



Review of Dementia Services  
in Westminster  
*December 2009*

A Scrutiny Review by the Health Policy  
and Scrutiny Sub-Committee



City of Westminster

## Acknowledgements

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## Background

+ As part of the 2009/10 work plan, the Health Policy and Scrutiny Sub-Committee Scrutiny Task Group agreed to undertake a scrutiny review of the Dementia Services available within Westminster.

+ Cllr Frances Blois was elected Lead Member for the Dementia Services Review.

+ This report summarises the main findings of the review. For more information on any aspect of the review please contact Simon Lewis at [slewis2@westminster.gov.uk](mailto:slewis2@westminster.gov.uk) or 020 641 4298.

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## Lead Member's Introduction



I am delighted to introduce this report. As members of the post war baby boom, we are probably better informed than any generation of the consequences of old age, whilst the new 60s is now considered to be the old 40s.

Scarcely a day goes by where there is not a press report or television programme about the problems encountered by those suffering from dementia either at home or in care homes. In many cases people and their families suffer in silence just blaming advancing years until a serious crisis presents itself. Early diagnosis and a care plan with help from services such as the new Memory Service and appropriate day centres to enable carers, particularly if they are a close relative, to have a break are all essential. Appropriate care homes or respite care are also alternatives.

This report, which covers the visits made and group sessions attended, is an attempt to address dementia issues in Westminster. I enjoyed meeting the patients, carers and professionals during late summer and autumn 2009 and hope that the findings and recommendations in this report will help in the treatment and future well-being of those in all stages of dementia.

My thanks goes to Jude Sweeting for helping to coordinate all the various strands and my best wishes go to all who so willingly contributed to this report which I hope will help to increase our knowledge base.

**Councillor Frances Blois  
Lead Member on the Review  
of Dementia Services in  
Westminster  
Health Policy and Scrutiny  
Sub-Committee  
December 2009**

## Executive Summary

As part of increasing media attention and in response to the *National Dementia Strategy (NDS)* our Westminster Health Policy and Scrutiny Sub-Committee has undertaken a review of dementia services provision across the city. The review has looked at a cross section of service offered by the council, the Central and North West London (CNWL) NHS Foundation, NHS Westminster and our partner organisations.

Within Westminster dementia services are offered by the council, NHS Westminster, the Central and North West London NHS Foundation, a number of third sector partners and agencies and other volunteer groups. A wide range of services are offered by these agencies to those living with dementia and their family carers. Services include respite and peer support services for family carers while those living with dementia are offered diagnosis, treatment and therapies, as well as on-going care support and day centres.

The review outlines that 70% of people living with dementia in Westminster remain undiagnosed and this number is set to increase from 1,648 to 2,567 by 2025. Whilst this remains 7% of the expected population, the combination of a high percentage of older people living alone and a number of hard to target groups means that the need for care packages will increase greatly.

The review has focused on the experiences of service users, both family carers and those living with dementia, and in line with the NDS, the findings are organised around the three key objectives of:

### 1 Knowledge and Awareness

### 2 Early Diagnosis

### 3 Good Service Provision

Our review shows that dementia care in Westminster is already at a high standard, however the research has also recognised some service gaps. Specifically it is noted that Westminster fits the national context of providing services only at the point of crisis and the review makes a strong argument that early diagnosis and referrals are vital.

Looking to the future it is imperative that the new Westminster Memory Service succeeds. More widely, the potential for transforming existing services and developing hub based dementia provision should be explored through bold and innovative approaches.

## Recommendations

### Experiences of Dementia

+ We need to take all necessary steps to involve people with dementia in their own lives. This must be done in the way that they want, no matter if at home or in residential care.

+ Service users should be provided with help to complete forms and the paperwork related to benefit applications, and attendance allowances must be simplified.

+ Steps should be taken to support family carers particularly in relation to their well-being, financial security and quality of life.

### Westminster Services: Knowledge and Awareness

+ A strong publicity campaign is required to raise awareness of service provision and to raise the profile of dementia throughout Westminster in order to further reduce stigma.

+ The council should support the new Memory Service with a targeted and well informed advertising campaign. This campaign should be in multiple languages and be delivered by trained personnel to target our over 50s population and hard to reach groups such as BME (Black and Minority Ethnic) communities. Particular attention should also be given to raising awareness amongst porters and wardens due to the significant role they can play in their local communities.

### Westminster Services: Early Diagnosis

+ There is a need to develop tailored but open and honest communication with family carers and patients from initial diagnosis. A support plan for each patient which anticipates future scenarios should be mapped out.

+ Diagnosis needs to be made much earlier to avoid crisis care delivery. Strong links must be built with both NHS and private GP surgeries in order to encourage them to pick up signs of dementia at an earlier stage and refer to specialist services more readily.

