

Healthier Communities and Older People Overview and Scrutiny Panel

Subject: Dementia

PURPOSE OF REPORT AND EXECUTIVE SUMMARY

This report addresses and sets out recommendations on how to make the borough of Merton a Dementia-friendly community and proposes strategies on how other councils are addressing this challenge.

1. DETAILS

1.1 Dementia- a definition:

The word dementia does not describe an illness or disease but refers to a set of symptoms associated with a loss of mental ability such as difficulties with memory, completing everyday tasks and problems with communication. It usually occurs when the brain is damaged by a disease like Alzheimer's or by small strokes or conditions like Lewy-Body Dementia.

According to the Alzheimer's Society there are around 800,000 people in the UK with dementia. One in three people over 65 will develop dementia, and two-thirds of people with dementia are women. The number of people with dementia is increasing because people are living longer. It is estimated that by 2021, the number of people with dementia in the UK will have increased to around 1 million.¹

As the conditions which cause dementia are progressive it has become a leading cause of disability and death in individuals aged over 65. It must be noted that there are a number of different types of Dementia yet around 62%² of individuals who are diagnosed with the condition have Alzheimer's; whilst the remainder have Vascular dementia, Dementia with Lewy Bodies (DLB) or Frontotemporal dementia (FTD, also known as Pick's disease).

1.2 The impact of Dementia:

On everyday life

Individuals who suffer from dementia have a strong desire to live well and stay connected to their interests, social life and communities. However, research has shown that people with dementia usually withdraw from everyday life:

- 35% of people with dementia said that they only go out once a week or less and 10% said once a month or less.
- Shopping was identified as the most common activity that people with dementia do in their local area (79%), followed by socialising (72%), eating out (69%) and leisure activities (55%) such as going to the park, library or cinema.

¹ Dementia Report: Opportunity for Change 2014

² <http://www.merton.gov.uk/health-social-care/publichealth/jsna/older-adults/dementia-jsna.htm>

- 63% of people with dementia did not want to try new things and the underlying issues of confidence, worry and fear must be overcome in a Dementia-friendly community.

Every experience of dementia is varied, in terms of symptoms and rate of progression and as of yet there is no cure. However, this only means that there is a lot that can be done to make sure that those with dementia can be supported and live well through a Dementia-friendly environment.

On the NHS

Currently, the estimated cost of Dementia on the NHS is approximately £26.3 billion for individuals living within care and the community which works out at an average annual cost of £32,250 per person. This consists of £4.3 billion of healthcare costs and £10.3 billion of social care of which:

- £4.5 billion spent on publically-funded social care.
- £5.8 billion spent on privately-funded social care.
- £11.6 billion of unpaid care.
- £111 million on other dementia costs.

The £11.6 billion cost of the 1.34 billion hours of unpaid carer provided each year has been calculated on the basis of the replacement and opportunity costs of this care.³ According to the Alzheimer's Society, for every person who is able to live at home rather than in residential care there would be a saving of £11,926 per year. Thus, the concept of dementia friendly communities is an answer both to the individual need and to the recognition that the future financial cost of increasing incidence of dementia may be unsustainable if the only responses are through the health and social care systems.

2. Key statistics on dementia for Merton

Merton is fortunate to have strong partnership arrangements that help support older people and the issues they face. These partners are crucial in the borough as the number of people (aged 65 and over) predicted to have dementia is forecast to grow by 51% from (1,782) in 2015 to (2,683) in 2030.

According to the NHS Dementia Prevalence Calculator, Merton has 72% of dementia cases diagnosed as at March 2015. This may put a strain on services due to the increased number of referrals thus Merton must ensure that there is a sufficient capacity to meet the increase in demand. This can also be seen as an opportunity to improve Merton, whilst considering dementia friendly initiatives.⁴

2.1 Merton and South West London comparators

Figure 1 below shows Merton dementia prevalence and comparators from March 2015. There are 1,926 people in Merton with dementia according to the NHS Dementia Prevalence Calculator (DPC) out of a total registered population of 217,858. This gives a prevalence of 0.9% for Merton which is statistically significantly lower than three of the South West London comparators (Sutton, Richmond and Croydon) and statistically significantly higher than Wandsworth.

