of life; **DPC**
- prevention and health promotion; **DPC**
- advanced level professional practice, including self directed learning, managing risk, autonomous practice, higher level communications skills. **DPC**

It can be concluded from this that there is an at least 83% compatibility between the two roles. Although the roles of community matron and DPC are not identical, both are advanced, highly skilled practitioners with many parallel competencies and skills as demonstrated above.

### **Feedback from stakeholders**

This section is based on stakeholder feedback both electronic and from meetings at Stafford and Worcester, and feedback from users and carers, a document entitled Living with dementia in Telford and Wrekin – a survey of the views of sufferers and carers (Shropshire and Telford Branch of the Alzheimers Society and Telford and Wrekin Senior Citizens Forum, 2008) which sets out the results of interviews with 13 people with dementia and 81 carers.

Discussions suggested that in general there was consensus for a new role working in the dementia field which should be accessible by a person with dementia or their carers following diagnosis. Stakeholders also reported that they believed the post-holder should be responsible for coordinating the involvement of other agencies and ensuring processes are in place for contemporary practice. However there was little consensus from stakeholders on the types and levels of skills and competencies required for the post, and stakeholders also raised issues related to professionalism.

The following competencies were regarded as critical by stakeholders:

- Sensitivity
- Caring attitude
- Advocacy
- Someone who 'talks to you, listens to you and does things for you' (from a participant in a café) and 'ability to listen and understand' (from a users group).
- Ability to support people with dementia to 'carry on doing the things they enjoy', to remain active, and to try new things (users group feedback)
- Consistency/ keeping in touch/ regular discussions (users group feedback)
- Giving users and carers the opportunity to talk (users and carers feedback)

Stakeholders flagged the following issues as important:

- Where do people who are given a diagnosis of MCI sit in relation to services and this role?
- Terminology is confusing – dementia advisors, dementia advocates, dementia pathway coordinators, dementia navigators .....
- How do people with alcoholic dementia fit into services and relate to this role?
- Discharge policies: one of the reasons why this role is needed is because services discharge people when they are living with a chronic deteriorating illness and this then delays them accessing what they need as things move on. Instead of adding in an extra worker one thing to consider is stopping discharging people and having an existing team member keeping in contact with them (or is that the core DPC role?)
- Work contexts: the roles people fulfil cannot be separated from the organisational contexts, policies and procedures within which they work – nor the issue of proper resourcing of services.
- There is a danger of putting too many expectations on this role and setting it up to fail.
- 'the value of having a named and trusted individual to whom sufferers and carers can turn at time of crisis' (Shropshire and Telford Branch of the Alzheimer's Society and Telford and Wrekin Senior Citizens Forum, 2008; page 17) and 'a key point of contact ... who is known to the sufferer and where appropriate their carer(s) and who is able to rapidly mobilise appropriate support'.
- What outcomes should be achieved by the DPC ie what added value does the role bring? (questions posed by a GP)

The key issues for stakeholders reported were:

- It is important that the DPC does not discharge people until death (and may support family carers after the death of the person with dementia)
- The DPC should ensure that an annual review is carried out
- The DPC should keep in touch with families living with dementia who are not in contact with secondary care services after receiving a diagnosis of a dementia

This document is the first attempt to set out a clear set of competencies for the DPC role. In the absence of this work, stakeholders have started to implement roles to work with those who have been given a diagnosis of dementia. It should be stressed that these emergent roles do not necessarily meet the specification set out in the West Midlands report (Saad et al, 2008).

In the West Midlands specification (Saad et al, 2008) the DPC has a high level of skill and is able to carry out their own assessments, to enable people to live well with dementia and to advocate for their needs and the needs of their family carers. They work primarily with the group of people who are currently discharged from secondary care services – if people are being managed in secondary care services and have a care coordinator then they do not need a DPC. Therefore these DPCs will work mainly with people early in their dementia journey, or people later in the journey who do not have complications such as BPSD, mood disorders, complex comorbidities. They will need to be skilled in talking with and supporting families, and should be embedded in a team for support and access to other workers. The expectation is that the person with dementia remains as part of the DPC's caseload until after death, and that the person is not discharged should secondary care be required. These requirements are closely aligned with the wishes of many users and carers.

In developing the DPC competencies we have drawn on the work of Tsaroucha et al (2010) in developing a core competency framework for the West Midlands dementia workforce. Table 1 lists the core competencies identified for the West Midlands dementia workforce in Tsaroucha's work.

**Table 1: Table showing Dementia workforce core competencies (Tsaroucha et al, 2010)**

<b>Competency</b>
Knowledge/Awareness of Dementia and dementia related issues
Understanding the behaviours of individuals with dementia
Enriching the life of individuals with dementia and their carers
Interaction with individuals with dementia
Interaction with carers/families
Dementia worker personal development and self care
Person Centred Care
Promoting best practice

### **The DPC in the West Midlands: competencies required**

The competencies of the DPC will need to be provided within the dementia workforce. Table 2 sets out the required competencies and skills. Interaction with people with dementia and interaction with their carers, bringing into these interactions person-centred care and best practice, are key areas for the DPC.

**Table 2: Competencies required for role of West Midlands Dementia Pathway Coordinator (developed from Tsaroucha et al, 2010)**

Competencies	Skills	Comments
Knowledge/Awareness of dementia and dementia related issues	basic understanding of dementia	<p>Knowledge/ awareness of Dementia and the services available in a locality for people with dementia and their families are critical competencies, as is the ability to make a holistic assessment, in a broad sense e.g. understanding what that person with dementia/carer needs at a particular point in time, and to use this assessment to develop the best possible care plan. This includes understanding how a person's dementia might progress and considering needs related to end of life care and advance planning</p> <p>Full knowledge of the local health and social care ecology and resources available in relation to dementia and stakeholders is essential in order to help families navigate systems and services</p> <p>Knowledge and understanding of services includes appropriate understanding of how to assist/ support people with dementia and their families in navigating services as they progress along the dementia pathway</p>
	awareness of the primary causes of dementia	
	awareness of the most common types of dementia	
	awareness of the different stages of dementia	
	awareness of the common signs and symptoms of dementia	
	ability to identify the differences between dementia, depression and delirium	
	awareness of the impact of dementia (and/or terminal diagnosis) on the individuals and their families/carers	
	awareness of the impact of physical, social and emotional aspects of the environment on the individual with dementia	
	basic understanding about risks and safety of individuals with dementia	
	basic knowledge of health standards and care	
	basic knowledge and understanding of local services and contact points	
	to promote health and well-being by applying health promotion and disease prevention strategies appropriately, including knowledge of preventative strategies required in the care of older people	
	basic knowledge of the dementia strategy	