+ Westminster needs to operate with a full remit of staff, trained to a high standard and recruited with the 'right attitude'. Recruitment must respond quickly to any service gaps and think innovatively about the best ways to attract committed staff.

### Westminster Services: Good Service Provision

#### Accessibility

+ There is a need to further examine the apparent disparity in service provision between the North and South of Westminster.

+ Our research indicates there may be a need for more frequent day services within Westminster, especially in the South. Pullen Day Centre could be extended beyond one day per week and services at Tresham could be extended or opened up to weekend use by the Young Onset Dementia Service (YODS).

#### Quality of Care

+ The care we provide must be more consistent and the reliance upon bank workers must be redressed. It appears that more support services may be needed and specifically the delivery of respite support should be examined.

+ Westminster should attempt to encourage community cohesion through outreach work in order to increase responsiveness to signs of dementia.

+ Our service providers must recognise a possible tension between choice within care provision and the need to deliver vital care tasks.

### Looking Forward

+ Looking to the future, Westminster City Council should be innovative and ambitious in its provision of dementia services. We could explore the possibility of developing a hub approach to service provision; such service redesign should involve our existing service providers.

+ There is a need to use existing advocacy services within Westminster to raise the profile of dementia within council services. The council should gear mainstream services towards providing accessible provision for people living with dementia.

+ Westminster needs to operate with a full remit of staff that has been trained to a high standard and recruited with the 'right attitude'. Recruitment must respond quickly to any service gaps and think innovatively about the best ways to attract committed staff.

## Introduction: Dementia

The term ‘dementia’ is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions, including Alzheimer’s disease, stroke and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with practical tasks, speech and understanding.

Dementia is still understood by many to be a natural part of ageing; however there is nothing normal about dementia and those that live with dementia often require a wide range of assistance. It is estimated that only one third of people with dementia are diagnosed and there could be up to 700,000 people living with dementia in the UK. This number is set to rise to 1.4 million people in the next 30 years with a potential cost of £50 billion per annum to government health services.

There are several diseases and conditions that cause dementia. These include:

**+ Alzheimer’s disease** – this alters the structure and chemistry of the brain, Alzheimer’s disease is the most common cause of dementia.

**+ Vascular disease** – this is a loss of oxygen supply to the brain which causes brain cells to die and dementia to develop, e.g. a stroke.

**+ Dementia with Lewy bodies** – this is where Lewy bodies, protein structures that develop inside nerve cells, lead to the degeneration of brain tissue.

**+ Fronto-temporal dementia** – damage is focused in the front part of the brain bringing more behavioural changes than memory loss.

In February 2009 the Department of Health (DH) launched the first national dementia strategy for the UK entitled *Living Well With Dementia: A National Dementia Strategy (2009)*. The strategy aims to shift the focus of care in order to put people first. Care is to be personalised so that the individual is at the centre of designing their own care package.

The economic rationale behind the review is that costs will be offset by reductions in hospital admissions and the length of hospitalisation. The new dementia strategy widens the group of people understood to be affected to include: younger people with dementia, people with learning disabilities with dementia who have increased risk, and (the needs of) BME communities. The strategy has three broad aims:

- + To increase knowledge and awareness of dementia.
- + To ensure people with dementia are diagnosed early.
- + To develop a range of services for people with dementia and their carers which fully meet their changing needs over time.

These objectives have been used to structure our review.

## Westminster Context: Incidence and Direction of Travel

It is estimated that 529 have been diagnosed with dementia in Westminster. However, Greater London Authority (GLA) population figures suggest there are 1,648 people in Westminster with dementia meaning 70% of cases remain undiagnosed.

According to the GLA, Westminster will not see the predicted level of nationwide increases in dementia. Instead by 2010, it is estimated that 1,882 of Westminster residents aged over 65 will have dementia out of a population of 26,700 (7%). By 2025 this number will have increased to 2,567, and this will still equate to 7% of the population. However, within this demographic the number of very old people, those over 85, will increase. This means that the level and intensity of care needed will increase as individuals are likely to have multiple and complex needs.

### Hard to target groups

Within Westminster’s older population a high percentage live alone; 57% compared to the London average of 43%. When combined with the second lowest level of unpaid care provision in the UK, the result is high levels of social isolation.

A number of groups experience dementia differently than may be anticipated. Dementia is less well understood among Black and Minority Ethnic (BME) communities within Westminster and the symptoms appear to carry a more restrictive stigma.

The risk of developing the symptoms of dementia is four times higher in people with existing learning disabilities, and early stages of dementia are more likely to be missed or misinterpreted. Communication of deterioration in symptoms can also be hard to ascertain.

