Croydon Joint Strategic Needs Assessment 2011/12

Key Topic 3: Dementia

Lead Author

Bernadette Alves (Locum Consultant in Public Health)

Co-authors and those who have made a significant contribution.

Anne Mbonu, Barbara Jesson, Jan Saines, Jason Parsons, Nerissa Santimano, Rachel Nicholson, Sara Corben.

croydonvoluntaryaction celebrating 100 years

Shadow Healthwatch Croydon

CROYDON www.croydon.gov.uk

NHS South West London Croydon Borough Team

Contents

1 Executive summary

- This needs assessment on dementia is the third and final 'deep dive' topic forming part of the 2011/12 Joint Strategic Needs Assessment in Croydon.
- It is structured around the following framework, based on the government's dementia priorities:
    - **Early diagnosis** and interventions
    - Better **care at home** or care home
    - Better **care in hospital**
    - Appropriate use of **antipsychotic medication**
    - The underpinning theme of support for **carers**

What is dementia?

- Dementia describes illnesses such as Alzheimer's disease and vascular dementia that involve a loss of brain function, such as memory and communication. Symptoms get worse and are eventually severe. People can die from dementia, although they usually live for many years.
- Dementia is more common in older people, those with a family history of dementia, smokers, those with poor heart health and some other health conditions. It is much more common in people with learning disabilities. One third of people with dementia live in care homes.
- Dementia is a devastating illness, not just for the person with dementia, but for their families and carers.
- Carers play a central role and may themselves have health problems and experience financial difficulties because of the burden of caring.
- Dementia is common, expensive and growing. There are an estimated 750,000 people with dementia in the UK – mostly female and the numbers are set to double in the next 30 years
- Dementia costs the UK around £17 billion per year and costs are expected to triple over the next 30 years.

Dementia in Croydon

- Compared to other London boroughs, Croydon has a population with higher need and this need will grow over the coming decades. It has and will have very large numbers of people aged 65+ with dementia, people in care homes, people living alone and people providing unpaid care.

- The numbers of people aged 65+ living in Croydon is expected to rise by 14% by 2021. The older BAME (Black, Asian and Minority Ethnic) population will grow over 20 times more than the white population.
- There are around 3,300 people with dementia in Croydon, with a rise to over 4,500 predicted by 2025. Approximately two thirds are female.
- There are around 5,000 carers aged 65+ in Croydon and this is expected to rise to over 7,000 by 2030. There are approximately 1,100 carers in contact with Croydon adult social services - about a quarter care for someone with dementia.
- Less than 1 in 20 deaths in Croydon were caused by dementia. Taking account of the increased risk of death associated with dementia, the deaths attributable to dementia are estimated at between 1 in 7 and 1 in 10.

Services for dementia in Croydon

- There are a wide range and number of dementia services in Croydon, covering all aspects of the pathway, from concerns about memory, through diagnosis, living with dementia, coping with crises and end of life.
- Services are provided by health, social care, the voluntary and private sectors. Some, such as primary care, span the whole pathway.
- Croydon spends less on primary care medication for dementia than any other London Borough.

Early diagnosis

- Early diagnosis and intervention improves quality of life, reduces behavioural problems and delays or prevents unnecessary admissions into care homes and hospital.
- The Croydon memory service assesses and diagnoses dementia where appropriate. Numbers seen by the service are growing, and the service is widely recognised as a highly innovative and effective service.
- Only two fifths (43%) of people with dementia receive a diagnosis in Croydon. This is similar to the London average. In primary care, there is a tenfold variation in the proportion of people with a diagnosis of dementia.
- In primary care, people from Asian groups are 60% less likely to have a diagnosis of dementia than the white British population. This needs exploring as it may be a sign of inequality of access. The older BAME population is set to grow faster than the older white population over the next few years.

Care at home and in care homes

- Croydon has more care homes than any other London borough. It has approximately 180 care homes of which half completely or partly specialise in care of people aged over 65 or people with dementia.

- People with dementia can live with the condition for seven to twelve years after diagnosis. The support that they and their carers need will change and become more complex and the system can be difficult to navigate.
- The physical and mental health needs of people with dementia and their carers should be reviewed annually in primary care. Compared to London, general practices in Croydon are less good at doing this. In the poorer performing practices, less than two thirds of people receive a review.
- Croydon social care does not currently have a comprehensive list of people with dementia. Some people receiving social care have a diagnosis of dementia that is not known to the people providing social care. This limits our understanding of social care support provided and our ability to plan services.
- Half of the people in contact with the older adult Community Mental Health Team (CMHT) service have a primary diagnosis of dementia. This group stays with the team longer.

Care in hospital

- Dementia is much more common in general hospitals than in the community. An estimated 30% of older people in general hospital have dementia. People with dementia in general hospitals have worse outcomes – they stay in hospital longer, are more likely to die and are more likely to be discharged to a care home.
- In caring for people in hospital who have dementia, there are low levels of performance across the whole country: no hospitals are meeting all of the essential standards. Croydon's performance is about average for London and slightly worse than England.
- Whilst there are specialist services in Croydon University Hospital (CUH), the fact that dementia is so common in hospital means that care of people with dementia in hospital should not be a specialist skill.
- Recording of dementia as a secondary diagnosis in CUH is low. One in 20 admissions in people aged 65+ has dementia as a secondary diagnosis, approximately one sixth of the expected figure.
- CUH guidelines suggest that on admission, all inpatients should be assessed for confusion, delirium and cognitive impairment so that everyone can receive the right support even if they do not have a diagnosis of dementia

Antipsychotic prescribing

- Antipsychotic medication can help treat behavioural and psychological symptoms in people with dementia. However, it can cause harm and is sometimes given inappropriately. Nationally there are an estimated 1,800 excess deaths and 1,620 extra strokes each year because of antipsychotics.
- Croydon has relatively low levels of antipsychotic prescribing, estimated at 12% (in 2012) compared to the national figure of 25% (in 2009). A prescribing audit is underway that will give us a better understanding and more accurate figures.

- Croydon has piloted a care home Local Enhanced Service that stopped or reduced the dose of antipsychotics in almost half of people reviewed although not all care homes were involved. Croydon also provides training to GPs and to staff in care homes.

Views of stakeholders

- Many of the services that Croydon provides are good and are recognised as being assets in dementia care. Stakeholders identified the following priorities to improve dementia care in Croydon:
    - Integrated pathways of care, from early detection through to end of life, across health, social care and the voluntary sector, with the needs of people with dementia and their carers at the centre
    - Comprehensive accessible information for everyone, potentially using a single point of access
    - Better ways for people with dementia and their carers to navigate through the system
    - A focus on outcomes, based on the experiences of people with dementia and their carers
    - Greater recognition and support for carers
    - Reduced fear and stigma of dementia
    - Improved dementia care in hospitals using successful models in other areas.

- Only a handful of Croydon services collect information routinely about the experience and views of people with dementia and their carers. Without the support of carers, health and social care services would be overwhelmed. Good support for carers can reduce or delay admission to care home.
- Compared to England, carers in Croydon report lower levels of satisfaction with the support they receive and are less likely to seek advice and information.

Cost

- The total annual cost to Croydon of people with dementia is estimated at £83 million.
- NHS Croydon spends about £10 million per year on people with “organic mental disorders”, some of whom will have dementia.
- Croydon council spends about £5.3 million on mental health for older people per year.

