



Bracknell Forest Joint Commissioning Strategy for Dementia 2014 – 2019





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Executive Summary

This Bracknell Forest Joint Commissioning Strategy for Dementia 2014 – 2019 takes account of the needs of people with dementia and their carers, and responds to the priorities identified within the Bracknell Forest Health and Wellbeing Strategy “Seamless Health”, national policy, and current best practice in line with national and local research.

Many people are now living longer and healthier lives and so the world population has a greater proportion of older people. People are at increasing risk of developing dementia as they get older; the vast majority of people with dementia are aged over 65. Dementia significantly impacts a person’s mood, memory and their ability to communicate and reason, as such, a diagnosis impacts not only the person’s life but also that of their friends and family.

The average age expectancy in Bracknell Forest is higher than the national average and the most notable projected population increase is in people aged over 65. Locally, a significant increase in the number of people with dementia is predicted over the next 5 years placing greater demand on resources.

Improving diagnosis rates, access to early intervention and improving the knowledge and awareness of the whole community are all important in achieving better outcomes for people with dementia and their carers.

In producing this strategy, people with dementia and their carers were asked for their views. The consultation exercise identified that people with dementia and their carers in Bracknell Forest have the following priorities:

- Better dementia knowledge and awareness
- Improved information and advice
- Improved support for carers
- Personalised support and independent living
- A dementia friendly town centre
- Early diagnosis and intervention
- Integrated health and social care services
- More accessible transport
- Improved support in care homes
- More dementia aware GP services
- Improved support for people with dementia in hospital
- Specialist support and services for people with dementia
- Younger people with dementia

This strategy proposes the above evidence based priorities which the Dementia Partnership Board will incorporate into an action plan.

Introduction

If you need help to understand the language in this document, there is a Glossary on page 21 to explain what some of the words and terms mean. Words in this document that are explained in the glossary are underlined.

The term 'dementia' describes a group of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. Dementia is progressive, which means the symptoms will gradually get worse over time. There are many different conditions that lead to dementia, the most common of which are Alzheimer's disease and vascular dementia.

Many people are now living longer and healthier lives and so the world population has a greater proportion of older people. As of 2010, there were an estimated 35.6 million people with dementia worldwide¹. It is estimated that about 800,000 people are living with dementia in the UK and 1,062 people aged over 65 living with dementia in Bracknell Forest².

Dementia mainly affects older people over the age of 65, but it can affect people who are younger. In the UK there are 17,000 younger people (aged under 65) living with dementia³. There will be over a million people of all ages with dementia by 2021³.

The 'Dementia 2010' report⁴ revealed that the cost of dementia in the UK is twice that of cancer, three times as much as heart disease and four times as much as stroke⁵. Dementia costs the UK economy £23.4 billion a year³. Family carers of people with dementia save the UK public purse over £12 billion a year³. By 2040, whilst the number of people affected is expected to double, it is claimed that the costs are likely to treble due to inflation in health care costs and the number of people whose lives are impacted when someone is diagnosed with dementia⁶.

Having a close relative with dementia does not mean that dementia is inevitable. Whilst there are some genetic mutations which affect a person's risk of developing dementia, the effects of these genes are subtle and but do not directly cause the disease. In addition, these genetic mutations are rare, for example genetic mutations count for less than one in 1,000 cases of early onset Alzheimer's disease⁷.

¹ <http://www.alz.co.uk/research/statistics>

² POPPI (Institute of Public Care - POPPI database) June 2013 (POPPI = Projecting Older People Population Information)

³ www.alzheimers.org.uk/statistics 2013

⁴ Luengo-Fernandez et al. 2010

⁵ <http://www.dementia2010.org/reports/Dementia2010Full.pdf>

⁶ Comas-Herrera A, Wittenberg R, Pickard L and Knapp M (2007). 'Cognitive impairment in older people: future demand for long-term care services and the associated costs'.

⁷ <http://www.alzheimers.org.uk/factsheet/405>

⁸ 'Forecasting the global burden of Alzheimer's disease' Brookemeyer et. al. *Alzheimer's and Dementia* 2007 Jul; 3(3): 186-91

Everyone can reduce their overall risk by adopting a healthy lifestyle which combines a healthy diet with physical, social and mental activity. Encouraging people to adopt a healthy lifestyle is also important as delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year⁸.

This Strategy responds to the identified priorities within the Bracknell Forest Health and Wellbeing Strategy – *Seamless Health* – and is in line with *Living Well with Dementia*, the national strategy for dementia. As part of the *Seamless Health* priority for addressing the mental health needs of the population, Bracknell Forest Council is committed to significantly improving outcomes for people with dementia and to improving efficiency by shifting the focus of support towards preventing dementia as well as early diagnosis and intervention as soon as dementia arises. In addition, the council is committed to supporting the Bracknell Forest community as a whole to become more aware of dementia and to understand how to support people with dementia when going about their day to day life.

What is a Commissioning Strategy?

A commissioning strategy is a document which sets out how support and services for individuals will be developed. In order to decide what outcomes the council and its partners on the Dementia Partnership Board and Health and Wellbeing Board need to work together to achieve and how the strategy will be implemented, the following has been taken into account:

- the views of local people including carers
- relevant legislation and national guidance
- an analysis of the needs of the local population and how these are likely to change in the future
- an overview of the strengths and limitations of current support and services
- resources currently available

People in Bracknell Forest have been consulted to find out what the local issues are. The priorities they have identified are identified on page 17.

This information, together with guidelines published by the Government, has informed the development of this strategy to ensure that people with dementia living in Bracknell Forest and their carers are able to have choice and control to live well with dementia and live as independently as possible.

⁸ 'Forecasting the global burden of Alzheimer's disease' Brookemeyer et. al. *Alzheimer's and Dementia* 2007 Jul; 3(3): 186-91

Key Information

- Across the UK an average of only 44% of people living with dementia have a formal diagnosis⁹.
- In the UK 61% of people with dementia are female and 39% are male¹⁰.
- The proportion of people with dementia doubles for every 5 year age group and one third of people over 95 have dementia¹¹.
- More than 17,000 younger people (aged under 65) with dementia in the UK¹².
- There are over 11,500 people with dementia from black and minority ethnic groups in the UK¹³.
- It is estimated that in 2011 in England, there were 1,191,000 people with a learning disability which is 2.2% of the population¹⁴. 1 in 3 people with Down's syndrome develop dementia in their 50s¹⁵.
- At any one time, a quarter of people staying in hospital beds are people with dementia aged over 65¹⁶.
- Two thirds of people with a diagnosis of dementia live in the community while one third live in a care home¹⁷. 80% of people living in care homes have a form of dementia or severe memory problems¹⁸.
- There are 670,000 carers of people with dementia in the UK¹⁹. These unpaid carers save the UK economy £12bn every year²⁰.
- The expense to the UK economy of each person with dementia is £27,647 per year; more than the UK median salary (£24,700). By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year²¹. Most of the cost of providing support for people with dementia in the UK (£12.4 billion every year) is met by unpaid carers²².
- Government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, which just £50million is invested in dementia research²³.

More in-depth key information can be found in Annex 1.