In 2007 it was estimated that 150 people had young onset dementia within Westminster and Kensington. The needs of people with young onset dementia are different as many are still of working age and often have family and financial commitments. They also tend to be more physically fit than their older equivalents; and there is a more damaging stigma attached to the condition.

## What We Did

In order to understand what was already happening in Westminster the research group undertook a range of different research and evidence gathering activities. These are listed below:

- + We mapped out service provision within Westminster looking at borough wide coverage and type of provision available.
- + We examined the changes we expect to make in Westminster as a result of the *National Dementia Strategy*. We considered how our new Memory Service could help make a diagnosis of dementia easier to live with for all concerned.
- + We visited a number of services and asked frontline workers and family carers about how well Westminster supports people with dementia. Specifically we wanted to find out where there are gaps and how we can improve our service.
- + We talked to people living with dementia and family carers who use our existing services and asked how well we have supported their sense of choice, independence and control.

### The sites we visited:

#### Diagnostic & Assessment Services

- + South Westminster Older People's Community Mental Health Team (CMHT)
- + Young Onset Dementia Service
- + Memory Service

#### Community Support Services

- + Tresham Dementia Services
- #### Support for Family Carers
- + Six Steps Forward
  - + Carers Network Westminster

## Provision: Mapping of Services

Our review found that the level of service provision in Westminster is good and as a borough we are performing well. However, the service picture is complex, with multiple agencies providing support, and some gaps do exist.

Within Westminster dementia services are offered by the council, NHS Westminster, the Central and North West London NHS Foundation, a number of third sector partners and agencies and other volunteer groups. A number of these agencies work in partnership sharing both responsibility and funding streams, with staff members from different organisations working closely together. This effective partnership working should be encouraged.

A wide range of services are offered within Westminster to both those living with dementia and their family carers. Family carers are offered respite support to relieve them from daily caring duties and peer support sessions so that they can share experiences. For those living with dementia a range of diagnostic services deliver assessment and treatment, while home-based and community care support are offered by a number of dementia facilities. Specialist day centres and residential homes are also available.

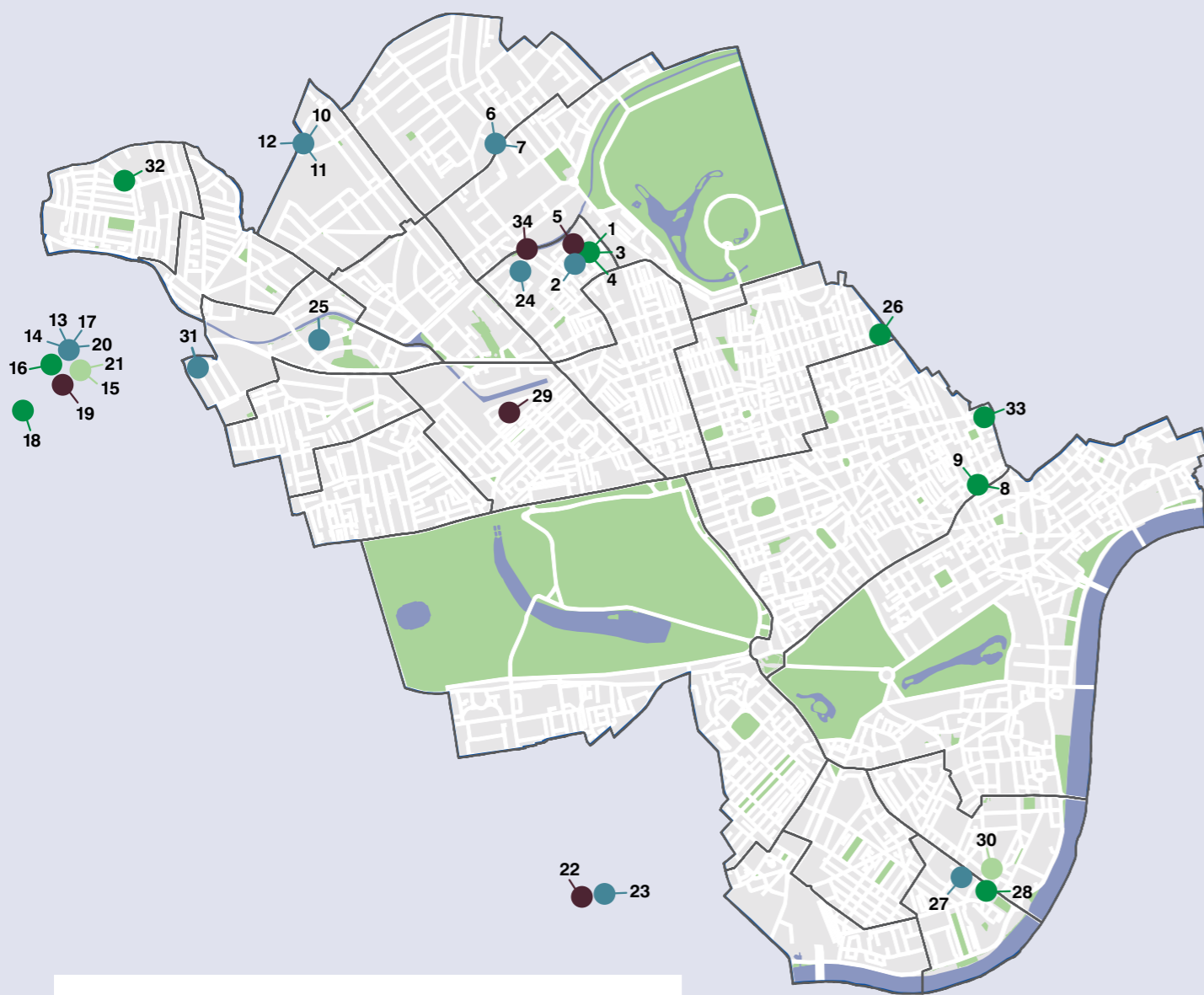
To illustrate the service picture we aimed to comprehensively map all dementia 'specialist' services across the city.