Key Recommendations

1. ***Services should be developed to meet future needs***. Need for dementia care in Croydon is higher and will continue to be higher than many other London boroughs over the next decade. There will be a relatively large number of older people from BAME (Black Asian Minority Ethnic) groups. Croydon should develop dementia services to meet the growing needs of its population.

2. ***The views of people with dementia and their carers should be used as outcome measures*** Croydon should collect and use the views and experience of people with dementia and their carers to develop services and measure their quality. All providers should capture the experiences of those who use their services in a systematic way and use them to develop and deliver services. Croydon should consider undertaking a survey of the views and experiences of people with dementia and their carers in Croydon

3. ***Support to carers should be increased*** Croydon should improve support to carers through regular assessment, information, advice, training, respite and peer support. Providers of dementia care should commit to greater engagement of people with dementia and their carers in an explicit and planned way to inform service provision, service development and decision making. Involvement should be on-going and meaningful.

4. ***The early diagnosis rate for dementia should be increased*** Only two fifths of people with dementia in Croydon have a diagnosis. Croydon should take steps to increase the proportion of people who receive a diagnosis, particularly in Asian communities.

5. ***The needs of people with dementia and their carers should be regularly reviewed*** Croydon should ensure that people with dementia and their carers have their mental and physical needs regularly assessed in primary care. Croydon should reduce primary care variation in the proportion of patients reviewed every year.

6. ***Services for dementia in Croydon should be integrated*** Croydon should develop clear pathways of care from early detection through to end of life across all agencies including health, social care and the voluntary sector. SDS (self-directed support) can help people with dementia and their carers to manage and personalise their support and Croydon should seek to improve the take up of SDS.

7. ***Access to information about services should be improved and navigation through services should be made easier*** Croydon should develop comprehensive accessible information for everyone: people with dementia, their carers, providers of care and those making referrals. Consider a single point of access to information to develop a shared understanding of what is on offer with a single phone number. Where possible, build on existing initiatives such as the Carer's hub. Bring together the many existing online directories of advice into a single website. Croydon should find ways to help people with dementia and their carers to navigate through the system and obtain the right support and care.

8. ***Awareness and skills of workforce should be increased*** Croydon should continue to provide training and support for people who work in primary care, secondary care, care home staff and other agencies.

9. ***Care for people with dementia in general hospitals should be improved*** Croydon should focus on audits, staff training, and promoting good practice across the Trust, discharge planning, use of specialist advice and closer working with other agencies.

10. ***Antipsychotic prescribing should be reduced*** Croydon should develop more non-drug interventions to help manage behavioural and psychological symptoms, provide on-going training for staff in primary care and care homes and continue to review regularly the medication of those prescribed antipsychotics.

11. ***Data quality should be improved*** Croydon should improve the information it holds about dementia care. For example, service providers should systematically collect information about dementia patient experience. The primary register of people with a diagnosis of dementia should be shared with social care. Carers' services should collect the condition of those who they are caring for.

12. ***Recommendations from this needs assessment should now be addressed in the forthcoming local dementia strategy*** Croydon should now ensure that the recommendations from this needs assessment are taken forward in the forthcoming strategy and that SMART (specific, measurable, achievable, realistic, and time-bound) targets and goals are developed to address the identified gaps and issues.

The data in this chapter was the most recent published data as at 31 March 2012. Readers should note that more up-to-date data may have been subsequently published, and are advised to refer to the source shown under figures or listed in the appendices for the chapter for the latest information.

2 Introduction

2.1 Aims of the needs assessment

The term 'dementia' refers to illnesses such as Alzheimer's disease that involve a loss of brain function. Dementia is a common, expensive and growing condition that is more common in older ages and has a major impact on sufferers, family and carers. For Croydon to provide good care for people with dementia there must be systematic, integrated and co-ordinated efforts from a number of different agencies including health, social care and the voluntary sector. Informal care from family and friends plays an important role in supporting people with dementia.

This needs assessment aims to provide an overview of current and future need, to identify assets and gaps in dementia care in Croydon, and to provide a firm basis for the development of the forthcoming local dementia strategy.

For a list of terms and definitions used in this chapter, including acronyms and ICD10 codes for dementia, please refer to Appendix 1.

2.2 Background

Support for people with dementia and their carers was chosen by the shadow Health and Wellbeing Board (HWBB) as one of three key topic areas for Croydon's 2011/12 Joint Strategic Needs Assessment (JSNA). JSNAs have been a statutory obligation of local Directors of Public Health, Children's Services and Adult Social Care since 2008, although local approaches vary greatly. More information on the Croydon approach to the JSNA can be found on the Croydon Observatory website.[1]

This topic was chosen for a number of reasons:

Dementia is common, expensive and growing.

Dementia affects a large proportion of people (1 in 14 of those aged 65+, 1 in 6 of those aged 80+) and numbers are increasing because the population is ageing. The number of people with dementia in Croydon is growing. Over the next 15 years, it is expected to increase by 37% from 3,300 (2011) to 4,500 (2025). Nationally, total costs for dementia care are estimated at £17 billion per annum and are set to treble over the next 30 years.[2] This scales down to approximately £83 million for Croydon.[3]

Early intervention is cost effective and improves quality of life.

Early diagnosis and support can reduce behavioural problems, improve quality of life and delay admission to a care home. Whilst diagnosis rates have improved in recent years, only two fifths of those with dementia receive a formal diagnosis or have contact with specialist services at any time in their illness.

[1] http://www.croydonobservatory.org/jsna/
[2] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London
[3] See Section 7 for details of Croydon estimate

There is variation in service provision in Croydon.

Some components of care for people with dementia in Croydon are very good. Croydon's memory service was the model adopted by the national strategy. However, there is some evidence that other components could be improved. This needs assessment is an opportunity to identify areas for improvement as well as assets and strengths.

Support to carers can improve quality of life and reduce admissions.

The impact of dementia on carers is vast. The burden of care increases and changes as the condition progresses and caring responsibilities can adversely affect the carer's health. Strong carer support is a factor in preventing admission to care homes and informal care by family members accounts for a third of the cost of dementia care.

Better planning can help to use limited resources effectively.

Dementia is a complicated and challenging condition involving significant levels of resource and staff time. As well as informal care by families, services are provided across all sectors: NHS, social care, the voluntary and private sectors. Reviewing dementia care provides an opportunity to identify broader health and social care issues in care for patients with long term conditions.

A local dementia strategy is in development.

The joint health and social care commissioners of mental health services for older people are committed to developing a dementia strategy for Croydon. The findings and recommendations that emerge from this needs assessment can be rapidly incorporated into setting strategic direction.

The Croydon 2010/11 JSNA chapter "Living well in Later Life" recommended that Croydon improves the prevention and early management of dementia and training for carers and staff and finds new ways of supporting carers.

Dementia is a national priority.

Dementia and the care of older people and carers was and is a priority for the previous and current government and it makes up two of four areas in the 2012/13 NHS Operating Framework for England highlighted as needing "particular attention". The current coalition government built on and developed the aims of the National Dementia Strategy[4] and the work on reducing antipsychotic use[5] in its outcomes focused implementation plans.[6]

Appendix 2 gives a brief timeline of a number of key documents setting out policy, identifying need and highlighting issues in quality of care.