⁹ www.alzheimers.org.uk/statistics 2013

¹⁰ <http://www.alzheimersresearchuk.org/dementiaFAQ/>

¹¹ www.alzheimers.org.uk/statistics 2013

¹² http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

¹³ www.alzheimers.org.uk/statistics 2013

¹⁴ <http://www.arcuk.org.uk/membersarea/wp-content/uploads/2012/05/IHAL-PWLD-England-2011.pdf>

¹⁵ http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 2013

¹⁶ Counting the Cost. Alzheimer's Society. 2009.

¹⁷ www.alzheimers.org.uk/statistics 2013

¹⁸ www.alzheimers.org.uk/statistics 2013

¹⁹ www.alzheimers.org.uk/statistics 2013

²⁰ www.alzheimers.org.uk/statistics 2013

²¹ Dementia 2010' Alzheimer's Research Trust

²² www.alzheimers.org.uk/statistics 2013

²³ <http://www.alzheimersresearchuk.org/dementia-statistics/>

National & Local Context

National

The National Dementia Strategy – Living Well with Dementia 2009

Living Well with Dementia is one of the first strategies of its kind in the world. It set the standard for improving the lives of people with dementia, for their families and their carers, through raising awareness, encouraging earlier diagnosis and providing high-quality treatment and care.

The aim of the strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia. This strategy is a catalyst for a change in the way that people with dementia are viewed and cared for in England.

Alzheimer's Society: Delivering on Dementia 2012-2017

The Alzheimer's Society 5 year strategy is guided by 7 things people with dementia have told the Society they want to see in their lives:

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have the knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future



Prime Minister's Challenge on Dementia: March 2012

This document builds on the achievements of the national dementia strategy – Living Well with Dementia. The Prime Minister asked social care and health services across the country to come up with lots of ideas to help people with dementia and their families and carers. It is an ambitious programme of work to push further and faster to deliver major improvements in dementia care and research by 2015. The “Challenge on Dementia” is a challenge to the whole of society as well as government.

It focuses on three key areas:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research in order to understand how to prevent, treat symptoms and develop a cure for dementia

The Care Bill (May 2013)

The Care Bill proposes to modernise over 60 years of care and support and brings together over a dozen different pieces of legislation into a single, clear law built around people's needs and what they want to achieve in their lives.

The Bill highlights the importance of early intervention and prevention to reduce acute needs, and putting people in control of their care and support. For the first time, it puts carers on an equal legal footing with those for whom they care, creates national eligibility criteria, reforms how care and support is funded and creates a cap on the care costs that people will pay.

The Health and Social Care Act 2012

This legislation changed the way the health service (NHS) works to deliver person-centred healthcare by:

- Giving patients greater choice, control and involvement – “no decisions about me without me”
- Improving health outcomes
- Removing unnecessary bureaucracy, cut waste and make the NHS more efficient
- Creating Clinical Commissioning Groups (CCG) where local GPs deliver health services based on their community's needs

Health and Wellbeing Boards have also been created in each local authority area with the specific role to improve health and wellbeing for all, and reduce health inequalities between different people.

Personal Health Budgets

From October 2014 people will have the right to have a Personal Health Budget. Similar to personal budgets for social care, Personal Health Budgets offer people greater choice and control over how their support is planned and arranged and flexibility in how to meet their health needs.

Many people with a personal budget choose to arrange all or part of their care using direct payments. This is when the council provides cash instead of services, so that people can arrange and buy their own care and support. On 1st August 2013, the Direct Payment in Healthcare regulations came into force across England. This means that the NHS can now lawfully offer direct payments for healthcare.

QIPP (Quality, Innovation, Productivity and Prevention)

QIPP is a large scale programme of change in the health services (NHS), involving all NHS staff, clinicians, patients and the voluntary sector and improves the quality of care the NHS delivers and make up to £20 billion of efficiency savings by 2014-15 which will be reinvested in frontline care. There are a number of national work streams designed to support the NHS to achieve the quality and productivity challenge it has been set.

Think Local, Act Personal: Next Steps for Transforming Adult Social Care

Think Local, Act Personal builds upon 'Putting People First (2007)' and sets out the principles for 'Personalisation'. An important emphasis in transforming social care is different organisations in different sectors working together to achieve a whole systems approach. The development of Joint Strategic Needs Assessments (JSNA) and Local Performance Frameworks are key features of this approach. Personalisation gives each individual choice and control over how their support is provided and delivered. The focus of "Think Local, Act Personal" is on areas where further action is required.

Local

Bracknell Forest Dementia Partnership Board

The Dementia Partnership Board is responsible for developing this Dementia Strategy and overseeing the delivery of the Action Plan to make sure support and services are delivered to people in need of support because of dementia in line with both the local strategy and action plan and national legislation and guidance.

The members include officers from Bracknell Forest Adult Social Care, Health and Housing department, health practitioners from Bracknell and Ascot Clinical Commissioning Group, Berkshire Healthcare NHS Foundation Trust and organisations representing people affected by dementia including the Alzheimer's Society and carer representatives.

Bracknell & Ascot Clinical Commissioning Group (CCG)

The CCG is the statutory organisation led by local GPs which is responsible for commissioning local health services. They do this by commissioning or buying health and care services.

At national level, NHS England will make sure that the CCG has the capacity and capability to commission services successfully for local people and to meet their financial responsibilities.

GP surgeries are using the Adjusted Clinical Groups (ACG) system to determine the likely resources needed to support individuals affected by various conditions. They use this information to estimate the financial and social impact of these predictions so they can work with individuals to form better long-term care plans.

Bracknell Forest Health and Wellbeing Board

The Health and Wellbeing Board is a partnership of commissioning leaders from the health and care system that must work together to improve the health and wellbeing of their local population and reduce health inequalities. The Board is accountable to local people.

The Board provides a forum for challenge, discussion and the involvement of local people and brings together the Bracknell & Ascot Clinical Commissioning Group, NHS England, Healthwatch and the Council. They have a legal responsibility for developing a shared understanding of the health and wellbeing of the community through a wide ranging assessment of health and wellbeing needs by:

- producing a Joint Strategic Needs Assessment (JSNA)¹⁵
- setting priorities for improving the health and wellbeing in a Joint Health and Wellbeing Strategy (JHWS) which will take into account information from the JSNA and other commissioning strategies. This strategy has identified that dementia, as a mental health condition, is a priority within Bracknell Forest.
- assessing other plans and strategies to make sure they align with the JHWS
- encouraging organisations to work together and share resources

As a result, patients and the public should benefit from more joined-up services from the NHS and Bracknell Forest Council.

Public Health

Bracknell Forest Council has responsibility for public health functions some of which will impact on services for people with dementia including:

- Local programmes to promote physical activity, improve diet/nutrition and prevent/address obesity as well as mental wellbeing
- Drug misuse and alcohol misuse services
- Tobacco control, including stop smoking services and prevention activity
- NHS health checks
- Local initiatives to prevent accidental injury, including falls prevention
- Local initiatives to reduce seasonal mortality



Needs Analysis

A needs analysis is a way of estimating what the needs of a population are so that appropriate support can be planned. In this strategy the council has identified the expected local need through the Joint Strategic Needs Assessment, Census and other data sources. Local people and organisations were also asked for their feedback on needs and priorities for people affected by dementia.