	<p>awareness of the vulnerability of individuals with dementia</p> <p>understanding of ageing and age related care issues</p> <p>understanding the need for the process that results in people with dementia and their carers discussing and agreeing life and advanced care decisions planning and review processes</p> <p>knowledge of how to adapt the environment to suit the person with dementia</p> <p>awareness and provision of palliative care</p>	
<p>Understanding the behaviours of individuals with dementia</p>	<p>ability to identify the emotional and physical health needs of individuals with dementia</p> <p>ability to establish a diagnosis of an individual's health status</p> <p>understanding of non-verbal communication (i.e. signs of pain, hunger, thirst, boredom, frustration or need for assistance)</p> <p>understanding that behaviours may reflect emotions or unmet needs</p> <p>identify the concerns and priorities of individuals with dementia and their families in relation to their mental health and mental health needs</p> <p>identify potential triggers for behaviours of concern</p> <p>identifying individual's needs and strengths</p> <p>recognise signs consistent with financial, physical/emotional abuse/neglect of the individual with dementia and report to appropriate person/service</p> <p>ability to identify and respond to behaviours that are considered challenging or difficult</p>	<p>Awareness of the need for continuity and consistency for both service users and carers</p> <p>Awareness of causes of behavioural difficulties associated with dementia and what can be done to assess properly and treatments/strategies for coping</p> <p>Understanding how the persons social situation, psychological and health history contributes to behaviour</p> <p>Ability to understand appropriate interventions to support people with dementia particularly when they are in / show signs of distress and awareness of non verbal ways of expressing distress in dementia</p>

	<p>ability to identify and respond to crisis situations</p> <p>understanding/recognising the losses associated with a diagnosis of dementia and increasing losses as the condition progresses</p> <p>understanding/awareness of the behavioural changes associated with the progressing condition and support needed</p> <p>ability to assess risks linked with health conditions</p>	
<p>Enriching the life of individuals with dementia and their carers</p>	<p>support/address individual needs for a stable and familiar environment</p> <p>support/help individuals with dementia engage in activities</p> <p>enable people to choose and participate in activities that are meaningful to them</p> <p>provide activities that are appropriate to the individual, reflecting their cultural likes and dislikes</p> <p>use family carers as a resource where appropriate to assist in developing appropriate activities by accessing information about individuals' memories and routines</p> <p>promoting /supporting self care, health promotion and stay healthy actions (use of appropriate early interventions, such as CBT, etc)</p> <p>promoting safety</p> <p>promoting recovery</p> <p>promoting autonomy</p> <p>support individuals to retain, regain and develop the skills to manage their lives and environment</p>	<p>Ability to be creative when thinking about how to meet a person's needs</p> <p>Understand how to identify people with dementia's occupational, psychological and physical needs</p> <p>Ability to think about the effect of environments on people with dementia and how they support the person's well-being. This will include understanding of the role of assistive technology/ telehealth resources</p> <p>Enriching the lives of PWD may require an ability to negotiate and tolerate risk</p> <p>Ability to educate individuals with dementia and their carers about their condition and ability to develop individuals' self management of their health condition</p>

	<p>support the protection of individuals with dementia</p> <p>support individuals who are troubled, distressed or experience significant life events and transitions</p> <p>support individuals with specific communication needs</p> <p>support individuals to identify and promote their own health and social well being</p> <p>support individuals to access and use appropriate services and facilities</p> <p>support individuals through the end of life process</p> <p>contributing to/leading the process that results in people with dementia and their carers discussing and agreeing life and advanced care decisions planning and review processes</p>	
<p>Interaction with individuals with dementia</p>	<p>effective communication (verbal and non-verbal)</p> <p>ability to use a range of communication strategies to maximise engagement of the person with dementia such as eye contact, gentle touch, short simple statements</p> <p>active listening /openness</p> <p>ability to provide emotional and physical support</p> <p>ability to establish and maintain a therapeutic relationship</p> <p>ability to use special ways, such as memories frequently to connect with individuals with dementia</p> <p>ability to maximise cooperation and provide reassurance to individuals with dementia by using reality orientation including : reminders of the day, time, relationships, occasions, using reassuring words, phrases and body language</p>	<p>Interaction with people with dementia is critical in terms of advanced communication and relationship skills, empathy and sensitivity</p>

	ability to allow and deal with expressions of distress	
	ability to communicate significant news to individuals with dementia and their carers with sensitivity	
Interaction with carers/families	effective communication	<p>Working with carers and support to carers are critical competencies. Being confident to work with family groups and encourage open communication is essential where the DPC is a skilled practitioner</p> <p>Being able to promote a person centred approach to the carer is also an important skill</p> <p>Knowledge of the needs of carers and families in relation to how dementia can affect family and their relationships and role, including dealing with conflicting needs of people with dementia and their carers</p>
	empower families, carers and others to support individuals with dementia	
	establish and maintain working relationship with relatives and carers and take into account their needs	
	balancing the needs of carers and those of individuals with dementia	
	maximise cooperation with families and carers, by listening effectively, showing trust, etc.	
	provide support and guidance to family carers where appropriate to assist them to understand the disease, its impact on the individual and some approaches to providing care	
	ability to treat families/carers with respect	
	ability to communicate significant news with sensitivity	
Dementia worker personal development and self care	continuing personal/professional development, learning and practice	Ability to seek opportunities for appropriate managerial and practice/clinical supervision
	identify personal feelings, beliefs or attitudes that may affect relationships with people with dementia and their families/carers	Knowledge of mandatory and statutory training requirements as including awareness of policies and how to put into practice e.g. lone working /whistle blowing

