

South West Dementia Partnership



An evaluation of dementia support worker roles

Title	An evaluation of dementia support worker roles.
Description	A review of evidence supporting the provision of a dementia support worker role in communities is presented, together with a review of roles currently in existence in the UK. With the intention of informing and guiding the future commissioning of new roles, any improvements to quality and efficiency demonstrated by roles to date have been emphasised.
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Executive summary

This report presents an evaluation of existing models of community-based support for people with dementia, their families and carers.

The intention is to present practical information, within wider NHS and Social Care policy contexts and drivers, which will inform and assist commissioners and providers in the development of much needed sustainable quality and productivity improvements in dementia services.

The evaluation includes that of reported qualitative and quantitative benefits to local health and social care systems of the models of service delivery, including the role and important competencies of employees of the service and a cost/benefit analysis.

Reference is also made to available published research, a new funding opportunity announced in September 2011, and Department of Health analyses prior to, and following on from, the publication of the national Dementia Strategy (2009).

“I feel overwhelmed with advice but there is not enough practical help and support. It seems that this comes only in a crisis, when maybe it’s too late.”

[Carer, Regional User Involvement Project]

1. Introduction

The term dementia describes a group of usually progressive neurodegenerative conditions characterized by intellectual deterioration and gradual erosion of mental, and later physical, functions. A person with dementia will experience a reduction in social capacities and physical abilities, resulting in needs for support and care which change over time requiring continued review and adjustment. The average life expectancy from diagnosis to death at present is 5 years, although with the current emphasis on earlier diagnosis this prognosis is expected to lengthen.

There are currently approximately 825,000 people in the UK with dementia (Alzheimer's Society 2007, forecast), with prevalence rising with increasing age. The current recorded prevalence rates in England are around 30-50% of expected prevalence according to age and gender bands, and this is reflected in the NHS South West region.

The overall financial burden of dementia in the UK is enormous, greater than stroke, heart disease and cancer combined. Dementia is estimated to cost the UK taxpayer £20 billion per annum at present, much of this being in social care rather than health budget costs, but it is also estimated that private carers (usually family members) save the UK taxpayer an additional £5.4 billion per annum (Alzheimer's Society, 2007) by continuing to care for people with dementia in the community.

On top of this existing disease burden, forecasts predict dramatic rises in the recorded prevalence of dementia, partly due to the increased longevity of the population and partly due to better identification of the disease. This will result in significant increases in the overall cost of dementia care within the UK, to both state and individual, if care continues to be delivered in the way it is today.

Aside from cost there are strong ethical and moral reasons for improving the care that people with dementia and their carers currently receive today (Nuffield Council

on Bioethics, 2009), and good evidence that the care that such service users receive from statutory organisations at present are inadequate (National Audit Office, 2007).

We therefore face a challenge in both health and social care in the UK: to improve the quality and consistency of services provided for people with dementia and their carers, yet provide these services in a much more cost-effective way.

To address this challenge the UK Government has published a number of policies to guide and drive the commissioning of dementia services. Some are specific to dementia, such as the national Dementia Strategy (2009) and subsequent publication of Quality Outcomes for people with dementia (2010) including four priority objectives. Others are more generic, such as the Quality, Innovation, Productivity and Prevention agenda (Nicholson, 2010), which is driving the development of better services which are more cost-efficient across healthcare and is directly applicable to the dementia challenge.

In addition to these drivers to improve dementia services there also remain major barriers to identifying and diagnosing patients with dementia amongst healthcare professionals (Iliffe, 2009). General Practitioners report both a lack of knowledge, training and skills in assessing and managing dementia (National Audit Office, 2007), but also a perceived lack of benefit to the patient (therapeutic nihilism) or even worse a perceived fear of stigmatising or labelling them unnecessarily (Iliffe, 2009), which people with dementia and their carers and families do not themselves report as a concern.

Given this scenario the authors of this evaluation report have identified community dementia support as a potentially crucial and powerful tool. It offers the potential to improve services yet reduce both health and social care costs per patient; it provides visible post-diagnosis care to reduce perceived therapeutic nihilism; it can help service users (both people with dementia and their carer and/or families) access

what they need at the right time for them; and above all it offers patients and carers the support that they need to remain in their chosen environment for longer.

An important consideration when providing support for both the person with dementia and their carer or family is the need for support workers to be aware of the interactions between the person with dementia and their carer/family, and the distinct impact of these interactions on each person. Consideration of both the relationship history and the current relationship should allow identification of strengths and vulnerabilities, and allow tailoring of interventions to meet the needs of both the person with dementia and their carer or family.

Recent reports from other organisations support this view: the Alzheimer's Society (2011), the All Party Parliamentary Group on Dementia (2011), and the Princess Royal Trust for Carers (2011) all stress the importance of good patient and carer support throughout their dementia journey. Furthermore, the Department of Health's impact assessment (2008), prior to publication of the national Dementia Strategy (2009), estimated that a service such as those discussed in this report can be expected to be cost neutral after 4 years and offer the potential for cost savings, to both state and individual by 10 years.

Published research led by Professors Louise Robinson (2010), Dawn Brooker (2010) and Sube Banerjee (2003 & 2007) in this country, and an important paper by David Weimer *et al.* from the USA (2009) are now not only supporting the provision of community dementia support but also demonstrating real cost benefits.

Therefore we intend in this report to present a range of some of the varied community dementia support roles currently in existence in parts of the UK. This report has endeavoured to include any benefit realisations identified by each service provider. The evidence presented has varied from anecdotal feedback to more robust evidence via formal audit or service evaluation. It is important to emphasise that this report is purely showcasing the service principles of different models and is

neither a comparative analysis nor intends to offer an extensive list of all models within the UK.

This information aims to support and inform commissioners in developing local services for their populations in the most cost-effective way to generate the greatest benefits. Overall it appears that a tiered model of service delivery offering differing intensity of support is most effective at delivering care.

Further support with development of local services is provided by the Department of Health's Dementia Commissioning Pack (2011) which sets out an outcomes-based commissioning framework for treatment, care and support at the different stages of the disease. The Pack is particularly relevant to the commissioning of higher-level specialist mental health community support for primary care in the management of dementia-related problems. A detailed costing tool allows the calculation of not only the potential cost of a new service for the selected Primary Care Trust but, more importantly, the calculation of expected savings due to reduced need for acute hospital admission or shorter hospital bed stay durations.

To support the start-up funding requirement of a new role, commissioners may wish to consider David Behan's announcement in September 2011 of an additional £10 million Government funding across England to support the delivery of memory services.

“Given the high financial costs of dementia and the human cost of failing to provide good quality support, commissioners and planners will miss a vital opportunity if they do not treat dementia as a priority area for improving cost-effectiveness. The APPG believes there is ample opportunity for using resources more effectively while at the same time improving outcomes for people with dementia”.

[All Party Parliamentary Group on Dementia (2011)]

2. Project Design

The project team was established and timescale agreed with the South West Dementia Partnership (SWDP). It was agreed to evaluate a range of different models of community dementia support in operation nationally, giving consideration to how the role operates, the costs and the function of the workers. It was also agreed to highlight any benefits realised around quality, innovation, productivity and prevention.

Methods employed were a literature search, identification of service models both in the South West and nationally, detailed information-gathering about each role, and telephone interviews or face-to-face group discussions with key stakeholders, service users and carers.

2.1 Methods

Literature Review

The aim of the literature review was to identify key features of dementia support from published research.

Identification and information-gathering from existing models

Awareness of existing roles was achieved through a variety of methods:

- discussions with local commissioners at regional meetings;
- Department of Health demonstrator site information;
- published reports;
- the domino effect: one role then raised awareness of other roles it was based on.