³ https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=418

⁴ Dementia Health Needs Assessment 2015/16, Public Health, London Borough of Merton October 2015

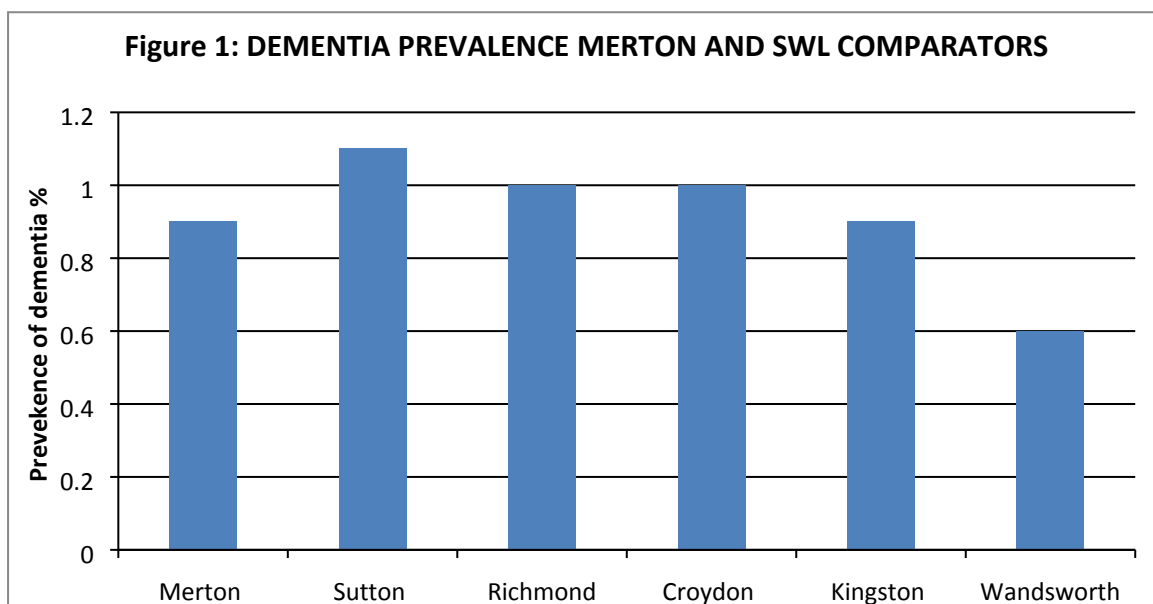


Figure 1. Source: NHS Dementia Prevalence Calculator (DPC) as at March 2015

2.2 BAME Groups

Merton's latest dementia needs health assessment, it is estimated that 332 BAME (aged 65 and over) have dementia in Merton in 2015. Furthermore, there is an anticipated growth of 56% in people aged 65 and over from BAME groups from 2015-2025.

There is a higher prevalence of dementia amongst the Merton BAME community (5.5%) compared to all other communities (0.9%)⁵. This is in line with previous research that indicates that the Black African Caribbean and South Asian UK Population have a higher prevalence of dementia compared to the White UK Population since these groups have higher incidences of vascular diseases.⁶ See figure 2.

2.3 What are the living arrangements for people with dementia?

The DPC estimates that 83% of people with dementia in Merton are in the community and 17% are in local care homes, see figure below. As the majority of people with dementia are in the community, this shows that unpaid/informal carers play a very important role in Dementia care in Merton. This exemplifies the need for the borough to adopt dementia friendly initiatives especially if more people with dementia are living within the community.

⁵ Dementia Health Needs Assessment 2015/16, Public Health, London Borough of Merton October 2015

⁶ Dementia Health Needs Assessment 2015/16, Public Health, London Borough of Merton October 2015

ESTIMATED PREVALENCE OF LATE ONSET DEMENTIA IN THE MERTON BAME POPULATION IN 2015

Age	%Prevalence of all dementias in BAME communities	Merton BAME population within that age band (GLA projections 2015)	Indicative number of people from BAME communities in Merton with dementia in each age band.
65-69	1%	2007	20
70-79	4%	2865	115
80+	17%	1159	197
TOTAL		6054	332

Figure 2. Source: Dementia Health Assessment 2015/16, Public Health, London Borough of Merton October 2015.