	<p>identify helpful ways to prevent and cope with personal stress and burnout</p> <p>ability to identify ways to cope with grief and loss</p> <p>identify ways to promote personal safety when dealing with high risk patients</p> <p>ability to seek support when required</p>	<p>Awareness of risk assessments, and their limitations.</p> <p>Enthusiasm for attending further appropriate training.</p>
Person Centred Care	<p>ability to involve the individual with dementia in their own care planning</p> <p>sensitivity to gender, cross cultural, and spiritual differences and issues</p> <p>compassion</p> <p>empathy</p> <p>flexible attitude</p> <p>open mindedness</p> <p>positive attitude</p> <p>positive value base – dignity, respect and honesty, choice, etc</p> <p>caring nature and patience</p>	Value base that supports person centred care models, equity and opportunity.
Promoting best practice	<p>awareness of policies and legislation</p> <p>ability to record/ analyse and evaluate data, utilising IT/ computerised systems where appropriate</p> <p>people management skills</p> <p>team working and care coordination skills</p>	This involves the ability to make appropriate, timely and targeted referrals, and to signpost both the person with dementia and their carer to services required to address their needs

	<p>ability to provide effective health care to think critically, reflectively and evaluatively</p>	<p>Team working and service integration are critical aspects here. Coordination of care requires knowledge and understanding of the local health and social care ecology and practical skills in care coordination, communication and liaison with a range of other services and workers.</p> <p>Also use of IT, data recording/ analysis and awareness of evaluation methods are important.</p>
<p>ability to respect, support and promote equality and diversity</p>		
<p>ability to work in a variety of settings</p>		
<p>ability to practice ethically</p>		

Table 3 illustrates how some of the DPC competencies may already be present in the workforce but may be in need of further development, and some may be additional competencies.

**Table 3: Competencies Development List**

Existing competencies which may need development	Additional Competencies which may be needed
Case management	Interpersonal communication
Communication across services	Empathy
Networking between services (developing productive relationships)	Problem-solving complex care needs
Record keeping	Knowledge/Awareness of Dementia
Team/ collaborative working/ Service integration	Understanding behaviour of individuals with dementia
Interaction with patients	Dementia worker self care
Interaction with carers/families	Enriching the life of individuals with dementia
Knowledge of person-centred care	Knowledge of Mental Capacity Act
Understanding of best practice	Understanding of risk
Promote equality and valuing diversity	Knowledge of adult vulnerability and abuse
Understanding patient/ client confidentiality	Communication with senior and professional NHS workforce members
Able to listen to and understand patient/client need	Conducting needs assessment
Able to set appropriate boundaries	Responding to crisis situations
Discharge management	Ability to educate individuals with dementia and their carers about their condition
Telephony skills	Ability to develop individuals' self management of their health condition
Understanding health and safety	
Develop productive relationships	
Enable individuals to access and use information	
Operate office equipment (including computers)	

## **Illustrative Job Description and Person Specification**

We offer here an illustrative Job Description and Person Specification for the role of DPC: these have been informed by four key factors:

- Feedback and discussion from stakeholder group
- Responses for service users and carers
- A literature review exploring service provision, job roles and skills required
- Responses from Dementia Advisor Pilot Sites as part of the National Dementia Strategy

The Job Description and Person Specification have taken account of discussions within the stakeholder group and with service users and carers.

### **Skills and Job Role**

Specific personal qualities expected of a DPC were identified within stakeholder meetings, discussions with service users and carers and from literature identified in the literature review. Qualities identified included: warmth, sensitivity, attitude, empathy, and advocacy. These personal qualities are difficult to assess within the context of an interview process, however it is recommended that personal qualities are explored through case example or case study response in an interview context to assess applicant ability.

### **Dementia Advisor Pilot Sites**

The Dementia Advisor model currently being tested at identified pilot sites bears similar characteristics to the proposed DPC post identified by NHS West Midlands. Dementia Advisor pilot sites were contacted to draw upon their experience. Each site was asked for job descriptions and/or person specifications used in the recruitment of workforce members. Additionally a Google search was carried out to identify information provided online related to Dementia Advisor Pilot Sites and the recruitment of Dementia Advisors.

The Alzheimer's Society, in its development of a Dementia Advisor service, has issued a standard job description for a Dementia Advisor post that had been utilised by the majority of respondents in the recruitment of pilot site Dementia Advisors.

Information was received from the following Dementia Advisor pilot sites:

Site	Information received
Bradford	Job description
Bristol	Job description
Lancashire	Executive summary and job description
Medway	Advertisement, framework and job description
East Sussex	Job description and service specification
Kirklees	Job description
Northamptonshire	Job description
Redcar and Cleveland	Job description
Warwickshire	Job description

Information was gathered via web searches about the following Dementia Advisor pilot sites:

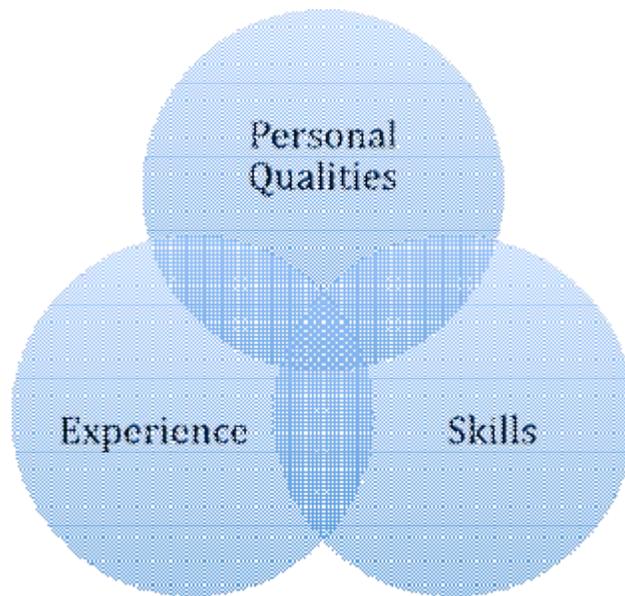
Site	Information collected
Hampshire	Advertisement for Dementia Advisor posts
Norfolk	Strategy document identifying and outlining new post
Oxfordshire	Job packs and outlines of 3 Dementia Advisor posts

The project team at Staffordshire University are grateful to each of the responding Pilot Sites for their willingness to share information and experience. All the documentation received was reviewed and a general person specification was constructed to test grading level and skill expectation according to model utilised. In the initial construction of a Person Specification the resource used to shape the specification was fully referenced and sent out to the Stakeholder group for further comment and consultation. The project team are grateful to Stakeholder group responses that have helped shape the resulting roles.

## Construction of Illustrative Person Specification and Job Description

The Person Specification and Job Description have been placed in a general format utilised by Staffordshire University in the recruitment of staff. They seek to bring together the combination of experience, personal qualities and skills identified in the project.