The map shows:

- + Dementia facilities
- + Outreach and community services
- + Specialist services and personnel

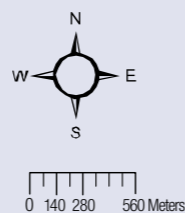
The mapping exercise indicates an apparent disparity in the level of service provision between the south and the north of Westminster with the south appearing to have fewer dementia facilities and specialist personnel.

## Dementia Services in Westminster



### Map Key

- Dementia facilities in premises
- Outreach and community services
- Specialist personnel
- Diagnostic, assessment and management services
- Ward boundaries



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### Tresham Dementia Services

|   |  |
|---|--|
| 1 | Tresham Community Care Team                                |
| 2 | Tresham Day Centre   |
| 3 | Tresham Dementia Services Carers Dementia Support Services |
| 4 | Tresham Dementia Services Home Care Plus                   |
| 5 | Tresham Dementia Services End of Life Nurse                |

### Hospital of St. John's and Elizabeth

|   |                        |
|---|------------------------|
| 6 | Blenheim Day Centre    |
| 7 | The Butterworth Centre |

### St. Anne's Church Anglican, 55 Dean Street

|   |                    |
|---|--------------------|
| 8 | Six Steps Forwards |
| 9 | Advocacy Plus      |

### Carlton Dene Elderly Resource Centre, 45 Kilburn Park Road

|    |                           |
|----|---------------------------|
| 10 | Carlton Dene              |
| 11 | Carlton Dene Day Centre   |
| 12 | Carlton Dene Short Breaks |

### St. Charles Hospital, Exmoor Street

|    |  |
|----|--|
| 13 | Chamberlain Day Hospital   |
| 14 | KCW Older Adults Family Therapy Service                          |
| 15 | KCW Young Onset Dementia Service                                 |
| 16 | North KCW Home Treatment Team                                    |
| 17 | Oak Ward   |
| 18 | South KCW Home Nursing Team                                      |
| 19 | Westminster Admiral Nurse Service                                |
| 20 | Westminster Intermediate Mental and Physical Health Care Service |
| 21 | Westminster Psychological Service for Older People               |

### South Kensington & Chelsea Mental Health Centre

|    |  |
|----|--|
| 22 | Chelsea and Westminster Hospital Liaison Service |
| 23 | Kershaw Ward                                     |

### Non-Clustered Services

|    |   |
|----|---|
| 24 | 60 Penfold St                           |
| 25 | Forrester Court Nursing Home            |
| 26 | North Westminster CMHT for Older People |
| 27 | Pullen Day Centre                       |
| 28 | South Westminster CMHT Older People     |
| 29 | St Mary's Liaison Service               |
| 30 | Westminster Memory Service              |
| 31 | Westmead Care Home                      |
| 32 | Carers Network Westminster              |
| 33 | Westminster Carers                      |
| 34 | Development Officer Dementia            |

## Experiences of Dementia

Dementia deeply affects and has many ramifications for people living with dementia and their family.

### The impact on people with dementia

The small discussion group that we held with service users at Tresham Day Centre revealed that they were well settled and happy with the service. All three of the service users that we spoke to were experiencing the early stages of dementia when they first began attending Tresham Day Centre. The most significant signs of their dementia were in the home setting where the daily struggles of memory loss and the subsequent confusion meant their stress levels could increase dramatically in response to minor events.