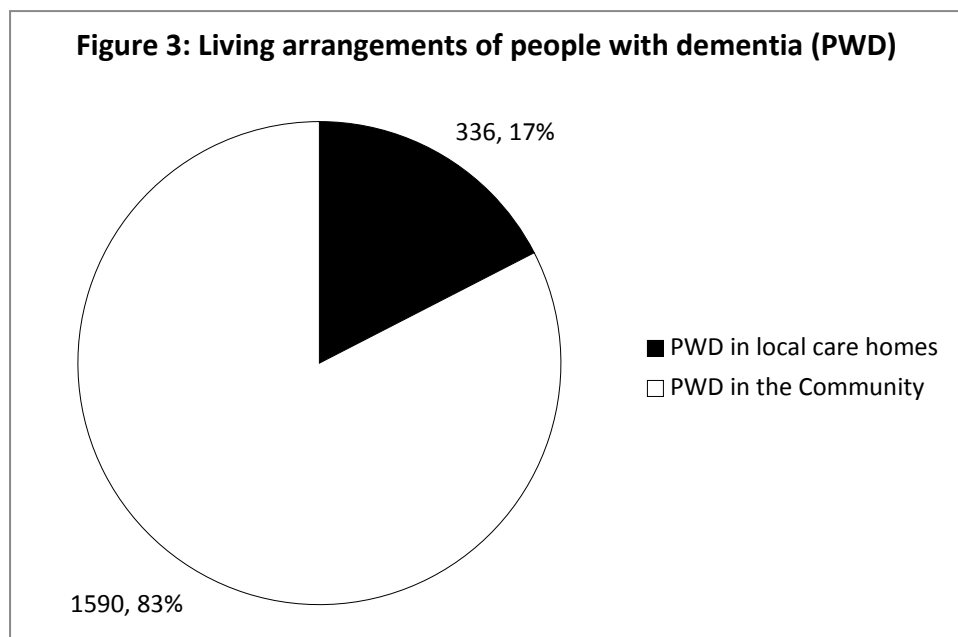


Figure 3. Source: DPC as at February 2015

3. What is Merton council and partners doing to support people with Dementia?

Within the borough, individuals who suffer from Dementia are able to access local services for support and advice:

3.1 NHS

For medical diagnosis, treatment and management of dementia the NHS provides services through primary care (GPs) and secondary/tertiary/specialised services through the South West London and St George's Mental Health NHS Trust. The Mental Health Trust also provides community support through a community mental health team. It is also running a Memory Clinic at Claire House, St George's Hospital, where patients with dementia are reviewed along with their medication. The Memory Clinic also diagnoses people with a diagnosis of dementia for the first time.

3.2 Merton Council – Social Care

Merton Council provides a variety of services for people with mild to moderate dementia, who need opportunities for additional social support and contact, and respite for carers – these needs are predominantly met through non-specialist day centres.

3.3 Merton Dementia Hub, Mitcham

The main aims of the Merton Dementia Hub are to raise awareness and understanding amongst the local community, provide early diagnosis and support for individuals and support the Living Well with Dementia Strategy. Formed as a part of the Alzheimer's Society it provides additional outreach services held across the borough and works in partnership with the Merton Older Peoples CMHT (Community Mental Health Trust) Memory Clinic.

The Hub has information workers who raise awareness and promote the benefits of diagnosis amongst professionals and the local community. Alongside this, the Dementia Adviser Service provides early diagnosis and works with newly diagnosed individuals to identify their specific needs and preferred styles of support. Service users are also able access facilitated peer support at this stage which has been shown to be highly beneficial as highlighted through the National Dementia Strategy for England (NDSE) in 2009. The hub also offers activities such as the Dementia Cafes and Singing for the Brain, which address the social needs of people with dementia and their carers. They can be an opportunity for both parties to enjoy a more social activity together.

4. What are Dementia-friendly Communities?

Dementia-friendly Communities (whether cities, towns, villages or streets) do as much as possible to remove the barriers to everyday living that people with dementia and their carers face. They also help people with dementia to make the most of their own capabilities, encouraging them and including them in what is going in the community (see figure 4 below).

Dementia-friendly communities



Figure 4. Source: Alzheimer's Society, 'Building Dementia-friendly communities: A priority for everyone, August 2013.

4.1 What is the Dementia-friendly initiative?

Since the introduction of Living Well with Dementia: A National Dementia Strategy (2009), significant improvements were made in the diagnosis of dementia, with more and more people getting a diagnosis at a stage when they still have potentially many years of independence ahead of them. This of course started a chain reaction, with many charities and organisations' introducing programmes and initiatives to highlight the wider issue of dementia, by showing that dementia was an issue that incorporated communities, not just individuals.

Age UK, launched their Dementia-friendly initiative in 2012, after the Prime Minister's Challenge on Dementia during February of that year, which called for increases in early diagnosis and research as well as more dementia friendly community support. Thus, as a part of the "Fit as a Fiddle" programme, the dementia friendly initiative's chief aim was to work with local Age UKs in order to make their mainstream services more Dementia-friendly.