**Figure 2: A representation of the relationship between experience, personal qualities and skills**



The Staffordshire University Project Team recommend that the recruitment, selection and appointment process deployed for the new DPC workforce draws together these three key elements. Personal qualities are important in respect of the person's ability to communicate effectively and to demonstrate empathy and excellent listening skills. The DPC will be interacting with people with dementia and their caregivers post-diagnosis: this can be a period of trauma and confusion as the person and/or caregiver seeks to respond to the diagnosis received, to meet immediate need and to consider the future. At this point the person with dementia and their caregiver require interaction with workforce members who can provide understanding and warmth, combined with the ability to "hear" what the person is saying and requesting from them. The DPC will require considerable skills in networking and problem-solving in order to effectively communicate across service boundaries to meet the needs of people with dementia and their caregivers. Skills are more easily evidenced

within a recruitment and selection process than personal qualities, which may require a case study approach at interview to enable applicants to effectively demonstrate knowledge and understanding of what might be required of them as a DPC. Experience is the final factor to be added into this mix, particularly experience of meeting complex needs and awareness of impact of dementia upon the person diagnosed and their caregivers. The utilisation of the experienced practitioners' experience can be assessed through both references and examples from practice.

## Person Specification for Dementia Pathway Coordinator

Essential/Desirable Factors for the Post Give details below of requirements <i>E= Essential, D=Desirable</i>	E	D	Comment
<p><b>(1) Qualifications and Training</b></p> <p>Relevant health professional, nursing or social work qualification.</p> <p>Holds a first degree</p> <p>Post-graduate qualification in relevant area</p> <p>Evidence of ongoing training and development</p>	X		
<p><b>(2) Work Background and Experience</b></p> <p>Experience of successful working within healthcare and/or social care environments.</p> <p>Awareness of communication challenges in mixed healthcare environments.</p> <p>Evidence of case management and networking to support people with long term health needs.</p> <p>Experience of record keeping and report writing and meeting deadlines for submission.</p> <p>Experience of communicating with senior managers and healthcare staff, within health and or social care settings</p>	X	X	
<p><b>(3) Specific skills, aptitudes, knowledge</b></p> <p>Knowledge of and a commitment to a person-centred approach when supporting patients</p> <p>Knowledge or experience of dementia care/support for people diagnosed with dementia and their carers.</p> <p>Knowledge of relevant legislation and guidance including Mental Capacity Act</p>	X	X	

Able to work in a collaboratively in a team within a team structure.	X		
Excellent communication skills both written and verbal with good negotiation skills	X		
Able to listen effectively	X		
Able to set appropriate limits and boundaries with clients.	X		
Able to assess and evaluate client need.	X		
Good IT skills and experience and knowledge of all aspects of Microsoft Office.	X		
Able to educate clients and their carers about their condition			
Able to develop patients' self management of their health condition			
<b>(4) Personal Qualities</b>			
Commitment to patient confidentiality and the ability to handle sensitive information	X		
Empathy	X		
Commitment to and understanding of equal opportunities	X		
Understanding of the inclusion agenda and its relevance within a diverse society	X		
Self-motivated, demonstrates creativity and resourcefulness in working with clients with varying needs across organisation boundaries.	X		
<b>(5) Special Requirements</b>			
Enhanced Criminal Records Bureau Disclosure	X		
Commitment to personal development and further training as required	X		
Ability to travel independently within the service area	X		

## Job Description for Dementia Pathway Coordinator

### 1. General details

Job title	Dementia Pathway Coordinator
Location	
Normal work base	
Salary	Subject to Agenda for Change Banding

### 2. Job Purpose

Assessing need and enabling access to appropriate information and/or services for people with dementia and their caregivers contributing to a stable and safe care environment

### 3. Relationships

Responsible to:

Responsible for:

### 4. Main Activities

1. Enabling the delivery of a post-diagnosis support service to people with dementia and their caregivers to meet complex care needs
2. Working with people with dementia and their caregivers, post-diagnosis, to assess and identify required information and service needs
3. Maintaining an awareness of and access requirements for appropriate services within the locality for people with dementia and their caregivers
4. Demonstrating problem-solving and networking skills to enable people with dementia and their caregivers to access appropriate services in a timely manner
5. Directly supporting people with dementia and their caregivers to sustain a stable and safe care environment
6. Working with people with dementia and their caregivers to conduct regular assessments of ongoing needs and the continuing appropriateness of services accessed

7. Demonstrating care co-ordination and case management skills
8. Demonstrating advanced level professional practice, including self directed learning, managing risk, autonomous practice, higher level communications skills

### **5. Person Sought**

The successful applicant will be an experienced health or social care practitioner holding a relevant professional qualification and graduate degree. It is anticipated that the successful applicant will have experience of working in health and/or social care environments, conducting assessments, supporting complex care needs and providing case management. With excellent interpersonal, communication and listening skills the successful applicant will have knowledge of a person-centred approach to supporting people with long term health needs and their caregivers, and committed to providing excellent service delivery. The successful candidate will be able to evidence problem-solving and networking skills while maintaining service user confidentiality and positive boundaries with clients.

### **6. Special Conditions**

The appointment of the successful candidate will be subject to an Enhanced Criminal Records Bureau check

## **Training of the DPC**

Skilled Practitioners would be expected to have achieved professional status prior to appointment as a DPC. They will need to develop a competency skill set centred on providing appropriate and timely resources and care for people with dementia and their caregivers, and to address relationship orientated aspects of care. Therefore training in a competency-based framework would be best placed in a Higher Education setting as per Downs et al's (2009) observations of the benefit of Higher Education in enabling higher level skills, e.g. critical thinking, reflection and action. Such skill levels are represented at post-graduate level (e.g. Staffordshire University's MSc in Ageing, Mental Health and Dementia) enabling practitioners to develop professional competencies and critical knowledge in dementia care. It will be important to address the need for feedback from users and carers in training and/or professional development.

## Discussion

The use of a competency framework in developing the DPC role is vital so that staff have the necessary levels of competency to carry out the role. Further work is needed to examine ways of assessing competency levels and how the views of people with dementia and their carers can feed into this assessment process. In designing training programmes for DPCs account should be taken of the competencies which need to be developed in order to fulfil the role requirements.

One of the challenges of this project has been that it was clear from consultations with a wide range of stakeholders that implementation of the DPC role has already commenced within local services and does not necessarily address the expectations laid out in the West Midlands Dementia CPG report (Saad et al, 2008). The priorities identified in consultation with service users and carers concentrate on the need for consistency, reliability, and what has been called 'relational aspects of care' (Bridges, Flatley and Meyers, 2010) – it is important that these priorities do not get lost in the rush to implement change.