Information was then gathered from stakeholders of each role using semi-structured interviews in order to assimilate, as much as possible, the information from each role. Such questions covered the following areas:

- features of existing dementia support worker roles;
- the qualitative benefits of dementia support worker roles;
- cost benefit analysis of existing dementia support roles, where available;
- competencies of existing dementia support workers;
- training and education needs of existing support workers;
- current dementia workforce service provision within general practice and community.

Group discussions and interviews

Group discussions with dementia commissioners were held during the development of this report.

A combination of face-to-face and telephone interviews were held with key academic researchers in this field.

The Regional User Involvement Project (South West Dementia Partnership) has also gathered the views and experiences of people living with dementia across the South West using a variety of different engagement methods, and across a number of localities and subjects.

“[Our liaison worker] has been supportive and helpful with everything; I have been able to rely on her to support me through a very difficult time. I like the fact that I can speak to her direct on the telephone, without having to wait for someone to get back to me. She told me about services that I didn’t know about and explained things in a way that I would understand. I have never felt that I am being rushed and I feel that I am being listened to”

[Carer, Barnsley]

3. Findings

3.1 Service user and carer needs

Key themes from the service user and carer focus groups (see appendix, section 8.2) and other national Government and Alzheimer's Society surveys suggest the following factors are important to people with dementia, their carers and families:

- access to early and accurate diagnosis;
- support focussed on the person with dementia which works in partnership with any carer or family members;
- learning adaptive coping skills;
- having a carer who supports and understands, is well-informed;
- the provision of advocacy, mentoring and peer support;
- appropriate and safe accommodation;
- respite opportunities, carer support groups (i.e. considering the needs of the carer and wider family);
- services that offer an acceptable means of diagnosis including written information at the time;
- signposting to, or navigating through, mainstream services such as counselling, services addressing specific issues and not just part of mental health services, support for other health related issues;
- support with benefits applications or eligibility;
- information on different stages of the disease process at a time that is tailored to suit the person with dementia or their family/carers;
- awareness raising across health and social care and wider society;
- a single, personalised point of contact to access information, services and support, with continuity of care to allow the building of a sustainable professional relationship.

These features are also supported by academic research (Brooker, 2009) and ethical considerations (Nuffield Council on Bioethics, 2007).

“I think the dementia support worker is a hugely valuable service. Many patients have found the input and support very useful. The dementia support worker has taken off some of the pressure from me as a GP by organising social support and general follow up. The dementia support worker has involved me when appropriate and communicated concerns and developments well. It has been good to have a dementia support worker as part of the team. I hope the role can be extended and continued.”

[GP, Cornwall & Isles of Scilly PCT, on their local support worker pilot]

3.2 Examples of existing dementia support worker roles

These examples of dementia support worker roles (from single locations) are intended to give an illustration of the range and diversity of roles currently in existence across the UK.

Significant differences will be apparent between these illustrations, for example the different level of skills required or background profession. However, it should be noted that where a given role carries a name that is widely used across the country (e.g. Dementia Adviser, Admiral Nurse), there are likely to be important differences between different roles with that name, depending on where they are commissioned geographically.

1. Primary care memory nurse service

This role is of a primary-care based, and provided, nurse-led service developed by a single GP surgery in Cornwall. Key features include:

- being based in one GP surgery and sharing information using the GP computer system, thereby maintaining a prominent presence within the primary healthcare team;
- active involvement in case-finding within the surgery population but also taking onto the caseload patients with an established diagnosis or patients referred by GPs within the surgery;
- undertaking part of the diagnostic work-up including cognitive testing, social history gathering and arranging blood tests;
- assisting the GPs in the actual diagnosis of the vast majority of patients with dementia within the surgery population;
- providing a single, named point of contact for all patients and carers, both before and after diagnosis and including people with mild cognitive impairment;

- maintaining a caseload and only discharging patients if they die or move out of area;
- offering people on the caseload education, signposting, promoting independence, co-ordination of complex care needs, and undertaking annual dementia reviews;
- the development of individual care plans (including palliative care) with each person on the caseload;
- ensuring regular pro-active contact with the patient and/or carer, between weekly and monthly intervals, for the majority of the caseload;
- applicants to the post were expected to be Band 6 nurses with previous skills and experience in assessing and caring for elderly patients suffering from some form of cognitive impairment and/or mental ill health. A specialist dementia qualification, or psychological therapy qualification, was desirable but not essential;
- ongoing nurse professional development and support is provided by the local community mental health team;
- the service was initially commissioned as a 2 year pilot for evaluation.

Benefits of this role include:

- ✓ every patient with dementia or mild cognitive impairment is permanently kept on the caseload: the 0.4 whole time equivalent memory nurse carries a caseload of 88 patients within the GP surgery population of 5000 people;
- ✓ recorded dementia prevalence in the GP surgery has risen from 40% to 75% of estimated population prevalence;
- ✓ 10 people with dementia have remained at home for 6 months rather than entering permanent care home placement, saving an estimated £25,000;
- ✓ unnecessary prescribing of dementia drugs (particularly anti-psychotics) as been reduced, saving an estimated £1345 per annum;

- ✓ carer education about prompt identification and management of urinary tract infections has helped to prevent unnecessary admissions to hospital;
- ✓ there is a large amount of very positive qualitative feedback from patients and carers.

Cost

- Total annual cost £26,623.79, including nurse salary and all on-costs.

Contact: Dr Will Howe, GP, William.Howe@lostwithiel.cornwall.nhs.uk

2. Dementia Adviser including diagnostic support

This is a voluntary sector based, and provided role, National Vocational Qualification level 3 (NVQ3) in South Staffordshire. Key features include:

- provided by the Alzheimer's Society;
- informal referrals accepted from primary care and other sources.
- the Adviser is involved in pre-diagnosis work-up including cognitive testing, depression screening, social history gathering and ensuring blood tests are performed at the patient's GP surgery;
- the Adviser liaises with a local consultant old age psychiatrist who then completes the diagnostic process at a community-based clinic, usually in a local GP surgery;
- the Adviser is also involved with the consultant in the development of a personal care plan when a patient is diagnosed;
- post-diagnosis the Adviser provides signposting, liaison and information providing for all patients diagnosed with dementia and their carers;
- liaison with Age Concern assists people with dementia and carers with benefits advice and applications;
- the Adviser is supported by a team of volunteers from the Alzheimer's Society;

- ongoing Adviser training, governance and professional development is provided by a co-working organisation with input from Staffordshire University, Age UK, the Alzheimer's Society and the Carer's Association.

Benefits of this role include:

- ✓ each full-time Dementia Adviser carries a caseload of 200 people with dementia;
- ✓ the new consultant psychiatrist community diagnostic service, supported by the Adviser role, has reduced the cost of the initial specialist diagnosis appointment from £325 per patient (Memory Clinic) to £70 per patient (new service);
- ✓ the new diagnostic service has capacity for 6 patients per session, in 13 community clinics PCT-wide, which has significantly reduced waiting times for assessment;
- ✓ the initial pilot for this service won a Royal College of General Practitioners' GP Enterprise Award;
- ✓ the 6 Advisers cover a total PCT population of 615,000;
- ✓ in the first 2 years of the initial pilot service, only 2 out of 80 people with established dementia required long-term care home placement.

Cost

- The 6 Advisers cost £150,000 per annum including salaries, on-costs and also including £25,000 per annum for training, governance and professional development from the co-working organisation.