[4] Department of Health (2009) *Living well with dementia: a National Dementia Strategy,* London: The Stationery Office

[5] Department of Health (2009) *The use of antipsychotic medication for people with dementia: Time for action,* London: The Stationery Office

[6] Department of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*. London: The Stationery Office

2.3 Stakeholder involvement in the Needs Assessment

Over the course of the production of this needs assessment, a wide range of individuals have been involved, and will need to be engaged further in the development of the dementia strategy. We would like to thank the JSNA Steering Group as a whole, people who attended the consultative meeting, members of the Health and Wellbeing Board and the following individuals in particular for their input and involvement in this needs assessment:

Individual	Organisation
Anesa Kritah	Strategic intelligence unit, Croydon Council
Anna D'Agostino	Croydon BME Forum
Anne Mbonu	Mental health commissioning, Croydon borough team, NHS South West London
Brenda Scanlan	Department for adult services, health and housing, Croydon Council
David Osborne	Public health, Croydon borough team, NHS South West London
Fiona Assaly	Public health, Croydon borough team, NHS South West London
John Haseler	Mental health commissioning, Croydon borough team, NHS South West London
Laura Jenner	Department for adult services, health and housing, Croydon Council
Rajeev Sagar	Croydon Clinical Commissioning Group
Selina Lim	Croydon University Hospital
Simon Cook	South London & Maudsley NHS Foundation Trust
Trevor Mosses	Department for adult services, health and housing, Croydon Council

Special thanks to Jenny Hacker, Public health, Croydon borough team, NHS South West London, as chapter editor.

2.4 Governance arrangements for forthcoming dementia strategy

This needs assessment will be made available following sign off by both the JSNA Steering Group and shadow Health and Wellbeing Board. The development of the subsequent dementia strategy will be led and overseen by the joint mental health commissioners in the local authority and NHS South West London Croydon Borough Team.

2.5 Priority framework areas

To help guide the development of both the needs assessment and the strategy, the four dementia priority areas identified by the current government were used as a framework.

1. Early diagnosis and interventions
2. Better care at home or care home
3. Better care in hospital
4. Appropriate use of antipsychotic medication

Support for carers is a further government priority that underpins all four themes and is considered in this needs assessment.

2.6 Purpose and scope of the Needs Assessment

This needs assessment aims to inform the development of the dementia strategy by addressing the following questions:

What is dementia and what is the level of current and future need?

Who is most at risk from dementia? What is the scale of the problem? How will it change? What is the relative current and future need? (Section 3)

What care is available and what is the quality of care provided for people with dementia and their carers?

What is the care pathway? What services are provided? How good is the care provided in Croydon and how does it compare to other areas? Are there any gaps? (Section 4)

What do stakeholders think are the strengths and weakness of services?

How well do we collect information about the experiences of people with dementia and their carers? What do people who provide care and people with dementia think are Croydon assets? What are we doing well? What could we be doing differently? (Section 6)

How much does Croydon spend on dementia? (Section 7)

What are our **key messages and recommendations** for the strategy team? (Section 8)

We captured the views of stakeholders through a consultative meeting held in early March 2012.

Summary sections are included at the end of every section.

2.7 Croydon policy context

Croydon's Older People's Strategy 2010-13 recognises the demographic changes occurring in Croydon. It focuses on supporting older people to live the best life they can, by enabling them to make personal choices about the health and social care they receive and how this is provided. The strategy indicates plans to utilise resources from a wider range of stakeholders and partners in order to provide choice and improve service quality. Its key priorities are to improve health and quality of life, improve independence, choice and control, to improve opportunities to make positive contributions, to ensure dignity, equality, respect and freedom from discrimination and to promote economic well-being.

Croydon's draft integrated carers' strategy of 2011-2016 is an update of the previous strategy of 2008-11. It is aligned with the current government's 2011 refresh of the

National Carers Strategy.[7] This draft strategy recognises the valuable input of carers and aims to support carers by providing information, support, advocacy and respite breaks as appropriate.

Summary of section 2: Introduction

- This needs assessment aims to provide an overview of current and future need, identify assets and gaps in dementia care in Croydon, and provide a firm basis for the forthcoming local dementia strategy.
- Support for people with dementia and their carers was chosen by the shadow Health and Wellbeing Board (HWBB) as one of three key topic areas for Croydon's 2011/12 Joint Strategic Needs Assessment (JSNA)
- To help guide the development of both the needs assessment and the strategy, the following framework was used based on the government's four dementia priorities:

  1. Early diagnosis and interventions
  2. Better care at home or care home
  3. Better care in hospital
  4. Appropriate use of antipsychotic medication

- Support for carers is a further government priority that underpins all four themes and is covered in this needs assessment.
- Views of stakeholders have been incorporated into this needs assessment.

[7] Department of Health (2010) *Recognised, valued and supported: next steps for the Carers Strategy.* London: The Stationery Office

3 Need

3.1 Overview of the condition

This section gives an overview of dementia nationally and draws in large part on a number of key documents, including the Dementia UK report[8] and the National Dementia Strategy.[9]

Dementia is a set of illnesses that have in common a loss of brain function that is usually progressive and eventually severe. Dementia is a terminal condition; however, people can live with it for seven to twelve years after diagnosis. Dementia is associated with:

- A decline in cognitive function - memory, reasoning and communication skills,
- A gradual loss of skills needed to carry out daily activities,
- Behavioural symptoms such as agitation, aggression, sleep disturbance, wandering and apathy,
- Psychological symptoms such as anxiety, depression, delusions and hallucinations.

Dementia can either have an early or late onset, and has several forms. Over 80% of dementia cases are one of the following:

- Alzheimer's disease - brain cells deteriorate through the build-up of a protein
- Vascular dementia - brain cells are damaged by repeated less of blood supply e.g. through strokes
- Mixed dementia - mixture of vascular and Alzheimer's

Rarer types include dementia with Lewy bodies, dementia in Parkinson's disease and Fronto-temporal dementia.

Early-onset dementia refers to those who develop dementia before the age of 65. The causes and characteristics of people with dementia differ between early and late-onset cases and they can benefit from different treatment approaches.[10]

Among those with *late onset dementia*, over half (55%) have mild dementia, one third (32%) have moderate dementia and 1 in 8 (13%) have severe dementia.

Those at higher risk

Many factors, including age, genetic background, medical history and lifestyle can combine to lead to the onset of dementia. It is not an inevitable part of aging; 70% of people aged over 90 do not have dementia. However, it is more common in older

[8] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London
[9] Department of Health (2009) *Living well with dementia: a National Dementia Strategy,* London: The Stationery Office
[10] NICE (2011) *Dementia,* Clinical Guidelines CG42

people.[11] One in 14 people aged 65+ has a form of dementia but this increases from 1.3% of those aged 65 to 69 (1 in 75) to 20% of those aged 85 to 89 (1 in 5) ; prevalence roughly doubling every five years over the age of 65.

The prevalence of dementia is higher still amongst older adults with learning disabilities compared to the general population. Over 1 in 5 people with learning disabilities aged 65+ are affected. People with Down's syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population.[12]

Men are more likely to have early-onset dementia than women. For older ages, women are slightly more likely to have late-onset dementia.

Mild cognitive impairment (MCI) is used to describe people who have some problems with their memory but do not have dementia. People with MCI are at higher risk of developing dementia - more than 50% later develop dementia.[13]

Prevention

Those with poorer heart health, including smokers, those with high blood pressure, high cholesterol and excessive alcohol consumption are more likely to have vascular dementia. Up to 50% of dementia cases may have a vascular component and this creates the possibility of preventing or minimising dementia by means of promoting better cerebrovascular health.

People with dementia – UK

There are over 750,000 people with dementia in the UK.

Because women have a longer life expectancy and higher prevalence rates at older ages, it is estimated that two thirds of people with dementia are women.