Another challenge has been that of terminology and lack of clarity regarding new roles. The terminology related to the roles of members of the dementia workforce is becoming confused. Organisations (statutory and third sector) are already appointing individuals to a wide variety of posts as dementia advisers/ advisors, dementia navigators, dementia pathway coordinators and others, in health, social care and third sector settings and in primary and secondary care. This is occurring before the dementia adviser pilot sites report on their experiences. There is also dissonance between national, regional and local levels. The National Dementia Strategy is driving developments nationally in England. The Strategic Health Authorities are driving workforce developments in their regions, and local organisations are already commissioning without the benefit of learning from the initiatives ongoing at other levels. There is potential for replication and duplication of activity at all these levels (eg new roles, competencies and curricula are being scoped at three levels and possibly more) with absence of shared learning, joined up thinking and consensus. Although these developments are intended to complement services and assist users and carers in their journeys with dementia, they have the potential to fragment services and worsen service integration. There is also lack of clarity about how the posts will be governed and a risk that, if the new posts are not integrated into services, fragmentation of services will be exacerbated. Alongside this there is concern that financial imperatives, rather than the need to improve services on the ground for users and their families, will shape these service

developments. Thus service integration will need to be a focus when looking to implement the DPC competencies.

There is a need to build research and evaluation into the introduction of these new roles and their impact on dementia care which must not be forgotten in haste to implement the National Dementia Strategy.

The introduction of the DPC role to the West Midlands dementia workforce carries the potential to improve the service on the ground for people with dementia and their families. It is important that this remains the focus of DPC activity.

## Recommendations

The Staffordshire University Project Team recommends:

1. That the DPC role is that of a skilled practitioner with a wide range of high level competencies. Commissioners and providers should consider how to ensure that the full range of DPC competencies is made available to people with dementia and their families.
2. That consideration is given to employing the core competency framework developed by Tsaroucha et al (2010).
3. That the recruitment, selection and appointment process deployed for the new DPC workforce seeks to draw together experience, personal qualities and skills.
4. That in training people who will work as DPCs, key issues for users and carers are addressed, namely person-centred cared and relationship based aspects of interaction with people with dementia and their families.
5. That training should be competency based and should include feedback from users and carers.
6. That innovative development in the dementia workforce, including the introduction of the DPC, should be evaluated and the evaluations used to develop and improve services.
7. That service evaluations should assess how people with dementia and their carers view the new roles.
8. That in assessing and evaluating changes in the dementia workforce clinical efficiency should be considered and addressed.
9. That transitions between services (particularly secondary and primary care, and health and social care) and service integration are important areas to investigate.

## References

Abendstern, M., Reilly, S., Hughes, J., Venables, D., Challis, D. (2006) Levels of integration and specialisation within professional community teams for people with dementia.

*International Journal of Geriatric Psychiatry*, 21, 1, 77-85.

Agnew, T. (2005) Community Matrons role 'one of the worst' claims moderniser. *Nursing Standard* 19, 44, 10.

All-Party Parliamentary Group on Dementia (2009) Prepared to care: Challenging the dementia skills gap. Available from

[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=735](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=735) [accessed 27-03-10].

Alzheimer Scotland – Action on Dementia (2003) Signposts to support – understanding the needs of carers of people with dementia. Alzheimer Scotland – Action on Dementia, Edinburgh.

Alzheimers Research Trust (2010) Dementia 2010. The economic burden of dementia and associated research funding in the United Kingdom. Available at:

<http://www.dementia2010.org/reports/Dementia2010Full.pdf> (accessed 12/3/2010).

Alzheimer's Society (2009) *What is a dementia advisor?* Available from

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

Alzheimer's Society (2007) *Dementia UK: The full report*. Published by the Alzheimer's Society, UK.

Armstrong, M. (2001) Widening benefits of support for carers and staff teams. *Journal of Dementia Care*, 9, 3, 18-19.

Armstrong, M. (1997) Dementia: supporting the patient and the carer. *Nursing Times*, 93, 32, 44-45.

Ball, J. (2006) *Advanced and Specialist Nursing Roles Results from a Survey of RCN members in Advanced and Specialist Nursing Roles*. RCN, London.

Banerjee, S. and Wittenberg, R. (2009) Clinical and cost effectiveness for early diagnosis and intervention in dementia. *International Journal of Geriatric Psychiatry*, 24, 7, 748-754.

Banerjee, S. Willis, R. Matthews, D. Contell, F. Chan, J. Murray, J. (2007) Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry*, 22, 8, 782-788.

Banning, M. (2006) Medication Review: The Role of Nurse Prescribers and Community Matrons. *Nurse Prescribing* 4, 5, 198-204.

Barnet Primary Care Trust (2007) *Evaluation of Barnet PCT Community Matron Service*. Barnet PCT. Available at:  
<http://www.barnet.nhs.uk/files/trustuploads/evaluation%20of%20barnet%20pct%20community%20matron%20service.pdf> (accessed: 17/06/2010).

Beattie, A., Daker-White, G., Gilliard, J., Means, R. (2005) 'They don't quite fit the way we organise our services' – results from a UK field study of marginalised groups and dementia care. *Disability and Society*, 20, 1, 67-80.

Bee, A. and Clegg, A. (2007) Community Matron Implementation: Meeting the challenge in Leeds. *British Journal of Community Nursing*, 1, 2, 64-67.

Bender, C., Constance, G., Williams, J. (2007) Wadebridge Memory Bank – three years on. *Journal of Dementia Care*, 15, 3, 16-17.

Biernacki, C. (2000) Involving service users in dementia care planning. *Professional Nurse*. 16(3): 947-950.

Bird, D. and Morris, T. (2006) Using Community Matrons to target Long Term Conditions. *Nursing Times* 102, 23, 19-20.

Bhaduri, R. and Sutcliffe, C. (2007) Implementing evidence-based training in dementia care for frontline workers in the social care workforce – reaching the horizon? *Journal of Care Services Management*, 1, 3, 294-302.

Bowes, A. and Wilkinson, H. (2003) "We didn't know it would get that bad": South Asian experiences of dementia and the service response. *Health and Social Care in the Community*, 11,5, 387-396.

