

# **Living well with Dementia**

## **A strategy for Trafford**

**2018 -21**

CONSULTATION DRAFT

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## **Trafford's vision**

With an ageing population and improving treatment, we can expect more and more people in the borough to have their lives touched by dementia. This might be as patients, as carers, as family members or friends, as specialist or non-specialist providers of services, or in local businesses and community groups. The sheer number of people affected means that we need to take an inclusive approach to dementia in Trafford. This will focus on people's needs and rights, and support us all in making life with dementia as easy and as positive for patients and carers alike.

The strategy described here is particularly aimed at the statutory and voluntary organisations working in the borough, to identify actions that we need to take to improve the lives of people with dementia, their families and carers.

To deliver the required improvements to care, we need to review all aspects of life with dementia, from improving our diagnosis rates and the services and support offered following a diagnosis, to improving the skills of the workforce and improving palliative and end of life care.

We recognise that family carers can often be old or frail themselves and that the strain of caring for someone with dementia can cause physical or mental health problems for the carer.

Our local strategic approach will promote community-led Dementia Friendly Community initiatives, and the use of data and outcome related performance measures for people with dementia, as well as focussing on collaborative working between statutory, voluntary and private sectors, with the goal of providing safe, effective and person centred care for people with dementia. This will involve all sectors, including leisure services, shops and businesses, and travel and transport, as well as health and social care.

Finally, Trafford would like its residents to be offered opportunities to participate in research on dementia and to assist in looking for a cure.

## **Governance, Implementation and Evaluation of the Dementia Strategy**

The Dementia Strategy Group (DSG) is responsible for the delivery of the Dementia Strategy and associated Action Plan. The DSG reports to the Mental Health Partnership Board and the Ageing Well Sub Board of the Health and Wellbeing Board, and through this to the CCG Board and to the Council and the Trafford Partnership. This enables the Strategy to influence all the major partners in Trafford, including health, local authority, housing, police and the voluntary sector. This governance structure will allow us to report back on progress on the implementation of the policy and the evaluation of its impact.

## What is dementia?

Dementia is associated with an ongoing decline of the brain and its abilities. These include: thinking, language, memory, understanding, and judgment. All types of dementia are progressive and the person's ability to remember, reason, understand and communicate gradually declines over time. How quickly this happens depends on the individual.

People with dementia may also have problems controlling their emotions or behaving appropriately in social situations. Aspects of their personality may change. Most cases of dementia are caused by damage to the structure of the brain.

Diagnostic criteria have been developed in order to improve the accuracy of the clinical diagnosis of dementia. However, it is important to remember that there is no single diagnostic test; and clinical assessments usually last at least 6 months. We must support people and their families effectively during this assessment process.

Different types of dementia have characteristic clinical features, and listed below are some of the common different types of dementia.

- Alzheimer's disease: where small clumps of protein, known as plaques, begin to develop around brain cells and disrupt the normal workings of the brain.
- Vascular dementia, where problems with blood circulation result in parts of the brain not receiving enough blood and oxygen.
- Dementia with Lewy bodies, where abnormal structures, known as Lewy bodies, develop inside the brain.
- Frontotemporal dementia, where two parts of the brain begin to shrink. Unlike other types of dementia, this type dementia

## What are the symptoms?

In terms of the course of the disease, true dementia (as opposed to pseudodementia due to depressive illness, or dementia like symptoms due to thyroid disorder) is at present untreatable and has a progressive course often divided into 3 development stages:

### Early Stage:

- Short Term Memory impairment
- Changes in behaviour and mood (irritable, loss of motivation, anxious)
- Loss of daily living skills
- Disorientation (Time / place)
- Reacting much slower
- Language and word finding difficulties

### Middle Stage:

- Increased difficulty with language and memory (including long term memory)
- Increased disorientation / confusion leading to frustration / anxiety.
- Decreased depth perception / visual abilities
- Wandering, sleep problems, hallucinations/delusions, 'odd' behaviours, apathy.
- Further deterioration in self-care skills / incontinence
- Physical problems (e.g., decreased mobility)

### Late Stage:

- Walking / Balance problems
- Difficulty recognising familiar faces, objects, sounds, smells
- Loss of ability to speak / write / understand spoken/written language
- Loss of eating / drinking skills
- Increase in stereotyped behaviour, sometimes aggression, sexual aggression or disinhibition
- Development of epilepsy
- Often require 24 hr care / become bedridden
- Death typically due to pneumonia, congestive heart failure or other acute causes

usually develops in people who are under 65.

### **Are there any particular risk factors for dementia?**

Dementia is very common and can affect anyone whatever their gender, ethnic group or social background. There are some lifestyle factors that are associated with higher rates of dementia. These include **smoking, alcohol use, and physical inactivity** – all factors that are associated with other health risks, including cancer and cardiovascular disease. Dementia risk is also higher in people who suffer significant hearing loss in middle age. There is some research suggesting a genetic link to dementia. Knowing at an early stage that there are risks of dementia onset may lead to earlier opportunities for preventative services or for mitigation of impact.

### **Dementia and learning disability**

People with learning disabilities are at particular risk of developing dementia, and this is becoming more apparent as advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. About 20 per cent of people with a learning disability have Down's syndrome, and they are at particular risk of developing dementia. This risk goes up with age, with about 10% of people with Down's syndrome in their forties having dementia, rising to over half of people in their sixties. (Prasher 1995) In the general population, dementia is extremely rare in people in their forties, rising to 1-3% of people aged 60-64, and around 35% of people aged 85+ (Chen 2009).

Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. There is no evidence that dementia affects people with learning disabilities differently to how it affects other people. However, the early stages are more likely to be missed or misinterpreted. A person with learning disabilities may find it hard to express how they feel and their abilities / skills and their comprehension may have never been assessed or fully understood. Frequent turnover of support staff in supported living or changes to support services can lead to people being supported by unfamiliar support / care staff, which can also lead to difficulties in diagnosis. Therefore it is vital that people who understand the person well are involved when assessment and diagnosis is being explored.

### **Dementia and Alcohol**

Alcohol-related brain damage (ARBD) is a brain disorder caused by regularly drinking too much alcohol over several years. The term ARBD covers several different conditions including Wernicke-Korsakoff syndrome and alcoholic dementia. In contrast to common causes of dementia such as Alzheimer's disease, most people with ARBD who receive good support and remain alcohol-free make a full or partial recovery. In addition, there is a good possibility that their condition will not worsen. In Trafford we have found that identifying this cohort of patients is hard,

not least because assessing cognitive function in patients with on-going alcohol dependence is difficult, with small windows of opportunity when a patient is admitted and detoxed in a crisis. We need to ensure that such opportunities are not missed.