Contact: Dr Ian Greaves, GP, ian.greaves@nhs.net

3. Secondary care navigator service

This is a secondary care based, and provided, mental health nurse-led role in Barnsley. Key features include:

- jointly commissioned by PCT and Local Authority;
- the care navigator is a Band 5 mental health nurse;

- provision of a central point of contact for people with dementia and their carer, aiming to empower individuals to sustain independence and optimum levels of functioning;
- the navigator role is designed to guide the person through their journey with dementia via education and assistance with accessing the right health, social or voluntary sector support at the most appropriate time;
- provision of the navigator role has been in tandem with older persons' mental health service redesign, with a significant reduction in inpatient services and redistribution of staff to the community setting including the navigator role.

Benefits of this role include:

- ✓ reduced isolation and increased confidence for the person with dementia through improved information and carer support;
- ✓ 50% of people known to the service reduced their contact with their GP by 50% during the 10 month evaluation period;
- ✓ admissions to the inpatient dementia ward reduced from 65 (before service redesign) to 13 (after redesign) over comparable 10 month periods;
- ✓ earlier discharge from the dementia assessment ward due to improved post-discharge service navigation;
- ✓ reduced length of time on CMHT caseload;
- ✓ service redesign has reduced staff costs by £200,000 per annum.

Cost

- £65,000 per annum (Two Agenda for Change Band 5 mental health nurses, salaries plus on-costs).

Contact: Philippa Slevin, Matron Manager, Philippa.Slevin@swyt.nhs.uk

4. Dementia Adviser service

This is a voluntary sector based, and provided, NVQ3 role in Somerset, but with many similarities with other Dementia Adviser roles across the UK. Key features include:

- provided by the Alzheimer's Society;
- initially a Department of Health demonstrator site through a joint bid between Somerset County Council, NHS Somerset and the Alzheimer's Society, Department of Health funding finished in March 2010;
- service currently commissioned by NHS Somerset;
- Dementia Advisers undertake to provide signposting and information for people with dementia and their carers;
- referrals are accepted from health and social care professionals using a proforma, as early in the patient journey as possible but a diagnosis of dementia must be established first;
- self-referrals are also accepted by the service;
- training and professional development is provided by the Alzheimer's Society;
- each Adviser can carry a caseload; patients may be discharged from the caseload if not requiring assistance;
- Adviser caseload provision currently covers approximately 5.5% of the estimated dementia prevalence in Somerset;
- each Adviser may additionally be supported by trained volunteers from the Alzheimer's Society whose primary function is to provide follow-up telephone support;
- Advisers are trained to develop, with patient and carer, an agreed 'information plan' which indicates when in the dementia journey information is likely to be needed and where it can be found;
- networking of Advisers with other dementia service provider organisations, including benefit agencies, is actively promoted.

Benefits of this role include:

- ✓ Low relative cost;
- ✓ 85% of surveyed service users felt listened to by Adviser;
- ✓ 81% of carers felt the information provided was relevant;
- ✓ 66% of patients, and 86% of carers, felt the Adviser helped them access other services;
- ✓ service users prefer visits in their own home (Alzheimer's Society, 2010).

Cost

- the service costs £145,285 per annum for 2.5 WTE advisers including administration support and overheads. The salary for each whole time equivalent Adviser is £20,909 per annum.

Contact: Debbie Donnison, Alzheimer's Society, ddonnison@alzheimers.org.uk

5. Dementia integrated care pilot

This is a secondary care based, and provided, mental health nurse liaison role in one town in Cornwall. Key features include:

- joint commissioning by PCT and local council;
- this service is part of the Department of Health demonstrator site programme, a 2 year pilot which completed in April 2011;
- the new service model comprises several components:
 - named Memory Nurses, based with the community mental health team, allocated to each GP surgery to undertake the majority of case management and signposting of dementia patients registered at that surgery, including fast-tracking new patients into the diagnostic service;
 - Dementia Liaison Nurses provide specialist and regular in-reach support to care homes, community hospitals and GPs;
 - GP dementia diagnostic service following specific training and with support from the local community mental health team;

- improved partnership working with social care provider;
- the Memory Nurse role is staffed by a combination of mental health auxiliaries and community mental health nurses, cases being allocated according to complexity;
- the overall service has also identified Dementia Link Workers in local district nursing and community hospital teams, who receive additional dementia training in order to provide peer support in their organisations;
- the Memory Nurses do not carry a caseload, but all patients with dementia at the GP surgery they are linked to will be known to them in list form. Case management is then provided as necessary on a needs basis;
- links have been developed with the community complex care teams so that where general nursing issues arise the community matron becomes involved;
- the secondary care provider provides nurse training and ongoing professional development and governance.

Benefits of the role include:

- ✓ a rise in dementia recorded prevalence from 36% to 64% of predicted prevalence during 22 months' running of the pilot service;
- ✓ all patients diagnosed with dementia are now being provided with an individualised care plan at diagnosis;
- ✓ high patient and carer satisfaction ratings for primary care dementia care under the new service;
- ✓ named Memory Nurse for each GP surgery facilitates liaison, even though the Nurse isn't actually based in the surgery;
- ✓ facilitation of appropriate care pathways;
- ✓ high staff satisfaction ratings for the service including perceived effectiveness, and better GP skills in the diagnosis and management of dementia;

- ✓ new service de-coupled from existing mental health services and centred on the person with dementia and primary care to encourage uptake.

Cost

- the service costs £230,916 per annum, covering an approximate population of 27,949 of whom 225 are registered as having dementia;
- these costs include new staff (One Band 6 mental health nurse's pay at £20,771 for 6 months on the project, one project support worker's pay at £16,000 per annum, and one project manager's pay at £35,000 per annum);
- the costs also include those of existing secondary care staff whose time was wholly or partially co-opted for the project;
- all figures are drawn directly from the Primary Care Trust's cost submission to the Department of Health's Demonstrator Site programme.

Contact: Angie Turner, Service Lead Complex Care and Dementia, Cornwall

Partnership NHS Foundation Trust, Angie.turner@cft.cornwall.nhs.uk

5. Admiral Nurse service

Admiral Nurses are qualified mental health nurses who specialise in dementia care. They were established in 1999 as a result of the experiences of the family of Joseph Levy, who had vascular dementia and was known as Admiral Joe because of his keen interest in sailing.

The Admiral Nurse Service is run by the charitable organisation Dementia UK in partnership with NHS providers and commissioners, local authority social services and voluntary and community organisations. There are currently around 90 Admiral Nurses in England, with clusters in the South East and the West Midlands but none in the South West to date.

Although the majority of Admiral Nurses are based in NHS Trusts, some work across a range of sectors and organisations including memory clinics, primary care services, hospices, residential and nursing homes, and social services.

Admiral Nurses aim to maximise the quality of life for people living with dementia and their families using a family-centred approach, including comprehensive assessment and a range of psychosocial interventions.

This example is of an Admiral Nurse Service in Worcestershire.

Key features include:

- the Admiral Nurses are band 6 community mental health nurses, with one Band 7 team leader;
- the Nurse provides skilled needs assessment, detailed information and practical advice, guidance over accessing local services effectively, and emotional and psychological support during the diagnostic process, for the person with dementia and anyone involved with them (including family, carer and professional carers);
- the Nurse also provides assistance for carers or families to improve skills in care-giving, to promote positive approaches to living with dementia, and to enable them to express their wishes and views about services received;
- the Nurse is able to provide specific interventions such as psycho-education, coping strategies, anxiety & stress management, family-centred care and end of life support;
- co-ordinated care provision is facilitated by collaborative working with other health and social care agencies in the statutory, independent and voluntary and community sectors;
- the Admiral Nurse 'brand', together with training and ongoing personal development (including an annual national forum), are provided by the charitable organisation Dementia UK;
- being a specialist service the Nurse may also be involved in end of life care for the person with dementia;

- the role has been in existence in many areas for much longer than the Department of Health demonstrator site programme: NHS Worcestershire has employed Admiral Nurses since 2003.