Year	2012	2015	2020
Number of people with dementia	1,062	1,195	1,420

Table: People aged 65+ living in Bracknell Forest estimated to have dementia.

Source: POPPI Database.²⁴

Expected Local Need

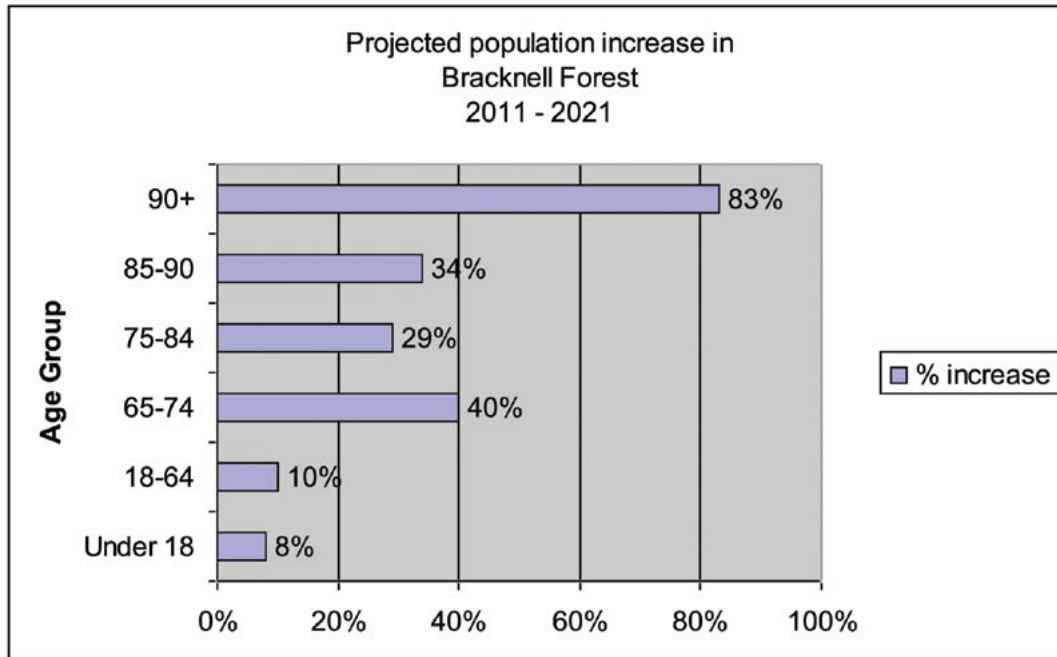
At the last census, 2011, the estimated population for Bracknell Forest was 115,000²⁵. Between 2001 and 2011 the population grew 3.7%, less than the national growth rate (7.1%) and the South East growth rate (7.6%).

Understanding growth rate is important because the most significant risk factor for developing dementia is age. In Bracknell Forest, the largest population increase is predicted to be amongst those aged over 90 – a 83% increase between 2011 and 2021.



²⁴ POPPI (Institute of Public Care - POPPI database) Crown copyright 2010

²⁵ Office of National Statistics 2011 census



Source: Office for National Statistics August 2013

Life expectancy in Bracknell Forest is higher than the national average at 79.7 years for men and 83.8 years for women. This is compared to 78.3 years for men and 82.3 years for women throughout the United Kingdom²⁶.

In 2013, 694 older people aged 65+ were being supported by the Community Mental Health Team for Older Adults (CMHT (OA)): 465 (67%) were female and 229 (33%) were male²⁷.

Of the 694 older people aged 65+ being supported by CMHT (OA), 339 (49%) have an unpaid carer²⁸.

Approximately 13 people being supported by the Community Team for People with Learning Disabilities (CTPLD) have dementia²⁹.

In addition, people with dementia as a secondary support need receive support the team for Older People and Long Term Conditions (OPLTC).

At August 2013, CMHT(OA) supported 39 people aged under 65 with dementia: 22 (56%) were female and 17 (44%) male³⁰.

Most people receiving support in Bracknell Forest identify themselves as being White British (93.9%) which is in line with national population data³¹.

²⁶ Joint Strategic Needs Assessment 2011/12

²⁷ RIO Stats

²⁸ RIO Stats

²⁹ Bracknell Forest LD Dementia Register 2013

³⁰ RIO stats

³¹ RIO Stats

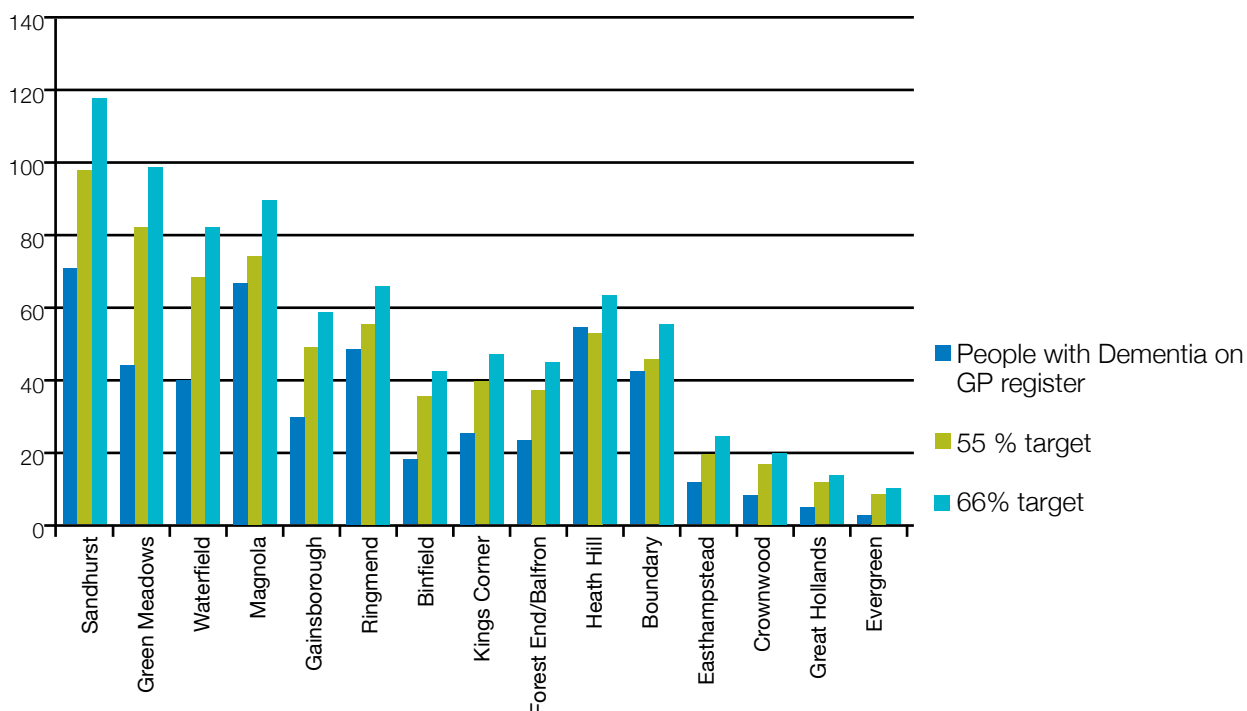
In 2012, 2,098 people in Bracknell Forest were predicted to have a learning disability³². This is 1.9% of the local population. In Bracknell Forest, 13 people with a learning disability have dementia and 43 are currently being assessed³³.