### **The National Context**

In 2012, the then Prime Minister, David Cameron, recognized the impact of dementia on individuals, families, communities and services with the launch of his *Challenge on Dementia*. In this, he noted that the numbers of people suffering from dementia were expected to double in the next thirty years, and that the costs in the UK were predicted to triple to 50bn, creating a global health and social care challenge similar in size to cancer, heart disease or HIV/AIDS. In 2015 his Challenge was updated to include the Government's key aspirations for the changes that should be achieved by 2020. These are included in **Appendix A**, and reflect the Government's stated aims that by 2020 England should be the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and the best place in the world to undertake research into dementia and other neurodegenerative diseases.






### **Tackling dementia across Greater Manchester**

In recognition of the importance of this topic, and the impact of dementia on health and social care services, Greater Manchester has identified improving dementia care as one of its key areas for transformation. There are two major strands of work being developed across Greater Manchester.

The first is ***Dementia United***, which, over the next five years, is aiming to make Greater Manchester the best place in the world to live for people with dementia. It will do this through working with partners across Greater Manchester to improve the lived experiences of people with dementia, and reduce pressure on the health and social care system.

Dementia United has developed a number of standards, across various domains, as follows:

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 Risk of people developing dementia is minimised	 Timely diagnosis, integrated care plan, and review within first year	 Access to safe high quality health & social care for people with dementia and carers	 People with dementia can live normally in safe and accepting communities	 People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
<b>STANDARDS:</b> Prevention <sup>(1)</sup> Risk Reduction <sup>(2)</sup>	<b>STANDARDS:</b> Diagnosis <sup>(1)(3)</sup> Memory Assessment <sup>(1)(2)</sup> Concerns Discussed <sup>(3)</sup> Investigation <sup>(4)</sup> Provide Information <sup>(4)</sup> Care Plan <sup>(2)</sup>	<b>STANDARDS:</b> Choice <sup>(2)(3)(4)</sup> BPSD <sup>(5)(2)</sup> Liaison <sup>(2)</sup> Advocates <sup>(3)</sup> Housing <sup>(3)</sup> Hospital Treatments <sup>(4)</sup> Technology <sup>(2)</sup> Health & Social Services <sup>(2)</sup>	<b>STANDARDS:</b> Integrated Services <sup>(1)(2)(5)</sup> Supporting Carers <sup>(2)(4)(5)</sup> Carers Respite <sup>(2)</sup> Co-ordinated Care <sup>(1)(5)</sup> Promote independence <sup>(1)(4)</sup> Relationships <sup>(2)</sup> Leisure <sup>(2)</sup> Safe Communities <sup>(2)(5)</sup>	<b>STANDARDS:</b> Palliative care and pain <sup>(1)(2)</sup> End of Life <sup>(4)</sup> Preferred Place of Death <sup>(5)</sup>
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.				
<b>COMMISSIONING GUIDANCE:</b>				
<ul style="list-style-type: none"> <li>• Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.</li> <li>• Agree minimum standard service specifications, set business plans, mandate and resources.</li> <li>• Work with ADASS, PHE &amp; other ALBs on co-commissioning strategies to provide an integrated service.</li> </ul>				
<b>MEASUREMENT:</b>				
<ul style="list-style-type: none"> <li>• Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.</li> <li>• Identify data sources and agree with HSCIC, et al on the extraction processes.</li> <li>• Set 'profiled' ambitions for each metric, to form the basis of the transformation plan.</li> </ul>				
<b>TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:</b>				
<ul style="list-style-type: none"> <li>• Transformation: using CCG scorecard to set &amp; achieve a national standard for Dementia services.</li> <li>• Intervention: Intensive Support Team to provide 'deep-dive' support and assistance for CCGs that fall short.</li> <li>• Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.</li> </ul>				

These standards, how to measure them and how to deliver them across the 10 boroughs of Greater Manchester is the focus of the next stage of the programme. Trafford is fully engaged in this work and has been developing our local response to the different themes. The Action Plan that supports this strategy (currently in development) will be organised into the themes and headings above.

The second area being developed across Greater Manchester is particularly related to the Living Well theme above, and relates to creating **Dementia Friendly Communities**. Since the launch of David Cameron's Prime Minister's Challenge, there has been an increasing shift to a focus on how we can enable people who have been diagnosed with dementia to live as full a life as possible and encourage communities to work together to help people to stay healthier for longer. Councils have a key role in developing inclusive dementia friendly communities, working in partnership with their local communities to develop innovative ways to enable people with dementia to take part in everyday activities and retain their independence for as long as they are able. Examples include developing dementia friendly streets, where as a result of simple adaptations and awareness-raising among staff working in shops, shopping becomes easier for people with dementia

Simple changes to existing services, and awareness raising for those who come into day-to-day contact with people with dementia such as staff working in libraries or in

leisure centres, also help people with dementia feel more confident and welcome in using services.

A dementia-friendly community has been described by people living with dementia as one that enables them to:

- find their way around and feel safe in their locality, community or city
- access the local facilities that they are used to (such as banks, shops, cafés, cinemas and post offices, as well as health and social care services)
- maintain the social networks that make them feel still part of their community.

The concept is based on inclusion and a 'strengths-based' approach – building on what people can still do and the contributions they can still make. It is the kind of approach that supports people living with dementia to feel welcome, not stigmatised and able to remain **in their own homes** for as long as possible. It is the antithesis of the risk averse and deficit model that is so often applied to people living with dementia under the term EMI (Elderly Mentally Infirm) care.

Within Trafford, we are fully committed to develop and implementing the above initiatives, and our Strategy and Action Plan reflect this.

### **Prevalence of Dementia in Trafford**

Public Health England compiles a Dementia Profile for each area, to provide health intelligence with which to inform the provision of care of people in England who have dementia. Appendix B gives some comparative data for Trafford and our statistical neighbours (areas that are similar to Trafford on a number of demographic indicators.).

Prevalence is defined as the number of people with dementia recorded on the GP practice register as a proportion of people registered at each GP practice. In total, 1,999 individuals are on the register with 1946 (4.81%) aged 65+ (2016/17 data). This ranks as 4<sup>th</sup> highest out of the 10 GM local authorities and as the 4<sup>th</sup> highest figure among nearest neighbours, as below. This high prevalence figure for Trafford is likely to reflect the older age of Trafford's population over 65 population relative to other areas of Greater Manchester.

For a variety of reasons, not everyone with dementia is identified by their GP or included on the GP's dementia register. The estimated dementia diagnosis rate is 74%, higher, though statistically similar, to the England average (67.9%) and 4<sup>th</sup> highest among a group of 15 other similar authorities (2017 data)

From this we can see that the number of people on a GP dementia register will be considerably fewer than the numbers with the condition. In Trafford, in 2013 it was estimated that 2,847 people aged 65 and over had a form of dementia. By 2030



we are projecting that there will be approximately 3995 people with dementia in Trafford. This is an increase of over 50% from 2010.