Through this, Age UK was able to identify clear areas for improvement in the accessibility of mainstream services. Due to the changing demographic and with individuals being diagnosed with dementia at much earlier stages people did not need or want specialist services at the time they were diagnosed, they wanted to remain part of their communities, which is what made the prospects of Dementia-friendly communities all the more important.

5. Why is it important for Merton to become a Dementia-friendly borough?

Local councils as leaders and service providers have a civic duty to support and lead the development of sustainable and community led approaches for individuals living with dementia in the borough so that they can overcome daily struggles and live well within their communities. This can be done by working with key partners and communities locally, councils can alleviate the pressures that are put on health and social care services and as a result enable people living with dementia to become a part of the wider community.

The main aim of Dementia friendly boroughs are to create an environment in which individuals with dementia feel as if they are in control of their lives and that their carers are being properly supported. Many health and social care services are able to involve the people they treat in shaping services and the development of strategies. However, carers have been the proxy voice for people with dementia speaking on their behalf as people with dementia tend to be diagnosed at a late stage of their illness, making care a priority rather than an involvement.

6. What are other councils doing to make their local areas Dementia-friendly?

In recent years councils have already started working towards becoming Dementia-friendly. These communities are more inclusive of people with dementia, are able to improve their ability to remain independent and have a greater control over their own lives. According to the Alzheimer's Society, there are 20 areas that are listed as Dementia-friendly but listed below are three that have made a significant steps towards improving the lives of people with dementia.

6.1 Bradford

Bradford has been Dementia-friendly since 2011 and its local Alzheimer's Society has built links with eight organisations to work on dementia awareness and develop good practice. The organisations were made up with small community groups and bigger companies such as Lloyds TSB, the Diocese of Bradford, Bolton Road Gurdwara and a local pharmacy. Once these organisations were committed to becoming dementia friendly, they were helped to draw up an action plan identifying the changes that they would make and how they would implement them.

Notably, the Bradford dementia friendly community programme used a range of approaches when raising awareness and influencing businesses and organisations. Many were invited to awareness sessions within their ward. Work to raise awareness of dementia and train staff by Co-operative stores in Bradford has been communicated throughout the broader co-op organisation. Local banks in the area have also been responsive and connected to national initiatives developed through Dementia Action Alliance.

6.2 Manchester

The towns of Cheetham and Crumpsall, Manchester, have a combined population of 4,462 who are aged 60 years or over. One of the programme's aims was to explore the extent to which local organisations and providers of services are disposed to support progress towards dementia friendly community.

One success was through the Supporting Health Dementia Programme (SHDP) which was established in 2007, started working with community and voluntary groups in an attempt to tackle the lack of understanding about dementia within the community. Cheetham and Crumpsall have a high proportion from the BAME community and through previous partnership work has shown a lower level of awareness about dementia and the existence of stigma.

Due to the programme, one of the aims of the partnership event with Anchor Housing (a sheltered housing scheme in Cheetham) was to bridge the gap between Anchor and the broader community. As a result of the event, local services, and organisations have begun to have discussions and build partnerships with Anchor; a clear outcome of this work has been that the Manchester Community Health Trainer Service now provide monthly sessions drop in sessions at Anchor.

6.3 York

Organisations in York have agreed to try and make the city more dementia friendly through their project, 'York Dementia without Walls'. Through this project it was shown that there were many resources and services in a place which can be harnessed for the benefit of people with dementia.

The aim of this work was to make individuals with dementia feel as if they were part of the project and thus were making a contribution to society. This occurred through working groups and a sounding board event. It emerged that the most important aspects to consider when making a community more dementia friendly were place, people, resources and networks. As a result of this, British Transport Police colleagues worked with the project to improve their understanding of dementia. They have also offered to support people with dementia and their families in building confidence to travel safely by rail.⁷

7. What measures could be implemented in Merton?

When considering the measures that could be implemented in Merton is it important that they are both beneficial for People with Dementia in the borough and cost effective. Though it is clear that funding for local councils and thus its services have been reduced, dementia is a health issue that 1 in 14 people over 65 have in their lifetime⁸. This coupled with a rise in life expectancy in Merton, means that dementia is an issue that requires a community response through active involvement.

7.1 Promoting befriending and social group schemes

A main issue for those who have Dementia and those that care for dementia patients is the challenge of breaking down stigma and increasing understanding within their communities. Following the Merton JSNA (2015), social isolation and loneliness contribute to poor health outcomes of older people.