There are 13,719 patients (13% of the population aged 18+) on depression registers in the Bracknell and Ascot CCG. This prevalence rate is statistically above the national average and above the South Central average of 9.2%.³⁴ Depression and anxiety are frequently experienced by people with dementia and their carers. The causes of depression and anxiety in someone who also has dementia are likely to be similar to those for depression and anxiety in general. However, in the early stages of dementia these conditions may be linked to a person's worries about their memory and about the future. Chemical changes in the brain, caused by the dementia, may also lead to depression or anxiety.

Bracknell Forest Council currently spends approximately £3 million per annum supporting people with dementia. This sum is subject to review in the context of the council's medium term financial plan.

It is estimated that 42.5% of people with dementia living in Bracknell Forest receive a formal diagnosis³⁵. In accordance with the NHS Quality Premium Guidance, GP surgeries in Bracknell Forest are currently working towards increasing the diagnosis rate to 66% as shown in the graph below:

Comparison Numbers of patients on dementia registers Vs numbers required to reach 55% and 66% of total



Source: Bracknell and Ascot Clinical Commissioning Group. August 2013.

³² Institute of Public Care (PANSI database) July 2013

³³ CTPLD Health Spreadsheet August 2013

³⁴ This prevalence information has been taken from the QOF for 2011/12 and shows the number of people on GP Practice lists who had a current diagnosis of depression on 31/3/2012.

³⁵ Department of Health prevalence calculator 2013

Stakeholder Engagement

The development of this strategy was informed by a 12 week stakeholder consultation which began with a public event on 22nd April and closed on 19th July 2013. The consultation event and the paper and on-line questionnaires were promoted through local media. Invitations were sent to people with dementia and their carers who have been supported by the Dementia Advisor and local voluntary groups supporting people with dementia. Over 120 people attended the consultation event including people with dementia, carers, voluntary groups and practitioners supporting people with dementia.

People were asked to think about what they thought the priorities are when considering support for people to live well with dementia and what would make Bracknell Forest a friendlier place to live for people with dementia and their carers.

In addition, people also told us about what was going well. The Dementia Advisory service and the Memory Service were frequently praised by people with dementia and their carers for being knowledgeable, easy to contact and providing support to people early on following a diagnosis.

If people were unable to attend the event or wanted to add more information later, they were given the opportunity to complete the consultation questionnaire which was distributed and publicised throughout the local area.

Bracknell and Ascot Clinical Commissioning Group held its annual planning event in June for all member GPs and practice staff. Dementia was high on the agenda as a top priority for the CCG. At this event, the priorities identified by the stakeholder consultation event were discussed and the contributions from the GPs have also informed the development of this strategy.

A total of 598 comments were received which relate to the experiences, needs and wishes of the people who responded.

Conclusion

Throughout the UK, people are living longer. Despite on-going improvements in healthcare and research, older age remains a key risk factor affecting the likelihood of developing a wide range of illnesses and conditions. This ageing population is having a considerable impact in the prevalence of dementia. Over the next 10 years, the proportion of the population of Bracknell Forest reaching their 65th birthday is higher than the UK average; it is imperative not to underestimate this inevitable increased demand on dementia support services.

Dementia does not just affect the person with the diagnosis. Family and friends become carers and the impact of this new role can be overwhelming as well as the inevitable emotional distress caused by a diagnosis. When planning support for people affected by dementia, adult social care and health services must consider the needs of carers as well as those diagnosed with dementia. Dementia is a condition which can affect a whole community. As time goes on, there will be very few people who do not have a friend or family member with dementia.

This strategy demonstrates the need to focus on improving dementia awareness across the community, investing in early diagnosis and intervention and supporting carers.

Priorities

The following priorities have been informed by people with dementia and their carers and the Department of Health Outcome Frameworks. Commissioners will take these into account when designing and delivering support and services.

Better Dementia Awareness

Evidence

“We need a wider awareness about dementia in the community... we need to reduce the stigma and fear associated with dementia”

The overwhelming majority of people who responded to the consultation agreed that public awareness and understanding of dementia needs to be improved. There are several common misconceptions about dementia such as the false belief that memory problems are to be expected and tolerated as a normal part of getting older. The accuracy of people’s knowledge needs to be improved. Alongside national publicity campaigns, local activities to inform local people about dementia are needed to nurture a community which understands and knows how to help. A lack of public awareness means that people said that they were worried about the stigma of dementia and that a diagnosis might lead to losing friends and experiencing discrimination.

In addition, people with dementia and their carers told us that better dementia awareness is needed when organisations are planning buildings, public facilities and town centres. Consideration needs to be given to ensuring clear and consistent information such as using appropriate fonts, colours and pictures in signs and the use of plain English rather than jargon. Also the needs of people with dementia and their carers need to be considered when developing policies, such as carers being able to accompany the person they care for when using changing room facilities, public transport and so on.

Priority areas identified for improved understanding and awareness were shops, transport providers and children and young people.

Local outcomes

Organisations and businesses will understand dementia and know how to help which will enable people with dementia and their carers to feel welcome and safe throughout the local community.

This fits with National Adult Social Care and Health Priorities as below:

- People are able to find employment when they want, maintain family and social life and contribute to community life, and avoid loneliness or isolation.
- Everyone enjoys physical safety and feels secure.
- People are free from physical and emotional abuse, harassment, neglect and self-harm.

Information and Advice

Evidence

“The worst thing is not knowing what to expect, we need more explanation after diagnosis”

People told us that being diagnosed with dementia can be a frightening time for the person with dementia as well as their family and friends. Having accessible, clear and accurate information and advice about dementia helps people to become better informed and to cope with the impact such a diagnosis may have on their lives. Information about how symptoms may develop, technology which may help and planning for the future were identified as priority areas for improving provision of information and advice in Bracknell Forest.

The Dementia Advisory Service was identified as a highly valued provision. People told us they appreciated the one-to-one support, information all being in one place and having a named contact following diagnosis.

Local outcomes

People with dementia and their carers will have the information they need to understand their diagnosis, be prepared for the future and have choice and control over their lives.

This fits with National Adult Social Care and Health Priorities as below:

- Everybody has the opportunity to have the best health and wellbeing throughout their life and can access support and information to help them manage their care needs.
- People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

Carers

Evidence

“Dementia is a diagnosis which affects families, not just individuals”

Many illnesses can have an impact on a whole family and this is especially true of dementia. Carers told us that their loved ones forgetting them and their life together is one of their biggest fears when a diagnosis of dementia is given. Carers play a pivotal role in people with dementia being able to stay in their homes as long as possible and are a vital support. However, caring for someone with dementia can be extremely demanding and throughout the consultation, carers said that opportunities to take a break or longer respite options are desperately needed so that they can continue to care for their own wellbeing as well as that of their loved ones.