### **Dementia: Recorded Prevalence (aged 65+) – Trafford vs nearest neighbours**

Compared with benchmark Dark Blue: Lower, Amber: Similar, Light Blue: Higher, Grey: Not compared

Dementia: Recorded prevalence (aged 65+) Sep 2017				Proportion - %	
Area	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	436,777	4.33	4.31	4.34
Peterborough	11	1,364	5.12	4.86	5.39
Darlington	15	1,067	5.07	4.78	5.38
Stockport	7	2,793	4.87	4.70	5.05
Trafford	-	1,949	4.81	4.61	5.03
Poole	13	1,540	4.73	4.51	4.97
Reading	12	1,252	4.47	4.24	4.72
Warrington	1	1,649	4.29	4.09	4.50
Swindon	2	1,431	4.15	3.94	4.37
Solihull	3	1,838	4.11	3.93	4.30
Cheshire West and Chester	10	2,824	4.04	3.89	4.19
South Gloucestershire	6	1,959	3.96	3.80	4.14
York	8	1,618	3.96	3.78	4.15
Thurrock	5	971	3.96	3.72	4.21
Bedford	9	1,149	3.93	3.71	4.15
Milton Keynes	4	1,535	3.86	3.67	4.05
Telford and Wrekin	14	1,116	3.61	3.41	3.82

Source: NHS Digital

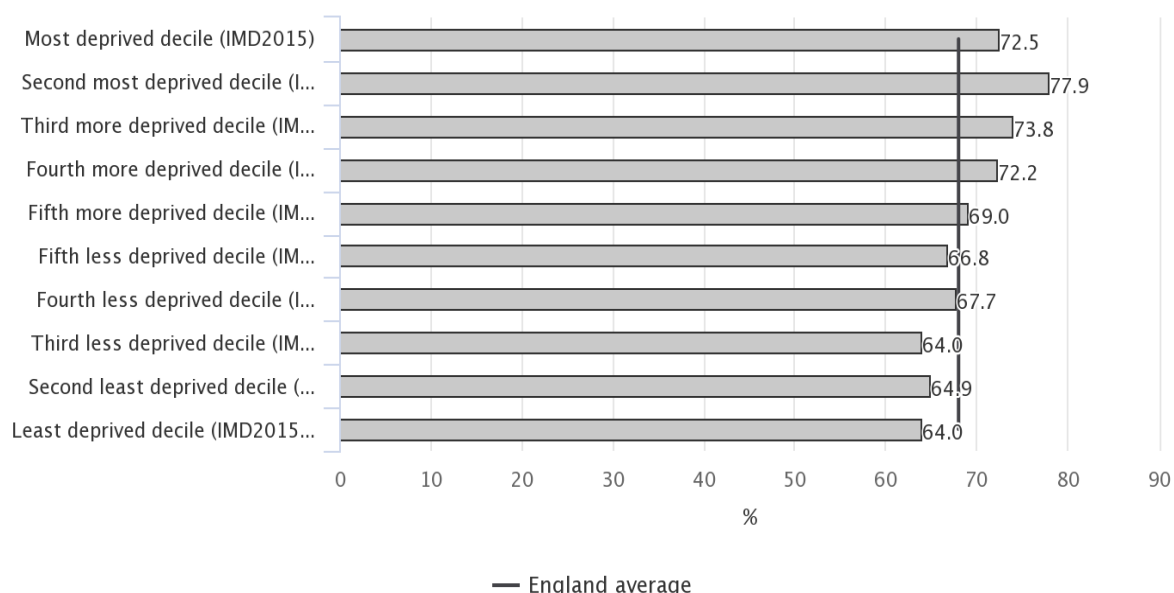
Source: PHE dementia profile <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/>

Nationally, an estimated 15,000 people from black and minority ethnic groups have dementia, and six per cent will have young onset dementia, compared with two per cent in the wider UK population. For Trafford this translates as follows for 2013:

Age group	Estimated no. of non-white persons in age group	Prevalence rate for dementia	Estimated no. of persons with dementia
40-64	8722	1 in 1400	6
65-69	1083	1 in 100	11
70-79	1901	1 in 25	76
80+	1215	1 in 6	203
<b>Total</b>	<b>12920</b>		<b>296</b>

Interestingly, and not completely borne out by the Greater Manchester data, It can be seen from the diagram below that in general the more deprived deciles have notably higher diagnosis rates (over 70%) for dementia, when compared with the least deprived (below 65%, lower than the England average). This may, in part, reflect the greater number of underlying conditions (such as smoking and high blood pressure) which are present in more deprived populations. This increases the risk of developing dementia or other long term conditions, and may mean that people are likely to visit their GP more often thus giving more opportunity to discuss such issues. In Trafford, we need to interrogate local GP practice systems to ensure that we are identifying people at the expected rates.

Estimated dementia diagnosis rate (aged 65+) - England, 2017 - Data partitioned by County & UA deprivation deciles in England (IMD2015)



### Key priorities for Trafford

Within Trafford, the dementia strategy and emerging action plan are part of the work of the Health and Wellbeing Board, delivered within the Age Well Sub-Board. This allows us to consider dementia within the wider context of ageing, and make the necessary links to other strands of work such as the developing Age Friendly plans, home care and care home developments, the falls and frailty work, and the planning for the end of life. This work also encompasses themes such as addressing social isolation, and supporting carers.

As a borough, we are committed to adopting the Alzheimer's Society statements, as we feel anyone living in Trafford should be able to expect these as a right. We recognise that achieving all of these consistently will require considerable work, but we would wish to test our services against these standards.

The statements are as follows:

- We have the right to be recognized as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognized as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

Delivering these 'We' statements will lead to the following outcomes for Trafford:

- 1. Investment in effective preventative services to reduce demand and cost pressures**
- 2. All sections of our community will be aware of the risk factors for dementia, will be aware of how to reduce these risks and are supported in doing so.**
- 3. An increase in the number of people with dementia living independently and well in their own homes**
- 4. People with significant care needs to have a choice of home based care and for moves into residential or nursing care to be planned rather than crisis driven.**
- 5. Sufficient capacity and high quality care for people with challenging behaviour.**
- 6. Services provided for people with dementia will demonstrate a focus on the individual's assets, gifts and talents**
- 7. Reduce inequalities in the level of support offered to different sub populations within Trafford.**
- 8. An increase in people using personalisation approaches, so that people have real choice and control over the support they need to improve outcomes, measured by an increase in the number and proportion of people with dementia using personalised budgets.**
- 9. Carers of people with dementia will feel they are effectively supported.**
- 10. People with dementia and their carers will feel they have choice and control over the support they need to improve their lives.**

Achievement of these outcomes will be measured through the development of a set of SMART objectives and through analysis of routinely collected data. These are described in the Action Plan associated with this Strategy.