Benefits of the model include:

- ✓ a study of the Admiral Nurse Service in Flintshire, Wales, found that 91% of carers rated the service as 'excellent' (Woods, 2009);
- ✓ high intensity service offers more scope for therapeutic intervention and complex needs assessment for both the person with dementia and their carer(s) and family;
- ✓ high intensity service significantly reduces need for CMHT input;
- ✓ long-term care and support;
- ✓ support for Worcestershire Dementia Advisers;
- ✓ greater opportunity to delay care home placement and avert hospital admission.

Cost

- cost per Band 6 Nurse is approximately £38,000 per annum including on-costs;
- in Worcestershire 7.5 WTE Band 6 Admiral Nurses have been commissioned, with an additional Band 7 lead nurse at an annual cost of approximately £45,000;
- additional costs include administrative support (sometimes provided by the hosting secondary care organisation) and training and professional development (this is borne by Dementia UK, roughly £4000 per nurse per annum including postgraduate study fees);
- because there are a number of differences between Admiral Nurse roles across England these costs only apply to the Worcestershire service and should not be taken as an indication of likely cost of another service with the same name elsewhere.

Contact: Kate Read, Worcester University, k.read@worc.ac.uk

6. End of life dementia care service

This is a community based, third sector provided, specialist end of life mental health nurse role in London. Key features include:

- the not-for-profit housing and care organisation Housing 21 has employed one specialist community mental health nurse with expertise in dementia, end of life care, symptom control and effective communication;
- the nurse, called a Dementia Voice Nurse, has both mental health and general nursing qualifications;
- referrals are accepted from anyone: health or social care professional, person with dementia, carer or family;
- being an expert practitioner, advocate and facilitator the nurse is able to support the multiple and complex needs of people with dementia nearing the end of their lives. These needs are identified and monitored through on-going assessment of people's health and wellbeing;
- empowerment of family carers is critical in helping people with dementia to remain at home for as long as possible, such empowerment being subject to a number of local contextual factors (Dutton, 2010);
- improved assessment and management of pain, including education of other care workers;
- the provision of consistent links with primary care, secondary care services and voluntary and community sector agencies;
- the Dementia Voice Nurse takes on responsibility for the sourcing and effective co-ordination of existing services for her patients;
- as well as caring for patients in their community setting, the Dementia Voice Nurse also follows them up if they are in hospital wards, giving opportunities for education of staff in those settings;
- a London Dementia Voice Nurse won the Dementia Nurse of the Year award in 2010.

Benefits of the service include:

- ✓ savings of £239,000 over 19 months through reduced acute hospital and care home admissions and reduced need for ambulance services;
- ✓ this includes an estimated avoidance of 250 care home days during the 19 month period;
- ✓ 75% of service users died in their preferred place of death, where that preference was known;
- ✓ the Nurse has contributed to the assessment of situations, and offered responses, from an holistic, neutral standpoint.

Cost

- Information unavailable.

Contact: Rachel Dutton, Housing 21, rachel.dutton@housing21.co.uk

“My husband’s moods are now much more settled and he continues to be active with the choir and local community... He would be lost without the support of our memory nurse”

[Carer feedback on Cornwall memory nurse service]

"The isolation of those with dementia and their carers requires proactive interventions and support as many carers, often due to their age profile, do not have the energy, or time, to access services or information for themselves."

[Mike Vango, carer, Torbay]

4. Analysis of key differences in existing roles

Function

The majority of existing dementia support worker roles predominantly function as named contacts for people with dementia, their carers and their families (service users). They assist with navigating through, or signposting to, suitable support services at times which suit service users best.

Some roles also provide pre-diagnosis support, both for service users and for primary care and specialist diagnostic services, the support therefore being continuous from pre-diagnosis through to end of life. This benefits the person with dementia and their carer but also offers cost benefits by allowing care pathways to be streamlined.

A few roles provide active liaison between primary care, secondary care, social care and third sector providers, including advocacy for the person with dementia and/or their carer to ensure they receive the care they need and to guide them through the process. This seems to be particularly beneficial to carers, resulting in them being less susceptible to carer stress or depression and less likely to stop being able to care for the person with dementia. Furthermore, a recent paper published by the Alzheimer's Society supports the commissioning of brokerage services to facilitate and empower access to personal budgets among people with dementia (Alzheimer's Society, 2011).

Finally, some high-intensity roles provide more detailed needs assessments and specific therapeutic interventions for the person with dementia, their carer and/or their family. Such interventions may include coping strategies, emotional support, specific psychological support for anxiety and/or depression, and support with transitional stages in the dementia journey.

Focus of support

There are clear differences between different support worker roles in relation to the main focus for the support they offer. Some services are centred more around the person with dementia, whilst others focus on the carer or family. Although most roles do acknowledge the needs of both parties, adequate consideration of the past and current relationship between them and how that might impact on each person's support needs may not always be clearly defined. Higher intensity roles such as the Admiral Nurse Service may be better able to assess these relationship factors and apply them to a tailored support programme for the person with dementia and their carer: this offers the potential to increase the longevity of a strong relationship and thus the length of time care continues in the family home (Ablitt 2009).

Some of the challenges related to the focus of support include a need to respect the autonomy of the person with dementia yet adequately support the carer or family. There is often a difference in outlook between that of the person with dementia and that of their carer. A previously balanced relationship will have developed into a caring/cared-for relationship and this may put strain on both parties (Hogg 2010).

Role competencies

Current dementia support worker roles vary in terms of prior experience required and this is reflected in their salary costs. The minimum qualification requirement indicated in this evaluation is NVQ level 3 or similar; the maximum salary level is an experienced mental health nurse (NHS Agenda for Change Band 6 or 7).

Evaluations of existing roles, and research findings, suggest that the most important personal features of a successful dementia support worker are the possession of compassion, empathy and warmth towards service users (De Vries, 2010).

Promoting integrated working

Many service delivery models utilise joint health and social care commissioning arrangements. This is intended to maximise on joint working and liaison between the organisations, and the efficient use of resources.

Ensuring proper and effective liaison between primary care, secondary care and third sector providers can challenge pre-existing ways of working, and needs careful consideration to ensure effective governance and working arrangements.

Collaboration with voluntary sector and other agencies

A key feature of the different roles has been to form good working relationships with, and knowledge of, voluntary and community sector services and to offer information and signposting.

Location of workers

The findings of published research (De Vries, 2010) together with experience from some existing roles suggest that locating dementia support workers in primary care - for example by providing a desk and the ability to access and update patient computer records in a GP surgery - can be extremely effective not just for the quality of service provision but also for promoting earlier diagnosis and improved diagnosis rates.

Cultural change

The impact of having a named dementia support worker appears to improve both the confidence and expertise of other health and social care workers in their approach to working with people with dementia and their carers. It also appears, importantly, to support the normalisation of dementia as a long term condition and reduce stigma associated with the disease.

Benefits realisation

The different roles all appear to show evidence of improved quality of care. There has generally been a reduction in the time taken to diagnose dementia and, in the case of the Cornwall model, a dramatic rise in local recorded diagnosis rates. Improved availability of support and services is clearly valued by people with dementia and their carers and having someone to contact can reassure and prevent crisis.

Some models have evidenced that service users have been able to remain in their homes for longer, some to the end of their lives. Access to diagnosis, care, medication, services and support has improved. Dementia support workers have been shown to contribute to a more holistic for the person with suspected dementia, and carers or families.