Local outcomes

Carers will report that the care they provide is valued and recognised by health and social care providers and they will have suitable opportunities to take a break from their caring role.

This fits with National Adult Social Care and Health Priorities as below:

- Carers can balance their caring roles and maintain their desired quality of life.
- Enhancing quality of life for carers.
- People who use social care and their carers are satisfied with their experience of care and support services.
- Carers feel that they are respected as equal partners throughout the care process.

Personalised support and independent living

Evidence

“Staying at home as long as possible is very important, the use of technology (e.g. to remind me to take my pills) is very useful”

Throughout the consultation process, people with dementia and their carers said that keeping busy, having company and being treated as an individual is important to them. Having choice and control over their life and support is key to living well with dementia. People told us that they enjoy attending activities in the community as well as day centre support and that these activities need to be designed around the needs of people with dementia, including younger people with dementia. Many people said that they feared having to move into residential care and that it was important to them that they receive support to stay in their own homes for as long as possible.

Local outcomes

People with dementia who want to live at home will be supported to do so for as long as possible. People with dementia and their carers will lead fulfilling lives socialising to the extent they choose and taking part in activities they enjoy.

This fits with National Adult Social Care and Health Priorities as below:

- People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.
- People are supported to plan ahead and have the freedom to manage risks the way that they wish.
- Helping older people to recover their independence after illness or injury.

A dementia friendly town centre

Evidence

“Finding way around can be difficult – familiarity is important”

“The [Bracknell] Town Centre regeneration is an opportunity to improve community”

People said that getting around Bracknell and the town centre can be challenging with a lack of clear signposting and convenient places to park close to amenities. In addition, people with dementia and their carers said that they would like to see more frequent opportunities to sit and take a rest around the town centre. Early in 2013, the council asked people with dementia and their carers what would make Bracknell Forest a friendlier place to live for people with dementia. The overwhelming response was that improving the dementia awareness and skills of staff working in shops and transport is a high priority. This is an area the council are already working on improving and will continue to do so throughout the lifetime of this strategy.

Local outcomes

Bracknell town centre will be easily accessible and a welcoming place for people with dementia and their carers. The wider community in Bracknell Forest, including customer service staff, will understand dementia and know how to help.

This fits with National Adult Social Care and Health Priorities as below:

- Everyone enjoys physical safety and feels secure.
- People are free from physical and emotional abuse, harassment, neglect and self-harm.
- People are able to find employment when they want, maintain family and social life and contribute to community life, and avoid loneliness or isolation.
- People know who to contact when they need help.

Early diagnosis and intervention

Evidence

“Good quality early diagnosis is a high priority”

Often dementia goes undiagnosed for quite some time. This can be because people mistake the symptoms for ‘normal ageing’ or are anxious about receiving a diagnosis. Also early symptoms and their impact can vary significantly, especially with people with learning disabilities and younger people who may be diagnosed with depression and/or stress or, in women, the onset of the menopause. However, receiving a diagnosis is a vital first step in receiving appropriate medication and support. People told us that educating and encouraging people to go to their GP if they have concerns about their memory is important as well as ensuring there is support available for people who have recently been diagnosed. This priority links in with raising awareness and improved GP services.

Local outcomes

GP services will understand dementia and work closely with memory services to improve diagnosis rates.

This fits with National Adult Social Care and Health Priorities as below:

- Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services.
- Everybody has the opportunity to have the best health and wellbeing throughout their life and can access support and information to help them maintain their wellbeing.

Integrated health and social care services

Evidence

“Dementia is not a ‘stand alone’ condition... older people are often frail and as a result minor changes in their health have major consequences especially on the amount of care that person will require to stay at home”

People told us that they really value named contacts and knowing who they can talk to about their dementia and other health concerns. Having to repeat their personal information and medical history to several practitioners was highlighted as a significant annoyance. It is important that health, social care and voluntary organisations continue to focus on improving communication and partnership working to share best practice and ensure a sensible joined-up approach which is easy to access and navigate by people with dementia and their carers.

Local outcomes

Health, social care and voluntary organisations supporting people with dementia and their carers will communicate well with one other. Referral and other processes will be clear and permit secure sharing and storing of information.

This fits with National Adult Social Care and Health Priorities as below:

- People who use social care and their carers are satisfied with their experience of care and support services.

Transport

Evidence

“Transport improvements are needed to reduce isolation”

When people are unable to drive or walk long distances, loneliness and isolation can become part of everyday life. Many people said that they find it difficult to travel around Bracknell Forest on public transport and rely on lifts from family and friends or expensive taxi services. People said that bus routes do not always run frequently enough or close enough to their homes to make using a bus a viable option. When using a car, people with dementia and their carers told us that having parking, waiting and dropoff areas close to the town centre, doctors and hospitals is a priority.

Local outcomes

The needs of people with dementia and their carers with regards to transport will be advocated as appropriate by the Dementia Partnership Board. Bracknell town centre will be accessible and welcoming to people with dementia and their carers. Transport providers will better understand dementia and know how to support people using their services.

This fits with National Adult Social Care and Health Priorities as below:

- People are able to maintain family and social life and contribute to community life, and avoid loneliness or isolation.

Care Homes

Evidence

“I think care homes should be an inclusive environment where everyone is respected and included regardless of the stage of their health condition”

Where residential care was mentioned, the vast majority of respondents said that they wanted to stay in their own home for as long as possible. However, people said that where residential and/or nursing care is necessary, the transition from home or hospital to a residential home could be a very difficult time and that support should continue to be as personalised as possible.

Local outcomes

People with dementia who want to live in their own home will be supported to do so for as long as possible. Where moving to residential care is necessary or chosen, people with dementia and their carers will be supported through this process. People with dementia living in residential care settings will continue to have choice and control over their lives.

This fits with National Adult Social Care and Health Priorities as below:

- When people develop care needs, the support they receive takes place in the most appropriate setting, and enables them to regain their independence.
- Improving the experience of care for people at the end of their lives.

GP services

Evidence

“Early diagnosis can only be achieved with better awareness and greater knowledge for GPs”

“GPs need to be more aware and sensitive to carers and families”

In order to obtain a diagnosis, people first need to see their GP for a referral to memory services. During the dementia consultation event, people were reminded of the importance of visiting their GP if they have concerns about their memory. In this respect, this priority links with the need for better awareness; people need to understand that getting a diagnosis is really important and is a positive step. In addition, people told us that they feel that GPs could benefit from a better understanding of how dementia impacts on people's lives and also how this affects families and carers. At the CCG annual planning event, GPs said that with better dementia awareness they would be better able to support people with dementia and their carers.

Local outcomes

People living in Bracknell Forest will understand that and that memory problems are not a normal part of ageing and that a diagnosis of dementia means that positive steps can be taken to improve their lives. People with concerns about their memory will visit their GP knowing that they will be listened to and referred to specialist services if necessary.

