

The Dementia Voice Nurse Service Pilot

**Overview of Findings and Learning from
the Evaluation of the Two Year Pilot Programme**

December 2008 – December 2010

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1 Summary of Findings

Housing 21 - Dementia Voice was awarded funding from the King's Fund for a two year pilot project to employ a dementia specialist community-based End of Life Care Nurse to work within its dementia services team in London. The Dementia Voice Nurse (DVN) Service opened for referrals in December 2008. The information reported here is based on data gathered across the 24 month pilot period.

1.1 Numbers of Referrals, Assessments and Deaths

For the two year pilot period:

- 51 referrals were received
 - 2 were withdrawn before assessment
 - 5 died very soon after they had been referred before there was time to carry out an assessment.
- 42 assessments were carried out by the DV Nurse
- 4 of those assessed were found not to meet the service criteria
- 1 was withdrawn after assessment.

At the end of the pilot period:

- there were seventeen service users on the DV Nurses case load
- 20 had died whilst receiving the DVN service, the majority (84%¹) in their preferred place of death.

1.2 Achieving the Service Aims

The remit of the DVN role was for a qualified nurse with expertise in dementia, end-of-life care, symptom control and effective communication to act as an expert practitioner, advocate and facilitator. The multiple and complex needs of people with dementia nearing the end of their lives were to be identified and monitored through ongoing assessment of patients' health and wellbeing. The DVN was to liaise with external agencies and provide a consistent link with GPs and other primary healthcare practitioners. Crucially, the Nurse was to be able to fill an important gap - taking on the responsibility for the sourcing and effective coordination of existing services. The evidence gathered from the evaluation of the pilot service strongly indicates that the DVN has done just that, and the service has been successful in achieving its aims:

- improving quality of life, and quality of dying, for people with dementia
- improving the availability of support, services and equipment for people with dementia at the end of their lives and for their families

¹ For those whose preferred place was known

- improving support available to Housing 21 staff and staff from other care and health organisations
- empowering staff by improving their knowledge and skills in supporting clients in end of life situations.

1.3 Key Outcomes of the DVN Service

Through the specialist assessments and interventions provided by the DVN:

- the amount of support provided to the person with dementia or the family carer has increased
- service users have been able to remain in their homes for longer than they otherwise would have done, some through to the end of their lives
- their diagnoses, care, medication, services and support have improved/increased including many incidences of significantly better identification and management of pain
- there have been avoidances of admissions to hospital and nursing homes
- the ability of family carers to cope has increased
- crises and breakdowns in care have been avoided
- families have been able to recognise their relatives are nearing the end of their lives and have been given – often for the first time - advice and information regarding planning and decision making for the future
- professionals from social and health sectors in many different settings have been supported by and highly appreciative of the service
- overall, professionals from health and social care sectors have reported, both formally and informally, that the involvement of the DV Nurse has made a big difference to, among other factors, the well-being of the people with dementia and their family carers; the ability of the family carer to cope, to provide care, as well as the amount of support they receive from external agencies
- some services, including those on hospital wards, have changed practices and procedures in the way they care for people with dementia following their joint working with the DVN
- care workers' and team managers' concerns about changes in health or wellbeing of a service user are now taken seriously by care managers and GPs as they are channelled, investigated and verified through the DVN
- there have been improvements in communications and better co-ordination of services

- at the end of the two year pilot period the DVN service was granted core funding and has become a permanent part of the Dementia services provided by Westminster
- the Department of Health has granted three years of funding in order to expand the DVN service to Kent and Bristol. Other PCTs and Local Authorities are considering funding the service in their areas.

1.4 Key Benefits of the Service

1.4.1 Meeting Needs and Making a Difference

Findings from the evaluation show that the DVN Service offers a unique and flexible service that is successfully filling the gaps and meeting the needs that were identified before the service began.

During the two year pilot period the operation of the DVN Service had a big impact on circumstances for people with dementia and their families in Westminster. There is evidence of significant improvements for service users in terms of wellbeing and quality of care. The DVN has had a positive impact on family members caring for their loved ones in terms of waylating their fears and anxieties, enabling them to reach informed decisions on behalf of the people with dementia who no longer have mental capacity, reducing family conflict, and enabling them to provide the right kind of care and support so that the service users' quality of life is as best as can realistically be achieved.

Views received from family carers have been extremely positive showing that the DVN greatly enhanced their knowledge and understanding of what was happening to the person they were caring for, greatly improved their wellbeing and stress levels, made a very positive difference to the person with dementia they were caring for, and gave them the opportunity - often for the first time - to start to plan for the end of life.

In answer to statements relating to the degree of difference the involvement the DVN makes to people with dementia and their families, the majority of professional workers stated across a range of indicators that the difference is big.

Overall there has been a very positive attitude towards, and a welcoming of, the DVN Service in Westminster. There is a strong recognition from a wide range of professionals, including hospice staff, Community Matrons, health and social care sector workers, that the service is addressing very important gaps including difficulties being faced in generic palliative care and in residential homes² in dealing with people at the end of their lives with dementia.

1.4.2 Uniqueness

- The DVN Service is a service which focuses on people with dementia, a group not used to having palliative services dedicated to it
- The service is a longer term service than generic services. This is essential for people with dementia whose disease progression is difficult to determine or predict
- The service is multi-setting. Besides being a community service, the DVN Service has followed up patients in hospital, both psychiatric and physical wards. The DVN has been able to support and advise staff as well as providing continuity of care and a familiar face to the person with dementia

² E.g. a manager of two residential homes expressed how he has no support when residents express the wish to die in the residential home

- Being based in a care and housing organisation has been seen as greatly advantageous in giving the DVN:
 - impartiality when dealing with other services and professionals
 - the ability to advocate for patients and carers
 - great flexibility and autonomy
 - accessibility and acceptance equally by social care workers and managers and by health professionals
- The Nurse has wide and specialist knowledge and skills. Patients with dementia commonly suffer with co-morbidities and the DVN skills and knowledge of different conditions gave additional and valued support to staff in different specialist areas including those on psycho-geriatric wards, geriatric wards, general medical wards, hospices, nursing homes, Community Mental Health Team, District Nurses, and social services. This support from the DVN has made real positive differences for patients, family carers and professionals.

1.4.3 A Combination of Important Roles

- The DVN Service has worked successfully as a link service for referring, consulting and as a central resource. For example, Housing 21 staff consulted the DVN in areas they are not conversant with or when they wanted a diagnosis to be made for someone with memory problems
- The DVN has had a liaison role attending CMHT meetings contributing to discussions regarding patients who could also be under hospice care, Housing 21, JBK or extra supported residential care, etc
- She has taken on the key worker role for patients under Hospice care
- She has advocated for patients in terms of care packages.

1.4.4 Increasing Services and Choice

- The DVN has affected changes in medication for many service users, including the prescription of pain killers and anti-depressants
- She has increased access to appropriate services and support
- She has enabled family and professional carers to continue to look after service users in their preferred place of care
- The DVN has been able to maintain some patients at home who had been discharged from Hospice care and care management
- The DVN has provided a pro-active family carer support service during illness and after death
- Family carers have benefited from training, advice and advanced care planning with the DVN and from making choices of preferred priorities of care.

1.4.5 DVN Training

- The DVN offered a free training and support service for anyone in the Westminster area who wanted Dementia palliative care training in their work environment
- She has provided a series of very well received training sessions and talks to H21 staff and professionals from other settings including rehabilitation units, continuing care, and extra support units.

1.4.6 Cost Savings / Cost Effectiveness

It is estimated that the DVN service wholly or partly contributed to total cost savings over 24 month period in terms of avoided hospital, residential and nursing home admissions and ambulance services of £314,440.

1.5 Key Enablers for the DVN Service

Key enablers identified for the service include:

- Having a nurse with both psychiatric and general nursing qualifications is key, plus having additional knowledge and experience of social services, care providers and housing
- True partnership working. Key partners including:
 - Dementia Development Officer at Westminster City Council (Jude Sweeting)
 - Central and North West London Foundation NHS Trust
 - Consultant Psychiatrist/Lead Clinician Older Adults with Central and North West London Foundation NHS Trust (Dr Cornelius Kelly)
 - Consultant and Senior Lecturer in Old Age Psychiatry at Oxleas NHS Trust and Memorial Hospital (Dr Adrian Treloar)
 - Community Mental Health Team
 - Local General Practitioners (GPs have been very supportive in helping people to be cared for as long as possible)
 - St John's Hospice who have arranged for the DVN to have an office base at the hospice to improve her access to NHS information and communication systems
- The majority of professionals accepting and recognising the many benefits the role of the DVN can bring, including the Psychiatry Liaison Team, CMHT, palliative teams, district nurses, Housing 21 staff, care managers, consultants, ward doctors and their teams, and GPs who are happy to fax information at the request of the DVN and take notice of the requests and suggestions made by the DVN
- The wide recognition of the need, and enthusiasm for, the new DVN Service. Feedback from a wide variety of sources indicates that such a role has been wanted by a lot of people in many different sectors and settings

“I feel this is a valid role with the likelihood of it being needed more in the future with the promotion of end of life care at home” District Nurse

- Working from outside the NHS has proved very useful for the DVN in terms of being able to assess situations holistically from a different, ‘neutral’ perspective. For example, she has been able to quickly identify practices and decisions in hospitals where improvements could be made for the service user and has been able to make a positive influence on these. Joint and collaborative working with other sectors, such as social care, has also been very positive as they are used to dealing with professionals from housing and care providers

“I would highlight that a degree of independence/advocacy ability is inherently important in this work” NHS Consultant

- Working alongside other care providers enabling them to familiarise themselves with some issues and how their services can be improved e.g. administration of medication by carers, care plans in people’s homes, and the necessity to standardise practices
- The referral system is simple: anyone can refer which means that even if one team did not think of referring a person they could still be referred by someone else in contact with that person.

1.6 Key Barriers for the DVN Service During its First Twelve Months

1.6.1 Barriers External to the Project

- ***Gaps in GP knowledge of palliative treatments***

Some GPs are not conversant with palliative treatments and so it is paramount that the DVN is able to access palliative doctors in cases where palliative medication is needed.

- ***Initial professional scepticism***

During the first year, working from a housing and care organisation sometimes meant a lack of support and approval from peer health professionals until the DVN had proved herself to them.

Some MacMillan Nurses and District Nurses were unsure of their own positions in relation to the DVN and did not appreciate the differences in their expertise and roles and what the benefits could be for clients.

Recommendation for Year Two: The role of the DVN needs to be clearly defined for everyone to understand the DVN remit and how this role compliments and supports them.

- ***Lack of shared information***

There is a lack of information regarding what services are available in the borough.

There are also no shared databases between agencies and organisations. In each person's home there are separate care plans and notes from all the different providers involved.

1.6.2 Barriers Internal to the Project and How These Have Been Addressed

- ***Lack of knowledge of the service by other services and professionals, this resulted in few referrals being generated initially***

To increase awareness of the service during the first year the DVN presented at conferences, workshops, team meetings and trained different teams. A poster was developed for the DVN to pass on to teams and offices. The DVN distributed her business card, taking opportunities for advertising the service, and lobbying for referrals. The DVN was also introduced to some GPs in Westminster and gave talks at some surgery team meetings.

There is still need for lobbying and continuous reminders of the DVN presence in the Borough. There was reduced scepticism in the second year and more appropriate referrals were made, however due to the changing nature of services and staff, continuous lobbying has remained vital.

- ***Lack of knowledge of referral criteria and process***

By the end of the first year the service became known and a lot of referrals began to be received for people who were at the very end stages of dementia to the extent that the person died before, on the day, or soon after assessment.