Although the amount of quantitative data available from different community dementia support worker roles varied significantly, a broad analysis has been possible. This analysis takes the cost of the role (including overheads or on-costs) and applies that cost to the caseload of dementia patients (where defined) and the total population covered geographically:

- The service cost varies from £8.26 [integrated care model] to £0.24 [Adviser with diagnostic support model] per person of the total population, or £1,026 to £21.43 per person with dementia [same models] (appendix 8.4).

A similar analysis may be applied to identified savings as a result of investing in a community dementia support role:

- Identified savings vary from £0.49 [Adviser with diagnostic support model] to £5.27 [memory nurse model] per person of the total population, or £42.86 to £300 [same models] per person with dementia. All figures are per annum (appendix 8.4).

It is, however, important to stress that realisation of full financial benefit may not be possible for at least 4 years from the start of provision of a new support worker role (Department of Health, 2008), and none of the roles - where such cost benefits have been measured - have been running for more than 2 years to date. This is because there is a delay to measurable reduction in permanent care home placement costs, even if a reduction in other costs such as acute hospital admission, prescribing or community mental health team referrals may be much sooner.

“Richard was diagnosed before the advent of Dementia Advisers, so we muddled our way through, trying to find information and help, through the maze of different set-ups, who did not seem to be in contact with each other. To have this service to call on straight away after diagnosis is a really splendid idea, and must be very helpful and reassuring”

[Carer in Somerset]

Comparison table of different dementia support worker roles

This table is intended to facilitate comparison of 4 dementia support worker roles drawn from the specific examples given in section 3.2.

The cost per 100 patients with dementia is derived from the cost of the service and the current recorded prevalence of dementia in the geographical area covered. It is not the cost per patient on any given caseload.

Title	Memory Nurse	Dementia adviser	Integrated care memory nurse	Admiral Nurse service
Location	Cornwall	Staffordshire	Cornwall	Worcestershire
Base	Primary care	Third sector	Secondary care	Secondary care
Function	Assessment towards diagnosis, education, proactive contact, signposting, enabling, development of care plans, leading complex care co-ordination, undertaking annual QOF dementia reviews. Case load held (180 per WTE). All dementia and MCI patients in area kept on caseload.	Signposting and six-monthly proactive information provision for patients and carers. Pre-diagnosis patients accepted. Information plan development. Case load held (200 per WTE). 6% of patients with dementia on caseload at any time.	Support service for GPs, co-ordinating care on basis of need, and providing opportunistic education for GPs. Provision of face to face contact with patients and carers for assessment of needs and information provision. No case load but awareness (by register) of patients with dementia at each GP surgery attached to.	Expert practitioner, patient advocate and facilitator. Variably commissioned depending on location. Complex needs assessments undertaken. Specific interventions offered such as psychotherapies. Caseload held (80 per WTE). 9% of patients with dementia on caseload.
Role	Band 6 nurse	NVQ3	Band 6 MHN	Band 6 or 7 MHN

Title	Memory Nurse	Dementia adviser	Integrated care memory nurse	Admiral Nurse service
Benefits	Patients and carers supported through journey from pre-diagnosis to end of live care. Delayed care home placement. Reduced secondary care memory assessment (reduced costs). Crisis avoidance resulting in reduced hospital admissions. Data entered onto GP computers.	Remain on caseload, no need to re-refer. Users report satisfaction of government outcomes. Dementia awareness-raising amongst primary care staff.	Reduced numbers needing CMHT or memory clinic input. Better signposting to appropriate service. Better GP liaison for education and support.	Patients remain at home for longer. Reduced acute hospital and care home admissions. High intensity specialist support reduces need for CMHT, even for specific therapies. Improved care co-ordination. High carer satisfaction in surveys. Brand value for ready identification and fund-raising.
Risks	Cost. Control of workload with rising prevalence.	Stigma around 'dementia' in job title. Information-sharing with health and social care less easy.	No caseload: new problem requires re-referral by GP. Contact not pro-active unless patient is currently actively case-managed.	High-intensity interventions may restrict availability; however the service mitigates this risk by offering variable intensities of support to a wider range of service users.
Cost /100 patients	£30,254	£3,714	£102,600	£4,209

Table 1: comparison of 4 typical existing support worker models. Cost per 100 patients with dementia has been calculated from available data on service cost and local dementia recorded prevalence. MHN = mental health nurse; NVQ = National Vocational Qualification.

Note on estimating costs

The cost per 100 patients has been calculated using the sum of support worker salaries plus overheads or on-costs. The on-costs can be taken to include the cost of training, ongoing professional development, travel, fixed assets (e.g. computer, room space, mobile phone) and administrative support. The authors have been careful to consult with the key stakeholders for each role to ensure the accuracy and comparability of data, and in 3 out of the 4 roles illustrated the total service delivery model cost to the applicable PCT was acquired. Because some roles do not hold a specified caseload, or the caseload is a small fraction of the total dementia population, the cost of the role is given as that per 100 patients on dementia registers in the geographical area covered by the role workers.

Discussion

It is suggested that a role positioned within the community that is responsive and comprehensive in order to meet the needs of people with dementia and their carers and families, and is also in a position to work collaboratively with other health and social care professionals providing advice, education and support, is required in areas that do not currently commission such a role.

With the potential cost savings in the health and social care system, there is scope to ensure that provision is cost-neutral after 4 years from implementation.

Furthermore, with non-recurring pump-priming funding announced by the Government in September 2011 (Behan, 2011) the opportunity exists to introduce new roles and redesign pathways to achieve better outcomes for people with dementia, and their carers and families.

The first challenge faced by commissioners is which specific dementia support worker role to adopt or adapt in their area, to maximise on both qualitative and quantitative benefits, minimise risks, and fit best with existing services.

The second challenge faced by commissioners and providers is how to ensure, and adequately demonstrate, that the service delivers on the intended outcomes. This will be essential to guarantee the longevity of the service in an era of financial constraint.

To assist in tackling these challenges we hope that commissioners and providers find the examples of existing services earlier in this document helpful. Subsequent sections of this paper are intended to provide additional guidance.

Considerations

This list of issues for commissioners to consider has been collated using information and feedback from stakeholders in existing services, dementia care researchers and service users.

- A face-to-face, rather than telephone, support service is likely to maximise the confidence felt by the person with dementia, their carer and/or family, that the support they need is actually available.
- The support worker role should aim to support the person with dementia, but also to work in partnership with - and directly support where necessary - any carer or family members involved (see appendix, section 8.2). The emphasis on support, not care, is particularly made by service users. Careful consideration may be needed about how to strike the best balance between respecting the autonomy of the person with dementia and providing adequate support to the carer or family, whether their needs are congruent or conflictual.
- The information needs of the person with dementia ('more in the present, how to manage now') are likely to be very different to those of carers or family ('more future-facing, what's likely to happen'). The type and degree of information required, and provided, is also likely to vary over time, for example shortly after diagnosis, or when service users move into an area from elsewhere. These factors are likely to impact on the workload of support workers.
- A clear definition of any new dementia support worker role, and how that role fits into existing care pathways and interacts with other services, is important in maximising the understanding and acceptance of the role by existing health and social care workers. Priming local service providers about the new service before it begins will assist with this process.