### **Developing and delivering the Action Plan in order to deliver these outcomes.**

In order to develop these outcomes, we will group the underpinning actions into themes, with named leads responsible for pulling together the individuals and organisations required to develop and deliver these.

Some of these actions will need more localised action, whereas others may be better led at a Greater Manchester level. Below is a description of each theme, together with a brief explanation of the rationale for inclusion.

#### **1. Preventing Well**

There is strong evidence that lifestyle and behaviour can significantly affect the chance of developing dementia. Broadly, the same factors that increase the risk of cardiovascular disease or cancer also increase the risk of developing dementia *'What's good for the body is good for the brain'*. Reducing the number of people in Trafford who smoke, drink unsafe levels of alcohol, or who are physically inactive, will reduce the number of people who go on to develop dementia. Ensuring that people at increased risk have good access to prevention services and support with behaviour change will help us deliver against this outcome.

There is an equal need to **improve public awareness** of dementia and the risk factors for this. Currently, while people are in the main very aware of the impact of lifestyle choices on their physical health, few people understand the impact on their dementia risk. Equally, while many people fear dementia, they are not always well aware of the signs and symptoms, what treatment is available, or the support that is available to them either as people with dementia or as a carer. Improving public awareness of all aspects of dementia, including how to respond to people with dementia in a helpful and constructive manner, is essential if we are to reduce the fear and stigma related to this condition.

The Dementia Profile includes measures on lifestyle factors such as smoking and obesity. Trafford as a whole tends to do well against nearest neighbours for most indicators within this section, although there are stark differences in performance across the borough, with areas of higher deprivation performing significantly worse. The borough as a whole also scores poorly on the recorded prevalence of depression which is considered below.

#### **Depression: Recorded prevalence (aged 18+) for 2016/17 - Trafford vs nearest neighbours**

*Compared with benchmark Dark Blue: Lower, Amber: Similar, Light Blue: Higher, Grey: Not compared*

**Depression: Recorded prevalence (aged 18+)** 2016/17

Proportion - %

Area	Neighbour Rank	Count	Value		95% Lower CI	95% Upper CI
England	-	4,187,797	9.1	I	9.1	9.1
Telford and Wrekin	14	18,111	12.6	H	12.4	12.8
Trafford	-	21,331	11.4	H	11.3	11.6
Stockport	7	27,204	11.1	H	10.9	11.2
Darlington	15	9,092	10.6	H	10.4	10.8
Warrington	1	16,714	10.3	H	10.2	10.5
Bedford	9	14,131	9.9	H	9.7	10.1
Poole	13	11,853	9.6	H	9.5	9.8
Swindon	2	16,571	9.5	H	9.3	9.6
South Gloucestershire	6	19,399	9.2	H	9.0	9.3
Cheshire West and Chester	10	26,135	9.0	H	8.9	9.1
Thurrock	5	11,689	8.9	H	8.7	9.1
Milton Keynes	4	19,972	8.7	H	8.6	8.8
Solihull	3	15,049	8.4	H	8.3	8.6
York	8	16,263	8.3	H	8.2	8.5
Peterborough	11	12,554	8.0	H	7.8	8.1
Reading	12	14,317	7.7	H	7.5	7.8

Source: QOF

Source: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/>

The rationale for the inclusion of this indicator in the dementia profile is due to the 'NICE disability, dementia and frailty in later life – mid-life approaches to prevention' publication which states that there is emerging evidence on the importance of psychosocial risk factors throughout life such as loneliness, isolation and depression. The ambition is to reduce the number of people with depression, as this may reduce the resilience to dementia onset and progression, and to encourage further research into this association.

Trafford has the second highest figure here at 11.4, above the England figure of 9.1.

**Recommendations:**

- We need to promote a greater public awareness of the risk factors for dementia, so that appropriate action can be taken to reduce these risks. For example, we must ensure that all materials promoting healthy lifestyles stress the protection that is offered by such lifestyles against dementia, as well as against physical conditions such as cardio-vascular disease and cancer.
- We need to ensure that our social prescribing offers include an understanding of reducing dementia risk
- We need to reduce the inequalities in rates of smoking, alcohol use, obesity or physical inactivity between different population sub-groups, in order to reduce inequality in outcomes
- We need to ensure that providers, especially in primary care, recognise the importance of identifying and treating depression in older people.
- We need to ensure that the environment in Trafford is one that promotes a healthy lifestyle '*making the healthy choice the easy choice*'.

## 2. Diagnosing Well

### Improving diagnosis across all population groups

Diagnosis is important as timely diagnosis enables people living with dementia, their carers and healthcare staff to plan accordingly and work together to improve health and care outcomes. The definition is GP recorded dementia as a proportion of expected population prevalence of dementia. The estimated dementia diagnosis rate for Trafford is 74.0 and ranks as the 4<sup>th</sup> highest figure among nearest neighbours.

The indicator is coded as Red, Amber or Green with Green highlighting significant difference from England figure, Amber denoting similar to England figure and Red highlighting a figure significantly different from the England figure.

Estimated dementia diagnosis rate (aged 65+) 2017						Proportion - %	
Area	Neighbour Rank	Count	Value		95% Lower CI	95% Upper CI	
England	-	432,152	67.9		61.2	73.7	
Darlington	15	1,052	79.5		70.2	87.6	
Peterborough	11	1,305	78.4		69.5	86.2	
Stockport	7	2,814	75.2		67.3	82.0	
Trafford	-	1,946	74.0		65.9	80.9	
Warrington	1	1,615	70.9		62.9	77.8	
Poole	13	1,485	69.0		61.5	75.8	
Reading	12	1,218	68.4		60.6	75.2	
Milton Keynes	4	1,529	67.8		60.0	74.5	
Cheshire West and Chester	10	2,789	65.0		58.1	71.0	
Swindon	2	1,366	64.0		56.8	70.3	
Thurrock	5	926	63.1		55.4	69.7	
South Gloucestershire	6	1,954	62.7		55.9	68.6	
Telford and Wrekin	14	938	62.3		54.7	68.9	
Bedford	9	1,150	62.1		55.0	68.4	
Solihull	3	1,783	60.7		54.2	66.5	
York	8	1,577	60.4		53.7	66.2	

Source: NHS Digital

Source: PHE dementia profile

The estimated **prevalence** of dementia is higher than the actual number of diagnoses – many people with dementia are not diagnosed in a timely manner. Separating out those people who have dementia from those with mild cognitive impairment can be difficult, and for many people, and their carers, considering dementia as a diagnosis can be a fearful thing and this may reduce their likelihood of presenting at the GP.