The DVN discussed with her Clinical Supervisor how to attract more appropriate early referrals and has forwarded suggestions to the CMHT: there is a need to raise awareness among all health and social care professionals so that they recognise the need for end of life care and planning in a timely way. The appropriateness of referrals improved in the second year as organisations became more aware of the criteria.

- ***Short project time span***

Due to this being a two year pilot project it felt there was pressure to produce results as early as possible. New community services such as this require a great deal of work initially to raise awareness and develop understanding, trust, networking and effective referral and communication channels. It also takes time to be familiarised with the environment, to develop workable tools to use.

1.7 Key Learning Points for Providing Services to People Nearing the End of Their Lives with Dementia

1.7.1 Person Specification for the DVN Role

The DVN has to be very knowledgeable in different aspects of dementia and end of life issues to be able to advise staff, palliative teams and families effectively.

1.7.2 Contextual Factors Influencing the Level of Empowerment of Family Carers

It was predicted that the empowerment of family carers would be a critical aspect of helping people with dementia to be able to remain at home for as long as possible. Local contextual factors that were found to affect the empowerment of family carers during the DVN Service pilot project include:

- the personality, attitude, level of understanding, knowledge and communication style of family carers
- the personality, attitude, understanding, knowledge and communication style of professionals including GP
- the family situation and other commitments of family carers
- the type of accommodation
- the extent of data sharing across organisations
- the extent and effectiveness of communications across people who are working for different organisations
- the willingness of organisations to work together
- the availability and accessibility of relevant support services for carers.

Examples - Enablers

- A G.P. and a District Nurse who provided immediate and effective joint working with the DVN which facilitated rapid, comprehensive assessment and instant provision of care at home for a lady who was actively dying
- Good personal relationships and communication links with care staff at an extra care setting containing a number of units for people with dementia.

Examples - Barriers

- A family who were reluctant to receive outside, professional support for some time, despite an identified need for a continuing care package and proper equipment such as a hospital bed to allow dignified management of pressure sores and frailty
- A lady who was a wheelchair user. She slept in an upstairs bedroom which made escorting her out difficult
- Unmatched Borough and PCT boundaries adversely affecting service delivery
- One family informed the DV Nurse that accepting support from her would signify dependence which is frowned upon in their culture. The level of empowerment the DVN could reach with them as a result was low.

1.7.3 Different Providers, Different Practices

Different providers carry out different practices when providing care for individuals in their homes (including some illegal practices such as crushing tablets). This can cause confusion and tension with family carers as they do not understand why carers from one agency will not follow the same practices as those from another.

Discussions with other housing providers indicated that there is a need for education and familiarisation around end of life care. The DVN found providers to be sceptical about the idea of handling, or even discussing, end of life issues with residents.

Some housing providers were sceptical about having people die in the accommodation they provide as some are not suitable for palliative care having only single bedrooms, and/or are in high rise flats. Their staff are not trained to handle people dying, and buildings may not be easily altered to suit the requirements as the service user would be a tenant rather than an owner.

1.7.4 The Importance of Advanced Care Planning

The importance of having discussions around advanced care planning, preferred place of care and end of life issues cannot be underestimated and should be every body's business, not just for the diagnosing doctor. This should be carried out as early as possible, before the person loses capacity to make decisions, and the person should be informed of the effects of dementia so that they can make informed decisions and choices.

The DVN found that asking people with dementia about their life history provided a very effective platform from which to tactfully elicit their current expectations and hopes, and their feelings about how and where they would like to be cared for at the end of their lives and can be very useful in developing best interest decisions. The DVN encouraged care workers, and staff in nursing and residential homes to carry this out as early as possible with any clients who have dementia.

1.7.5 Shifting 'Curative' Approaches to End of Life Care

The ethos on hospital wards tends to be 'curative'. Looking after people at the very end of their lives requires a different approach and the focus should be on supporting people to die comfortably.

1.7.6 The Importance of Pain Identification and Management

The DVN has found that pain identification and management among people with dementia is particularly poor with some families and professionals even believing that people with dementia do not feel pain. People with dementia can suffer with both or either nociceptive or neuropathic types of pain. The pain may be physical and mentally distressing and they may have difficulties in articulating it. Joint working activities with the DVN service brought comprehensiveness in assessment, diagnosing, planning and management of pain and distress.

1.7.7 Communication and Information Sharing

There is need for improved communication systems in terms of reporting, data access and data input with all referrers in order to avoid delays and omissions. **A single assessment and care planning tool for different organisations is required.**

Weekly meetings with the CMHT were important for identifying potential new referrals and for discussing current cases.

Joint working with palliative care teams has been invaluable in terms of sharing expertise.

1.7.8 Key Challenges for the Future

The main challenge remains to continue the work in raising awareness of the issues of caring for people with dementia nearing the end of their lives through training, presentations, workshops and further joint working activities.

2 Introduction

2.1 Scope of Report

This report provides an overview of findings and learning from the two year Dementia Voice Nurse Service pilot project.

2.2 Background to the Project

Housing 21 - Dementia Voice was awarded funding from the King's Fund for a two year pilot project to employ a dementia specialist community-based End of Life Care Nurse to work within its dementia services team in London. This was one of a handful of successful projects chosen from more than 100 proposals for 'Service Delivery' projects submitted to the King's Fund's 'Partners for Health in London' funding programme.

Housing 21 is a leading provider of retirement housing, care and support services for older people. Housing 21 has been providing specialist services for people with dementia from Tresham Dementia Services Resource Centre in Westminster over the last 20 years and currently runs carers support services, community care, and specialist home care services. Staff at the centre have a wealth of skills and experience working with people with dementia in many settings and throughout the trajectory of their illness. They offer flexible and relationship-centred support, promote emotional well-being, and provide continuity while the person is in hospital or in respite care.

2.3 Identified Need for the Service

Tresham teams were regularly working with people with dementia and their families in their homes at the very end of their illness and in need of palliative care. More often than not they were providing the only service available to them. It was common for staff to be supporting people who are having to care for a loved one with dementia with little or no nursing back up. Resources to support people with dementia and their carers historically have been very scarce. Moreover, people with dementia tend not to be seen as terminally ill which makes it notoriously difficult to get suitable services or a prompt response from local practices. Carers are often left struggling and distressed, with the person with dementia not getting appropriate end-of-life support and even going without the most basic medical care. Staff were finding that input from a palliative care nurse, whilst very rarely available is vital due to the myriad of problems that occur together such as pressure area care, incontinence management, pain, weight-loss, stress, depression, anxiety and other symptoms.

As well as a lack of appropriate end of life care, those dying with dementia do not have the same opportunities to die at home, where most of us would prefer to be (Munday et al, 2007³), as those suffering from other terminal illnesses. The reality for

³ Munday, D., Dale, J., Murray, S. (2007) Choice and Place of Death: individual preferences, uncertainty and the availability of care. *Journal of the Royal Society of Medicine*. 2007; 100: 211-215.

people with dementia is that most will die in hospital or in a nursing home and even in these settings they may find hospital staff have insufficient training or time to manage their needs, and nursing homes may lack training in palliative care, provide poor symptom control and management, and not be able to provide essential psychological and emotional support (Harris, 2007⁴). Giving people the opportunity to plan, and a real choice of where they want to die, is advocated in many recent key publications including 'Progress with Dementia - Moving Forward: Addressing Palliative Care for People with Dementia' published by the National Council for Palliative Care (2007), and the Department of Health's End of Life Care Strategy (2008) although, disappointingly, any significant reference to end of life care needs and services for people with dementia was missing from their subsequent 'National Dementia Strategy'.

2.4 Aims of the Project

The new 'Dementia Voice Nurse' service was designed to fill a critical need identified by Tresham Dementia Services together with Westminster City Council and the local PCT: to be able to provide for people with dementia and their families appropriate assessments and end-of-life support services that others with different illnesses have access to.

The project aimed to address current key gaps by providing: specialist assessments for the person with dementia and their carer(s); advice and support for service users in their own homes; specialist training and support for Housing 21 care and support staff; and co-ordination of services. The importance of having someone to take on a co-ordination role cannot be underestimated and is recognised in the End of Life Strategy (DH, 2008) as being crucial to, "ensure that each person approaching the end of life receives coordinated care ... across sectors and at all times of day and night". The nurse will be able to act as a consistent link with GPs and primary health care practitioners, statutory and voluntary agencies, in order to help achieve the best possible care.

Bringing a specialist dementia end of life nurse into a community team is a new way of delivering services. Funding from the King's Fund is enabling this innovative model to be tested to determine if it can be effective in enhancing:

- quality of life, and quality of dying, for people with dementia
- the availability of support, services and equipment for people with dementia at the end of their lives and their family
- support for staff at Tresham's Dementia Services, and their skills in supporting clients in end of life situations.

The development of this project was made possible with the involvement and collaboration of key partners including the following who are also Steering Group members:

- Jude Sweeting, Westminster City Council's Development Officer Dementia;
- Dr Cornelius Kelly, Consultant Psychiatrist/Lead Clinician Older Adults with CNWL Foundation NHS Trust (London); and

⁴ Harris, D (2007) Forget Me Not: Palliative Care for People with Dementia. *Postgraduate Medical Journal*. 2007; 83: 362-366.

- Dr Adrian Treloar, Consultant and Senior Lecturer in Old Age Psychiatry at Oxleas NHS Trust and Memorial Hospital.

During the pilot project, the DVN received clinical supervision from Dr Treloar, and further supervision from a Housing 21 Dementia Services Manager and an Admiral Nurse.

3 Methodology

A mixed methods approach was used for the evaluation of the DVN Service;

1. Tracking:

a wide range of detailed information was obtained on circumstances, unmet need, DVN interventions and outcomes for each service user and their relatives from 'client tracking files' that were completed and kept up to date by the DVN. These files included information relating to clients and their environment, their carer(s), reasons for referral, support being provided by other people and services, and incidences of avoided hospital, nursing and care home admissions.

2. Interviews were conducted at regular intervals with:

- care staff and professionals from Housing 21 and other organisations who had experience of the DVN Services
- family carers where appropriate, possible and permission was obtained
- members of the project steering group and wider stakeholders.

3. Feedback sheets were obtained on an ongoing basis from:

- family carers and relatives
- care staff and professionals who worked with the DVN and/or had attended DVN training events.

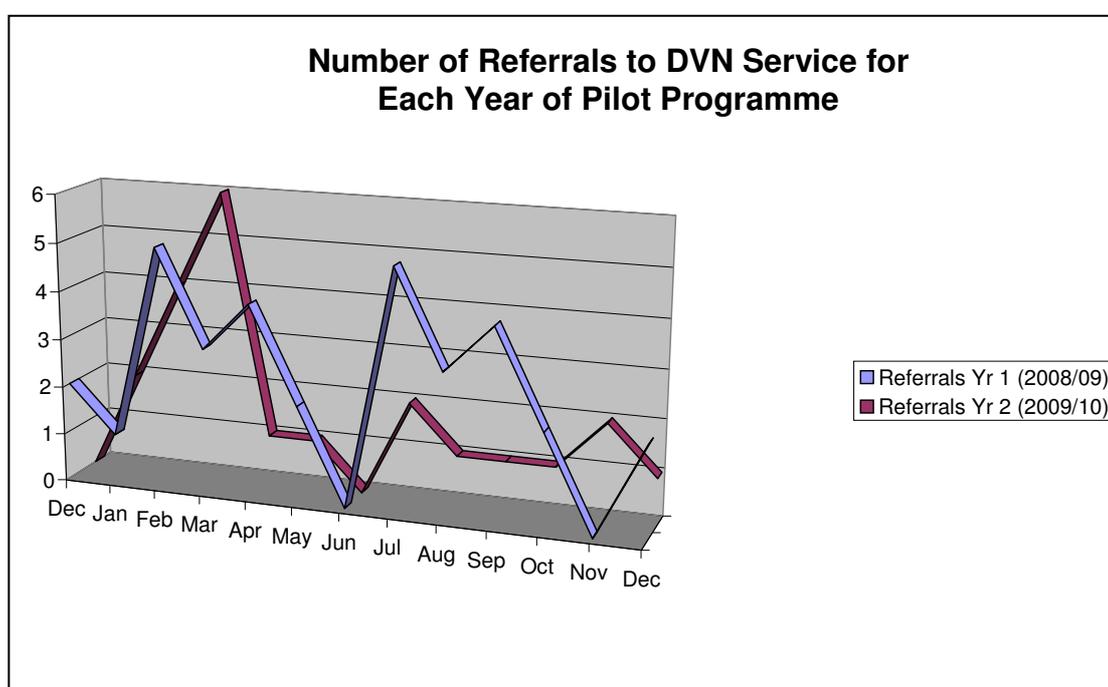
4 Results: Profile of the Service During Its First 24 Months

The Dementia Voice Nurse Service (DVN Service) opened for referrals in December 2008. The data below are from the two year pilot period (15th December 2008 – 14th December 2010).