Early onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK.[14]

Two thirds (63.5%) of people with dementia live in private households (the community); the remaining third (36.5%) live in care homes.

Nationally, approximately half of those aged 65+ living in care homes have dementia and this rises to 80% of those living in EMI (elderly mentally infirm) homes.

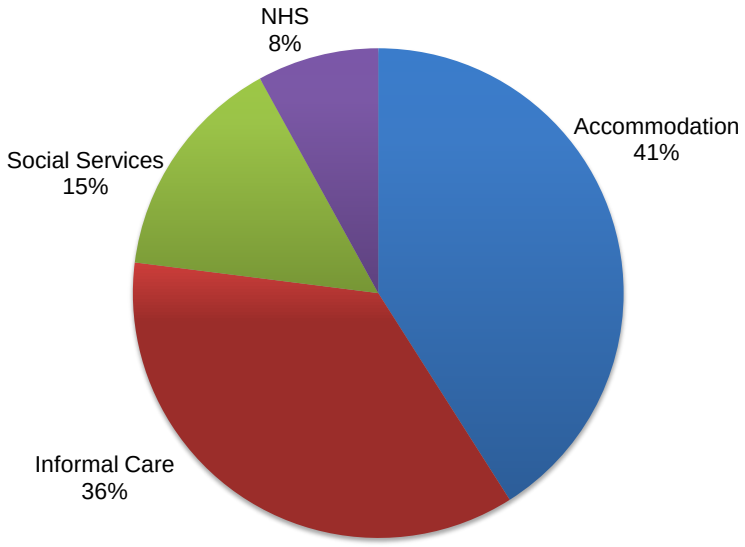
Cost

Dementia costs the UK £17 billion per annum, which is an average of £25,472 per person

[11] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London.
[12]Emerson E, Baines S et al (2011) *Health Inequalities & People with Learning Disabilities in the UK: 2011.* Improving Health and Lives: Learning Disabilities Observatory
[13] NICE (2011) Dementia, Clinical Guidelines CG42
[14]Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London

with late onset dementia.[15] The distribution of UK dementia service costs are shown in Figure 1.[16]

Figure 1 Distribution of costs of dementia services in the UK.



Source Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London

In Figure 1, 'accommodation' includes costs for people living in care homes, 'informal care' covers care provided by families to people with dementia costs, 'social services' includes packages such as home care, respite, carer support etc., and 'NHS' includes inpatient, outpatient, medication costs and so on.

National future numbers with dementia and future costs

The number of people with dementia in the UK is expected to double to 1.4 million in the next 30 years with dementia associated costs to the UK economy trebling from £17 billion a year to over £50 billion a year.

Impact on carers

The impact of dementia is vast. It can devastate families and have a serious impact on communities. Family carers are often old and frail themselves and have high levels of poor health. Carer health is affected by their caring role and can lead to tiredness, stress, disturbed sleep and feeling depressed.[17] Many carers also experience financial difficulties. Dementia is progressive and the carer burden changes and increases as the disease becomes more severe.

[15] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London.
[16] ibid
[17] Health and Social Care Information Centre (2010) *Personal Social Services Survey of Adult Carers in England - 2009-10.*

There is substantial tension regarding where dementia services should sit in relation to the boundary between NHS services (which is free at point of use) and social care (which is means-tested). This difference in funding can act as a barrier to integrated care that ensures that services are well co-ordinated around the needs of people with dementia and their carers.[18]

Summary of section 3.1: Need

- Dementia describes illnesses (such as Alzheimer's and vascular dementia) that involve a loss of brain functions such as memory and communication. People can also have behavioural and psychological symptoms such as agitation, aggression or depression and difficulties with activities like getting dressed.
- Dementia symptoms get worse and are eventually severe. One third of people with dementia live in care homes. People can die from dementia although they usually live for many years with the condition.
- It is more common in older people (1 in 75 in those aged 65 to 69, 1 in 5 in those aged 85 to 89). It is also more common in those with a family history of dementia, those who smoke, have poor heart health and some other health conditions. It is much more common in people with learning disabilities.
- Dementia is a devastating illness not just for the person with dementia but also their families and carers.
- Carers play a central role and may themselves have health problems and experience financial difficulties because of the burden of caring.
- Dementia is common, expensive and growing. There are an estimated 750,000 people with dementia in the UK – mostly female and the numbers are set to double in the next 30 years
- It costs the UK around £17 billion per year and costs are expected to triple over the next 30 years.

[18] The King's Fund and the Nuffield Trust (2012) *Integrated care for patients and populations: Improving outcomes by working together.*

3.2 Current and future need in Croydon

Croydon is the second largest borough in London and has an estimated resident population of 345,600[19]. It has 45,200[20] people aged 65+ and this represents a higher percentage of people aged 65+ (at 13%) than the London average (11.5%[21]). Between 2011 and 2021, the number of people aged 65+ is expected to increase by 14%. The largest increase is expected to be in BAME (Black, Asian and Minority Ethnic) groups. Over this time period, the white population is estimated to increase by 2% while the BAME population by 55%. (The Croydon 2011/12 JSNA Overview Chapter provides more details of predicted population changes).

There are an estimated 3,283 people living with dementia in Croydon (in 2011) and this is will rise by 37% to 4,507 by 2025 because the population is ageing. This increase will add pressure on services. Approximately two thirds (62%) are female (Table 1 and Figure 2)

Table 1 Estimated current and future numbers of dementia cases, by gender, Croydon 2011-2030

Females

	Year	2011	2015	2020	2025	2030
Croydon	Population (65 years or older)	25,200	26,900	28,600	31,500	35,900
	Dementia Cases	2,033	2,144	2,362	2,670	3,042
	Crude Rate per 1,000	80.7	79.7	82.6	84.8	84.7
England	Population	4,871,400	5,331,100	5,747,200	6,278,300	6,985,500
	Dementia Cases	405,221	435,015	486,808	561,635	652,634
	Crude Rate per 1,000	83.2	81.6	84.7	89.5	93.4

Males

	Year	2011	2015	2020	2025	2030
Croydon	Population (65 years or older)	20,200	22,000	23,500	26,300	29,700
	Dementia Cases	1,250	1,407	1,592	1,837	2,153
	Crude Rate per 1,000	61.9	64.0	67.7	69.8	72.5
England	Population	3,885,000	4,391,600	4,829,400	5,335,600	5,952,900
	Dementia Cases	223,603	257,216	306,571	365,029	431,735
	Crude Rate per 1,000	57.6	58.6	63.5	68.4	72.5