GM Area	Estimated Diagnosis rate (65+)	Rank
Bolton	79.6	5
Bury	85.3	2
Manchester	75.4	6
Oldham	83.4	3
Rochdale	67	10
Salford	86.7	1
Stockport	75.2	7

Tameside	81.7	4
Trafford	74	8
Wigan	69.2	9

Some groups in the population are at higher risk of developing dementia than others, and some of these groups access health and other services less readily than others. Ensuring that we improve our diagnostic rates across all population groups will help us to identify, in a timely manner, those who need support. For example, the Trafford RAID team have developed a protocol for identifying patients with alcohol dependence at high risk of alcohol related brain damage (ARBD) and Trafford is discussing how best to support patients identified through this process.

In Trafford, the local Community Learning Disability Team (CLDT) aim to offer people with Down's syndrome over the age of 30 a Dementia Baseline Screen. Once the baseline screen has been completed, the CLDT will review these individuals at intervals depending on their age. Currently in Trafford, individuals with Down's syndrome aged 30 to 44 years will be reviewed 5 yearly, those aged 44 to 54 years will be reviewed 2 yearly and those over the age of 54 years will be reviewed annually. At any time between review dates, if family and paid carers have concerns about the individual with Down's syndrome, they can contact the CLDT to carry out a review.

### Recommendations

- **We need to reduce the stigma relating to dementia, so that people are encouraged to discuss their concerns and fears, and access services earlier**
- **In particular, we need to ensure that people from higher risk groups are identified and that they are appropriately supported to access testing.**
- **We need to support GPs to make a timely diagnosis, and to make referral process easier, and we need to collect comparative data to identify where there may be under-diagnosis.**
- **We need to have a good understanding of minor cognitive impairment and how and whether it will progress**
- **We need good access to support services throughout the diagnostic period.**

### **3. Supporting Well**

Post diagnostic support is currently not always provided in a consistent or patient focused manner. Ensuring that an asset based approach is taken, and that the individual's concerns and interests are addressed will improve engagement with services. It will also help us to gather evidence on the impact of different types of support in order to develop a range of evidence based services and approaches, with clear and consistent access criteria. Of course, not all the support offered will be in the form of formal 'services' and the dementia friendly communities approached, outlined above, should help people with dementia to engage effectively in their local community and in universal/mainstream activities.

#### **Support for carers**

Unpaid carers, usually family members, provide enormous amounts of support to people with dementia. Without this support, many people with dementia would have many restrictions to their lives, or would have to use residential or nursing care, which is usually not what they want. Providing adequate and evidence based support to carers is crucial if we are to achieve our vision of supporting people with dementia to live independently as long as possible.

#### **Support by setting (home; care homes; hospital)**

The support required in different settings may be different. Ensuring adequate support in the different settings should increase people's ability to maintain their quality of life and independence and prevent care needs escalating unnecessarily. Too many people with dementia end up staying for too long in hospital because of a lack of appropriate alternative provision. We need to ensure that intermediate care services are able to provide for people with dementia, and that we have sufficient accommodation for people with challenging behaviour so that people can be discharged from hospital as soon as they are medically fit.

#### **Medication**

Ensuring that people with dementia have the right medication at the right doses and are supported to take this regularly is an important part of treatment. Equally, there are medications that need to be used with caution for people with dementia. Improving the quality of prescribing should help improve the quality of life for people with dementia.



## Recommendations

- We need to ensure that family carers are offered adequate training, support and respite, and that their own health is safeguarded.
- We need to improve the understanding of dementia in the paid workforce
- We need to carry out annual medication reviews for people with dementia, to ensure that it meets their needs as well as possible, and to ensure that other risks (such as falling) are not unacceptably high.
- We need to ensure that all care planning for people with dementia includes planning for crises such as illness, falls, or carer breakdown
- We need to ensure that when a person with dementia is admitted to hospital, that the hospital is aware of their additional care needs, and that the length of stay is minimised in order to reduce the risk of further deterioration.
- We need to ensure that there is sufficient high quality accommodation for those people with challenging behaviour that require it.

## 4. Living Well

Improving the lived experience of people with dementia, and of their carers, is a key goal of both the Greater Manchester and the Trafford Dementia Strategies. Within the Dementia United work, a major goal is to develop a '*Lived Experience Barometer*', in order to capture whether the planned service changes and community/ environmental changes lead to measureable changes to people's lives.

While this is being developed, there are a number of other measures that can be used to assess the quality of life of people with dementia. An example of this is the rate of emergency hospital admissions, as such admissions can be particularly damaging for people with dementia. Trafford ranks as the 6<sup>th</sup> highest figure among nearest neighbours, higher than the England average.

### **Directly Standardised Rate of emergency admissions per 100,000 (aged 65+) for 2016/17 – Trafford vs nearest neighbours**

Compared with benchmark Dark Blue: Lower, Amber: Similar, Light Blue: Higher, Grey: Not compared

Dementia: DSR of emergency admissions (aged 65+) 2016/17				Directly standardised rate - per 100,000	
Area	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	348,332	3,482	3,471	3,494
Warrington	1	1,814	5,240	5,000	5,488
Stockport	7	2,545	4,326	4,159	4,499
Milton Keynes	4	1,345	4,271	4,045	4,506
Peterborough	11	1,231	4,240	4,005	4,486
Solihull	3	1,932	4,036	3,857	4,221
Trafford	-	1,689	3,954	3,766	4,148
Thurrock	5	797	3,678	3,426	3,944
Bedford	9	1,124	3,674	3,461	3,897
Reading	12	782	3,666	3,412	3,933
Swindon	2	1,100	3,261	3,070	3,461
York	8	1,259	3,165	2,992	3,346
Telford and Wrekin	14	789	3,123	2,907	3,350
Poole	13	1,140	3,072	2,894	3,257
South Gloucestershire	6	1,546	2,988	2,840	3,142
Cheshire West and Chester	10	2,073	2,985	2,858	3,117
Darlington	15	630	2,948	2,722	3,188

Source: NHS Digital

Source: PHE dementia profile

Another measure relates to the quality of long term care. The Prime Minister's 'Challenge on Dementia 2020' highlights that people with dementia should have access to safe and high quality long term care services. In England, there are currently 436,380 people with a diagnosis of dementia (as of 31st March, 2017), and it is estimated that 70% may eventually require long-term residential care.