4.1 Referrals

51 referrals were received over the two years of the pilot

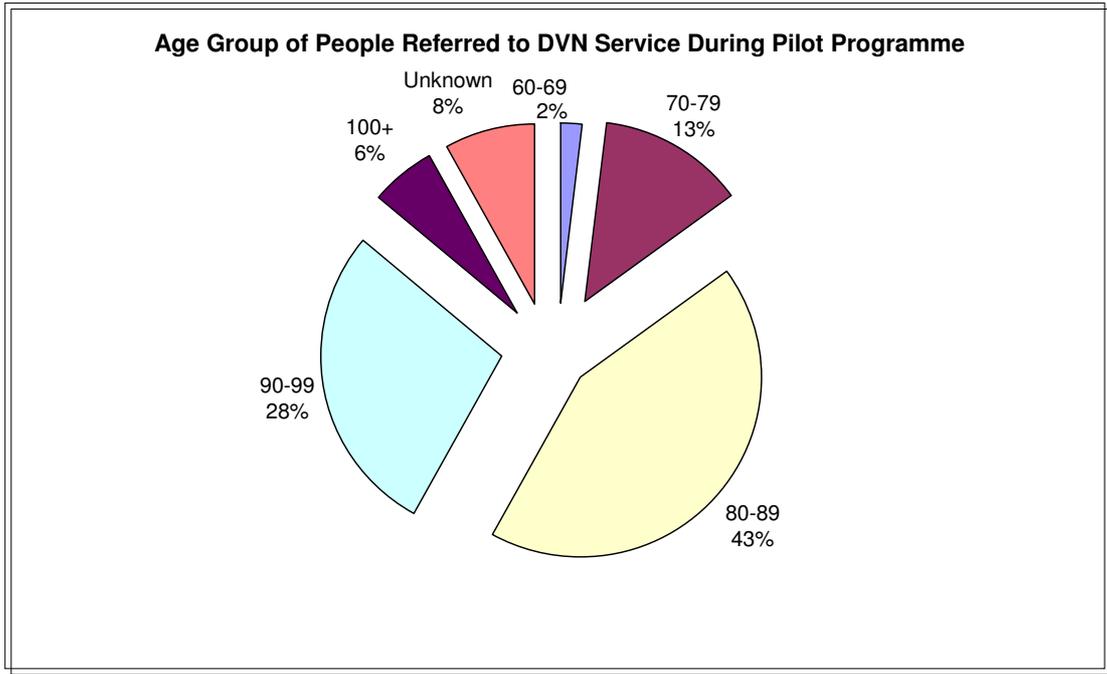
- 2 were withdrawn before assessment
- 4 were found not to meet the service criteria at assessment
- 5 died pre-assessment, very soon after they had been referred.



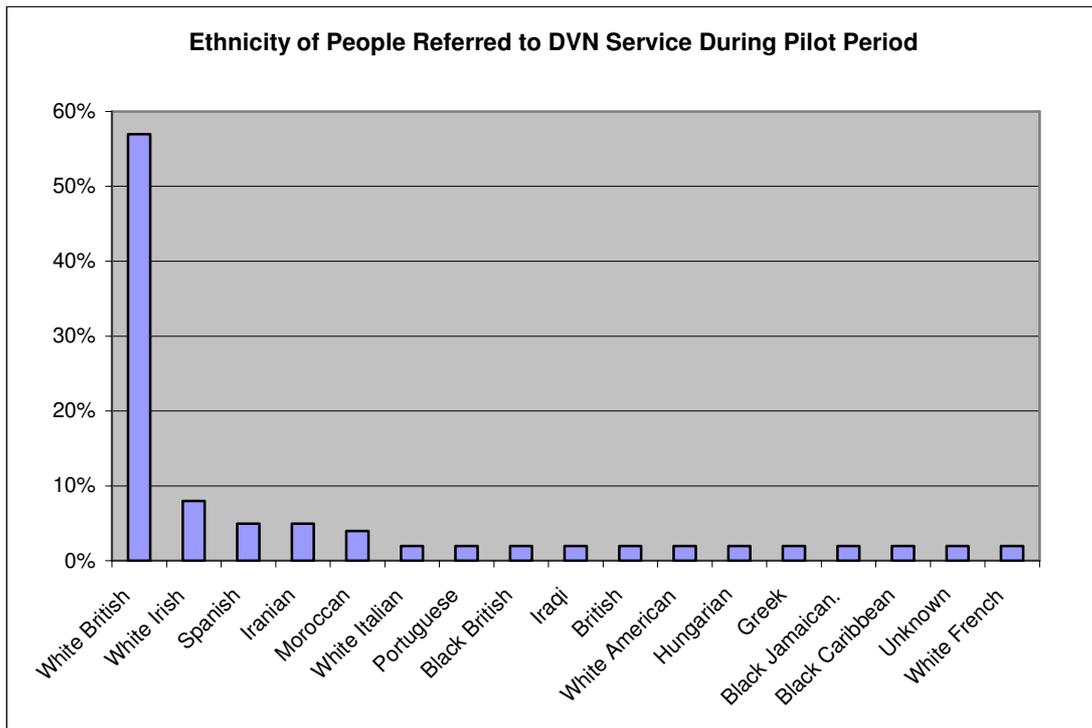
In year one, the peak period for referrals was in the first few months of the year once the service was initiated and advertised, and during the summer period when the DVN was carrying out a lot of training. In the second year the peak occurred again in the first part of the year. These peaks are possibly due to typical increased illnesses and depression seen in winter.

4.2 Age

The chart below shows that the largest proportion of people referred to the DVN Service were in their 80s (43%, 22 people) followed by 90s (28%, 14 people), and 70s (13%, 7 people). Three people were over 100 (6%) and one was in their 60s (2%).



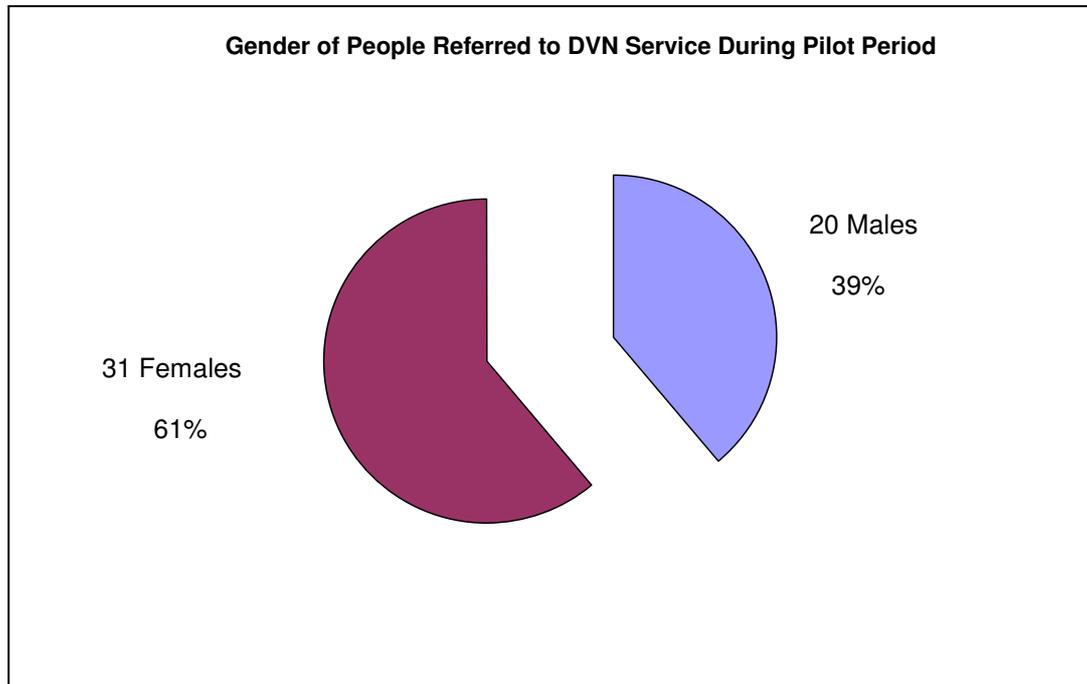
4.3 Ethnicity



People from at least 16 different ethnic groups were referred to the DVN Service. Over half of all referrals were classified as White British, the rest were distributed across a range of different ethnic groups including White Irish, Spanish, and Iranian.

4.4 Gender

The 51 referrals consisted of a higher number of females (61%) than males (39%).



4.5 Source of Referrals

By the end of the pilot period referrals had been received from 14 different sources (see table below). Housing 21 made the highest number of referrals (16), followed by St John's Hospice (8) and Social Services (6). It is worth noting that in the second 12 months, Housing 21 made three times as many referrals as they did in the first twelve months; many of the Housing 21 staff were initially sceptical about the service but training and awareness events across the various services resulted in a better realisation of the benefits of the service. St John's Hospice, the main source of referrals (7) in the first year, made one referral in the second year. There were three new sources of referrals in the second twelve months compared to the first 12 months: Westminster Rehabilitation Services; Admiral Nurses; Family Carer. Six services which referred to the Dementia Voice Nurse in 2009 did not do so in 2010: Pembroke Palliative Care Team; St Mary's Hospital; 60 Penfold Street⁵; Intermediate Physical and Mental Health Team; St Charles's Hospital and The Butterworth Centre.

Source of Referral	Number of Referrals in Year 1	Number of Referrals in Year 2	Total Number of Referrals
Housing 21	4	12	16
St John's Hospice	7	1	8
Social Services	4	2	6
District Nurse	2	3	5

⁵ three of the referrals in 2010 were Penfold clients even though Penfold did not refer; this was done by other agencies who were involved.

CMHT	3	1	4
Pembridge Palliative Team	3	0	3
St Mary's Hospital	2	0	2
60 Penfold Street	1	0	1
Intermediate mental and physical health care team	1	0	1
St Charles Hospital	1	0	1
Butterworth Centre	1	0	1
Westminster Rehab Services	0	1	1
Admiral Nurse	0	1	1
Family Carer	0	1	1
Total Referrals	29	22	51

4.6 Assessments

The DV Nurse carried out 42 assessments

- 1 was withdrawn after assessment.
- 4 of those assessed were found not to meet the service criteria.

4.7 Case Load

At the end of the pilot period there were seventeen service users active on the DV Nurse's case load.

4.8 Number Deceased

Twenty people have died whilst receiving the DV Nurse Service during the pilot project. Seven of these died very soon after they had been assessed, on average 7.7 days later. These were in the first year and were cases where referrals had been made to the service at the very end of life stage.