- Bowler, M. (2009) Exploring patients' experiences of a community matron service using storybooks. *Nursing Times*, 105, 24, 19-21.
- Bridges J., Flatley, M. and Meyer, J. (2010) Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47, 1, 89-107.
- Brown, K., Stainer, K., Stewart, J., Clacy, R. and Parker, S. (2008) Older people with complex long-term health conditions. Their views on the community matron service: a qualitative study. *Quality in Primary Care*, 16, 6, 409-417.
- Bryans, M. and Wilcock, J. (2001) Issues for nurses in dementia diagnosis and management. *Nursing Times*, 97, 44, 30-31.
- Butterworth, M. (1995) Dementia: The family caregiver's perspective. *Journal of Mental Health*, 4, 2, 125-132.
- Cantley, C. and Steven, K. (2004) 'Feeling the way': understanding how advocates work with people with dementia. *Dementia*, 3, 2, 127-143.
- Cascioli, T.R., Al-Madfai, H., Osborne, P., Phelps, S. (2008) An evaluation of the needs and service usage of family carers of people with dementia. *Quality in Ageing*, 9, 2, 18-27.
- Casey, D. and MacKereth, P. (2006) Developing Education for Long Term Conditions Management. *British Journal of Community Nurses*, 12, 1, 19-22.
- Castlefields Health Centre (2004) *Chronic Disease Management. Castlefields Health centre. Available at: <http://www.natpact.nhs.uk/uploads/Castlefields%20Reoprt.doc>* (accessed: 17/06/2010)
- Challenger, J. and Hardy, B. (1998) Literature Review. Dementia: the difficulties experienced by carers. *British Journal of Community Nursing*, 3, 4, 166.
- Chapman, L., Smith, A., Williams, V. and Oliver, D. (2009) Community matrons: primary care professionals' views and experiences. *Journal of Advanced Nursing* 65, 8, 1617-1625.

Chidgey, A. (2009) How we can radically improve life for people with dementia. *Working with Older People: Community Care Policy and Practice*, 13, 3, 15-17.

Clegg, A., Hamilton, S. and White, L. (2007) Becoming a Community Matron: The Transition from Acute to Primary Care. *British Journal of Community Nursing*, 1, 8, 342-344.

Coombes, E., Colligan, J., Keenan, H. (2004) Evaluation of an early onset dementia service. *Journal of Dementia Care*, 12, 1, 35.

Conroy, J. (2008) Increasing knowledge – can it improve practice? *Journal of Dementia Care*. 16(6): 30-32.

Cubby, A. and Bowler, M. (2009) Community matrons and long-term conditions: an inside view. *British Journal of Community Nursing*, 15, 2, 71 – 76.

Department of Health (2009) *Living well with dementia: A National Dementia Strategy*. London, DH.

Department of Health (2008) *Raising the profile of long term conditions care: a compendium of information*. London, DH.

Department of Health (2006) *Caring for People with Long Term Conditions: An Education Framework for Community Matrons and Case Managers*. London, DH.

Department of Health (2005a) *The National Service Framework for Longterm Conditions*. London, DH.

Department of Health (2005b) *Supporting people with Long-term Conditions: An NHS and Social Care Model to support Local Innovation and Integration*. London, DH.

Department of Health (2005c) *Liberating the Talents of Nurses who care for People with Long Term Conditions*. London, DH.

Department of Health (2004). *The NHS Improvement Plan – Putting People at the Heart of Public Services*. London, DH.

Department of Health (2001). *The Expert. Patient: A New Approach to Chronic. Disease Management for the 21st Century*. London: DH.

- Derbyshire Primary Care Trust (2008) *Long Term Conditions Evaluation. Community matrons and Allied Staff Interviews*. Derbyshire PCT. Available at: [http://www.derbyshire.gov.uk/images/Microsoft%20Word%20-%20Final%20report%20staff%20interviews\\_tcm9-136102.pdf](http://www.derbyshire.gov.uk/images/Microsoft%20Word%20-%20Final%20report%20staff%20interviews_tcm9-136102.pdf) (accessed: 19/06/2010).
- Dewing, J. and Traynor, V. (2005) Admiral nursing competency project: practice development and action research. *Journal of Clinical Nursing*, 14, 6, 695-703.
- Done, D.T. and Thomas, J.A. (2001) Training in communication skills for informal carers of people suffering from dementia – a cluster randomised clinical trial comparing a therapist led workshop and a booklet. *International Journal of Geriatric Psychiatry*, 16, 8, 816-821.
- Downs, M., Capstick, A., Baldwin, P.C., Surr, C., Bruce, E. (2009) The role of higher education in transforming the quality of dementia care: dementia studies at the University of Bradford. *International Psychogeriatrics*, 21, S1, 3-15.
- Duffin, C. (2009) The one-stop shop memory service. *Nursing Older People*, 21, 2, 14-15.
- Garwood, S. (2009) Partnership in word and deed. *Journal of Dementia Care*, 17, 1, 20-24.
- Ghiotti, C. (2009) The Dementia End of Life Care Project (DeLCaP): supporting families caring for people with late stage dementia at home. *Dementia*, 8, 3, 349-361.
- Gilmour, H., Gibson, F., Campbell, J. (2003) Living alone with dementia: a case study approach to understanding risk. *Dementia*, 2, 3, 403-420.
- Gladman, J.R.F., Jones, R.G., Radford, K., Walker, E., Rothera, I. (2007) Person-centred dementia services are feasible, but can they be sustained? *Age and Ageing*, 36, 2, 171-176.
- Gravelle, H., Dusheiko, M., Sheaff, R., Sargent, P., Boaden, R. and Pickard, S., Parker, S. and Roland, M. (2006) Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data. *British Medical Journal*, 334, 31-43.
- Greaves, I. (2008) Network: Dementia in primary care. *Journal of Dementia Care*, 16, 4, 18-19.

Griffith, R. (2006) Legal issues in nursing. Making decisions for incapable adults 1: capacity and best interest. *British Journal of Community Nursing*, 11, 3, 119-125.

Heathcote, J., Newton, C., Hong, C.S. (2007) A dementia service evaluated. *Journal of Dementia Care*, 15, 4, 13-14.

Herbert, G. (1997) Which hats should we wear today? Recruiting and developing the ideal workforce for dementia care. In Marshall, M. (ed) *State of the art in dementia care*. Centre for Policy on Ageing.

HM Government (2007) Putting people first. A shared vision and commitment to the transformation of adult social care. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118) (accessed 12/3/2010).