Our review found that people living with dementia felt that their world shrank and their lives altered greatly after diagnosis. For many, Tresham acts as their main social network and community setting. All of the service users enjoyed the wide array of activities and expeditions on offer at Tresham such as singing, quizzes, exercise, bingo and museum visits.

Consistency was found to be very important for service users and they were all keen to avoid changes they considered to be disruptive. We heard from one service user who initially did not settle at Tresham and had some difficulty accepting that she needed support. However, following a steady period of attendance she was able to settle. In this regard, people living with dementia need as much emotional support as they do physical support and our service users felt that they were more sensitive than other older people.

### The impact on family carers

Family carers often play a pivotal role in providing day-to-day care and support for relatives with dementia. However the stresses experienced by those who care for a relative can be considerable. Often this is compounded by a lack of understanding of dementia and therefore carers need as much, if not more, support than the service users; particularly around diagnosis.

Evidence has shown that post-diagnosis depression can be high in family carers. The social life of a family carer can quickly become curtailed once caring for their loved ones becomes too demanding. Many family carers described caring for someone living with dementia as a full-time job, and a number of stories were recounted of social situations in which the person suffering from dementia had been lost or anxious.

Family carers did not like the arduous forms required for care and benefits, for example attendance allowance and carers allowance, and said that too much of their time was spent filling these in. Many felt that more social service support with these forms would be beneficial and they were unaware of the benefits advice service in Westminster. Applications for lasting powers of attorney and changes due to personalisation were also viewed as complex. Carers found it frustrating to have to seek the consent of those living with dementia before they could get a problem solved.

Family carers struggle to understand the services on offer and a number complained of dementia services being the best kept secret. In this respect a lack of communication was the primary issue for family carers. Financial constraints also featured highly in feedback with many regarding the carer's allowance as too low and the attendance allowance as not readily promoted.

The all consuming nature of family caring means that respite support is incredibly important. Even short breaks to allow family carers to catch their breath and carry out normal activities can make a big difference. Many family carers feel guilty when they cannot support their loved ones but the breaks are vitally important and flexibility is required in provision. The family carers that we spoke to felt that flexibility was lacking.

One clear message coming from family carers was that the approach of individual practitioners matters. Some had GPs who were very helpful and professional carers who were consistent and dedicated, while others felt blamed and scrutinised by their professional carers and neglected by their GPs.

Family carers clearly appreciated the opportunity for peer support and regarded Carers Network and Six Steps forward as valuable services. The peer support allowed family carers to feel in control of their situation. However, our review found that there is still some way to go before Westminster truly puts people in control. Carers who we spoke to appeared in control through necessity, not choice, and tended to rely on reacting to situations as they arose.

### Recommendations

- + We need to take all necessary steps to involve people with dementia in their own lives. This must be done in the way that they want, no matter if at home or in residential care.
- + Service users should be provided with help to complete forms and the paperwork related to benefit applications and attendance allowances must be simplified.
- + Steps should be taken to support family carers particularly in relation to their well-being, financial security and quality of life.

## Westminster Services: Knowledge and Awareness

Our review found that within Westminster there is no central source of service information which can be easily accessed by people living with dementia, their family or their friends. Instead information is currently distributed by a number of service providers and the Development Officer for Dementia.

Fortunately, there should now be resources available to support awareness of the new Memory Service and for a limited campaign in order to publicise the new Dementia Adviser Service which will work in association with the Memory Service.

Dementia remains highly stigmatised and the problem remains that, once diagnosed, information is not readily available regarding the services on offer. Family carers felt more information was needed and that services should be advertised through posters in housing blocks and adverts in Westminster publications. With a large number of older people living alone in Westminster the family carers thought a strong argument could be made for targeting advertising material towards porters and wardens.

Having increased their catchment area to cover the whole of south Westminster, the Older People's Community Mental Health Team (CMHT) have not seen the expected increase in number of referrals. It is likely this is due to limited capacity to raise awareness with GPs and a corresponding low profile of dementia in the area due to staff shortages. Elsewhere, the Young Onset Dementia Service already provides and distributes leaflets to GPs. However, the challenge remains to get people referred early enough – this will require outreach education and a robust advertising campaign.

The Memory Service has recognised the importance of enhancing visibility and reducing stigma. They plan to use their full-time administrator to advertise the service through posters. It is important that the launch of the Memory Service is supported with a strong and well resourced advertising campaign.

Success of the Memory Service and other dementia services will require a culture change within GP and primary care practices. Peer discussions between GPs and the doctor at the Memory Service should facilitate a greater rapport which will enhance referrals. There is a need for better coordination with private GPs as, at the moment, they do not refer in the same manner, meaning they operate as an 'untapped resource'.