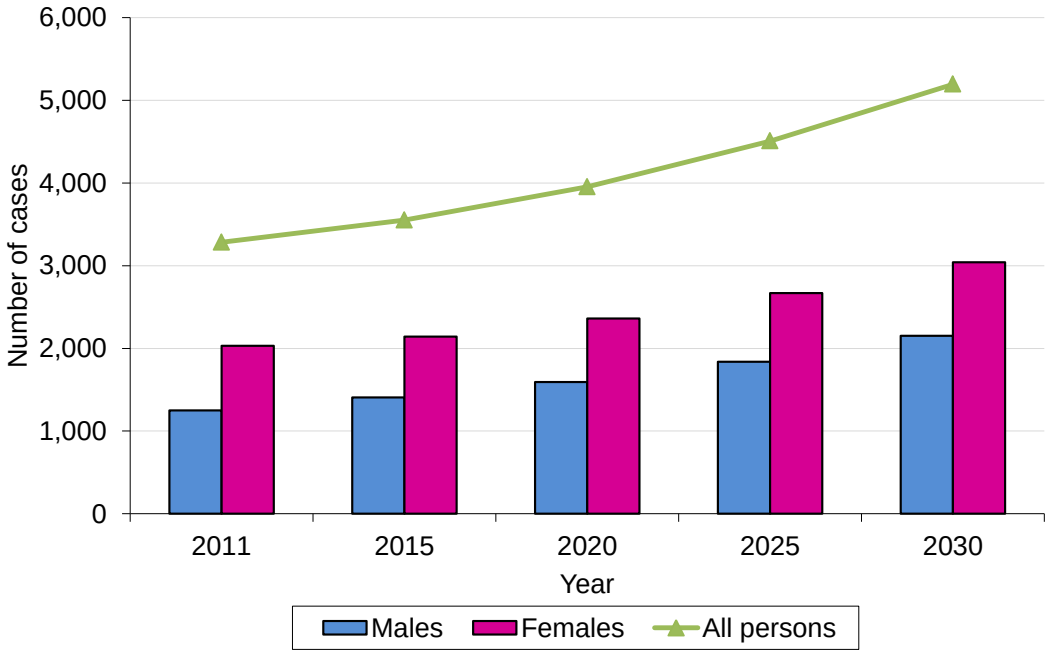
Total estimated future cases of dementia

Year	2011	2015	2020	2025	2030
Croydon	3,283	3,551	3,954	4,507	5,195
England	628,824	692,231	793,379	926,664	1,084,369

Source: Projecting Older People Population Information System (POPPI)

[19] ONS mid-2010 estimates
[20] Office for National Statistics, Mid-2010 population estimates
[21] Greater London Authority, population estimates and projections, 2009

Figure 2 Estimated future numbers of dementia cases, by gender, Croydon 2011-2030



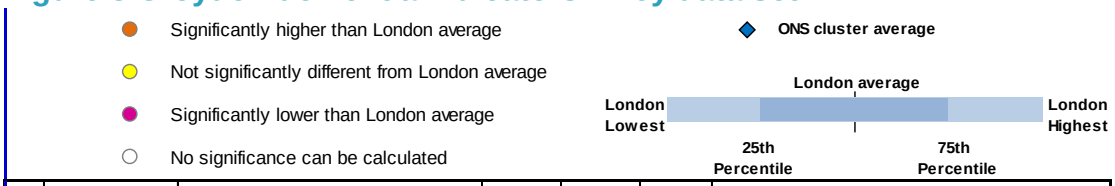
Source: Projecting Older People Population Information System (POPPI)

The key dataset in Figure 3 shows how Croydon compares with the rest of London for a range of indicators relevant to dementia. Note that this dataset compares with London averages rather than England averages that are used in the Overview chapter. At the time of this deep-dive, data for all England PCTs or Local Authorities was unavailable for some indicators; hence the decision was made to compare Croydon with PCTs and Local Authorities within London. It is also important to note that the dementia dataset, which incorporates indicators included in the London needs assessment[22] , includes mainly descriptive data. For this reason, the dataset has not been 'RAG rated'[23] in the same way as we the key dataset for the Overview Chapter of the JSNA. Those indicators which could be linked to performance, mainly Rate of diagnosis (indicator 7) and Patients reviewed in the last 15 months (indicator 8) are considered in more depth in sections 4.3 and 4.4.

Croydon's result for each indicator is shown as a circle. The average for London is shown by the black line at the centre of the chart while the average for Croydon's ONS statistical neighbours is shown by the blue diamond. The range of results for all local areas in London is shown as a blue bar. An orange circle means that Croydon is significantly higher than London for that indicator; while a pink circle means that Croydon is significantly lower than London. Either position could have importance to public health and dementia care.

[22] NHS London (2011) London Dementia Need Assessment 2011
[23] For RAG ratings, red indicates an area of concern, green indicators an area of no concern

Figure 3 Croydon dementia indicators – key data set



	Domain	Indicator	Croydon	ONS Cluster	London	London Range
Population	Population aged 65+	1. Proportion of population aged 65+	13.1%	12.2%	11.5%	
		2. Population aged 65+ from BAME groups	21.4%	19.3%	20.2%	
		3. Projected population aged 65+ from BAME groups 2021	29.2%	26.8%	26.5%	
		4. Increase in people aged 65+ living alone, 2011-2030	44.1%	33.5%	34.1%	
Population with dementia	Estimated numbers with dementia	5. People aged 65+ with late onset dementia	7.2%	7.4%	7.3%	
		6. Projected increase in dementia patients	23.4%	19.1%	15.9%	
	Diagnosis, Reviews and Costs	7. Rate of diagnosis	41.4%	42.5%	41.1%	
		8. Patients reviewed in the last 15 months	77.8%	80.2%	79.9%	
		9. Cost of prescribing	£13	£122	£121	
	Care at home or care homes	10. Dementia places in care homes	17	19	14	
		11. Increase in people aged 65+ in care homes	57.2%	45.8%	48.2%	
		12. Increase in people aged 65+ providing unpaid care	42.2%	34.9%	35.1%	
		13. Residents aged 65+ supported to live in mental health care homes	315.0	561.7	525.0	
		14. Residents aged 65+ supported to live in care homes	1525.0	1726.7	1935.0	
	Utilisation of Social Services	15. New mental health assessments for people aged 65+	21.4%	-	7.3%	
		16. Social care users for mental health	26.7%	-	21.7%	
		17. Social care users for dementia	5.1%	-	10.5%	
	Utilisation of Hospital Services	18. Hospital admissions rate for primary diagnosis of dementia	27.3	37.3	50.3	
		19. Inpatient admissions rate for any diagnosis of dementia	698.1	676.1	716.7	
		20. Psychiatric patient spells as a proportion of dementia prevalence	22.2%	13.8%	11.8%	

Source: see Appendix 3 for footnotes on data sources.

Figure 3 shows that, compared to London, Croydon has larger numbers of people aged 65+ (indicator 1) and aged 65+ from a minority ethnic group (indicator 2) and that need is growing more quickly in Croydon than in London. Compared to London, Croydon has larger projected increases in numbers of people with dementia (indicator 6), people aged 65+ in care homes (indicator 11), people aged 65+ providing unpaid care (indicator 12) and people aged 65+ living alone (indicator 4).

Compared to London, general practices in Croydon are less good at regularly reviewing the mental and physical health needs of people with dementia and their carers (indicator 8). In Croydon, 78% of patients with dementia are reviewed annually, compared to 80% in London. This difference is statistically significantly different.

The cost of primary care anti-dementia prescribing in Croydon (indicator 9) is the lowest in London. This may reflect good prescribing practice, but may also reflect high levels of

prescribing within secondary care. This would merit further exploration given the huge variation from the London average. NICE guidance on drugs for people with Alzheimer's was changed in 2011 and is now recommended as for a larger group of patients.[24]

The number of social care users recorded as having a diagnosis of dementia compared to the estimated prevalence of dementia is poor in London and very poor in Croydon. This figure is borne out by local data analysis described in section 4.4.2.

Among London's 33 local authorities, Croydon is expected to have:[25]

- the 3rd highest number of people aged 65+ in care homes by 2030,
- the 3rd highest number of people aged 65+ providing unpaid care by 2030,
- the 8th highest increase in the number of people from BAME groups with dementia by 2021.