Hope, T. (2009) Ethical dilemmas in the care of people with dementia. *British Journal of Community Nursing*, 14, 12, 548-550.

Ho, D. (2000) Mental health. Role of community mental health nurses for people with dementia. *British Journal of Nursing*, 9, 15, 986-991.

Hoskins, S., Coleman, M., McNeely, D. (2005) Stress in carers of individuals with dementia and Community Mental Health Teams: an uncontrolled evaluation study. *Journal of Advanced Nursing*, 50, 3, 325-333.

House of Commons Committee of Public Accounts (2008) *Improving Services and Support for People with Dementia. Sixth Report of Session 2007-08*. House of Commons Publication, The Stationary Office Ltd.

Howcroft, D. (2004) Continuing professional development. Alzheimer's disease: caring the carers. *Mental Health Practice*, 7, 8, 31-38.

Hussein, S. and Manthorpe, J. (2005) Older people with learning disabilities: workforce issues. *Journal of Integrated Care*, 13, 1, 17-23.

Iliffe, S. and Manthorpe, J. (2004a) The debate on ethnicity and dementia: from category fallacy to person-centred care? *Aging and Mental Health*, 8, 4, 283-292.

Iliffe, S. and Manthorpe, J. (2004b) The recognition of and response to dementia in the community: lessons for professional development. *Learning in Health and Social Care*, 3, 1, 5-16.

Iliffe, S., Wilcock, J., Haworth, D. (2004) A toolbox of skills to share across dementia care. *Journal of Dementia Care*, 12, 4, 16-17.

Innes, A., Cox, S., Smith, A., Mason, A. (2006) Service provision for people with dementia in rural Scotland: difficulties and innovations. *Dementia*, 5, 2, 249-270.

Jenkins, C. (1998) Bridging the divide of culture and language. *Journal of Dementia Care*, 6, 6, 22-25.

Keady, J. and Williams, K. (1998) Counselling skills for carers and early stage dementia care. *Elderly Care*, 10, 2, 15-17.

Kellehear, A. (2009) Dementia and dying: the need for a systematic policy approach. *Critical Social Policy*, 21, 1, 146-157.

Kumpers, S., Mur, I., Hardy, B., van Raak, A., Maarse, H. (2006) Integrating dementia care in England and the Netherlands: for comparative local case studies. *Health Place*, 12, 4, 404-420.

Kumpers, S., Mur, I., Maarse, H., van Raak, A. (2005) A comparative study of dementia care in England and the Netherlands using neo-institutionalist perspectives. *Qualitative Health Research*, 15, 9, 1199-1230.

Lombard, D. (2009) Workforce skills are key to dementia care. *Community Care*. 1757: 10-11. Available at: <http://www.communitycare.co.uk/Articles/2009/02/11/110688/workforce-skills-key-to-dementia-strategy-success.htm> [accessed 23/03/10].

Lorentzon, M. and Bryan, K. (2007) Respect for the person with dementia: fostering greater user involvement in service planning. *Quality in Ageing*, 8, 1, 23-29.

Lowin A, Knapp M., McCrone, P. (2001) Alzheimer's disease in the UK: comparative evidence on cost of illness and volume of health service research funding. *International Journal of Geriatric Psychiatry*, 16, 1143-1148.

- Lyndon, H. (2007) Community Matrons — A Conduit for Integrated Working? *Journal of Integrated Care*, 15, 6, 6-13.
- Lyndon, H. (2006) Developing the role of the community matron: The Cornwall experience. *Primary Health Care*, 16, 5, 14-7.
- Manthorpe, J. and Alaszewski, H. (2002) Listening to the dementia workforce: local providers' perceptions of dementia services. *Quality in Ageing*, 3, 2, 22-29.
- Masterson, A. (2007a) Community Matrons: Advanced Assessment Skills (part 3) *Nursing Older People*, 19, 6, 29-31.
- Masterson, A. (2007b) Community Matrons: Promoting self-management (part 4) *Nursing Older People* 19, 7, 29-32.
- Mayor, S. (2005) Case management to be used for people with chronic conditions. *British Medical Journal*, 330, 112.
- McDonald, A. and Heath, B. (2008) Developing services for people with dementia. *Quality in Ageing*, 9, 4, 9-18.
- McMillan, I. (2009) Least we forget. *Mental Health Today*, 9, 3, 12-14.
- Milne, A. (2001) Dementia Advice and Support Service: A nation wide early intervention service for people with dementia and their families. *MHF Updates*, 3, 7.
- Moriarty, J. (2001) Planning care for people with dementia. *Working with Older People: Community Care Policy and Practice*, 5, 1, 16-20.
- Morris, C. (2000) Working with people, making sense of dementia. *Journal of Dementia Care*, 8, 4, 23-25.
- Morris, C. (1999) Building up a toolbox of strategies for communication. *Journal of Dementia Care*, 7, 4, 28-30.
- Mountain, G.A. (2006) Self-management for people with early dementia: an exploration of concepts and supporting evidence. *Dementia*, 5, 3, 429-446.

Murphy, E. (2004) Case Management and Community Matrons for Long Term Conditions. *British Medical Journal*, 329, 1251-1252.

NHS Centre for Reviews and Dissemination (2008) *Finding studies for systematic reviews: a checklist for researchers*. Information Service, University of York.

NHS Modernisation Agency, Skills for Health (2005) *Case Management Competences Framework for the Care of People with Long-Term Conditions*. London: DH.

NHS West Midlands (10/09/09) (2009) *Workforce Development for Dementia*. Project Reference 0910/W1/HS/3. Issued by NHS West Midlands to enable tender process.

NICE-SCIE (2007) *Dementia: A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care*. Published by The British Psychological Society and Gaskell.

Nolan, K.J. and Keady, J. (1995) A stitch in time. Facilitating proactive interventions with dementia caregivers: the role of community practitioners. *Journal of Psychiatric and Mental Health Nursing*, 2, 1, 33-40.

Nurock, S. and Wojciechowska, M. (2007) What real outcomes matter to caregivers? *International Psychogeriatrics*, 19, 3, 355-362.