In order to reach BME populations the Memory Service will not just rely upon improving visibility within primary care units but will also actively engage with these communities. Discussions are underway to translate advertising material and develop innovative ways of projecting messages. Community connections will be built through work with churches, mosques, local advocacy groups and word of mouth. The Memory Service will look to best practice from other councils such as Croydon, Camden and Tower Hamlets – there may also be scope to learn from the Young Onset Dementia Service which has experience providing its service for BME populations.

Our service users noted that there was a lack of community within Westminster. Service provision and specific diagnosis would be more effective if communities were active. As such the Council should look for innovative ways to facilitate community understanding and engagement. Mechanisms should be in place for communities to respond to changes in people's behaviour and they should be able to report any concerns.

### Recommendations

- + A strong publicity campaign is required to raise awareness of service provision and to raise the profile of dementia throughout Westminster in order to further reduce stigma.
- + The council should support the new Memory Service with a targeted and well informed advertising campaign. This campaign should be in multiple languages and be delivered by trained personnel to target our over 50s population and hard to reach groups such as the Black and Minority Ethnic (BME) communities. Particular attention should also be given to raising awareness amongst porters and wardens due to the significant role they can play in their local communities.

## Westminster Services: Early Diagnosis

Within Westminster our diagnostic services note that they are still having first contact with people with dementia at the point of crisis. The change in emphasis from the National Dementia Strategy is therefore welcomed and the Memory Service will aim to emphasise early diagnosis.

Diagnosis at the Memory Service will be principally for over 65s. The service will not be a stand alone clinic but instead will be run on a hub and spoke model. The service's predominant activity will be outreach to the communities and will aim to personalise diagnosis for each individual referred. Assessments will be carried out at the home to ensure as much information as possible is collected and the team will take history from both the individual and their family carers.

The innovative position of Dementia Adviser will be introduced and will be seated in the third sector. The Dementia Adviser will provide support prior to and during diagnosis and stay in contact with the person until death. The aim is that the Dementia Adviser service will be a significant contribution to how advice and guidance is offered in Westminster. However, there is concern that one adviser will not be sufficient for the whole of Westminster and the issue of providing further financial resource is a problem in the current climate.

The Older People's Community Mental Health Team in south Westminster has had a difficult 2009 due to staff shortages which have meant that the service is stretched and unable to carry out awareness raising activities. However, the team offers an excellent service and they are now well located to provide care in the south. Across Westminster's services there are ongoing issues surrounding recruiting the full complement of staff, especially those with relevant skills and experience working with older people suffering with mental health problems.

For people with young onset dementia diagnosis is available through the Young Onset Dementia Service. This team operates on the model of a Specialist Community Mental Health Team with equal emphasis on medical and technical aspects such as neuropsychometry, brain scanning and diagnosis on the one hand and therapeutic, social and occupational support on the other. A specialist young onset dementia day hospital is held every Friday where therapeutic support is available in the form of individual and group therapies.

### Family carer's experiences of diagnosis

The research team heard very different experiences of how diagnosis was delivered and dealt with by dementia services in Westminster.

**Carer 1:** Carer 1's husband experienced rapid onset of dementia following a routine operation in hospital and received no initial engagement from social services. Her husband's challenging behaviour reached a crisis point at which stage he was admitted to A & E – this seemed an overreaction. Subsequently, frequent relocation meant there was minimal continuity of care and life was disruptive for both.

**Carer 2:** Carer 2's husband was diagnosed with dementia after a routine check-up for balance issues. This meant his dementia was caught very early. The GP delivered the news via a headed letter stipulating his condition – this was devastating and could have been addressed with more tact. However, subsequent sign-posting and service provision has been excellent.

**Carer 3:** Carer 3's wife, who was under 65 years of age, was misdiagnosed with depression, as oppose to dementia, and lived with this misdiagnosis for 3 years. After being diagnosed correctly she was placed on an excessive dose of neuroleptic medication – this has had lasting effects. Having since moved on to Aricept and through a combination of support the situation improved.

## Westminster Services: Early Diagnosis (continued)

With these experiences in mind our review found that in the initial stages of diagnosis and immediately post-diagnosis there is a need to pool expertise in order to manage people with dementia. It would be very helpful to link rigorously with other agencies to support diagnosis of a person who may already be known to other services. However, concerns over confidentiality make this more difficult.

More cooperation is needed between services and multiple issues should be dealt with at once in order to reduce the frequency of hospital visits. A rapid assessment team would assist in reducing problems of access, as well as doctors who are willing to visit their patients at home. One family carer commented on how important her doctor's understanding approach was.