A further five people died pending assessment. These also occurred in the first year of the pilot and were due to referrals being made at too late a stage.

4.9 Place of Death

At the end of the two year pilot period, twenty people had died who were in receipt of the DVN Service and of these 16 died in their preferred place (84% of those whose preference was known). For all those who died (a) at home, (b) in a hospice, or (c) in a nursing home, it was their preferred place. For three people, hospital was not their preferred place of death. Of the remaining two who died in hospital, for one their preference was unknown and for another whose preference it was to die in hospital, it was in a specialist dementia ward.

Another patient from the first year of the pilot who was withdrawn from the Dementia Voice Nurse Service by the District Nurse and subsequently died in hospital against their preference.

The table below shows that 12 people died in the first year and 8 died in the second year. The number of deaths in hospital reduced from 4 in the first year to 1 in the second year. This is possibly because referrals were more timely and assessments were carried out sooner as the pilot progressed.

<i>Place of Death</i>	<i>Number of Deaths*</i>	<i>Preferred Place for*</i>	<i>Not preferred place for*</i>
Home	8 (4 4)	8 (4 4)	0
Hospice	4 (3 1)	4 (3 1)	0
Hospital	5 (4 1)	1 (1 0) (1 Unknown)	3 (2 1)
Nursing home	3 (1 2)	3 (1 2)	0
<i>Total</i>	20 (12 8)	16 (9 7)	3 (2 1)

*(First Year | Second Year)

The DVN helped to enable people to die in their place of choice for example through arranging for continuous care packages, and through discussions on end of life plans made with families so that the individuals were not rushed in to hospital when dying because of the panic of not knowing what to do.

4.10 Avoided Hospital Admissions

It is estimated that the DVN Service has been responsible for, or significantly contributed to, 36 avoided hospital admissions.

Examples

- In some cases DVN intervention meant that the GP was able to come to assess service users at home and they could be treated and monitored from home instead of having to go in to A&E
- One lady was continuously being re-admitted to hospital unnecessarily because of not eating and through the DVN involvement, she was able to remain at home where she subsequently died
- A gentleman with dementia who was experiencing behavioural problems exacerbated by alcohol abuse. This gentleman lived with a friend who was also his carer. The carer controlled the finances and was spending a great deal on alcohol and very little on food. The gentleman's health was deteriorating as a result. The DV Nurse advocated for separate living arrangements for them both. This was eventually agreed despite initial opposition from other professionals. Alcohol consumption declined and food intake increased. The gentleman concerned became more compliant with his medication and his health improved

- A lady was being admitted to hospital due to a lack of appropriate care plans. DVN supported agency live-in carers by giving them information on care of the dying and dementia palliative care. Unnecessary transfers to hospital were avoided.

4.11 Avoided Nursing / Care Home Admissions

It is estimated that the DVN Service has been responsible for, or significantly contributed to, six avoided Nursing or Care Home admissions.

Examples

- A gentleman who died in extra supported accommodation was scheduled to be transferred to a nursing home if the DVN had not intervened
- A lady was able to die at home peacefully in the presence of her family as a result both of input provided directly by the DVN who supported family carers to confidently make difficult decisions, and liaison with Continuing Care Team, District Nurses, Hospice at Home/ MacMillan Nurses, GP and Community Multi-Disciplinary Team (MDT).

4.12 Early Hospital Discharges

It is estimated that the DVN Service has enabled two earlier hospital discharges, saving a total of around 26 hospital bed days.

4.13 Cost Savings / Cost Effectiveness

These estimations of basic cost savings have been calculated for the two year period of the DVN pilot service.

Avoided Hospital Admissions and Early Discharges

Number of avoided hospital admissions	36 admissions (14 people)
Estimation of number of bed days saved by avoided admissions ^[1]	900 days
Number of enabled early discharges	2 early discharges (2 people)
Estimation of number of bed days saved by early discharges (DVN estimate)	26 days
<i>Total number of estimated hospital bed days saved</i>	<i>926 days</i>

^[1] Estimated average length of stay is 25 days derived from average length of stay figures for people with dementia in hospital in 'Counting the Cost – Caring for People with Dementia on Hospital Wards' (Alzheimer's Society, 2009).

Cost of each bed day is £293^[2]

Cost of bed days saved = £293 x 926 = £271,318

Cost of ambulance / emergency transfers is £244^[3]

Cost of ambulances saved = £244 x 36 = £8,784

Avoided Nursing/Care Home Admissions

Avoided Nursing/Care Home admissions	6 (4 people)
Estimate number of Nursing/Care Home weeks avoided (based on circumstances of clients and dates of death)	59 weeks

Cost of Care/Nursing Home per week is £582^[4]

Cost of Nursing/Care Home weeks saved = £582 x 59 = £34,338

Total Estimated Savings

It is estimated that the DVN service wholly or partly contributed to total cost savings over 24 month period in terms of avoided hospital, residential and nursing home admissions and ambulance services:

£314,440

4.14 DVN Training Sessions

During the first year around 50 health and social care staff attended training sessions carried out by the DVN across Westminster including Extra Care Scheme Managers, Occupational Therapists, Operational Managers, Nurses, Ward Managers, Housing and Care Services Managers, Doctors and Consultants.

In the second year over 100 people were trained from a range of organisations and in a range of locations. These include Bank Managers from Barclays Corporate Healthcare and Carers from an Extra-Care scheme in Liverpool.

Very positive feedback was received from people attending the sessions. Attendees indicated the training made them feel more confident, more able to cope, more knowledgeable about people with dementia at the end of their lives and the skills and care required to look after them, and more able to offer appropriate help and support to clients and their families.

^[2] Cost per bed day for mental health services inpatient bed days for elderly patients from 'Unit Costs of Health and Social Care' (PSSRU, 2010)

^[3] National average from 'Unit Costs of Health and Social Care' (PSSRU, 2010)

^[4] From 'Unit Costs of Health and Social Care' (PSSRU, 2010). Used establishment costs only per permanent resident week: average for both Nursing and Residential Care.

4.15 DVN Presentations

The DVN has given presentations at a number of local and national events giving overviews of the DVN Service and information regarding what services and care people with dementia need at the end of their lives. The DVN has consistently received very positive feedback and was the only presenter to achieve a 100% satisfaction rating from attendees of the 'Improving end of life care in older people's housing' event in July 2009.

Events where presentations have been given include:

- Delivering effective end-of-life care: developing partnership working event (18 October 2008)
- *Ask Me What I Want*- Transforming End of Life Care in partnership with patients and carers (July 2009)
- Rising to the Challenge, Brighter Futures for All (October 2009) - policy session - Hopeful Horizons: Supporting people with long term conditions at the end of their life'
- Delivering the National Dementia Strategy (October 2010)
- UK Dementia Congress (November 2010)
- Barclays Corporate HealthCare (February 2011).

4.16 Awards

The DVN service has made significant achievements and this has been recognised by the following award and award nomination:

- Winner of Nurse of the Year, International Dementia Excellence Awards (2010)
- One of Five People Nominated for the Guardian Public Servant of the Year (2010).

5 Results: Identified Client Needs, DVN Interventions, and Impact of Service

The DVN has been carrying out specialist nursing assessments of the people with dementia referred to the service and their family carer(s) where appropriate, going on to provide interventions, access and co-ordination of services, and advice and support to service, their carers and families.

Common key functions employed by the DVN with the clients to date include:

- Accessing resource and services
- Liaison
- Medication recommendations
- Dementia and end of life expertise
- Advice, guidance and support to other professionals and family carers
- Advocate
- Helping professionals and family carers to realise the condition of client and prognosis
- Instigation of end of life discussions

Common key outcomes for services users and their families include:

- Referrals for specialist assessments
- Reviews of medications
- Changes to more appropriate medications and methods of administration
- Better identification and management of pain
- Increases in care packages
- Increases in expert advice and support available
- Increases in services provided
- Improvements in mental and physical states, in the quality of life and quality of dying
- Better co-ordination of services
- Improved communications between services, professionals, clients and family carers
- More appropriate approaches to care provided to people at the end of their lives
- Better knowledge, understanding, support, planning for end of life, and reassurance

More Detail of Needs, Service and Impact :

- The bulk of the Dementia Voice Nurse's activities centred around offering advice and support to carers, and liaising with various organisations in a key worker-type role
- Advice and support has proved to be a core part of the service and was offered in at least 34 cases, in most cases where it was not offered it was because the referral was inappropriate or too late. Even with inappropriate referrals, some level of advice and support was offered to signpost to the appropriate services
- Liaising with various organisations to put in place new services or improve the effectiveness of services being delivered took place in at least 25 (49%) of the cases. These included:
 - One case where the boundaries between boroughs and PCTs was causing acute problems for service delivery.
 - A few cases which involved arranging for respite care for the family member
 - Two cases where intervention by the DVN resulted in acquiring long sought for wheelchairs for the service user; she was able to ensure that the wheelchairs were delivered swiftly
 - The DVN regularly liaised with GP's, Community Mental Health Teams, MacMillan Nurses and Physiotherapists
- In most cases where family were involved they had the clients' best interests at heart though a few were not willing to accept that their relative was at the end of their life
- There were two clear cases of issues with family across the two years. One involved an alcoholic carer and the other a quarrelling set of relatives. On both occasions the Dementia Voice Nurse helped to improve the patients quality of life. In one case separating the alcoholic carer from the patient resulting in improved dietary intake and emotional well-being, in the other earning the appreciation of family members for her mediation.

The table below presents a set of examples of clients who have received a service from the DVN. The table shows key referral reasons and the identified unmet need(s), key activities and changes instigated by the DVN, and key impacts and outcomes.

Examples of Unmet Needs, Changes Instigated by the DVN, and Impact

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
1	General Deterioration, poor appetite. Lived alone, he was isolating himself, refusing to go to Tresham day centre, spent a lot of time staring in to space, and tearful at times.	<ul style="list-style-type: none"> DVN advocated for respite care in anticipation for change in care package. DVN liaison with Care manager; Tresham Day centre, ward staff, Carlton Dene Centre and family. On the DVN's recommendation the GP prescribed an anti depressant. 	<p>Accessing services and resources.</p> <p>Liaison.</p> <p>Medication recommendations.</p>	<ul style="list-style-type: none"> His mental state was assessed and managed at home. His mood improved he was able to continue with Day Centre. Avoided admission to Nursing Home and Hospital by DVN continually checking on him, interacting with him and his GP and district nurses.
2	Screaming and restless all the time, not eating.	<ul style="list-style-type: none"> DVN made recommendations on medication to manage pain and distress (the ward had never had a death, normally they would transfer to palliative teams or medical ward). Encouraged a more appropriate care approach - palliative rather than curative. Frequent ward visits. Liaison with generic palliative team Ensured that ward policies were 	<p>Medication recommendations</p> <p>Training / mentoring.</p> <p>EOL expertise.</p> <p>Liaison.</p> <p>Training / mentoring.</p>	<ul style="list-style-type: none"> Better pain management E.g. Encouraged ward staff to give medication as they hesitated feeling that it would hasten death Staff and relatives supported. Good communications. Liverpool care pathway used. Staff refrained from unnecessary feeding and suctioning during

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
		<p>known and followed by all involved.</p> <ul style="list-style-type: none"> DVN worked hand in hand with generic palliative team complimenting each other. 	Joint working	the last hours
3	<p>End stage dementia. Patient was bed bound, immobile, with pressure sores and had advanced dementia.</p> <p>Family were not aware the person was at the end of life stage. The family carer was employing active management of her poor oral intake anticipating that she would improve once she began eating again.</p>	<ul style="list-style-type: none"> On the DVN's recommendation the GP changed all medication to syrup as patient was no longer able to swallow tablets. DVN initiated discussions with the family on end of life plans. DVN continued to support daughter after death of patient. 	<p>Medication recommendation.</p> <p>EOL planning discussions initiated.</p> <p>Support to family carer after death.</p>	<ul style="list-style-type: none"> Patient able to receive appropriate medication. Family became aware that their relative was at EOL state and could prepare and plan for EOL. Daughter appreciative of knowledge, opportunity to plan and be prepared.
5	<p>Statutory carers had limited knowledge of end of life issues.</p> <p>Extreme exercises being employed by the daughter even when client had deteriorated.</p> <p>Disjointed care plans due to different care providers and care plans.</p>	<ul style="list-style-type: none"> DVN made referral to IMPS team Initiated physiotherapy assessment. Initiated discussions of EOL advanced care planning. Liaison 	<p>Joint working</p> <p>Access services / resources.</p> <p>EOL planning discussions initiated.</p>	<ul style="list-style-type: none"> Family ceased extreme exercises. A single point care plan developed.