Nursing Times (2008) *We can no longer ignore Dementia*. Available at: <http://www.nursingtimes.net/we-can-no-longer-ignore-dementia/1847790.article> (accessed: 19/06/2010)

Parish, C. (2005) Case Management cuts Hospital Admissions to 'Virtually Zero'. *Nursing Standard*, 20, 3, 10

Pateman, B. (2005) Community Matrons: What's in name? *British Journal of Community Nursing*, 10, 3, 109

Patrick, H., Roberts N., Hutt R., Hewitt P., Connelly J. and Oliver D. (2006) Evaluation of innovations in nursing practice: Report and discussion. *British Journal of Nursing* 15, 9, 520-523.

Pickard, S. and Glendinning, C. (2001) Caring for a relative with dementia: the perceptions of carers and CPNs. *Quality in Ageing*, 2, 4, 3-11.

Pollard, T. (2005) District Nurses: The new community matrons. *British Journal of Community Nursing* 10, 8, 356

Pooler, A. and Campbell P. (2006) NT Research. Identifying the development needs of community matrons. *Nursing Times* 102, 37, 36-38.

Pool, J. (2006) Best practice in dementia care – improving the health and well-being of older people with mental health needs. *Journal of Care Services Management*, 1, 1, 16-23.

Price, C. (2007) Monitoring people with dementia – controlling or liberating? *Quality in Ageing*, 8, 3, 41-44.

Query, J.L. and Kreps, G.L. (1997) Testing a relational model for health communication competence among caregivers for individuals with Alzheimer's disease. *Journal of Health Psychology*, 1, 3, 335-351.

Rosser, E. and Rickaby, C. (2007) *Community Matrons: Evaluation of the National Pilot Education Programme Preparing Community Matrons to Perform their Role*. University of West of England, Bristol.

Rothera, I. Jones, R. Harwood, R. Avery, A.J. Fisher, K. James, V. Shaw, I. Waite, J. (2008) An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods. *International Journal of Geriatric Psychiatry*, 23, 1, 65-72.

Russell, M., Roe, B., Beech, R. and Russell, W (2009) Service developments for managing people with long-term conditions using case management approaches, an example from the UK International. *Journal of Integrated Care*, 9, 1-10.

Ryan, T., Nolan, M., Reid, D., Enderby, P. (2008) Using the Senses Framework to achieve relationship-centred dementia care services: A case example. *Dementia*, 7, 1, 71-93.

Ryan, T., Nolan, M., Enderby, P., Reid, D. (2004) 'Part of the family': sources of job satisfaction amongst a group of community-based dementia care workers. *Health and Social Care in the Community*, 12, 2, 111-118.

Saad, K., Smith, P., Rochfort, M. (2008, April) Caring for people with Dementia: It's Really Time To Do Something Now! *Dementia Clinical Pathway Group*, West Midlands Strategic Health Authority.

Sadler, C. (2006) The whole story. *Nursing Standard*, 20, 29, 20-2.

Sargent, P. and Boaden, R. (2006) Implementing the role of the community matron. *Nursing Times*, 102, 13, 23-4.

Sargent, P., Pickard, S., Sheaff, R. and Boaden, R. (2007) Patients and Carers Perceptions of Case Management for long-Term Conditions. *Health and Social Care in the Community* 15, 6, 511-519.

Sheaff, R., Boaden, R., Sargent, P., Pickard, S., Gravelle, H., Parker, S. and Roland, M. (2009) Impacts of case management for frail elderly people: a qualitative study. *Journal of Health Services Research and Policy*, 14, 88-95.

Shropshire and Telford branch of the Alzheimer's Society and Telford and Wrekin Senior Citizens Forum (2008) *Now you see me, now --- ---*. Produced by Shropshire and Telford branch of the Alzheimer's Society and Telford and Wrekin Senior Citizens Forum, November 2008.

Skills for Care (2005) *Knowledge set for dementia*. Published by Skills for Care [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

Snayde, F. and Moriarty, J. (2009) Person-centred home care for people with dementia: Developing a specialist service in an ethnically diverse community. *Dementia*, 8, 1, 148-152.

Staines, R. (2007) Community Matron Role should stay despite poor recruitment. *Nursing Times*, 103, 19, 9.

St. John, T. (2004) Hidden shame – a review of the needs of Asian elders with dementia and their carers in a Kent community. *Journal of Integrated Care*, 12, 3, 20-26.

Stevenson, G.S., Ewing, H., Herschell, J., Keith, D. (2007) An enhanced assessment and support team (EAST) for dementing elders – review of a Scottish regional initiative. *Journal of Mental Health*, 15, 2, 251-258.

Sturdy, D. (2009) The National Dementia Strategy: nurses need to lead change. *Nursing Older People*, 21, 1, 12-13.

Tovey, R. (2005) *Eldercare Project in Cornwall (EPIC), One Year Evaluation Report*, October. North and East Cornwall Primary Care Trust, Central Cornwall Primary Care Trust and West of Primary Care Trust.

Trueland, J. (2008) Listen and Learn. *Nursing Standard*, 23, 7, 22-23.

Tsaroucha, A. et al (2010) Development of a West Midlands core competency framework. Dementia, in preparation.

UnitedHealth Group (2004) Implementing the Evercare programme. Interim report. London: UHG.

Ward, R., Vass, A.A., Aggarwal, N. (2008) A different story – exploring patterns of communication in residential dementia care. *Ageing and Society*, 28, 5, 626-651.

Watson, R. (1992) Is elderly care research-based? Nursing Elderly People. *Nursing Standard*, 6, 48, 37-39.

Wells, S. (2007) Dementia advocacy. *Working With Older People*, 11, 1, 25-27.

WHO (2005) *Preventing Chronic Disease. A vital investment*. Geneva: WHO.

Willis, R., Chan, J., Murray, J., Matthews, D., Banerjee, S. (2009) People with dementia and their family carers' satisfaction with a memory service: a qualitative evaluation generating quality indicators for dementia care. *Journal of Mental Health*, 18, 1, 26-37.

Wilkinson, H., Kerr, D., Cunningham, C. (2005) Equipping staff to support people with an intellectual disability and dementia in care home settings. *Dementia: the international journal of social research and practice*, 4, 3, 387-400.

Woodend, K. (2006) The role of Community Matrons in Supporting Patients with Long Term Conditions. *Nursing Standard* 20, 20, 51-54.

Woods, B. (1995) Dementia care: progress and prospects. *Journal of Mental Health*, 4, 2, 115-124.

Wright, K., Ryder, S. and Gousy, M. (2007) Community Matrons Improve Health: Patients Perspectives. *British Journal of Community Nursing* 12, 10, 453-459.