This fits with National Adult Social Care and Health Priorities as below:

- People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

Hospital

Evidence

“Going into hospital can be hard; any changes in my environment can have a major impact”

People said that going into hospital, being in hospital and returning home from hospital can all be particularly stressful times for people with dementia and their carers. It is

well documented that people with dementia find it particularly difficult to adapt to new environments and yet a large proportion of people in general hospitals have dementia³⁶. Alongside the need to support people to be cared for at home wherever possible, people said that the process of going into and out of hospital should be handled with sensitivity and with appreciation of the impact this has on carers.

Local outcomes

People with dementia receiving treatment in hospitals will feel and be safe and supported. People and their carers will be involved with planning admissions and discharges from hospital wherever possible.

This fits with National Adult Social Care and Health Priorities as below:

- Reducing time spent in hospital by people with long term conditions.
- Improving hospitals' responsiveness to personal needs.

Specialist services

Evidence

"It's important to feel you are talking to experts... The Dementia Advisor is an invaluable role, a real hub of information and personalised support"

A lot of praise was received for the Bracknell Forest memory service and Dementia Advisor with people saying that they appreciated the specialist knowledge and personalised support of these services. Knowing that the people providing support are specialists was highlighted as a priority by many people responding to the consultation.

Local outcomes

People with dementia and their carers will have timely access to support from people who have specialist knowledge and experience of dementia.

This fits with National Adult Social Care and Health Priorities as below:

- Everybody has the opportunity to have the best health and wellbeing throughout their life and can access support and information to help them manage their care needs.
- People who use social care and their carers are satisfied with their experience of care and support services.
- People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

³⁶ See the 'Key Information' section of this strategy.

Younger people with dementia

Evidence

“Activities may be too stereo-typed (bingo etc.) particularly for younger people with dementia. In addition, younger carers are often forgotten about because dementia is seen as an older person’s illness.”

Whilst there is a low number of people aged under 65 diagnosed with dementia in Bracknell Forest, it is important that people are able to find support which suits them as an individual. Personal budgets and direct payments enable people to have more control over their support, However, people said that there needed to be more options available for younger people with dementia.

Local outcomes

Younger people with dementia and their carers will be able to choose local support which suits their individual needs, interests and wishes.

This fits with National Adult Social Care and Health Priorities as below:

- People are able to find employment when they want, maintain family and social life and contribute to community life, and avoid loneliness or isolation.



Action Plan

The Action Plan will be developed by the Dementia Partnership Board and takes into account all elements of the Needs Analysis – the expected need and what people have expressed a need for through the consultation. The Action Plan is the document that will, to an extent, govern the actions the Council and the Clinical Commissioning Group undertakes over the next five years. It aims to link the needs identified to achievable priorities and on to items for action, mapped against the Outcomes Framework, which will be reviewed and assessed by Dementia Partnership Board regularly throughout the strategy lifetime.



Current Support and Services in Bracknell Forest

In the last Bracknell Forest Dementia Strategy set out commitments to:

- Continue to build on successful support and services and change and adapt support available, as appropriate, to meet people's needs
- Provide accessible support for people with dementia to enable them to stay in their own homes for longer and to help with timely discharge from hospital

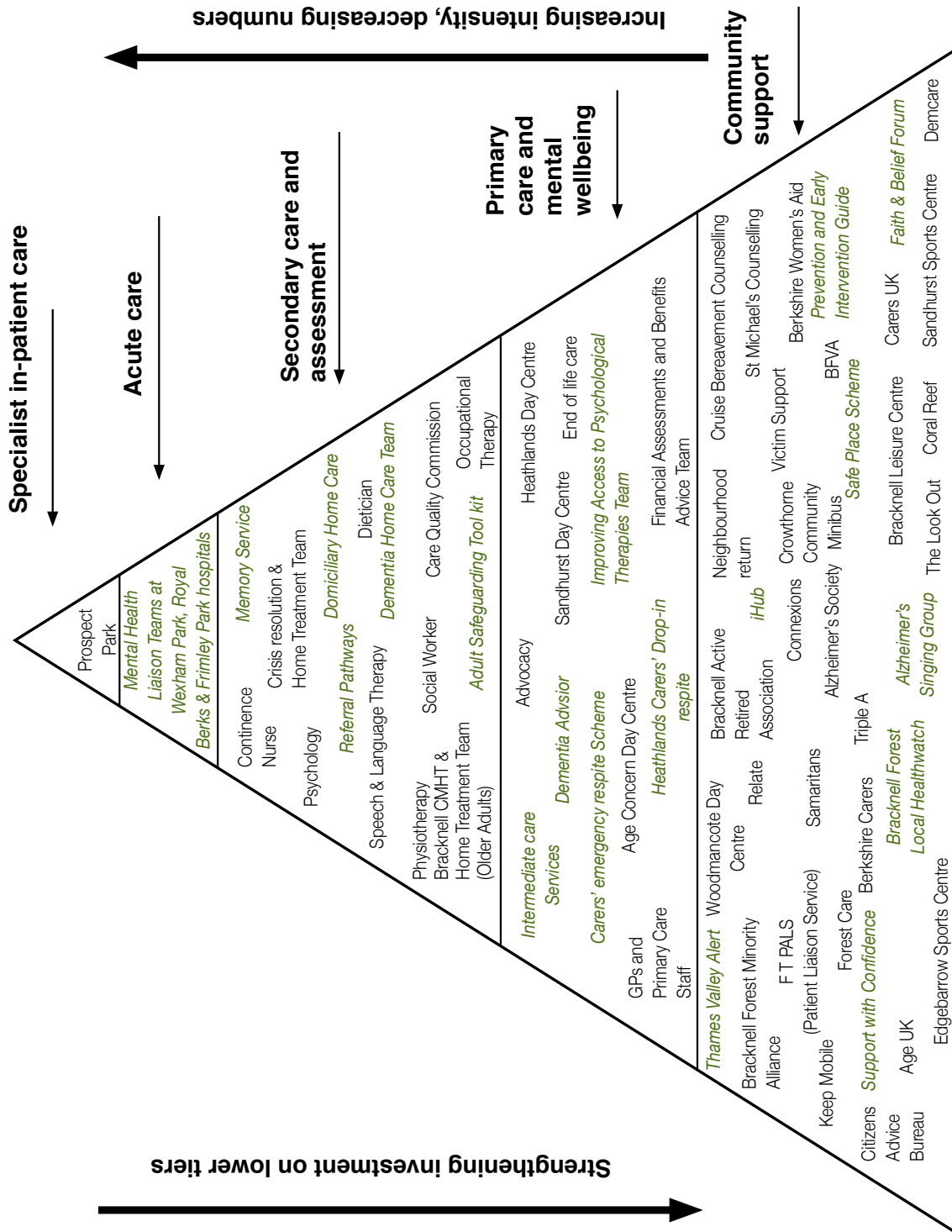
The 2009-2014 Bracknell Forest Dementia strategy indicated a move towards investing in community based, specialised support for people with dementia. As a result, people have been experiencing greater choice and control over their support due to the rollout of personalisation.

The diagram on the next page demonstrates an increase of support options available in the community and through primary care since the launch of the last dementia strategy. However, this strategy recognises the importance of continuing to focus on early diagnosis and intervention. Living Well with Dementia states that if “early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction...early intervention in cases of dementia is cost-effective and can improve quality of life for people with dementia and their families.”