Among London's 31 PCTs, Croydon: [26]

- has the 4th highest number of people aged 65+ with dementia
- is expected to have the 6th highest increase in the number of people aged 65+ living alone by 2030,
- will have the 4th highest number of people aged 65+ with late onset dementia

Croydon Carer needs

There are 30,000 people in Croydon who were providing regular unpaid care for family members or friends who are sick, frail or disabled according to the 2001 census. More recent POPPI (Projecting Older People Population Information) estimates suggest that in 2011, there were 5,000 older carers (aged 65+) and that by 2030 this will rise to 7,127.

There are approximately 1,100 carers in contact with Croydon adult social care services.[27] Based on a national survey of carers in contact with adult social services, approximately one quarter of these carers are looking after someone with dementia[28].

[24] NICE (2011) Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease. Technology Appraisal 217
[25] Based on NHS London (2011) London Dementia Needs Assessment 2011, updated with more recent figures where available
[26] ibid
[27] Croydon Council SWIFT system 2010/2011
[28] Health and Social Care Information Centre (2010) Personal Social Services Survey of Adult Carers in England - 2009-10

Mortality in Croydon

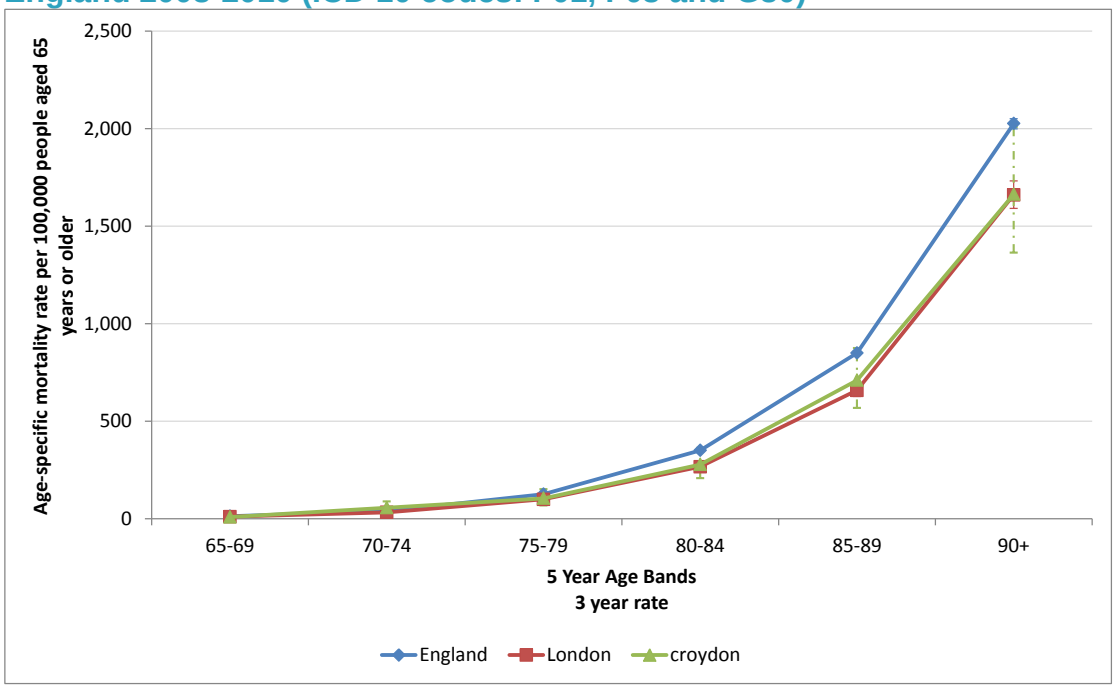
Dementia shortens the lives of those who develop the condition. It is difficult to assess the contribution of dementia to mortality because people with dementia often have other health conditions that may or may not be related to the dementia process, and which themselves may hasten death.

Although death certificates are acknowledged to be an imperfect source of information on dementia-related mortality, over the three years 2008-2010, less than 1 in 20 deaths (4.1%) in Croydon were caused by dementia (303 of 7,328 deaths). There was a slighter higher proportion in women (5.4%) than in men (2.7%).[29] Figure 4 shows that at older ages, the rate of mortality from dementia increases sharply.

Taking account of the increased risk of death associated with dementia, it is estimated nationally that in people aged over 65, 10% of deaths in men and 15% of deaths in women are attributable to dementia.[30]

This means that the proportion of deaths attributable to dementia in Croydon is approximately three times higher than deaths caused by dementia.

Figure 4 Mortality from Dementia (in people aged 65+), Croydon, London and England 2008-2010 (ICD 10 codes: F01, F03 and G30)



Source: Office for National Statistics, Vital Statistics, 2008-2010

[29] Mortality from dementia based on ICD codes F01, F03 and G30

[30] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London

Summary of section 3.2: Current and future need in Croydon

- Croydon is the second largest London Borough. Compared to other London boroughs, Croydon has a population with higher need and this need will grow over the coming decades. It has and will have very large numbers of people aged 65+ with dementia, people in care homes, people living alone and people providing unpaid care.
- The numbers of people aged 65+ living in Croydon will rise by 14% by 2021. The older BAME (Black, Asian and Minority Ethnic) population will grow over 20 times more than the white population.
- There are around 3,300 people with dementia in Croydon and this is predicted to rise to over 4,500 by 2025. Approximately two thirds are female.
- There are around 5,000 carers aged 65+ in Croydon and this will rise to over 7,100 by 2030. Not all carers look after someone with dementia. There are approximately 1,100 carers in contact with Croydon adult social services - about a quarter care for someone with dementia
- Compared to London, general practices in Croydon are less good at reviewing the mental and physical health needs of people with dementia and their carers on a yearly basis.
- Croydon spends less on primary care medication for dementia than any other London Borough.
- Less than 1 in 20 deaths (4.1%) in Croydon were caused by dementia. Taking account of the increased risk of death associated with dementia, the deaths attributable to dementia is estimated at between 1 in 7 and 1 in 10 (10% to 15%).