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
	<p>Administration of medication in food; feeding taking place in the toilet.</p> <p>Need for hospital bed as skin was disintegrating</p>	<p>with the care manager to encourage to call for a MDT meeting to finalised plans in partnership with family.</p> <ul style="list-style-type: none"> Discussed medication with District Nurses who checked with the GP. DVN liaised with District Nurse to try to obtain a hospital bed. Next of kin was continuously reassured and given information on the end stage of dementia. 	<p>Liaison and advocacy.</p> <p>Medication recommendation.</p> <p>Access to services / resources.</p> <p>Advice, support, EOL expertise.</p>	<ul style="list-style-type: none"> More appropriate feeding, medication and administration of medication. Unable to obtain a hospital bed as patient was still mobilising to some extent. Family carer felt very supported and was highly appreciative of the DVN Service (phone call).
6	<p>St John's Hospice patient, was physically deteriorating with lung cancer, was noticed to be having memory problems and there was a question of whether he had capacity to make decisions.</p>	<ul style="list-style-type: none"> DVN facilitated the psychiatric core assessment and formulation of the diagnosis. DVN worked with the social worker to explore issues of capacity to make decision to be discharged home and advocated for the patient to stay in the Hospice rather than being transferred to a nursing home. DVN liaised with the son and discussed end of care plans with him. 	<p>Access to services / resources.</p> <p>Expertise in dementia.</p> <p>Advocate.</p> <p>Joint working.</p> <p>Liaison. EOL planning discussions initiated.</p>	<ul style="list-style-type: none"> DVN became the link between Hospice and CMHT Died in preferred place. Involvement of son. End of life care plan.

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
7	<p>Family carer's anxieties. Despite many people involved no one had sat down with daughter to discuss dying issues openly.</p> <p>Coordination and liaison needed with a number of services in place.</p> <p>Patient needed flu immunisation to be done and carer was not able to get the GP to do it.</p>	<ul style="list-style-type: none"> • Provided advice, support and reassurances. • DVN referred and followed up with District nurses. • DVN communicated with GP on behalf of the family carer. 	<p>Advice and support. EOL and dementia expertise.</p> <p>Access to services / resources.</p> <p>Essential liaising.</p>	<ul style="list-style-type: none"> • Advanced care plan initiated. • DVN took on the coordination, key-worker and liaison with other services roles. • Patient eventually had the injection.
11	<p>Management of behaviour. Care manager reported that she was not getting a breakthrough in trying to organise an appointment with CMHT as patient was having behavioural problems of intimidating carers, lashing out and shouting.</p>	<ul style="list-style-type: none"> • DVN made a referral and discussed case in CMHT meeting and CMHT immediately took the case on. 	<p>Essential liaising.</p> <p>Access to services / resources.</p>	<ul style="list-style-type: none"> • Medication was reviewed and patient was able to be managed well at home.
14	<p>End stage of Dementia. Dying of Aspiration pneumonia.</p> <p>Lack of care and support.</p> <p>Significant gaps with no</p>	<ul style="list-style-type: none"> • DVN applied by fast track for continuous care funding. Organised for care hours to be increased and Hospice at Home was to cover from evening to night duty. Advised on care needs. 	<p>Access to services / resources.</p> <p>Advice and support.</p> <p>Expertise.</p>	<ul style="list-style-type: none"> • Improved general condition due to increased care package, and increase in quality of care. • Family relieved. • With frequent contacts/

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
	carer including nights.	<ul style="list-style-type: none"> DVN referred to IMPS team for Physio and OT therapy assessment for equipment to relieve contractures of the legs and fingers. 	Access to services / resources.	<p>stimulation from different people, patient improved physically, as she was dying from aspiration, this was prevented. The quality of care she was getting improved her in many aspects.</p> <ul style="list-style-type: none"> Pain and secretions were managed appropriately. Risk of pressure sores was reduced. Sacral sore healed up.
13	End of stage Vascular Dementia. Patient was living with live in carers who were not competent to look after her alone in that stage, so they were frequently transferring her to hospital when facing any challenges.	<ul style="list-style-type: none"> DVN ascertained preferred place of care was home and the carer was willing to look after her at home as long as there was support in situ. DVN clarified with the ward what stage of Dementia it was and what the best interest is according to the consultant and the ward staff. Supported the agency staff to cope with the dying stage through one to one skilling. Phone contact with next of kin to update on care being given and to draw up end of life care plans. 	<p>Liaison. Advice and support. Expertise.</p> <p>Up-skilling and mentoring.</p> <p>Contact with family. EOL planning discussions initiated.</p>	<ul style="list-style-type: none"> Recognition that the patient was in the end stages of Dementia and her best interest was not to be transferred back to the hospital unnecessarily. The patient was not unnecessarily transferred to hospital as before. Increase in quality of care provided. Family involvement. Family gave verbal appreciation of the care given and the fact that the carer was helped to manage the patient at the end stage of life.

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
15	Behavioural problems, Deterioration in mental state, deterioration in physical state. Needed continuous care.	<ul style="list-style-type: none"> • Application for continuous care package was done with the care manager. • Discussed with daughter the challenges of end stage of life. • Liaised with the GP and District Nurses, Housing 21 manager and staff. • Liaised with continuous care team and gave recommendations. • Advice and support to family carer. 	<p>Access to services / resources.</p> <p>EOL planning discussions initiated.</p> <p>Liaison.</p> <p>Advice and expertise.</p>	<ul style="list-style-type: none"> • EOL care plan. • Continuous care package approved. • Night carers were put in place and daughters were able to relax in their own homes and look after their own health as they were both poorly. • Patient died a peaceful death as had been desired by the daughter in the presence of the carer. • Information and support given to family carer where needed.
16	<p>Pain assessment was initially poor as client was transferred to a nursing home outside Westminster 3 days following a hip replacement without proper pain management therapy.</p> <p>She was only receiving Paracetamol - not sufficient for someone with cancer in the abdomen, a hip replacement, shingles and MRSA.</p>	<ul style="list-style-type: none"> • DVN discussed discharge plans with the hospital care manager. • DVN initiated Advanced Care Plans. • Communication with friends who were acting as Next of Kin to assess their needs and support them. • DVN alerted the nursing home the client was in urgent need of pain management therapy. 	<p>Liaison.</p> <p>Advice and support.</p> <p>Initiation of Advance Care Plan.</p> <p>Advice and support to family carers.</p> <p>Medication recommendations.</p>	<ul style="list-style-type: none"> • Ensured appropriate hospital discharge plan. • Advance Care Plan. • Family friends supported. • Referred to Palliative team for pain assessment and management.

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
				<ul style="list-style-type: none"> • Appropriate pain medication started.
17	<p>Displayed challenging behaviour including verbal and physical abuse of wife.</p> <p>Refused to take medication and suffered from paranoia.</p>	<ul style="list-style-type: none"> • Advocated for care package and shared information with continuing care team • Connected to memory clinic through Community Mental Health Team • Arranged for respite care of 1 hour per day 	<p>Access to services / resources</p> <p>Access to services / resources</p> <p>Access to services / resources</p>	<ul style="list-style-type: none"> • Wife able to chose for husband to die at nursing home as husband couldn't make own decision.
18	<p>Emotional and psychological needs</p> <p>Deterioration in physical health</p>	<ul style="list-style-type: none"> • Co working with Admiral nurse Monitoring progress and reviewing care. • Advocating for care package e.g. Respite for the wife (negotiating with care managers) • GP- Discussion about review of medication and need for antibiotics and antidepressants. • District nurses: Patient was not known by DN despite his disabilities and needs, so Rapid Response team was sent • Liaison with IMPS Team who motivated client and taught him to 	<p>Liaison. Advice and support.</p> <p>Access to services / resources</p> <p>Essential liaising. Medication recommendations.</p> <p>Essential liaising.</p> <p>Access to services / resources</p>	<ul style="list-style-type: none"> • Admiral Nurse discharged wife as there was no further need for their services. Wife felt supported by the DVN and her mood and health improved. • Client now able to mobilise with help from Zimmer Frame • Began sleeping in own bed again following a period of 5 years when he had slept on the couch. • Client felt he was feeling much better and was communicating better with his wife. • Productive cough improved.

Case Example	Key Referral Reasons / Unmet Need(s) Identified	Key DVN Activities and Changes Instigated by DVN	Key Intervention Categories	Impact / Outcome
		use Zimmer Frame. Exercise routine helped him to function more and find purpose to live again.		
19	Dehydration and Nutritional needs Deterioration in physical illness and carer's support	<ul style="list-style-type: none"> • DVN supported carer/friend who had alcohol problems but living with 34DVN. • Suggested POVA alert as the able friend was continuously buying a lot of alcohol for 34DVN instead of food. He was in control of the finances. MDT discussions felt it was not necessary as alcohol was not illegal. 	<p>Advice and support to family carers.</p> <p>Joint Working.</p> <p>Liaison and advocacy.</p>	<ul style="list-style-type: none"> • Separation of client and carer finally opted for and proved healthier. The client's nutritional intake improved and alcohol consumption decreased. He was compliant with medication and his health improved.
20	Suffering from falls and wandering, agitation. Possibly suffering from mini-strokes.	<ul style="list-style-type: none"> • Advocated for client to get money released from solicitor for food and clothing. • Advice & guidance to live in carers • Advocated for pain management and medication review. 	<p>Liaison and advocacy</p> <p>Medical recommendations</p>	<ul style="list-style-type: none"> • Funds were released to the care agency for food and new clothing • Improved quality of life.
21	Suffers from schizophrenia and memory problems	<ul style="list-style-type: none"> • Pain management • Behavioural management • Constipation management. 	Medication recommendations.	<ul style="list-style-type: none"> • Client back on psychiatric medication and feeling much better. • Constipation treated and walking better.

6 Results: Empowerment of Family Carers and Their Views of the Service

6.1 Building Knowledge and Skills among Family Carers

Building knowledge and skills among family carers is a key part of the service the DV Nurse provides. Understanding how this is done, and the changes it effects in family carers, formed an important part of the learning from this project. The DVN used a variety of methods to empower family carers and equip them in their roles as supporters of people with dementia who are in their end of life phase, including:

a) One-to-One Sessions

When warranted, one-to-one sessions are set up with the family carer. During these sessions, the DV Nurse explains, for example, the end stages of dementia and the mental and physical symptoms which may occur. Great care is taken to provide this information sensitively but honestly. As part of this process, the DVN emphasises the normalcy, in an end of life context, of these stages and symptoms. The importance of a comfortable end of life and how this can be promoted is also highlighted. The overall aim is to empower family members by helping them to remain calm and, as a result, in control, so that they provide the best quality care to their family member. For example, practical guidance is given on the steps to take, in a given situation, which would most benefit the person with dementia, such as who to contact and how. The objective is to avoid unnecessary hospital admissions which may cause undue distress to the person with dementia.

b) 'Showing and Telling'

Where appropriate, and with permission, the DV nurse will attend the person with dementia and their family carer in the presence of the formal carer and demonstrate, by example and in situ, the compassionate values and practical skills required for supporting the service user at the end of their lives. This hands on 'showing and telling' not only acts as useful instruction for any personal care or emotional support the family carer needs or wants to provide, but can reassure them that when the DVN is not present, the support being provided by the formal carer is following best practice. Such reassurance can act as an important additional calming benefit.

c) Other Resources

The DV Nurse augments all of the input above by offering reading materials and a DVD that explain each facet of end of life scenarios for people with dementia including the type of care required.