- Co-location of the support worker with specialist dementia services or local GPs is very beneficial. The host organisation will gain a sense of ownership of the service even if they are not directly providing it, which improves the quality of liaison and co-working.
- Strong links with primary care are essential. Dementia is a long-term condition and many of the problems which people with dementia experience are not directly caused by the dementia itself. Primary care is ideally placed to provide the majority of medical support and long-term management, but would benefit from the expertise and support which this role could provide.
- People are more likely to consider a service which is endorsed by their GP.
- The visible presence of post-diagnosis dementia support can help break down primary care barriers to diagnosis and dramatically improve diagnosis rates in the community. The effect on recorded diagnosis, and consequently access to treatment and care, appears to be most significant in models where the support worker is co-located in primary care.
- The potential for a support worker to assist and inform the diagnostic process should be considered by commissioners.
- The maintenance of a defined caseload by the support worker facilitates personalised care for the patient and carer and supports workload management. Development of entry criteria is important to avoid overloading the support worker as the role becomes established.
- Service provision by a voluntary and community organisation may result in greater acceptance, particularly if people with dementia, their carers and

families have had less positive experiences of care in the past from statutory health or social care organisations.

- Physical and contractual links between the support workers themselves and local primary care, secondary care and voluntary and community organisations is beneficial. For example, a dementia support worker might be based in a GP surgery, employed by a third sector organisation (who is the provider of the service) and receive training and professional development from the local secondary care mental health provider.
- Service delivery by voluntary and community organisations may also result in better liaison with other voluntary organisations such as Age UK, Citizen's Advice Bureaux etc. The service should not exist solely to promote the services of one organisation.
- It is essential to ensure any workers appointed to this role evidence both a range of appropriate competencies in dementia (see appendix, section 8.1) and also display the qualities people with dementia value, for example empathy, warmth and caring (see appendix, section 8.2).
- Advocacy is highly beneficial to people and dementia and carers/families. This can be both through representation at commissioner level, to inform the design and development of services, and also at service user level, to ensure people receive all that they are entitled to.
- A navigator or signposting role is only as good as the services to which people are signposted. However it is of importance in significantly reducing the inappropriate use of other local services.

- A two- or three-tier service, combining a low intensity advisory service with a moderate-to-high (or moderate *and* high) intensity specialist mental health worker, has been shown in Worcestershire to be extremely successful. This model therefore may be of interest to other areas.
 1. Low intensity interventions include signposting, patient and carer education, monthly proactive phone calls and local group-delivered support. In Worcestershire this is delivered by Dementia Advisers.
 2. Moderate intensity includes greater monitoring with fortnightly visits to help prevent deterioration of service users' functional status and promote independence.
 3. High intensity interventions include addressing complex care needs and delivery of specific interventions such as family therapy, in order to make significant improvements to the service users' well being. In Worcestershire moderate and high intensity services are delivered by Admiral Nurses.
- High quality supervision and continuing professional development is essential for all workers.
- People living with dementia benefit from roles where the support worker is actively involved in primary healthcare team meetings, including the discussion of complex and end of life care needs.
- A shift of care provision from reactive to proactive is likely to be highly valued by people with dementia and their carers, and be more effective in preventing crises.
- Development of good liaison with general and community hospitals is important to ensure good inpatient dementia care and to facilitate more timely discharge back into the community.

- Joint health and social care commissioning of dementia support services is beneficial, so that those organisations which stand to benefit from improved efficiencies are also investing equally in the service creating them, and to encourage true joint working. Joint commissioning may also facilitate the securing of resources over a longer term to ensure the future of a new or hitherto pilot service.
- Where end of life care is provided this is likely to be most effective if the support worker has dementia care, mental health and general nursing skills, to address all aspects of symptom control.

Evaluation

Any commissioned service should have adequate monitoring and performance indicators to be able to demonstrate effectively the value of continued provision of the service.

Indicators might include:

- patient and carer satisfaction.
- quality of care.
- referrals to specialist dementia services or memory assessment services.
- primary care diagnosis rates (QOF DEM 1).
- primary care clinical reviews at least every 15 months (QOF DEM 2).
- primary Care investigations and tests in screening for dementia (QOF DEM 3).
- general hospital admissions, and readmissions within 30 days for people over 65 years of age, and people with a primary or secondary diagnosis of dementia.
- inpatient psychiatric bed use by people with a diagnosis of dementia.
- length of stay in hospital (general, community, and psychiatric inpatient beds).

- primary care service use.
- antipsychotic drug prescribing.
- care home placement.

It appears that any dementia support worker role needs to provide an ongoing and integrated service throughout the whole care pathway (see Figure 1 on p.43: Dementia Care Pathway), and evidence suggests that this will lead to better outcomes for the person with dementia.

“Ideally a home-based service should NOT simply be a care service – it should provide trained workers who can facilitate and support the person with dementia continuing to perform tasks and pursuing activities as before i.e. going to the library, taking part in social activities, music etc. Someone needs to begin to get to know me, to be able to match people/services with my requirements.”

[Person with dementia, Regional User Involvement Project]

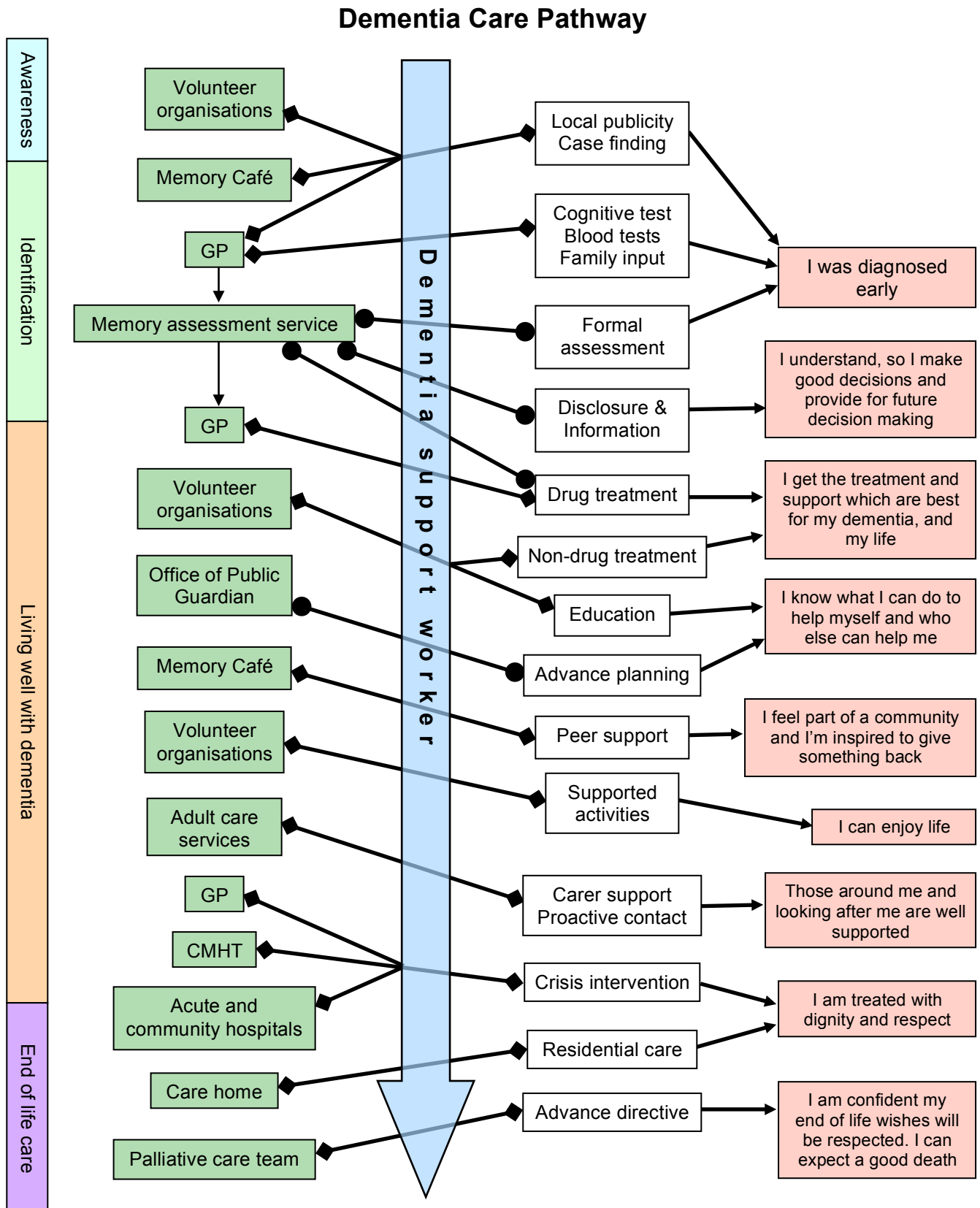


Figure 1: Dementia care pathway with reference to SCIE Opportunities for intervention and the Department of Health's quality outcomes.