4 Services

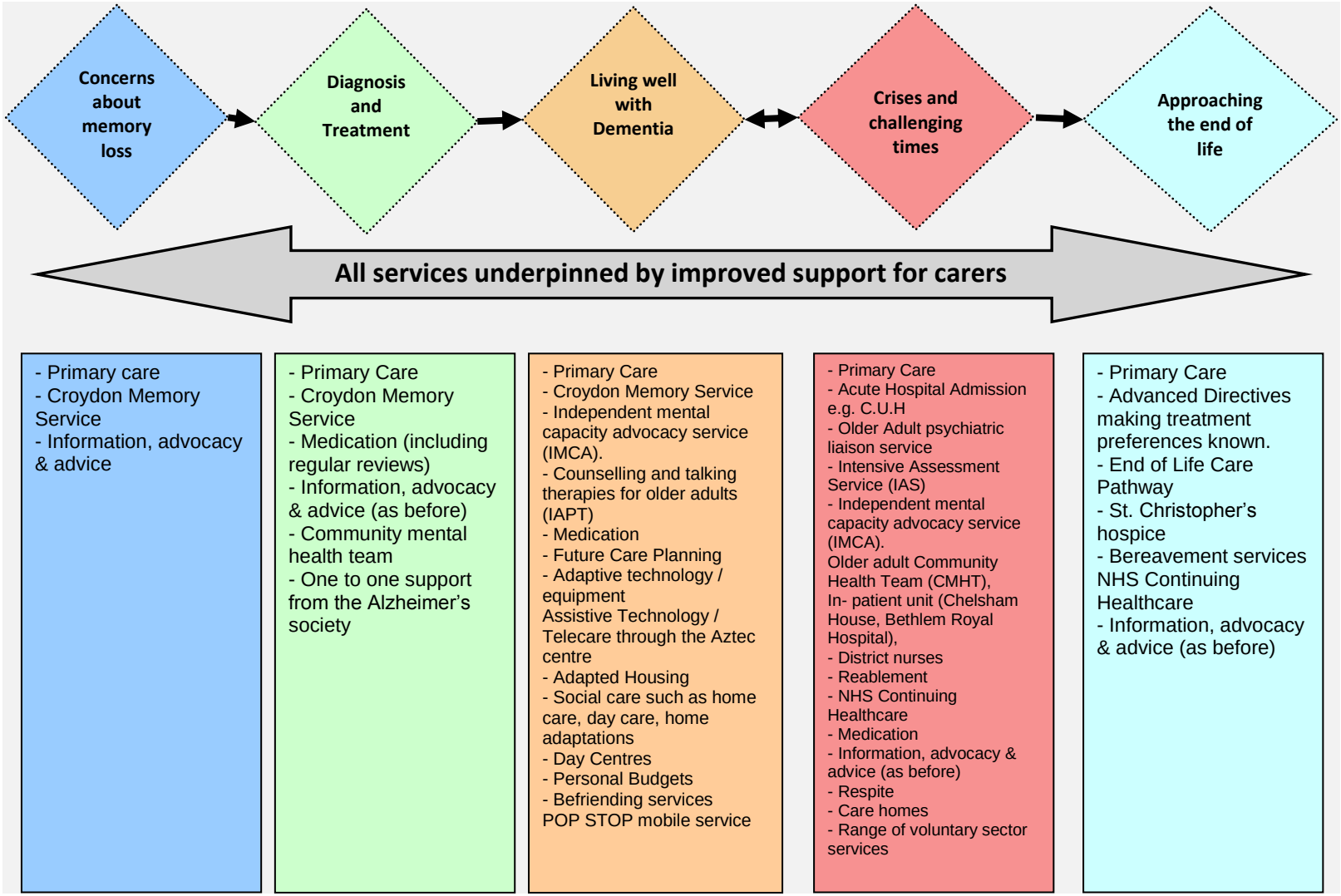
4.1 Pathway

There are a wide range of services for people with dementia and their carers in Croydon. The main services are shown in Figure 5, the Croydon dementia care pathway. This pathway covers care from concerns about memory, through diagnosis and early intervention, living with dementia, coping with crises and end of life. Services are provided by different agencies including health, social care, voluntary sector and the private sector, some are specialist, i.e. aimed specifically at dementia sufferers, and others are more general. Services (such as primary care and some voluntary sector services) span the whole pathway; others support individuals at particular moments. Alongside the journey of the person with dementia runs the journey of the carer. Most of these services are commissioned by Croydon Local Authority and NHS South West London, Croydon Borough Team. Main providers are listed below:

- Primary care services provided by GP practices
- The South London and Maudsley Foundation NHS Trust (SLaM), which provides:
    - Croydon Memory Service
    - Older Adult Community Mental Health Teams (CMHT)
    - Mental Health of Older Adults (MHOA) Psychiatric Liaison Service operating at Croydon University Hospital
    - Acute in patient unit based at Chelsham House, Bethlem Royal Hospital
    - A pilot Intensive Assessment Service (IAS) based at Greenvale – on-going provision is subject to uptake. The findings of the pilot are being evaluated.
    - Continuing Care Unit, Streatham
- Croydon Health Services – Croydon University Hospital (Acute General Hospital) provides acute hospital care – for some specialties, it is estimated that up to 35% of beds are occupied by people with dementia
- Voluntary sector organisations provide information, advocacy, advice and one to one support and include: Alzheimer's society, Age UK, Croydon Neighbourhood Care Association (CNCA), Partnership for Older People (POP) service, the Older People's Network and the carer's information service
- Independent Sector organisations that provide home care packages, respite care and long and short term care through nursing and residential homes.

Appendix 4 has a fuller description of services currently available for people with dementia in Croydon.

Figure 5 – Pathway of Croydon dementia services



4.2 Quality of services

One of the challenges in assessing the strengths and weaknesses of support for people with dementia and their carers is the range and complexity of the services making up the care pathway and the variation in the information that is readily available about them.

For some services, such as aspects of primary care, Croydon can be compared directly with other areas because there is a national framework for assessing quality known as QOF (the quality and outcomes framework). For many services there are no nationally comparable indicators of care quality. This section therefore uses data from a range of different information sources to highlight gaps and assets in dementia care in Croydon.

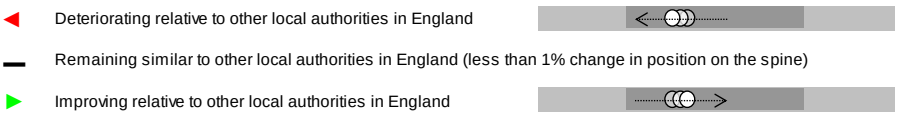
Figure 6 below shows sections of the 2011/12 JSNA Croydon Key Dataset of relevance to dementia and its care. (For the complete dataset and further information on its interpretation please see the Croydon 2011/12 JSNA Overview chapter at: Croydon Observatory: JSNA 2011/12 Overview Chapter). Figure 6 shows that Croydon performed less well compared to London in a number of areas, including the proportion of social care clients receiving self-directed support and proportion of carers receiving advice and information.

Figures for 2010/11 show that the proportion of clients receiving self-directed support had steadily increased over the year, and stood at more than 20% at year end. The (unconfirmed) figure for 2011/12 shows a further increase, with 47% in receipt of SDS at year end. This is a significant improvement from the previous year.

In terms of advice and support to carers, numbers have increased slightly since the Overview Chapter, though these are still below the London average. All carers are currently being identified and assessed with the option of offering them an enhanced assessment. Croydon has also launched an enhanced website, signposting people to resources across the borough, and have set up CroyCare, which is an emergency service for carers.

Figure 6 Extract of Croydon Key Dataset from JSNA 2011/12 Overview chapter.

The final two columns shown the direction of travel over one and three years, where data is available.



Domain	Indicator	Croydon	London	England	England Range	1 Year Trend	3 Year Trend
‘Community Life’							
Social care	14 Timeliness of social care assessment	94.0%	87.9%	81.3%		◀	▶
	15 Timeliness of social care assessment packages	98.0%	90.4%	90.5%		▶	▶
	16 Social care clients receiving Self Directed Support	5.9%	13.4%	13.0%		◀	◀
	17 People supported to live independently through social services	4062	3230	3067		▶	▶
	18 Delayed transfers of care	7.9	9.9	12.9		◀	▶
	19 Social care-related quality of life	18.3	18.0	18.7		no data	no data
	20 User reported measure of respect and dignity in their treatment	83.7%	81.9%	87.0%		no data	no data
Carer support	21 Carers receiving advice and information	12.7%	24.6%	26.4%		◀	◀
‘Later Life’							
Poverty	82 Older people in poverty	20.6%	27.0%	20.6%		no data	◀
Satisfaction with local area	83 Older people's satisfaction with home and neighbourhood	77.2%	77.1%	83.9%		no data	no data
Vaccination	84 Uptake rate for flu jab (ages over 65)	67.2%	71.4%	72.8%		◀	◀
Falls	85 Admissions for hip fracture (ages over 65)	403.8	443.8	457.6		▶	no data
Social care	86 Permanent admissions to residential and nursing homes	0.70	1.05	1.60		◀	▶
	87 Achieving independence through rehabilitation/intermediate care	65.3%	81.4%	81.2%		▶	no data
	88 Support for older people to live independently at home	23.6%	23.3%	30.0%		no data	no data

Source: Croydon JSNA 2011/12 Overview chapter

Information in the rest of this section is presented by the four national dementia priorities areas. Table 2 below shows how they map onto the dementia care pathway shown in Figure 5.