## Dementia: Quality rating of residential care and nursing home beds (aged 65+) in 2017 – Trafford vs nearest neighbours

Compared with benchmark Dark blue: Lower, Amber: Similar, Light Blue Higher, Grey Not compared

**Dementia: Quality rating of residential care and nursing home beds (aged 65+)** 2017 Proportion - per 100

Area	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	174,440	59.7	59.5	59.8
Reading	12	416	100	99.1	100
Thurrock	5	539	89.7	87.0	91.9
South Gloucestershire	6	755	77.9	75.2	80.4
Bedford	9	846	72.2	69.6	74.7
Peterborough	11	794	71.9	69.1	74.4
Warrington	1	953	68.5	66.0	70.9
Darlington	15	550	62.9	59.6	66.0
Milton Keynes	4	695	61.7	58.8	64.5
Poole	13	602	60.9	57.9	63.9
Telford and Wrekin	14	417	55.4	51.8	58.9
Solihull	3	577	51.9	49.0	54.9
Cheshire West and Chester	10	929	50.3	48.0	52.6
Swindon	2	382	42.9	39.7	46.1
Stockport	7	585	35.3	33.1	37.7
York	8	300	32.5	29.5	35.6
Trafford	-	341	31.3	28.6	34.1

Source: Care Quality Commission

Source: PHE dementia profile

Here, Trafford ranks bottom of the table among nearest neighbours. We need to work with our care home sector to support them to improve on this measure.

### Developing Dementia Friendly Communities

As described more fully above, taking local action to embed systems that support rather than disempower people with dementia can lead to a significant improvement in the engagement and integration of people with dementia in their local communities. This helps both the people themselves, and their carers, and can enable people to live independently for longer.

#### Recommendations

- **Trafford Age Friendly planning needs to incorporate all aspects of Dementia Friendly practice**
- **We need to increase public awareness of dementia and how to support people**
- **We need to ensure that shops, leisure services, and public spaces are open and accessible to people with dementia**
- **We need to ensure that care homes are of a high quality and can properly support people with dementia, and that we have sufficient capacity of care home places within the borough for people whose dementia leads to challenging behaviour.**

## 5. Dying Well

Although recording of dementia as a cause of death is increasing, health professionals do not always recognise it as a life limiting condition. As a result, the end of life phase is not always identified early enough or planned for effectively.

The Care Quality Commission (CQC) have identified that people living with dementia are one of the 'groups in society who experience poorer quality care'<sup>1</sup> at the end of their lives than others because providers and commissioners do not always understand or fully consider their specific needs'. Ensuring people living with dementia people have opportunities to create an Advance Care Plan as early as possible following diagnosis will assist in reducing this inequality<sup>2</sup>.

Advance Care Planning (ACP) enables greater choice and control to be exercised through the recording of an individual's wishes and preferences regarding their future care. For individuals with dementia this can act as an important guide to families and those responsible for their care at the time when the individual no longer has mental capacity to make such decisions. By increasing the number of Trafford residents with dementia with an ACP we will support them to 'die well', by documenting discussions such as their preferred place of death.

Deaths in usual place of residence is measured as part of the commitment to Objective 12 in the National Dementia Strategy (2009) which called for improved end of life care for people with dementia. In the absence of a method to measure the number of deaths which have occurred in an individual's preferred place of death, this indicator has been used as a proxy measure for quality and is considered against the number of deaths in other settings such as hospital or hospice. Trafford is eighth of the ten Greater Manchester authorities (and 3rd lowest among a group of 15 other similar authorities) on this measure. It is also lower than the England average, with higher numbers of people dying in hospital.

Accessing the right level of care is crucial to supporting more people with dementia to live well and die well. Finding the right level of support, whether it be home care, carer support, respite or hospice care or a long term stay in a care home can be difficult in Trafford. This is particularly the case for people with complex behavioural issues relating to their dementia, and this remains a longstanding and significant issue for Trafford. We need to review services in light of the increasing needs of this population, and to use the opportunities provided by the evolving provider landscape in the borough to explore new ways to deliver this care. This will form a major strand of work for our emerging Local Care Alliance.

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<sup>1</sup> [http://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_Dementia\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_Dementia_FINAL_2.pdf)

<sup>2</sup> <https://www.england.nhs.uk/wp-content/uploads/2018/04/my-future-wishes-advance-care-planning-for-people-with-dementia.pdf>

The trend line for Trafford shows a slight improvement from 57.5% in 2015 to 59.7% in 2016 but still well below the England average.

**Deaths in Usual Place of Residence: People with dementia (aged 65+)** 2016 Proportion - %

Area	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	-	58,101	67.9	67.6	68.2
Poole	13	285	76.2	71.6	80.2
Darlington	15	133	74.7	67.9	80.5
Cheshire West and Chester	10	426	72.3	68.6	75.8
Bedford	9	155	71.8	65.4	77.3
South Gloucestershire	6	261	69.4	64.6	73.9
Peterborough	11	189	68.5	62.8	73.7
Telford and Wrekin	14	167	68.4	62.4	73.9
Warrington	1	231	67.3	62.2	72.1
York	8	216	66.5	61.2	71.4
Stockport	7	335	65.3	61.1	69.3
Swindon	2	176	65.2	59.3	70.6
Reading	12	116	64.4	57.2	71.1
Solihull	3	225	60.0	55.0	64.8
Trafford	-	207	59.7	54.4	64.7
Thurrock	5	119	58.3	51.5	64.9
Milton Keynes	4	156	57.6	51.6	63.3

Source: Public Health England (Office for National Statistics Mortality File)

### Recommendations

- We need to ensure that people with dementia are able to die in their usual place of residence, if they so wish, with high quality of support.
- We need to ensure that frontline staff are adequately trained and feel supported to undertake timely and honest conversations regarding their future care.
- We need to ensure that we have Advanced Care plans in place for all of our residents with dementia
- We need to provide practical and emotional support to family carers in planning and delivering end of life care, to enable them to support their family member to die at home, if that is their wish.

### Cross cutting Themes

Each of these themes will include actions relating to the following cross cutting themes:

#### Information, education and training

Providing good education and training for patients, carers, staff and the general population will be critical to improving the quality of the services offered to people with dementia, and to improving people's lived experience.

#### Research

Within Trafford, we intend to continue to contribute to the developing research and evidence base in relation to dementia

## Summary of Recommendations

### Recommendations – Preventing Well

- We need to promote a greater public awareness of the risk factors for dementia, so that appropriate action can be taken to reduce these risks. For example, we must ensure that all materials promoting healthy lifestyles stress the protection that is offered by such lifestyles against dementia, as well as against physical conditions such as cardiovascular disease and cancer.
- We need to ensure that our social prescribing offers include an understanding of reducing dementia risk
- We need to reduce the inequalities in rates of smoking, alcohol use, obesity or physical inactivity between different population sub-groups, in order to reduce inequality in outcomes
- We need to ensure that the environment in Trafford is one that promotes a healthy lifestyle '*making the healthy choice the easy choice*'.