KEY: ◆◆ Liaison/raising awareness/signposting role. ●● Advocacy/supportive role

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8. Appendix

8.1 Competencies

A competency framework is helpful as a means of ensuring staff have the necessary knowledge and skills to carry out their roles within dementia care. The framework below offers some suggested competencies required for a typical memory support worker in the community intended as a helpful starting point.

It has been mapped where possible against national occupational standards. This has been based on the competency framework developed by South West Dementia Partnership. For further information:

www.southwestdementiapartnership.org.uk/workforce-development/

“Dementia is one of the most challenging illnesses to cope with both from the standpoint of the patient and, most poignantly, that of the carer.”

[Person with dementia, South West Dementia Partnership Regional User Involvement Project]

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Principle	Dementia Competency Framework
1. Prevention – Promote health and social wellbeing	Communicate with individuals about promoting their health and wellbeing & maintaining cognitive and mental wellbeing (HT2) Promote an information culture (GEN 29) Understand mental wellbeing and mental health promotion (CMH 301) Support individuals to retain, regain and develop the skills to manage their lives and environment (HSC344) Signpost to interventions with older people at risk of falls (OP F5) Provide tailored information to public and across all sectors of health and social care relating to prevention
2. Identification - Know the early signs of dementia	Understand and be able to describe dementia Understand key features of the theoretical models of dementia Know the most common types of dementia and their causes Understand factors relating to an individual's experience of dementia Dem201 (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45) Identify individuals with or at risk of developing long term conditions or related ill health (CHS42) Expert and detailed knowledge of different forms of dementia Provide education and teaching on dementia awareness to the general public and across all sectors of health and social care and families/carers
3. Assessment and diagnosis - Early diagnosis of dementia helps people	Provide information to individuals on how to live well with the diagnosis (CHS56)

receive information, support and treatment at the earliest possible stage	Support individuals to access and use information and resources (HSC26) Provide information and support to carers of individuals with dementia (CHS58) Work in collaboration with carers in the caring role (BSC387) Explain the need for an investigation of early signs of dementia in a way that is appropriate to the person Refer individuals to specialist sources of assistance in meeting their health care needs (CHS99) Be able to assess cognition and function specific to dementia Provide clinical information to individuals (CHS56) Develop care pathways for patient management (CHS173) Coordinate, manage and support the progress of individuals through care pathways (GEN79) Provide advice and information to individuals on how to manage their own condition (GEN14) Consider the person when assessing for dementia, taking into account usual interests, behaviour and support. Contribute to effective multi-disciplinary team working (GEN39) Observe, monitor and record the condition of individuals (HSC224) Signpost and link with hard to reach clients with dementia e.g. BME, younger people at risk. Knowledge of approved assessment tools Conduct pre-diagnostic screening for dementia Supporting individuals and carers through the screening/diagnostic process
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	Awareness of impact of diagnostic errors Understand the needs of younger people with dementia and their families Understand the needs of people with learning disabilities and dementia
4. Communicate sensitively to support meaningful interaction recognising that dementia may affect a person's ability to communicate and others may need to adapt	Understand the role of communication and interactions with individuals who have dementia (DEM 308) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45) Make use of the person's past experiences, culture and life story to support communicating with them Develop strategies to optimise individuals communication skills and abilities (CHS 151) Promote effective communication and relationships with people who are troubled or distressed (MH1)
5. Living well with dementia - Promote independence and encourage activity	Develop practices which promote choice, wellbeing and protection of all individuals (HSC45) Support individuals to identify and promote their own health and social well-being (HSC3112) Support individuals in their daily living (HSC27) Provide information and advice to support individuals in undertaking desired occupational and non-occupational activities (CME4) Provide a safe environment Contribute to supporting individuals in the use of assistive technology (SS OP 2.4) Enable individuals with long term conditions to make informed choices concerning their health and wellbeing (CMC3)

Develop practices which promote choice, well-being and protection of all individuals (HSC45)

Support individuals to represent their own needs and wishes at decision making forums (HSC366)

Collaborate in the assessment of the need for, and the provision of, environmental and social support in the community (GEN75)

Enable older people to cope with changes to their health and wellbeing (OP12)

Understand models of disability (SS OP 3.1)

Understand the person's life history

Facilitate person centred assessment, planning, implementation and review (HSC 3020)

Understand and meet the nutritional requirements of individuals with dementia (DEM 302) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45)

Signpost to therapeutic group activities

Recognise, respect and support the spiritual well-being of individuals (MH37)

Contribute to support of positive risk taking in everyday life (HSC 2031)

Understand the diversity of individuals with dementia and the importance of inclusion (DEM 310) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45)

Discharge and transfer individuals from a service or your care (GEN58)

Signpost for assistive devices to meet individual's needs

Awareness of and signpost to a range of psychosocial interventions e.g. reminiscence, reality orientation, cognitive stimulation, validation therapy, life story, art psychotherapies

	Knowledge and understanding of relationship centred care Understanding of issues around sexuality and intimacy Comprehensive knowledge and understanding around diversity and cultural issues Comprehensive knowledge and skills on the impact and adaptation of the environment and use of colour
6. Understanding and responding to unmet needs - Recognise communication of unmet needs and signs of distress resulting from confusion. Respond by recognising and meeting unmet needs, diffusing a person's anxiety and supporting their understanding of the events they experience	Contribute to working in collaboration with carers in the caring role (HSC227) Understand the person's experience of unmet needs, loss, identity, language, stress and different forms of communication Support individuals to prepare for, adapt to and manage change (HSC382) Respond to crisis situations (MH21) Identify triggers which cause behaviours that challenge the worker Be able to respond to behaviours through person-centred approaches Ability to advise others on communication of unmet needs and person centred approaches to respond to behaviours that challenge the worker
7. Family members and other carers are valued, respected and supported and are helped to gain access to dementia care advice	Enable carers to access and assess support networks and respite services (HN3) Work in collaboration with carers in the caring role (HSC387) Encourage family and friends to participate in shared activities with person with dementia Assess the needs of carers and families of individuals (MH6)

	Enable carers to support individuals (GEN20) Support families in their own home (HSC319) Signpost individuals whom are bereaved to appropriate services Knowledge of adult vulnerability and abuse
8. Work as part of a multi-agency team to support the person with dementia	Awareness of other agencies providing support Review and evaluate care management plans with individuals diagnosed with dementia (CHS85) Assist in the transfer of individuals between agencies and services (AG3) Contribute to effective multi-disciplinary team working (GEN39) Coordinate the progress of individuals through care pathways (GEN79) Liaise between primary, secondary and community teams (and acute teams) GEN44) Enable workers and agencies to work collaboratively (MH79)
9. Understanding the context of care and support for people with dementia and their families/carers	Understand the importance of equality, diversity and inclusion when working with individuals with dementia (DEM 209) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45) Understand key legislation (Mental Capacity Act, Deprivation of liberty) and agreed ways of working that ensure the fulfilment of rights and choices of individuals with dementia while minimising risk of harm Understand safeguarding