- The Alzheimer's Society through its introduction of Dementia Friends have been highly successful in spreading awareness and trying to contribute towards making a society that is dementia friendly.

⁷ Dementia communities York summary, JRF report. October 2012

⁸ 5 things you should know about Dementia: Alzheimer's Society

- Promote awareness of dementia in shops, businesses and services so all staff can show understanding and know how to recognise symptoms. Organisations can register and have training sessions in order to become dementia friends. Providing the training for people at all levels and sectors through online training is one way this could be done, as it has easy access and is affordable.
- Consider effectively promoting services at the Dementia Hub, raising the profile and developing strong links between existing services, e.g. The Dementia Hub and GPs as well as the Hub and social workers.

7.2 Training for support staff in housing

People with dementia and their carers live in a range of housing including privately owned homes to care homes. Councils and their partners can help to ensure that housing supports people with dementia to live independently and engage with their community as much as they can. Merton could implement methods such as:

- Training for support staff who are involved in housing which allows them to respond to the needs of people with dementia in the setting in which they work. This way, staff will be able to identify changes that can be made in people's homes to make them easier to live in with dementia.
- Providing training to staff that work within a housing association such as Merton Priory Homes.

7.3 Improvements for public transport hubs and training for staff

With Merton having an excellent public transport, it is important for residents of the borough to harness and benefit from them. However, for those with dementia, using public transport can become a challenge, especially through a loss of confidence and a fear of how unsuitable transport would be in accommodating their needs.

Many people with dementia are able to drive some time after diagnosis but as dementia progresses; many make the decision to stop driving. Not only is this an inconvenience but can also cause a psychological impact, as it may feel like a loss of independence.

Merton can help alleviate these problems however through service specifications and small changes for people with dementia such as:

- Training for customer-facing transport staff.
- Clear signage and written information about services.
- Ensuring that staff can be seen at key points in transport hubs.
- Clear explanations and support to understand changes and disruptions.

7.4 More activities for BAME groups

For Merton, dementia prevalence is higher in BAME populations, and is over 5.5%. This is higher than all other ages and ethnicities in Merton which is 0.9%. Furthermore, it is estimated that there will be a substantial growth of 56% in people aged 65 and over from BAME groups from 2015-2025.

Currently, there are limited 'culturally appropriate' community activities for BAME groups. Yet, a recommendation from the latest Dementia Health Needs Assessment from Merton Council states that the borough could develop 'culturally appropriate' community activities for

BAME groups and develop South West London Partnerships for BAME service developments.⁹ Other changes the council could introduce are:

- Consider targeted interventions at the BAME population as they have a higher prevalence of vascular disease and are more at risk of vascular risk factors.

Steps to make areas dementia friendly

- Provision made towards a clear referral pathway, integrated with services from other organisations where health professionals are aware of local services and are then able to diagnose dementia at an earlier stage. There must be one smooth care pathway for services users, where information about services is clearly signposted and accessible to all residents.
- Local businesses, shops or transport hubs in the area could sign up to the Dementia Action Alliance and allow employees to access e-learning on dementia. This would be easily accessible and low cost for businesses. By promoting the dementia friends initiative, amongst those who have customer facing roles, individuals can simultaneously raise the profile of dementia and be trained.
- Furthermore, there could be improved signage in Council buildings targeted towards people with dementia. Local shops and businesses could also display the dementia friendly logo.
- Identifying Dementia Champions who are able to train individuals, training can be given to Council employees and councillors who wish to be dementia friends.
- Leisure and cultural services provides a sense of well-being to individuals thus there is a need for activities be made available for people with dementia. This means activities should be varied; taking into account the changing needs of the ageing population. Leisure and cultural services must address the needs of dementia patients and their carers, encouraging physical and mental activity as appropriate when considering their plans for widening any participation in the borough.
- Provide more activities for BAME groups in Merton by coordinating with BAME organisations in the borough to spread awareness and battle stigma amongst communities.
- The council could coordinate the provision of community transport services between themselves and local partner organisations. Combatting loneliness and isolation in older people, is a growing challenge to modern Britain. Loneliness can lead to depression, anxiety and mental decline and those who feel isolated need more support from health and social care services¹⁰. Through community transport services, those with dementia could be given access to social opportunities and even opportunities to leave the house. This could even improve access to GPs and healthcare facilities by providing low cost and high quality means of transport for those who require it.

⁹ Merton Dementia Health Needs Assessment 2015

¹⁰ Tackling loneliness and isolation through community transport, Deloitte,