### Recommendations – Diagnosing Well

- We need to reduce the stigma relating to dementia, so that people are encouraged to discuss their concerns and fears, and access services earlier
- In particular, we need to ensure that people from higher risk groups are identified and that they are appropriately supported to access testing.
- We need to support GPs to make a timely diagnosis, and to make referral process easier, and we need to collect comparative data to identify where there may be under-diagnosis.
- We need to have a good understanding of minor cognitive impairment and how and whether it will progress
- We need good access to support services throughout the diagnostic period.

### Recommendations – Supporting Well

- We need to ensure that family carers are offered adequate training, support and respite, and that their own health is safeguarded.
- We need to improve the understanding of dementia in the paid workforce
- We need to carry out annual medication reviews for people with dementia, to ensure that it meets their needs as well as possible, and to ensure that other risks (such as falling) are not unacceptably high.

- **We need to ensure that all care planning for people with dementia includes planning for crises such as illness, falls, or carer breakdown**
- **We need to ensure that when a person with dementia is admitted to hospital, that the hospital is aware of their additional care needs, and that the length of stay is minimised in order to reduce the risk of further deterioration.**

#### **Recommendations – Living Well**

- **Trafford Age Friendly planning needs to incorporate all aspects of Dementia Friendly practice**
- **We need to increase public awareness of dementia and how to support people**
- **We need to ensure that shops, leisure services, and public spaces are open and accessible to people with dementia**
- **We need to ensure that care homes are of a high quality and can properly support people with dementia, and that we have sufficient capacity of care home places within the borough for people whose dementia leads to challenging behaviour.**

#### **Recommendations - Dying Well**

- **We need to ensure that people with dementia are able to die in their usual place of residence, if they so wish, with high quality support.**
- **We need to ensure that frontline staff are adequately trained and feel supported to undertake timely and honest conversations regarding their future care.**
- **We need to ensure that we have Advanced Care plans in place for all of our residents with dementia**
- **We need to provide practical and emotional support to family carers in planning and delivering end of life care, to enable them to support their family member to die at home, if that is their wish.**

## **Next Steps**

This Strategy will now form the basis for the development of prioritised Action Plans for each of the identified themes. These will include the development of SMART objectives and the development of measurable outcomes for delivery. In some cases, this may lead to reviews and/or recommissioning of existing activity, or in the development of approaches to improving the consistency, reach and impact of existing services or approaches.

This work and its impact will not be limited to the health and social care offer; instead, we need to involve the general public in increasing understanding of dementia, how to prevent it, and how to reduce any negative impacts to the individual, their family, and wider society.

CONSULTATION DRAFT



## Case Studies

The following three case studies are included to give a flavour of the experiences of people and their families of living with dementia in Trafford. These are not intended to demonstrate 'good' or 'bad' care but simply to provide an illustration of the reality of aspects of life with dementia in the borough.

### Story of Pauline and Lawrence\*: "Just tell me again" \*Names have been changed

Pauline and Lawrence married in 1961, and brought up their family in Trafford. Lawrence's work meant that they moved away for 10 years when they were in their fifties, and it was during this time that Lawrence first displayed symptoms of Alzheimer's disease.

Pauline remembers:

Lawrence loved sport, he swam, played football, cricket, badminton, tennis and bowls. He was a modest and thoughtful. He would, for example, would always note phone calls, and take time to consider anything said to him. Therefore, he already had in built strategies which masked some of his early symptoms.

But then "tell me again" started happening several times a day and Pauline knew that something wasn't quite right. A diagnosis of Alzheimer's was made, which was not unexpected but was still a shock. They told family and friends immediately and what a blessing that proved to be!

Lawrence's progression was slow, and they had excellent support from friends, and from the psychiatric nurse. The Alzheimer's Society ran social evenings, and Pauline's confidence grew.

However, Lawrence then started to become verbally abusive, and even physically violent. The family was worried, and asked for help from the Alzheimer's Society and the psychiatric nurse. Lawrence didn't remember the outbursts and was mortified and embarrassed. Fortunately, the violence stopped, and the abusive outbursts became less frequent.

Lawrence responded well to Aricept medications, but in 2017 the GP replaced this with a generic version despite Pauline warning that previous attempts had resulted in a marked difference in Lawrence. Lawrence then began to have 2 or 3 outbursts daily, and their daughters contacted the GP and voiced concerns not only for Lawrence himself but also Pauline. They described her as "not exactly hanging by a thread but by a strand of wool". The GP called, and Lawrence was returned to Aricept, calm was restored. However, Pauline feels that this change in medication marked the start of a speeding up of Lawrence's decline.

Lawrence and Pauline returned to Trafford about 5 years after his diagnosis. Lawrence still goes to the shops independently and will always ask for help and shop keepers and neighbours have been kind and helpful. Lawrence finds it hard to remember his address, and watching him walk straight past their new home towards the old one has been very upsetting for Pauline.

Age UK Trafford has provided support including a simple to use phone to contact Lawrence when he is out and help direct him back home. Lawrence now attends Age UK Trafford Day Support (specifically for people with dementia) every Thursday and this is now Pauline's "day off" when she can do her own thing.

Lawrence is still sporty. Pauline says: "There doesn't seem much wrong does there – but friends and family are very good picking him up and looking after him". However, when he is out, Lawrence will talk every child he meets – as he always had a love of children, Pauline worries about this as the views on children and strangers are very different today than they were years ago, and she feels he would be very hurt if anyone was to challenge him.

At the end the biggest worry is that Lawrence is very vulnerable, people with dementia are at the mercy of society.

**Case study 2** \*Names have been changed.

Margaret \*(78) contacted Trafford Carers Centre wanting to talk to someone about the impact caring for her husband was having on her physical and mental health.

Her husband, following a move from the South to Trafford to be closer to their daughter, had been diagnosed with depression after struggling to adapt to the new living arrangements. His GP had prescribed anti-depressants.

Apart from their daughter and grandchild, the couple had no social network or other support locally.

The Carers Centre arranged to talk to Margaret and her daughter. One main factor that arose was Margaret's worry was that her husband had dementia.

She had already contacted the GP who had made a referral to the memory clinic.

Trafford Carers supported Margaret and her daughter regarding their knowledge and understanding of dementia, and assessed their physical and emotional needs. This needed to be done at an early stage so as to prevent carer breakdown and to also help her build resilience.

Margaret attended six counselling sessions, where it was recognised that she needed further support to help her manage her husband's mental state and emotional support around coping with and coming to terms with the diagnosis.

After this Margaret started to come to an understanding about the diagnosis and the effect it would have on their lives. She felt she was more in control knowing what to expect, and felt ready to explore and increase her social circles. She was interested in the social activities held at the centre and on groups and activities that her husband could attend.

**Case study 3** \*Names have been changed

Patsy\* (79) came to Trafford Carers Centre, for a review of her caring role and the impact this was having on her. She was supporting her husband, George\*, who at the time was at pre-diagnosis for dementia and also had diabetes.