While early diagnosis is vital, the family carer's who we spoke with also flagged up the need for an honest conversation about what the future holds. This service should be offered at the initial stages of diagnosis and doctors and practitioners could help to outline the future steps and likely scenarios. Although this is a challenge, as the progression of dementia is unique to individuals, open and honest communication should underpin all of Westminster's practice.

### Recommendations

- + There is a need to develop tailored but open and honest communication with family carers and patients from initial diagnosis. A support plan for each patient should be mapped out which includes identification of future scenarios.
- + Diagnosis needs to be made much earlier to avoid crisis care delivery. Strong links must be built with both NHS and private GP surgeries in order to encourage them to pick up signs of dementia at an earlier stage and refer to specialist services more readily.
- + Westminster needs to operate with a full remit of staff, trained to a high standard and recruited with the 'right attitude'. Recruitment must respond quickly to any service gaps and think innovatively about the best ways to attract committed staff.

## Westminster Services: Good Service Provision

The research team heard from practitioners who believe Westminster, when compared with other boroughs, offers good services for people living with dementia.

### Accessibility

Westminster does have some service gaps and although we have residential care at Forrester Court for younger people with dementia the complex nature of young onset dementia does mean we have to place some people in nursing or residential care outside Westminster. For older people with dementia, residential support is more available. However, some family carers expressed concern with the limited support they received when looking for the best residential premises.

Within Westminster we need to review and expand the personalised and specialist community support we provide; for example we do not have a specialist day centre or respite beds in Westminster for younger people. Clients will instead attend the 'Templeton Centre' in Hillingdon. Contingent on demand, such a centre would be an excellent addition to Westminster's range of services.

For older people in north Westminster there are a number of day centres available for support. Tresham Day Centre and Carlton Dene are open 7 days per week and Blenheim Day Centre operates 5 days per week. The provision of day centres is much more limited in the south where frequency of contact appears to be a challenge. Pullen Day Centre, the only day centre in the south, only operates a dementia day once a week. If demand suffices then this day centre should be extended.

Specialist and more prolonged home care, which is not available in the north, attempts to cover some of the gaps in the south. However, this home care plus has in the past had a waiting list which has increased the pressure on other services. Demand also exists for the service to be extended to the north. Ultimately the challenge remains to provide more personalised outreach and home-based services.

Within Westminster it often seems that there are service gaps at the initial point of contact and despite us having a wide menu of support available it is often not explained to clients well enough. Our review found that the gaps in service provision could be addressed through more intensive use of the current services. Tresham Day Centre sits unused in the evenings and it could be used by the young onset dementia clients. There are also a number of minibuses that could be used for day trips during the week. Innovative thinking on the part of practitioners stands to make a big difference in service provision.

## Westminster Services: Good Service Provision (*continued*)

### Recommendations

- + There is a need to further examine the apparent disparity in service provision between the north and south of Westminster.
- + Our research indicates there may be a need for more frequent day services within Westminster, especially in the south. Pullen Day Centre could be extended beyond one day per week and services at Tresham could be extended or opened up to weekend use by the YODS.

### Quality of care

Service users at Tresham are introduced to support plans gradually. They begin by having a regular day at the day centre, building up to more frequent use. The centre is open from 10:30am to 3pm including both breakfast and lunch; while our review found that some family carers felt that the hours could be extended so that evenings and early afternoon were not as socially restricted, on the whole users were satisfied.

The centre uses technological advancements such as 'quiet care' to deliver their home care service and respond to need. However, a number of stories emerged from speaking with family carers that these services do not offer the rapid response required in a crisis and that unnecessary delays had been introduced when equipment had failed.

Tresham offers outreach support through home support and home care plus. The centre also houses an End of Life Care Nurse, provided by Housing 21 and Dementia Voice. This nurse coordinates and improves end of life care for people with dementia. One family carer we spoke with was very happy with her on-going support from the nurse; however, the innovative service needs to be advertised more readily as other family carers did not know the post existed.

The members of staff at Tresham hold hybrid roles, taking it in turn doing each task. Our review found that service users were very happy with the staff and praised them for their consistent caring approach and willingness to help. They felt that the staff had been hand selected and that their individual freedom was respected. This stems from an understanding, within the day centre, of the need to personalise care and tailor it to each individual. Tresham Dementia Services support the idea of deep personalised service provision and there is a commitment to involving the service users in the recruitment of staff.

The Memory Service will also aim to personalise their service and will actively engage in the local community. They will use space out in the community and will administer evidence based treatment. There will be no single day centre offered through the Memory Service but instead there will be a number of activities using publicly available spaces such as libraries and community halls.