Current Support and Services in Bracknell Forest

* New services/opportunities since the last strategy in *italics>*



Next steps

The Dementia Partnership Board will create an action plan. This plan will identify things that could be done under each priority to make sure outcomes are delivered for people affected by dementia.



Glossary

Adjusted Clinical Groups (ACG)	The ACG System measures the morbidity burden of patient populations based on disease patterns, age and gender. It relies on information about diagnoses found in insurance claims or other computerised medical records. This provides Clinical Commissioning Groups with a more accurate representation of the morbidity burden of populations, subgroups or individual patients – as a constellation of morbidities, not as individual diseases.
Alzheimer’s disease	Alzheimer’s disease is the most common form of dementia. Alzheimer’s disease was first described by a German neurologist Dr Alois Alzheimer. Alzheimer’s disease is a physical disease of the brain. During the course of the disease plaques and tangles develop in the brain leading to the death of brain cells. People with Alzheimer’s disease have a shortage of some important chemicals which are involved in transmitting messages within the brain.
Clinical Commissioning Group CCG	A Clinical Commissioning Group is group of GP practices that are working in partnership to arrange health services for local people. The Clinical Commissioning Group for Bracknell Forest is called the Bracknell Forest and Ascot Clinical Commissioning Group.
Clinician	A person who works in the health service whose job it is to give help and support to patients, e.g. doctor, nurse, optician, pharmacist
Commission Commissioning	To authorise or have a contract with a person or organisation to make something specific happen. This might be to provide a particular service such a nursing care. Often commissioners pay the providers to run a particular service.
Commissioners	The people or organisations that commission other people or organisations to do things. The Local Authority commissions Social Care services, and the CCG commissions Health services.
Commissioning organisations	See commissioners

Commissioning Plan	The plan that says exactly what commissioning organisations are going to pay or authorise other people or organisations to run. They should be quite detailed about the standards that are expected and the times by which they want things done.
Commissioning Strategy	Strategies are more “high level” than plans, and say the kinds of things that are going to be done to meet the needs and wishes that have been identified. Commissioning plans should be based on commissioning strategies.
Community Mental Health Team for Older Adults (CMHT-OA)	Community based team of specialist healthcare and social care practitioners, supporting older people with mental health conditions and people with dementia.
Department of Health	The Department of Health is a part of Government that is responsible for policy and some funding for health and social care services, and for improving the country’s health and well-being.
Dementia	<p>The term ‘dementia’ describes a set of symptoms associated with an ongoing decline of the brain and its abilities. This includes problems with:</p> <ul style="list-style-type: none"> • memory loss • thinking speed • mental agility • language • understanding • judgement <p>How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own way.</p>
Down’s syndrome	<p>Down’s syndrome is a condition that people are born with. People with Down’s syndrome are likely to have:</p> <ul style="list-style-type: none"> • a learning disability • reduced muscle tone leading to floppiness (hypotonia) • eyes that slant upwards and outwards • their palm may have only one crease across it (palmar crease) • a below average weight and length at birth
GP	General Practitioner: Most people are registered with a GP. Groups of GPs who work in the same surgery are often referred to as a GP Practice.

Health and wellbeing board	<p>Health and wellbeing boards are <u>partnerships</u> between the <u>Local Authority</u>, the <u>Clinical Commissioning Group</u> and the <u>Local Healthwatch</u> organisation for the area. Working in partnership and under a specific duty to promote the health of their population, in everything they do Boards must seek to:</p> <ul style="list-style-type: none"> • Improve health outcomes for local people • Reduce health inequalities between different people in the community
Joint Health and Wellbeing Strategy JHWS	A plan that sets out the priorities that commissioning organisations need to think about when developing health and social care services.
Joint Strategic Needs Assessment JSNA	An assessment of the health needs of the local population, which then identifies where there are particular problems that need attention.
Learning Disability	A learning disability happens when a person's brain development is affected, either before they are born, during their birth or in early childhood. A learning disability means a person finds it hard to learn new things in any area of life, not just at school and everyday activities can be difficult.
Local Authority	Refers to County Council, Borough Council, District Council, etc. For this strategy the Council is Bracknell Forest Council
Mild Cognitive Impairment	Mild cognitive impairment causes cognitive changes that are serious enough to be noticed by the individuals experiencing them or to other people, but the changes are not severe enough to interfere with daily life.
NHS	National Health Service
Outcomes	Something that happens as a result of action: it is important to focus on the outcomes for people rather than actions which may not have the outcomes people want.

The Outcomes Framework	The Outcomes Framework, created by the Department of Health, sets out the areas (domains) that the Council needs to concentrate on within the Action Plans associated with every strategy. The Outcomes Framework that relates to Adult Social Care also links into the Outcomes Frameworks for both NHS and Public Health services. For details on how these link together please see Appendix 1. Each of these areas in turn has more detailed requirements. The detailed requirements of the Adult Social Care Outcomes Framework (ASCOF) are listed below.
Partnership	An arrangement when organisations or people work together on things that they all have some responsibility for.
Primary Care Trusts	Large health organisations that were replaced by local CCGs.
Priorities	The most important or urgent things to work on. Things might be a priority because of the number of people affected, or because of what might happen if nothing is done.
Public Health	The prevention and management of diseases, injuries, etc. through the promotion of healthy behaviours and environments.
RIO	Patient Record System used by Berkshire Healthcare NHS Trust (BHFT)
Social care	Support for people in relation to personal care, social support and prevention of harm for people who are unable to be independent in those areas.
Statutory	Something that must happen because it is set out in law.
Vascular dementia	A person can get vascular dementia when their brain does not get the blood it needs to work properly. Over time, parts of the brain get damaged and eventually die from a lack of oxygen and nutrients.

Annex 1:

Key Information Explained

Diagnosis Gap

Across the UK an average of only 44% of people living with dementia have a formal diagnosis³⁷.

Receiving a formal diagnosis of dementia can be upsetting. Diagnosis is vital because whilst there is currently no cure, there is treatment available to improve symptoms.

Getting an early diagnosis of dementia enables people to:

- Gain access to information, resources and support
- Demystify and de-stigmatise the condition
- Maximise the quality of their lives
- Benefit from treatments
- Plan for the future
- Explain to family, friends and colleagues what has changed in their life and what their wishes for the future are

Getting an accurate diagnosis of dementia can take a very long time for younger people, often due to lack of awareness that dementia can happen to younger people. Medical professionals often misdiagnose younger people as being depressed, experiencing relationship difficulties, suffering from the effects of stress or, for women, it may be put down to the onset of the menopause.

Learning disabilities

Down's syndrome is the most common known cause of learning disability and people with Down's syndrome are at particular risk of developing dementia.

Dementia generally affects people with learning disabilities in similar ways to people without a learning disability, but there are some important differences. People with a learning disability who develop dementia may show different early symptoms, for example, changes in behaviour or personality are more often reported as an early symptom of Alzheimer's than memory loss. In addition epilepsy that appears in someone with Down's syndrome later in life is almost always a sign of dementia. People with Down's Syndrome are therefore less likely to receive a correct or early diagnosis as behaviour and difficulties are often attributed to the learning disability.