The extent to which a given family carer availed of these methods varied according to a range of contextual factors including: the family carer's wishes, emotional well-being, prior level of understanding and knowledge, and timeliness of the referral. All the knowledge and skill building methods were employed by the DVN with these contextual factors in mind.

6.2 Feedback from Family Carers

Family carers have given a lot of informal feedback to the DVN which has conveyed they are very grateful and hugely appreciative of the elements of the service offering outlined above. However, it has been difficult to encourage return of formal feedback sheets. Nine returned forms were received during the pilot phase. Responses from these have been extremely positive. They show that the DVN's involvement has contributed to effecting changes which empowered family carers by enhancing their knowledge and understanding. This enhanced knowledge and understanding impacted positively on the quality of care provided to the family member living with dementia. Results indicate that family carers felt: more informed, supported and confident; better able to cope, to access appropriate help and to control other support being provided; they had increased understanding of what was happening to the person they were caring for. A very positive difference to the person with dementia and the opportunity, often for the first time, to start planning for the end of life was also reported.

Did the involvement of the DVN contribute to you feeling ...

	<i>A lot more</i>	<i>a bit more</i>	<i>no change</i>	<i>a bit less</i>	<i>a lot less</i>
<i>... informed</i>	100% (9)				
<i>... supported</i>	89% (8)	11% (1)			
<i>... confident in your caring role</i>	100% (9)				
<i>... stressed in your caring role</i>					100% (9)
<i>... able to cope</i>	78% (7)	22% (2)			
<i>... able to access appropriate help when you needed it</i>	100% (9)				
<i>... you understood what was happening to the person you were caring for</i>	100% (9)				
<i>... in control of any other care and support being provided</i>	100% (8)				
	(1 stated not applicable)				

Did the involvement of the DV Nurse give you the opportunity to talk about where and how the person you were caring for could be looked after during their last few days?

Yes, for the first time: 67% (6 people)
 Yes, but not for the first time: 33% (3 people)
 No: 0%

Do you think that the involvement of the DV Nurse made a positive difference to you?

Yes, a lot: 100% (9 people)
Yes, a bit: 0%
Not really: 0%
Not at all: 0%
I don't know: 0%

Do you think that the involvement of the DV Nurse made a positive difference to the person you are caring for?

Yes, a lot: 100% (9 people)
Yes, a bit: 0%
Not really: 0%
Not at all: 0%
I don't know: 0%

5. Selection of Comments

"I do hope they keep this service and expand it. Having a family member with dementia is so challenging and professional support is so important to us. Although difficult to accept, it really helped to have the various stages explained as well as what to expect. Knowing who the contact when needed was a great help. I worry that with all these cuts it may be in jeopardy, and yet the number of people who will be affected by dementia is set to increase. I don't know what people will do."

"I owe a lot of her response to the care she received from a remarkable lady, *the DVN*, from Housing 21 Dementia Voice. Her dedication and professional approach enabled us to access further agencies who as a team gave our family advice, support and the knowledge that we were not alone. The DVN Service was extremely beneficial to us in our time of need and we would appreciate if this service could be made statutory for others in the same situation to access and benefit as we have. Thank you."

"*The DVN* was very helpful at all times. I was not able to talk to some of the hospital staff. *The DVN* also worked and talked to social services. *The DVN* is part of the family and helped us so much."

"I really appreciated talking to the DV Nurse in an open and frank way about a topic that often embarrasses people. She was informative and very clear about Mum's condition. I particularly valued the clarity given by the DV Nurse about the stage Mum was at. It was helpful to hear about the specific indicators that were apparent. It is so helpful to discuss our preferences and to be clear about Mum's care in these last days. I now feel confident that everyone involved is working together and in line with what Mum wants."

"Good to talk to a specialist who understands the impact of Alzheimer's Disease."

"At once, she helped me in time of great stress having not had such assistance in the past I am so grateful. I am now confident knowing that I have someone to help and support me through the difficult time ahead."

7 Results: Empowerment of Housing 21 Care Staff and Their Views of the Service

7.1 Building Knowledge and Skills among Housing 21 Care Staff

As with family carers, enhancing the knowledge and skills of Housing 21 Care Staff is one of the key functions of the DVN Service. Insights were sought by interviewing care staff and other professionals into how this is done and the changes that result from it.

Interviews with the DVN revealed that three main methods were used to build knowledge and skills among Housing 21 care staff:

a) An Open Door Approach

An informal 'open door policy' exists – the DV Nurse has a base at Tresham Resource Centre where most of the Housing 21 staff who provide end of life care are located. This allows staff to have ongoing access to share and discuss any concerns they have regarding the care they are providing.

b) Work Shadowing

Work shadowing is available when necessary. It entails the Housing 21 carer observing the DV Nurse in that aspect of her role which involves direct interaction with the person with dementia and the family carer - where one exists. Emphasis is placed on the compassionate values and specialised interpersonal and practical skills required for good quality support of people with dementia at the end of their lives. Observation by the DVN of the Housing 21 carer with the service user is a key component of this learning process.

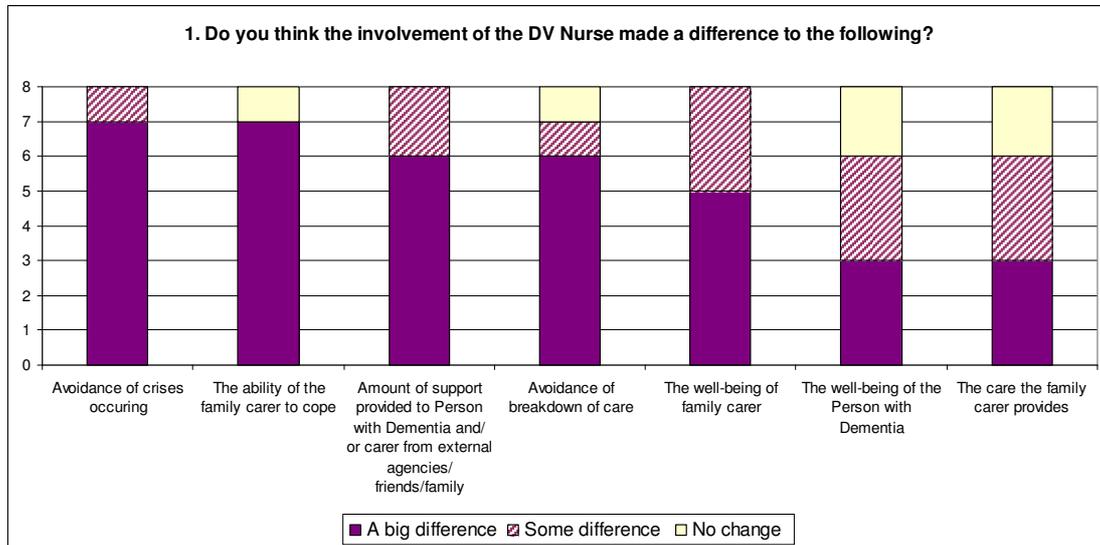
c) Formal Training Sessions

Formal half day training sessions are provided. They cover ten key topics including: understanding of the concept of dementia and terms such as 'end of life care' and 'palliative care'; the carers role in the end of life phase of dementia; key aspects of a good death and how to achieve them and understanding of advanced directives, advanced statements and preferred place of care. A 'Before and After' questionnaire is used as a tool to measure changes in knowledge. Two questionnaires containing the same set of questions are distributed: one prior to the training session to gauge existing knowledge and one afterwards, to assess what changes of knowledge and skills have occurred as a result of the training given.

7.2 Feedback from Housing 21 Care Staff

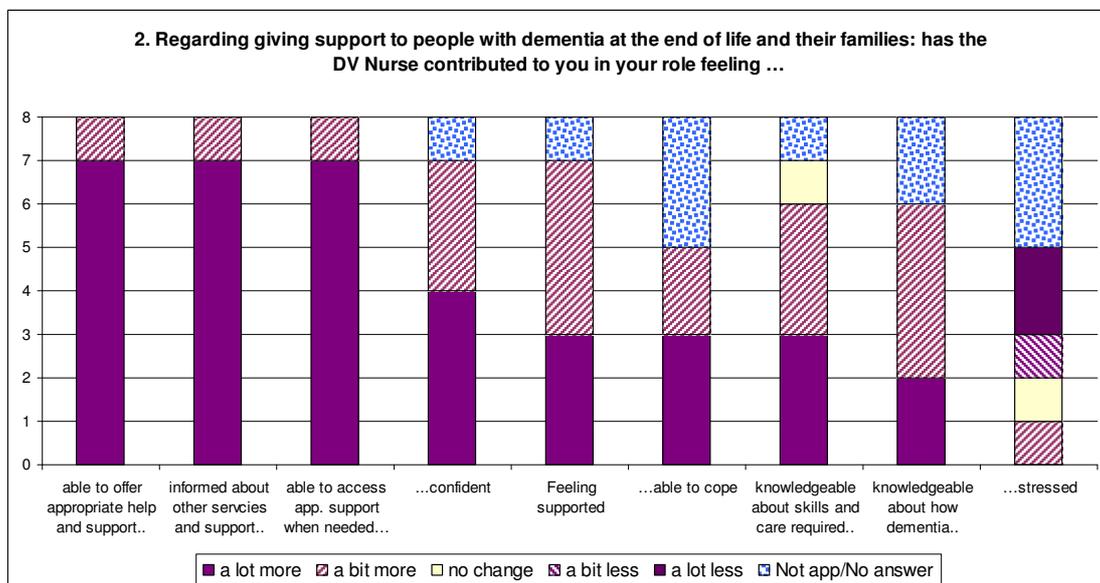
Eight feedback forms were received from Housing 21 Care Staff who have been providing support to people with dementia at the end of their lives. Their responses indicate that the majority felt a lot more empowered in their role as a result of the DV Nurse's contribution. This was evidenced by an overall positive response rate to a range of indicators regarding the skills and expertise required for their practice (see chart below). The majority felt that the nurse had had a particularly strong effect on:

- the avoidance of crises occurring,
- the ability of the family carer to cope,
- the amount of support provided to the person with dementia or the family carer
- The avoidance of breakdown of care.



The majority of staff felt more supported and confident, less stressed, better able to cope, and more knowledgeable about the affects of dementia and the skills required to care for people living with it at the end of their lives (see chart below). They felt:

- much more informed about other services and how to access them
- much better able to offer appropriate help and support to clients and their families (see chart below)
- much more able to access appropriate support when needed.



A selection of comments received from Housing 21 care staff are presented below:

Senior Personal Assistant Tresham Resource Centre

"The DVN provided myself and my 99 year old client with very useful information and helped by using her expertise and professionalism. Her assessments and reports were always accurate and covered all aspects of my client's care. I found her extremely efficient, reliable and compassionate. She understood my client's needs perfectly well in spite of the short space of time she had known her."