	Understand how to maintain privacy, dignity and respect when supporting individuals with dementia (DEM 211) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45) Be able to work in a person centred manner to ensure inclusivity of the individual with dementia Be able to work with others to encourage support for diversity and equality (DEM 313) (HSC21, HSC31, HSC41,HSC24, HSC35, HSC45) Understand the purpose and principles of Independent advocacy (ADV 301) Enable rights and choices of individuals with dementia whilst minimising risks (DEM 304) Signpost individuals to manage their financial affairs
10. End of life care – support is needed for those with dementia and for their families and carers	Awareness and provision of palliative care Support individuals through the end of life process (HSC385)
11. Dementia worker personal development and self care	Dementia worker professional and personal development and self care Ongoing professional development in dementia care ensuring up to date knowledge of research and evidence based practice
12. Service improvement is embedded throughout all practice	Understand and implement evaluation of services Knowledge of and application of different observational methodologies

8.2 Dementia support worker function checklist for commissioners

This checklist is intended to assist commissioners to identify local dementia support services currently provided and then easily identify service gaps. In addition it may assist commissioners in deciding the best provider and physical location (or base) for any new support service, so that it fits in optimally with existing services.

Where a service already provides a given support function, tick the 'yes' box and enter details in the green section.

Where a given support function is not provided, tick the 'no' box and enter details of possible, planned or proposed future service.

Support function	Currently provided?	By whom?	Where located?
Joint commissioning	Yes ☐		
	No ☐		
Primary care liaison ¹	Yes ☐		
	No ☐		
Existing support worker role	Yes ☐		
	No ☐		
Qualitative benefit measurement	Yes ☐		
	No ☐		
Quantitative benefit measurement	Yes ☐		
	No ☐		
Promote health and well-being of patient and carer ²	Yes ☐		
	No ☐		

Early identification of dementia ³	Yes	☐
	No	☐
Promotion of the benefits of early diagnosis ⁴	Yes	☐
	No	☐
Timely information provision	Yes	☐
	No	☐
Development of multi-agency care plan	Yes	☐
	No	☐
Support patient independent living	Yes	☐
	No	☐
Carer identification	Yes	☐
	No	☐
Proactively contact patient and carer regularly ⁵	Yes	☐
	No	☐
Signpost to local services ⁶	Yes	☐
	No	☐
Provide advocacy to support patient or carer ⁷	Yes	☐
	No	☐
Assistance with benefit eligibility and applications	Yes	☐
	No	☐
Support for future care choices ⁸	Yes	☐
	No	☐

Advice on driving	Yes	☐
	No	☐
Provision of specific interventions ⁹	Yes	☐
	No	☐
Links with local voluntary sector providers	Yes	☐
	No	☐
End of life care provision	Yes	☐
	No	☐

Commissioners may prefer to commission the majority of functions from one provider or as one role, or they may prefer to assign different functions to different provider sectors (health, social care or third sector) in order to encourage and support better channels of communication and co-working towards the common goal of better dementia care for patients and carers.

8.3 Service user and carer views

When discussing post-diagnosis support worker roles with service users and their carers in the South West region, common themes emerge:

1. Continuity is key – building a sustainable relationship with the person with dementia and their family.
2. Many examples were cited of people being diagnosed but not being given any information or the option of a post-diagnosis discussion.
3. People living with dementia have described being left to fend for themselves after the diagnosis, only being advised to return if things get worse.
4. People would like information tailored to their requirements at that time.
5. People want to be signposted/navigated and supported to find information and resources.
6. Sometimes people need support to understand and access what is on offer.
7. A key point of contact can make a real difference (including a helpline).
8. Attributes of the support worker such as personality, communication skills and how they work on behalf of people living with dementia can make a real difference. These attributes are independent of the role or organisation providing the service.

Other points identified from service user and carer feedback include:

- Engaging the GP in the service is likely to be successful as many people will more seriously consider a service endorsed by their GP.
- The support worker should be designed, first and foremost, to support the person living with dementia (rather than their carer or family). Feedback from some advisers, social workers and nurses illustrated that when they made contact with the family the person with dementia was often actively excluded from discussions (e.g. sent to a neighbour's house while the worker visited).
- People with dementia describe wanting support rather than care, to help them live as independently, or with as much autonomy, as possible.

- An awareness that the information requirements of the person living with dementia are likely to be different to those of their carer or family. The person is likely to want information relevant to the present, while the carer or family are likely to want information relating to the future.
- A 'one stop shop', where different needs are dealt with in one location, is extremely useful to service users. It aids inter-agency communication and reduces the need for several home visit appointments from different workers.
- The support worker should have a range of options at their fingertips and not exist solely to promote the services of one organisation.
- Several contacts between support worker and service user in a short period of time may be necessary to help address a range of relevant issues.
- A robust system for recording service delivery is vital in ensuring efficient use of support worker time, and sharing of information between agencies is important but often presents a hurdle.
- The support worker role is just as important for service users moving into an area as those newly diagnosed with dementia. Prompt signposting to local services similar to those previously enjoyed in another area is important.

8.4 Calculations for cost/benefit figures

The following calculation/data sources were used for the cost/benefit figures on page 35.

Cost of service

1. North Staffordshire Dementia Adviser with diagnostic support model:
 - a. Total cost of dementia Advisers = £150,000 per annum (page 20)
 - b. Population of PCT = 615,000
 - c. Recorded dementia prevalence = 7000
 - d. $a \div b = \text{£}0.24$ per person in total population
 - e. $a \div c = \text{£}21.43$ per person with diagnosis of dementia
2. Newquay Integrated Care Pilot model:
 - a. Total cost = £230,916 per annum (page 25)
 - b. Population of Newquay covered by service = 27,949
 - c. Recorded dementia prevalence = 225
 - d. $a \div b = \text{£}8.26$ per person in total population
 - e. $a \div c = \text{£}1026.00$ per person with diagnosis of dementia

Financial benefit of service

3. Lostwithiel, Cornwall, Memory Nurse model:
 - a. Total savings identified = £26,345 per annum (page 18)
 - b. Population of Practice covered = 5000
 - c. Current recorded dementia prevalence = 88
 - d. $a \div b = \text{£}5.27$ per person in Practice population
 - e. $a \div c = \text{£}300$ per person with diagnosis of dementia
4. North Staffordshire Dementia Adviser with diagnostic support model:
 - a. Total savings identified = £300,000 per annum (pages 19-20)
 - b. $a \div 615,000 = \text{£}0.49$ per person in PCT population
 - c. $a \div 7000 = \text{£}42.86$ per person diagnosed with dementia

Notes to checklist

¹ The presence of regular contact (or specified communication channels) between primary care, secondary care and third sector for the purpose of raising dementia awareness and providing solutions to patient or carer challenges on a case by case basis.

² Any service which actively checks patient and/or carer for health or well-being problems which are then flagged up with appropriate primary or secondary care services.

³ Any service which picks up on clues to the presence of dementia and signposts to suitable assessment providers.

⁴ Both with primary care and with patient, carer and/or family to support progress to assessment.

⁵ The frequency of contact and caseload defined, with suitable acceptance and discharge criteria for the service.

⁶ Any service which patient and carer have direct access to (e.g. by telephone, e-mail) to request assistance in where to access a required service. If there is a service providing proactive contact this may also provide signposting.

⁷ Such as benefits applications, Lasting Power of Attorney applications or supporting the patient through the diagnostic process.

⁸ Lasting Power of Attorney, advanced care directives, end of life care choices.

⁹ Such as problem-solving, cognitive stimulation, counselling or psychotherapy.