George was still managing to do most things for himself, albeit a little slower than before and with some practical help, particularly around personal hygiene and dressing.

Patsy herself had numerous health conditions including high blood pressure and diabetes, and had suffered a stroke. She had a care worker who attended once a day to help her with her own dressing and to help prepare meals

Patsy had worries about her financial situation and her inability to carry out tasks around the home, which lead to the home becoming unclean. Patsy had become socially isolated due to her and her husband's health conditions, and her social interaction was limited to attending church twice a week.

Patsy was allocated funding for a carpet cleaning service and for a gardening service, as George and Patsy both found the garden to be a peaceful and relaxing area but since it had become so overgrown it was adding unnecessary stress to Patsy.

Patsy was also referred to a welfare service and given information on finance and benefits, as well as African & Caribbean Care.

Following the initial contact and assessment, Patsy has stayed in touch to access emotional and practical support. Financial pressures remained a key worry and also not being able to get out to do something for herself.

Patsy was given a course of relaxation therapies provided to help her relax as well as to provide respite, and funds for her to enjoy meals out with close friends.

Most recently the conversation has turned to end of life and future planning. In the last year Patsy and George's son moved from his home down south to provide much needed support to his parents.

## Appendix A

### Prime Minister's Challenge on Dementia 2015

#### Goals to be achieved by 2020

- Improved public awareness and understanding of the factors which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.
- In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.
- GPs playing a leading role in ensuring coordination and continuity of care of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.
- Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available. This care may include, for example:
  - Receiving information on what post-diagnosis services are available locally and how these can be accessed, through for example an annual 'information prescription'.
  - Access to relevant advice and support to help and advise on what happens after a diagnosis and the support available through the journey.
  - Carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological

support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

- All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.
- All hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting.
- Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends into a global movement including sharing its learning across the world and learning from others.
- Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute.<sup>2</sup> Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.
- All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly 2 Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.
- National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.
- Dementia research as a career opportunity of choice with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.

- Funding for dementia research on track to be doubled by 2025.
- An international dementia institute established in England.
- Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, the NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation.
- Cures or disease modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.
- More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.
- Open access to all public funded research publications, with other research funders being encouraged to do the same.
- Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.

# Appendix B Public Health England Dementia Profile

Compared with benchmark Lower Similar Higher Not compared

Indicator	Period	England	Trafford	1 - Warrington	2 - Swindon	3 - Solihull	4 - Milton Keynes	5 - Thurrock	6 - South Gloucestershire	7 - Stockport	8 - York	9 - Bedford	10 - Cheshire West and Chester	11 - Peterborough	12 - Reading	13 - Poole	14 - Telford and Wrekin	15 - Darlington	
Estimated dementia diagnosis rate (aged 65+)	2017	67.9	74.0	70.9	64.0	60.7	67.8	63.1	62.7	75.2	60.4	62.1	65.0	78.4	68.4	69.0	62.3	79.5	
		<div style="display: flex; justify-content: space-between; font-size: small;"> <span>≥ 66.7% (significantly)</span> <span>similar to 66.7%</span> <span>&lt; 66.7% (significantly)</span> </div>																	
Dementia: Recorded prevalence (aged 65+)	Sep 2017	4.33	4.81	4.29	4.15	4.11	3.86	3.96	3.96	4.87	3.96	3.93	4.04	5.12	4.47	4.73	3.61	5.07	
People receiving an NHS Health Check per year	2016/17	8.5	9.8	9.4	8.4	10.6	9.8	11.3	6.1	7.9	0.2	6.6	5.9	10.4	5.1	2.2	4.8	9.6	
Smoking Prevalence in adults - current smokers (APS)	2016	15.5	12.6	12.6	14.9	11.7	14.5	20.8	9.7	12.2	12.6	15.1	11.7	17.6	15.8	16.5	15.6	17.3	
Hypertension: Recorded prevalence (all ages)	2016/17	13.8	14.1	14.0	14.0	15.0	12.3	13.9	14.0	14.7	11.7	13.5	15.0	11.7	11.2	14.7	13.7	15.6	
Percentage of physically active and inactive adults - inactive adults	2015	28.7	25.5	29.8	27.4	27.1	27.3	29.6	25.5	28.4	17.5	27.2	27.5	34.3	29.7	23.5	28.5	30.8	
Dementia: Ratio of inpatient service use to recorded diagnoses	2016/17	55.1	60.2	80.4	56.8	66.3	59.2	59.2	56.0	59.8	53.3	63.1	50.5	59.6	40.9	51.7	49.7	44.9	
Dementia: DSR of emergency admissions (aged 65+)	2016/17	3482	3954	5240	3261	4036	4271	3678	2988	4326	3165	3674	2985	4240	3666	3072	3123	2948	
Directly Age Standardised Rate of Mortality: People with dementia (aged 65+)	2016	868	824	1021	812	801	883	960	752	913	820	712	866	961	855	995	1001	846	
Deaths in Usual Place of Residence: People with dementia (aged 65+)	2016	67.9	59.7	67.3	65.2	60.0	57.6	58.3	69.4	65.3	66.5	71.8	72.3	68.5	64.4	76.2	68.4	74.7	

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## Appendix C Useful Documents

- GOVERNMENT DEMENTIA STRATEGY TO 2020  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414344/pm-dementia2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf)
- PHE DEMENTIA PROFILE  
<https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/0/gid/1938133052/pat/6/par/E12000002/ati/102/are/E08000009/nn/nn-1-E08000009>
- GM DEMENTIA UNITED STRATEGY  
<http://www.gmhsc.org.uk/assets/09-Dementia-United-Implementation-Plan-Cover-Sheet-v2.0-TD.pdf>
- DAA ACTION PLAN  
[https://www.dementiaaction.org.uk/assets/0000/3828/DAA Action Plan guidance for care homes.pdf](https://www.dementiaaction.org.uk/assets/0000/3828/DAA%20Action%20Plan%20guidance%20for%20care%20homes.pdf)
- GM REPORT FOLLOWING DECEMBER'S VISIT  
  
Dementia United  
Report
- CQC DTOC REPORT  
[https://www.cqc.org.uk/sites/default/files/20171219\\_local\\_system\\_review\\_interim\\_report.pdf](https://www.cqc.org.uk/sites/default/files/20171219_local_system_review_interim_report.pdf)
- GM COMMUNICATION STRATEGY  
<http://www.gmhsc.org.uk/assets/08-Communications-and-Engagement-Strategies-2016-17-v1.0-TD.pdf>
- DRAFT NICE GUIDANCE  
<https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0792>
- GM CARERS' STRATEGY  
  
GM Carers Strategy  
2015-18

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