Day Centre Team Leader

"I would like to take the opportunity of thanking you for your assistance with one of our service users. I have noticed that your word weighs heavier than day centre staff's, probably because you have a nurse's back ground and are higher up on the hierarchy ladder than we are. This is very important when dealing with vulnerable adults, such as most of our service users. When we can not get through to doctors, districts nurses or even care managers regarding important matters, we can turn to you.

I am thinking of one case in particular. The gentleman in question had been clinically depressed for several years, but although day centre staff notified both care manager and GP many times and requested an assessment for anti-depressants, nothing was ever done. Our service user deteriorated and would no longer leave his house.

When you got involved as an end of life nurse, the care GP would finally take our concerns onboard. Our service user is now taking anti-depressants and he has re-gained some of his will to live. He is attending the day centre and feeling much better in general.

You have also been involved in arranging appropriate accommodation for this man. You are using you knowledge in regards to the social care system to ensure he can exercise his right to use an advocacy service when his son doesn't want him to move into residential care.

The way you look at a service user's whole care package and life situation, in their best interest and with your back ground in the medical field, it quite unique. I think it is important that you service is used appropriately and that it is available for all social services' clients."

Tresham Community Care Team

"I would like to bring to your attention the great input End-of-Life Dementia Nurse has given to the wellbeing and care of Mr A, a service user of Housing 21. who's health and mental state has significantly deteriorated, due to old age and vascular dementia. Due to *the DVN's* involvement, Mr A is receiving more input from various community based services and he will be going into respite in March

The DVN's involvement with Mr A has significantly improved his well being and the quality of care that he is receiving."

8 Results: Feedback from other Professionals Working with the DVN Service

Below are examples of feedback from interviews, feedback forms and letters from health and care staff.

Deputy ward manager
“I really appreciate your support; I do not know what we would have done.”

Full-Time Live In Carer
“As the full-time carer and my first time coping with a dying person the support that I was given by <i>the DVN</i> was invaluable. It gave me and the family peace of mind to know that there was a care plan allowing the client to die in the comfort and serenity of her own home. <i>The DVN</i> gave me the confidence to deal with the situation and it was good to know she was only a phone call away. The family were very grateful to know that such a plan had been made available. Thank you for such a great service.”

A feedback sheet received from a full-time live in carer indicated how much of a difference the DVN had made:

	<i>A big difference</i>	<i>Some difference</i>	<i>No change</i>	<i>I don't know</i>
The well-being of the person with dementia	✓			
The well-being of family carer	✓			
The ability of the family carer to cope	✓			
The care the family carer provides	✓			
Avoidance of crises occurring	✓			
Avoidance of breakdown of care	✓			
The amount of support provided to the person with dementia and/or their carer from external agencies and/or friends/family	✓			

The full-time live in carer indicated how much of a difference the DVN made to her in her role feeling ...

	<i>a lot more</i>	<i>a bit more</i>	<i>no change</i>	<i>a bit less</i>	<i>a lot less</i>
... supported	✓				
... confident	✓				
... stressed					✓
... able to cope	✓				
... knowledgeable about how dementia affects people nearing the end of their lives	✓				
... knowledgeable about skills and care required to look after people with dementia nearing the end of their lives	✓				
... able to offer appropriate help and support to clients and their family	✓				
... informed about other services and support that may be available for people with dementia and their families	✓				
... able to access appropriate support when you needed it	✓				

Feedback from Pembridge regarding the collaborative working between the DVN, CNS from Housing 21 and the Palliative care CNS from the Pembridge Palliative Care Centre.

"I have been very fortunate to work with *the DVN* throughout the period of time Mrs FS and her family were receiving services from the Pembridge palliative home care team.

I greatly appreciated how flexible *the DVN* was in taking on the referral and that she explored ways to achieve this even though the patient lived outside her catchment area.

The district nurses were also very keen for the chance to do as much joint working as possible and take up the opportunity to learn more about assessing and planning care for a patient at the end stage of dementia.

There were some challenges with supporting the patient's family members who had very passionate, but conflicting ideas about the aims of the care and interventions their mother should receive. This had caused a great deal of ill feeling and conflict between the siblings. However, they all equally expressed a great deal of support and commitment towards making Mrs S's quality of life as good as possible.

The daughter that we met together on our first visit (H), expressed emotions of guilt and anger and said she felt very torn about the ethical issues of continuing to actively

prompt food, fluid and medications when her mother was often agitated and restless. She believed that this gentle continuation of prompting was the best for her mother's wellbeing but needed reassurance that the care she was providing gave the quality of life for her mother they all wanted to achieve.

The DVN's knowledge and communication skills were invaluable in providing the reassurance she needed. It also appeared to be the simple but crucial process of affirming to the daughter that the care and support the family were providing were very much the right things that would make her quality of life as best as could realistically be achieved.

Through *the DVN's* specialist knowledge of dementia she was able to waylay some of the fears and anxieties H had about how their mother may suffering or be experiencing discomfort and distress. These included:

- The use of antipsychotic medication in dementia.
- The progression stages of deterioration we expect to see in someone with vascular dementia.
- The physiological process of why Mrs F's desire to eat and drink has diminished.
- The ethical and comfort issues of when and when not to provide feed and fluids.
- Swallowing, hydration vs. dehydration.
- Agitation and calling out 'help me'.
- Mrs S's ability to express and communicate pain.

The DVN kindly sent a copy of her assessment documentation to me which I added to my records on Mrs S. I found this an excellent resource and tool for my own learning. It extended my insight into the types of questions and information I should be gathering when I have a palliative care patient with dementia as a primary diagnosis, or as part of their medical history.

Mrs S has recently passed away following a chest infection but thankfully remained at home which met the wishes of her three children in her final days."

9 Perspectives of Steering Group Members

Views were received from:

- Dementia Development Officer at Westminster City Council
- Consultant Psychiatrist/Lead Clinician Older Adults with Central and North West London Foundation NHS Trust
- Dementia Operational Manager, Housing 21
- Consultant and Senior Lecturer in Old Age Psychiatry at Oxleas NHS Trust and Memorial Hospital
- Medical Director of Clinical Services , St John's Hospice.

9.1 What are the Benefits and Strengths of the DVN Service?

- **Positive impact and outcomes on clients, their families and others providing care for them**

The majority stated that the key benefits and strengths of the service are the positive impact and outcomes on clients and staff.

For people with dementia and family carers:

“Very good assessment and ongoing support for those with dementia at home.”

“Supporting people living with dementia and their families/carers to remain in community settings.”

For care and health professionals:

“Social care staff have benefited from raised awareness of end of life issues. This ranges from Home Care staff to Care Managers, and enables people to be better informed and consequently better prepared to make informed decisions about a person’s care.”

“Home Care Staff and family carers should feel more confident about providing care and support to people with dementia in the last year of life.”

“Health care professionals have benefitted by having a specialist nurse provide information and support on appropriate nursing care and psychological well-being especially around ward based and long-term care.”

“Support and input to both palliative care and district nurses etc. to enhance understanding and competency in managing dementia towards the end of life.”

- **Raising awareness of end of life issues in dementia care across settings**

Many felt that the DVN Service has made a significant contribution to raising awareness of end of life issues in dementia care in community, hospital and residential/nursing home settings.

“Just having a person with this title and role has moved the issue to the forefront.”

- **Service based outside the NHS**

Three people highlighted the service being based outside the NHS as a significant strength:

“The major strength is that the service is provided from outside of a health care setting and from within a third sector organisation. This gives it a sense of independence and advocacy, which may have otherwise been difficult to find.”

“Not being part of an established team is unlikely strength as the DVN can be an independent advocate and not be bound by too many rules/regulations/policies/resource issues etc. I would highlight that a

degree of independence/advocacy ability is inherently important in this work. “

- **Partnership working**

“There have been many examples of good joint working, e.g. between the DV Nurse and Community Nurse Specialists in the St. John’s Hospice Community team, where the ability to draw on a wider range of specialist knowledge has helped to maintain people in community settings.”

- **The post requiring dual qualification**

- **Strong presences of dementia services in Westminster**

“The existing, strong presence of dementia services in Westminster helped the nurse find her way around the City quickly and opened a number of doors.”

9.2 What Have Been the Barriers or Weaknesses for the Project?

9.2.1 ‘External’ Barriers

- **Lack of awareness of benefits of the service and how it can work**

“A lack of awareness of the opportunities provided by a case managed approach leading to low referral rates from dementia services.”

“Problems engaging with primary care with anxieties on their part about the way in which support may come.”

“Inappropriate concerns about confidentiality and information sharing. “

“Acceptance by some district nurses”.

- **Newness of such a service provided by a third sector organisation**

“Working with third sector is new for people in public service - I think there was a bit of “Who is she/where has she come from etc; how is she linked into services”. This was true for primary and secondary statutory services.”

- **End of life is a taboo subject, perhaps more so with dementia**

- **The lack of awareness of prognostic indicators and what constitutes end-of-life care for people with dementia, particularly amongst social care staff**

“Because of this, and the lack of acceptance that dementia is a terminal illness, referrals for people approaching the last 18 months of life who are still living in their own homes have been very hard to get. This has impacted enormously on the project’s aims for care staff and family members to feel more confident about how they care and support the person with dementia. Instead, a considerable amount of work has

been taken up with providing a service to people who are in hospital, long term care or approaching final months or weeks of life.”

“Low referral rates at the slightly earlier stage of illness”.

9.2.2 ‘Internal’ Barriers

- **Challenges around which patient record system the nurse should use, with risks of dual recording and other inefficiencies**

- **Limitations in the initial set up of the service** (*largely due to changed emphasis of service from original conception?*)

“A lot of time had to be spent by the DV Nurse to overcome some of the misunderstanding of her role. The learning from this is to ensure that local implementation includes a project development phase in partnership with the NHSW/WAS so that any developing local strategies can be both taken into account and benefit from partnership working. Earlier joint working and a clearer marketing/ promotion strategy to inform all stakeholders of the new service together with an expected referral profile may have enhanced success. “

“Not having key personnel on the steering group from the beginning was a handicap, as there was no local representation from either Westminster City Council or NHS Westminster. As a consequence we had no tie-in to local health provision or investment from joint commissioners. This in turn led to difficulties in engaging with District Nurses, GPs, palliative teams, hospitals etc. Subsequent enrolment of key personnel from City of Westminster, NHS Westminster, and St John and Elizabeth’s Hospice onto the steering group helped turn lack of local engagement around.”

- **Access to appropriate healthcare professionals in the early stages of the project**
- **DVN time required for reporting and meetings working in partnership with many multiple organisations**

- **At the beginning, not being part of an established team/service**

“(although this could also have been a strength too); the DVN probably felt better when she moved into HSJSE.”

“it has not been clear what the expectations are around the provision of cover for the DV Nurses cases when she is on annual leave or off sick.”

- **Profile**

Two people felt more could have been done to raise the profile of EOLC in dementia amongst local professionals.

“This role needs clear leadership/ champion skills, taking a lead in training professionals in dementia and eolc, being recognised as the

local expert in dementia eolc care to which other clinicians/ professionals turn to for advice/ support.”

“We think the training role of the post may have benefited from partnership with Westminster's key training commissioners with regard to general awareness raising and widening the impact.” *[although training external professionals was not part of the original remit of the project].*

- **Efforts not been able to focus enough on gaining referrals from H21**

“Although the H21 Westminster Home Care Managers were welcoming of the DVN Service in terms of enabling the nurse to come to team meetings to provide training and information sessions, there seems to be little investment in making it work, presumably because of time and workload factors. An example is that care staff have been instructed not to contact the nurse directly, but to go through their senior managers, who would then have to check with Westminster Care Management for approval. I think the weakness was not having a plan on how to integrate and educate, or predict the problems that might be encountered; it was left, in a sense, for one person to tackle an entire institution and change its culture without thinking about how.”