Alongside the push towards personalisation there is a need for practitioners to recognise a possible tension between choice within care provision and the need to deliver vital care tasks. A danger exists that important tasks such as cleaning may be neglected if the service user does not expressly request these tasks. It is therefore the individual carer's approach that matters.

A number of family carers commented on the difficulties of inconsistent care provision. The lack of suitable cover for core workers and the reliance upon seemingly poorly trained or unmotivated bank workers made family carers unhappy. There were reports of bank workers blaming a family carer for interfering and making frequent errors when administering medicines. A team of carers should be built around each service user to maintain consistency.

It is important that Westminster grasps personalisation as an opportunity to build community awareness and support. Simple tasks such as helping older people with their shopping, and walking them back to their property can help to support our older people but also may provide insight into any early stages of dementia.

### Recommendations

- + The care we provide must be more consistent and the reliance upon bank workers must be redressed. It appears that more support services may be needed and specifically the delivery of respite support should be examined.
- + Westminster should attempt to encourage community cohesion through outreach work in order to increase responsiveness to signs of dementia.
- + Our service providers must recognise a possible tension between choice within care provision and the need to deliver vital care tasks.

## Looking to the Future

**In the immediate future it is imperative that the Memory Service is made a real success. We must hire and train a full remit of staff in good time and the launch must be backed by an effective publicity drive.**

As we look forward Westminster should attempt to innovate on a small scale to make genuine improvements. New research findings appear regularly and we should aim to incorporate new findings into practice. Stimulation through internet use and improved healthy eating through the introduction of vegetable patches are two small changes that would make real differences.

### Good practice from other boroughs

Westminster can look to other boroughs for examples of good practice:

+ Peer support offered through monthly Memory Groups (Tower Hamlets) or Dementia Cafes (Redbridge and Ealing) for people with dementia to interact.

+ Rapid assessment and collaboration with social work and discharge teams to increase return home rates, reduce length of stay and achieve readmissions (Bristol and Gloucestershire's acute hospital mental health liaison team).

+ Torbay Care Trust: has commissioned the voluntary sector to provide short breaks in a family environment. This includes a 'Day Out' scheme which offers structured day-care for up to 4 people in the host's home.

+ The Mount specialist centre (Luton) offers advice, information and support to 10 different community groups – includes befriending and life story work.

It is important that the profile of dementia is raised within the Council. Our existing advocacy services could be well placed to assist. Educational outreach could be explored and intergenerational practices encouraged by educating primary age children about dementia. This would assist in raising awareness of dementia and breaking down stigma. Our mainstream services should cater for the symptoms and our frontline staff should be aware of the different approaches required when dealing with someone living with dementia. Through this understanding people with dementia could stand to have greatly enhanced options and choice.

Longer-term our council should be ambitious in attempting to improve our existing and well regarded service provision. Looking to the future, Westminster could attempt to create a national centre of excellence for dementia. This would involve adopting a large site and bringing together a number of services at one headquarters. The benefit of this would be to encourage multi-agency collaboration and also to expand service provision to include services for dementia sufferers, older people and younger people with learning disabilities. Such a holistic service would reduce stigma around dementia further and also allow intergenerational practices which research has shown are of great value.

### Recommendations

+ Looking to the future Westminster City Council should be innovative and ambitious in its provision of dementia services. We could explore the possibility of developing a hub approach to service provision; such service redesign should involve our existing service providers.

+ There is a need to use existing advocacy services within Westminster to raise the profile of dementia within council services. The council should gear mainstream services towards providing accessible provision for people living with dementia.

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## Conclusion

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**Our review has shown that dementia care in Westminster is already provided to a high standard. However, the research has also recognised room for improvement and scope for bold innovation.**

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We have recognised the difficulty of dealing with dementia for both those living with the symptoms and their family carers, while noting the need to simplify the information we provide and to communicate more openly and honestly with service users.

The review has found that Westminster fits in with the national context in which dementia services are only offered at crisis point. There is a real need for the council to encourage primary care practices and general practitioners to refer patients earlier.

Our review has noted the gaps in service provision in Westminster and has mapped out a number of innovative ways in which these gaps can be redressed; alongside these innovations there is a recognised need for maintaining a full remit of staff within the council services. Specifically, there appears to be a disparity in service provision between the north and the south. Our review suggests that this needs attention.

Finally, our review has examined the shift towards personalisation of care and notes that this should be encouraged as the approach has been successful in Tresham Day Centre. However, there is also a need to recognise the possible tension between choice and effectiveness in some specific tasks, and more broadly the need for adequate training of staff for personalised services to be delivered.

Looking forward, this review believes that the increased media attention on dementia opens up opportunities for Westminster to build actively upon our existing service provision. We must be bold and ambitious in both our short and long-term strategy.



City of Westminster

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