³⁷ www.alzheimers.org.uk/statistics 2013

In addition, some people with a learning disability may experience a more rapid deterioration in memory and cognitive function. 1 in 3 people with Down's syndrome develop dementia in their 50s³⁸. However, people with a learning disability are more likely to already live with some support which can be adapted and may have developed alternative/ additional ways of communicating which may be helpful when dementia progresses.

There is no definitive record of the number of people with learning disabilities in England. However, it is estimated that in 2011 in England, there were 1,191,000 people with a learning disability which is 2.2% of the population³⁹. Down's syndrome is one of the most common genetic causes of learning disability; 15-20% of people with a learning disability have Down's Syndrome⁴⁰.

Gender

In the UK, 61% of people with dementia are female and 39% are male. This is mostly because women tend to live longer than men and dementia becomes more common as people get older⁴¹.

Age

Age is the most significant risk factor for developing dementia. The prevalence rates for dementia in the UK are:

- 40-64 years: 1 in 1400
- 65-69 years: 1 in 100
- 70-79 years: 1 in 25
- 80+ years: 1 in 6
- 90+ years: 1 in 3⁴²

There are more than 17,000 younger people (aged under 65) with dementia in the UK. However, this number is likely to be an under-estimate, and the true figure may be up to three times higher. Data on the numbers of people with young-onset dementia are based on referrals to services, but not all those with young-onset dementia seek help in an early stage of the disease.⁴³ Encouraging people to visit their GP as soon as they have concerns about their memory has been identified in this strategy as a priority.

³⁸ http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 2013

³⁹ <http://www.arcuk.org.uk/membersarea/wp-content/uploads/2012/05/IHAL-PWLD-England-2011.pdf>

⁴⁰ Pulsifier, M.B. (1996). The neuropsychology of mental retardation. *Journal of the International Neuropsychological Society*, 2, 159–176.

⁴¹ <http://www.alzheimersresearchuk.org/dementiaFAQ>

⁴² www.alzheimers.org.uk/statistics 2013

⁴³ http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

Hospital

At any one time, a quarter of people staying in hospital beds are people with dementia aged over 65⁴⁴.

Minority Ethnic Communities

There are over 11,500 people diagnosed with dementia from black and minority ethnic groups in the UK.⁴⁵ This is 1.4% of the total number of people estimated to have dementia. Lower levels of awareness about dementia and the existence of stigma within BME communities help explain why BME people are currently under-represented in dementia diagnosis figures.

Care Homes

Two thirds of people with a diagnosis of dementia live in the community while one third live in a care home⁴⁶. 80% of people living in care homes have a form of dementia or severe memory problems.⁴⁷

⁴⁴ Counting the Cost. Alzheimer's Society. 2009.

⁴⁵ www.alzheimers.org.uk/statistics 2013

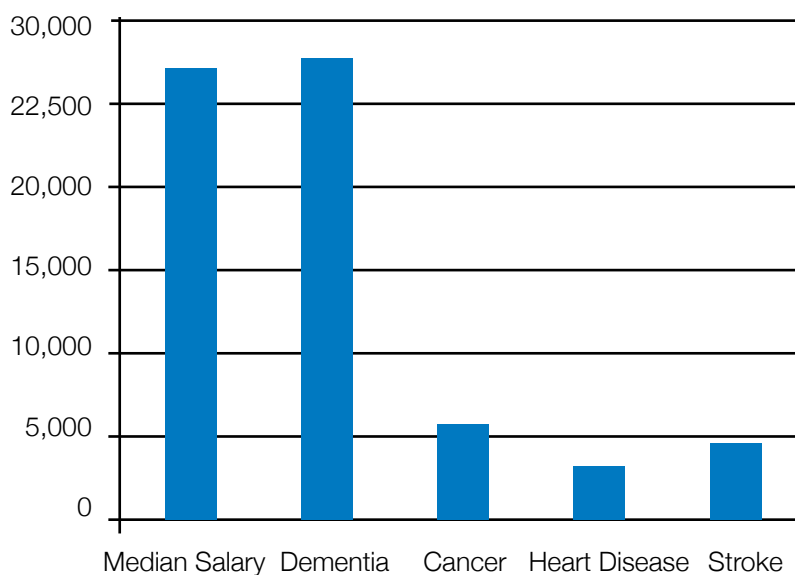
⁴⁶ www.alzheimers.org.uk/statistics 2013

⁴⁷ www.alzheimers.org.uk/statistics 2013

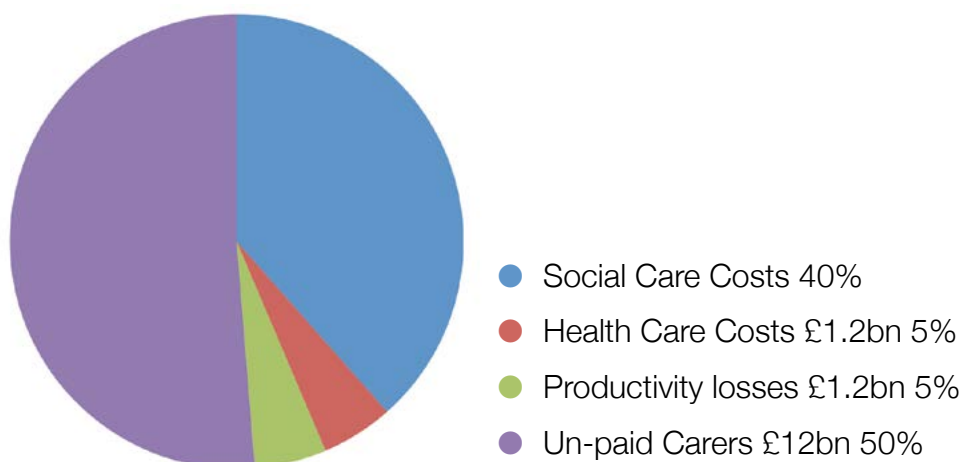
Research

Government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, which just £50million is invested in dementia research⁴⁸.

However the expense to the UK economy of each person with dementia is £27,647 per year; more than the UK median salary (£24,700). By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year⁴⁹. Most of the cost of providing support for people with dementia in the UK (£12.4 billion every year) is met by unpaid carers⁵⁰.



Dementia costs the UK economy £23.4 billion every year. How the expense to the UK economy is met is shown in the diagram below:



Carers

There are 670,000 carers of people with dementia in the UK⁵¹. These unpaid carers save the UK economy £12bn every year⁵².

⁴⁸ <http://www.alzheimersresearchuk.org/dementia-statistics/>

⁴⁹ 'Dementia 2010' Alzheimer's Research Trust

⁵⁰ 'Dementia 2010' Alzheimer's Research Trust

⁵¹ www.alzheimers.org.uk/statistics 2013

⁵² www.alzheimers.org.uk/statistics 2013

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Nepali

यस प्रचारको सक्षेप वा सार निचोड चाहिं दिइने छ ठूलो अक्षरमा, ब्रेल वा क्यासेट सून्नको लागी । अरु भाषाको नक्कल पनि हासिल गर्न सकिने छ । कृपया सम्पर्क गनुहोला ०१३४४ ३५२००० ।

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