9.3 How Have Barriers Been Overcome?

- **Demonstrating excellent assessment, care, liaison and communications, and individual case work**

“Being able to work physically with colleagues.”

- **Awareness raising and partnership working**

“Slowly building relationships and understanding.”

“By Westminster’s Dementia Service Development lead working with H21 and for the post to be supported/ located via one of Westminster’s recognised palliative care services. The latter has ensured both support to the DN, and recognition of her role within EOLC.”

- **Refocusing work with Housing 21 Care Services**

“Engaging fully with Housing21 Care Services is an ongoing piece of work involving liaison with home care management teams.”

9.4 What Have Been Enablers for the Project?

- **Joint working and relationships**

“Support for PCT and CMHT”

“A good diverse project team and willingness from the steering group.”

“A willingness of staff/professionals to listen and learn”
(CMHT/Butterworth)

“Input from NHS Westminster enabled greater entry into primary care services as well as CNWL mental health services. They enabled the

service to work alongside the palliative care at St. John and Elizabeth's Hospital.”

“The links forged with mainstream older people’s mental health services and specialist palliative care services have been crucial in giving legitimacy to the project.”

- **Qualities of the DVN**

“The Nurse, herself, has been an enabler in the way she has approached services and staff in a variety of settings”

“Her quiet, unassuming way opened doors.”

9.5 Greatest Achievements So Far

- **Positive outcomes**

“Very good outcomes have been achieved”

“Enabling people to die in their preferred place of choice“

“Enabling family carers to be better informed and prepared”

“Family carer feedback has been very positive”

“The personal 1:1 input to clients”

“The service has also been appreciated by the service providers benefiting from it and staff have felt supported.”

- **Partnership working**

“Good work with hospice”

“Building (albeit slowly) good relationships with PCT DN and CMHT.”

- **Raising awareness of the importance of end of life issues and early discussion/debate and thought among staff, people with dementia and their families**

“This is no mean feat in itself and I think the project and the DVN have achieved this relatively quickly. One question is how this might be maintained - certainly it would be worth highlighting the need to maintain this in dementia care settings.”

“The project has undoubtedly raised the profile of the need for proper planning for the end of life for people living with dementia.”

10 User Case Examples

Below is a range of case examples which demonstrate the wide variety of people and circumstances the DVN worked with.

10.1 Case Example DV-01

DV-01 Is living on his own in a flat in West London and has been attending Tresham Day Centre (a specialist day centre for people with dementia) for several years. Tresham Community Care Team (an outreach service), who had been visiting DV-01 since November 2006, referred him to the DVN Service. His condition had deteriorated and he no longer wanted to attend the Day Centre.

Following assessment the DVN contacted the service user's care manager, GP and next of kin who was unaware of his father's condition. She diagnosed also the service user as suffering from depression and he is now receiving medication for this condition. She was also able to organise him to receive increased input from various community based services, and it was arranged for him to go into respite.

DV-01 has improved both physically and mentally through advice, liaison and information sharing provided by the DVN, is now attending the Day Centre again, and there has been a reduction in transfers to hospital.

Feedback from Housing 21 staff stated that the DVN Service, "has significantly improved his well being and the quality of care that he is receiving". Housing 21 care workers also felt supported by the DVN.

A letter of thanks was received from Tresham Day Centre Team Leader, which contained the following excerpts:

"The gentleman in question had been clinically depressed for several years, but although day centre staff notified both care manager and GP many times and requested an assessment for anti-depressants, nothing was ever done. Our service user deteriorated and would no longer leave his house."

"When you got involved as an End of life nurse, the care GP would finally take our concerns onboard. Our service user is now taking anti-depressants and he has re-gained some of his will to live. He is attending the day centre and feeling much better in general."

"Your word weighs heavier than day centre staff's, probably because you have a nurse's back ground and are higher up on the hierarchy ladder than we are. This is very important when dealing with vulnerable adults, such as most of our service users. When we can not get through to doctors, districts nurses or even care managers regarding important matters, we can turn to you."

"You have also been involved in arranging appropriate accommodation for this man. You are using you knowledge in regards to the social care system to ensure he can exercise his right to use an advocacy service when his son doesn't want him to move into residential care."

"The way you look at a service user's whole care package and life situation, in their best interest and with your back ground in the medical field, it quite

unique. I think it is important that you service is used appropriately and that it is available for all social services' clients.”

10.2 Case Example DV-02

A service user had been admitted to a hospital ward which had no experience of caring for people in the dying phase as it was a dementia acute unit. The DVN was able to:

- alleviate staff anxieties
- up skill staff
- visit care of the dying policies
- advise on pain and behaviour management
- make suggestions regarding medical treatment (she requested use of low dose of an anti psychotic to alleviate patient's distress and also encouraged staff to use the Bu Trans patched prescribed by the Palliative team)
- support the family to put in place plans for a funeral director, and place of burial, and to freely talk about the anticipation of death and involvement of their spiritual support services.

DV02 passed away in hospital with her family present.

The Deputy Ward Manager wrote to the DVN, “I really appreciate your support; I do not know what we would have done without it”.

10.3 Case Example DV-04

At referral case DV-04 was experiencing deterioration in dementia (loss of mental capacity), poor oral intake, loss of weight. There were very poor family dynamics.

The DVN took part in a joint assessment of needs, risks and planning with the palliative home care team and worked jointly with the generic palliative team to provide holistic care. She was able to help the family to understand that their mother was approaching the end of her life, and enabled them to agree on arrangements pertaining to her end of life.

A letter of appreciation of the DVN Service was received from the Palliative team in which they highlighted,

- the joint working activities with the DVN was an effective way for them to learn and share some of the knowledge and skills of the DVN's specialist area, and to learn more about assessing and planning care for a patient at the end stage of dementia
- the DVN's knowledge and communication skills were invaluable in providing the reassurance that the family needed
- the DVN's assessment documentation was an excellent resource and tool for the palliative care team and has extended their insight into the types of questions and information they should be gathering when they have a palliative care patient with dementia as a primary diagnoses, or as part of their medical history.

Following a chest infection case DV-04 passed away at home which met the wishes of her three children. Her family felt she had died very comfortably and with the dignity they wanted for her.

10.4 Case Example DV-13

DV-13 was being looked after in her own home by a live-in agency carer who had no experience of people at the end of life. At the time of referral to the DVN Service the service user was not eating or drinking. She had been going in and out of hospital unnecessarily due to lack of knowledge, support and confidence of the agency carer to deal with the end stage of life.

The DVN supported the agency staff to cope with the dying stage through one to one skilling. She also made contact with the family, who did not live nearby, and kept them regularly updated by telephone. Unnecessary admissions to hospital ceased.

DV-13 passed away peacefully at home in the care of her carer. The family sent appreciation of the DVN Service and the fact that the carer was helped to manage the patient at the end stage of life.

The live-in carer completed a DVN Service feedback form which showed that she felt the DVN had contributed to her feeling a lot more supported, confident, able to cope and offer appropriate help and support, and a lot less stressed. She wrote that the DVN is "a great service" which gave her the confidence to deal with the situation, reassurance to know that the DVN was only a phone call away, and gave her and the family peace of mind knowing that there was a care plan allowing the client to die at home.

10.5 Case Example DV-14

The referral for DV-14 came through a hospice which was providing care for her at home during the night. The lady had been going in and out of hospital with pneumonia, and was evidently nearing the point of death. After the specialist DVN Service assessment the DVN applied for a continuing care package which enabled care to be provided during the day. The DVN has been given the 'key person' role and is currently co-ordinating the care. DV-14 has since made a significant improvement and is now eating again and interacting with visitors.

10.6 Case Example DV- 31

A family carer requested information on how to deal with issues her mother was experiencing in a private residential home. The DVN discussed the issues with the Community Mental Health Team Psychiatrist and the Care Manager who was in another Borough. Following these discussions a carer was put in place in the same Borough as the family carer.

10.7 Case Example DV- 35

DV - 35 was referred by Tresham Day Centre. She presented with recurring episodes of Urinary Tract Infections. She was also very lethargic and slept a lot at the day centre. Her mobility was poor and she had a poor food intake. There had been a notable deterioration. She lives in an Extra Care accommodation and the staff were finding it difficult to manage the care demands. They wanted to move her to a residential or nursing home but the son did not want her to be moved.

The DVN attended Case Presentation Meetings held by MDT. The DVN discussed this case with the Community Mental Health Team and advised the son to have an advocate to support him with his case. The DVN remained in constant contact with the son. Extra care time was awarded and the accommodation was equipped with a hoist.

10.8 Case Example DV- 39

DV-39 was referred by a District Nurse. She was being cared for at home by private carers with one overseeing the care being employed by the Power of Attorney (solicitors). She was bed bound, had a urine catheter and depended on the carers to achieve activities of daily living. She had live-in carers and some came on a daily basis to help with manoeuvres. The carers had no idea that DVN was actually in the end stage of her life and they were not trained in how to manage the dying. The DVN set up training at the premises for the carers and the manager. The team were able to look after DV-39 until she passed away at her home. The care team were highly appreciative of the training and support that had been provided by the DVN.

10.9 Case Example DV- 46

DV-46 was referred by the Housing21 Community Care Team. They had noticed a deterioration in their physical state with signs of depression, mobility problems and poor eating habits. The family carer was in need of support as she was being overwhelmed by the condition.

The DVN contacted the Community Mental Health Team (CMHT) to alert them to her involvement and she was involved in the Care Programme Approach (CPA) care planning. DV-46 was placed in a nursing home due to her risks of falls and suicide. The DVN supported the patient in the Nursing Home until they felt settled. The DVN participated in an MDT meeting and conveyed feedback to CMHT during a CPA discharge meeting.

10.10 Case Example DV- 49

DV-49 was referred by the Care Manager of a Nursing Home. As he spoke Arabic so there was a significant communication barrier and the son usually interpreted for staff. The son however, was disgruntled about the care his father had received. He believed the staff caused an injury to his father's ear. A POVA report was raised by the Care Manager. DV-49 had Vascular Dementia but was also blind, deaf and had cancerous tumour of the gums. He was under the care of the Head and Neck Clinic for his tumour and was entirely dependant on staff to achieve activities of daily living.

The DVN checked the pain assessment tools they used and advised on frequent pain medication. Training was provided on Dementia Palliative Care and the DVN maintained contact with staff to check on the progress of the case and offer support.

11 Sustainability of the Service: Life After the Two Year Pilot

A business case for the Dementia Voice Nurse Service was developed based on the interim review evaluation after the first year of the pilot. This was discussed with the Primary Care Trust and Westminster Borough Council who had their own dedicated Commissioner who aided the process. The significant savings that the service provided were positively identified and a decision was made to extend core funding for a further year on a trial basis. Following further encouraging findings and strong partnership working between the service and the local NHS services it was agreed to include the Dementia Voice Nurse Service in the tender for the Borough's range of Core Dementia Services. Success in this tender has ensured that the Dementia Voice Nurse has become a core offering of the Dementia Support Service in the Borough.

The success of the Dementia Voice Nurse Service in Westminster has made a compelling case for funding elsewhere across the country. The Department of Health has granted funding to carry out a further pilot of the service in two different settings for three years. In addition, other Primary Care Trusts and Local Authorities are in discussions with Housing 21 about rolling out the service in their area.

Recognising the importance and impact that this service can have to the quality of life of those with Dementia and their family, Housing 21 have included a target in their Corporate Plan to offer the service in at least 10 localities by 2016. The funding from the Department of Health that Housing 21 is receiving will enhance the sustainability and effectiveness of the service as through expansion in different locations further learning points and refinement is expected. Continuous expansion and improvement will increase the cost savings being accrued to the NHS and continue to contribute to improving the quality of life for the half a million people in England living with dementia and their families.