Table 2 National dementia priority areas and dementia pathway areas

National priority	Pathway
1. Early diagnosis and interventions	Concerns about memory, diagnosis and treatment
2. Better care at home or care home	Living well with dementia
3. Better care in hospital;	Crisis and challenging times
4. Appropriate use of antipsychotic medication.	Runs throughout the pathway although more often prescribed in those living in care homes.

Summary of section 4.1 and 4.2: Pathway and Quality of services

- There are a very wide range and number of dementia services covering all aspects of the care pathway, from concerns about memory, through diagnosis, living with dementia, coping with crises and end of life.
- Services are provided by health, social care, voluntary sector and private sector. Some span the whole pathway such as primary care and some voluntary sector services.
- The complexity of the services making up the care pathway and the variation in the information that is readily available about them present challenges in assessing the strengths and weaknesses of support for people with dementia and their carers.
- For some services, such as aspects of primary care, Croydon can be compared directly with other areas because there is a national framework for assessing quality known as QOF (the quality and outcomes framework). For many services, there are no nationally comparable indicators of care quality.
- This section therefore uses data from a range of different information sources to highlight gaps and assets in dementia care in Croydon.
- Croydon performs less well compared to London in a number of areas including the proportion of social care clients receiving self-directed support and proportion of carers receiving advice and information.

4.3 Early Diagnosis and interventions

The national dementia strategy points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes and hospital. People with concerns about poor memory should be referred by their GP to a memory service for assessment, diagnosis and treatment. Once diagnosed, people with dementia can access specialist services so they and their carers can plan for their future.

Memory Service

The Croydon memory service supports early intervention and management of dementia. It provides an assessment of an individual's memory capabilities to make a diagnosis accurately and quickly. If appropriate, the patient is then offered medical treatment and a range of therapies to help minimize the problems their poor memory causes. It is widely recognised as a highly innovative and successful service. It has attracted international awards[31] and has informed the National Dementia Strategy. The service has shown reduced behavioural disturbances and increased quality of life.[32] The National 2009-10 MSNAP (Memory Services National Accreditation Programme) report found that of the 25 services around the country that submitted full data, Croydon met more of its quality standards than any other service.[33]

Figure 7 shows that referrals have increased steadily between 2003 and 2011 from an average of 15 people per month in 2003 to 63 per month in 2011. However, waiting times from referral to assessment has remained low at an average of eight weeks.

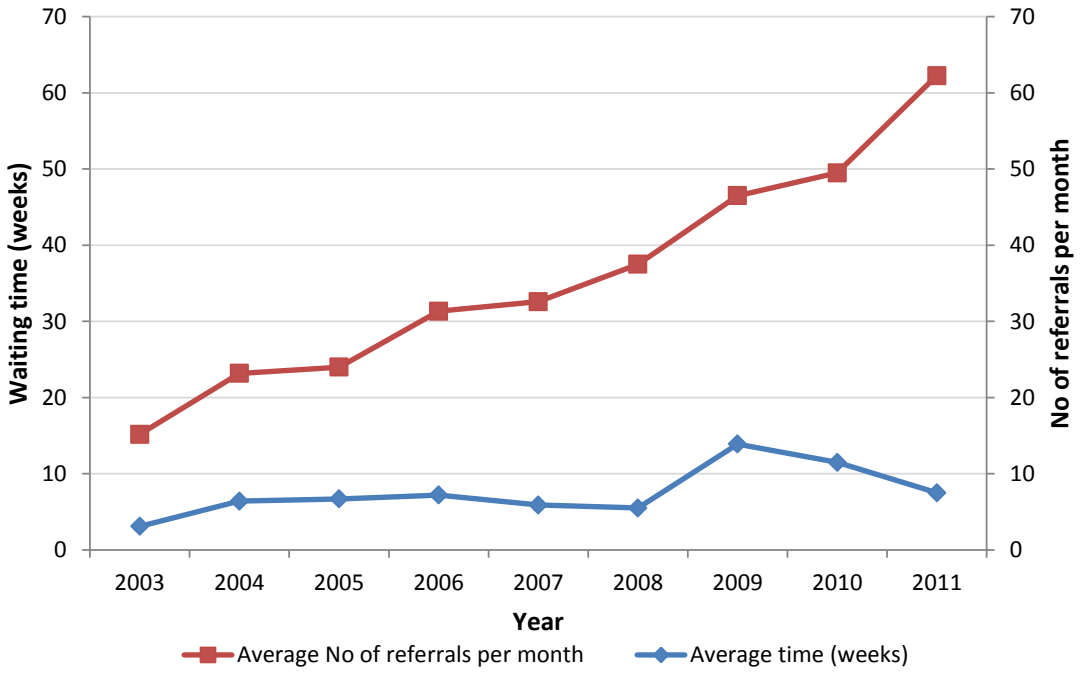
A high proportion of referrals are appropriate in that the percentage of people receiving a diagnosis of dementia ranges from 50% to 60% and has remained unchanged. The caseload over the last three years has been steady; between 400 to 450, despite growing numbers of referrals (see Table 3).

[31] http://www.slam.nhs.uk/media-and-publications/archived-news/croydon-memory-service-wins-international-award.aspx

[32] Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J. and Murray, J. (2007), Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. Int. J. Geriat. Psychiatry, 22: 782–788. doi: 10.1002/gps.1741

[33] Royal College of Psychiatrists (2010) MSNAP 1st National Report 2009-10.

Figure 7 Waiting times and referrals, Croydon Memory Service, 2003-2011



Source: Croydon Memory Service

Table 3 Referrals, caseload and percentage diagnosed, Croydon Memory Service 2003-2011

Year	2003	2004	2005	2006	2007	2008	2009	2010	2011
No. of referrals	182	278	288	376	391	450	558	594	747
% Diagnosed with dementia	61%	53%	53%	57%	60%	53%	52%	50%	57%
Caseload	119	154	176	203	281	328	414	432	440

Source: Croydon Memory Service.

Challenges to the memory service include:

- Keeping the waiting times from referral to assessment low whilst continuing to deliver interventions such as occupational therapy, psychotherapy and support for health lifestyles (physical activity, weight management etc.).
- Agreeing jointly on the care pathway between primary and secondary care services for this group of service users. Developing protocols for the discharge of stable, mild to moderate cases to primary care and transfer of moderate to severe cases to the community mental health teams.
- Working across health, social care and the voluntary sector to provide integrated care. Linking with specialists such as geriatricians to address physical health problems and optimise the non-dementia medication.

Primary care services

The dementia register maintained in primary care gives us the best overall estimate of the number of people with a diagnosis of dementia living in Croydon. The register can be compared with modelled need to give an estimate of the number of people who are living with dementia without a diagnosis and the diagnosis rate. Areas with good early diagnosis will have high dementia diagnosis rates.

Table 4 shows that Croydon has a dementia diagnosis rate of 43%. There are an estimated 3,283 people with dementia, of which 1,416 have been diagnosed, with a further 1,867 people with dementia but without a diagnosis and not in receipt of dementia services.

Table 4: Croydon diagnosis rate 2011

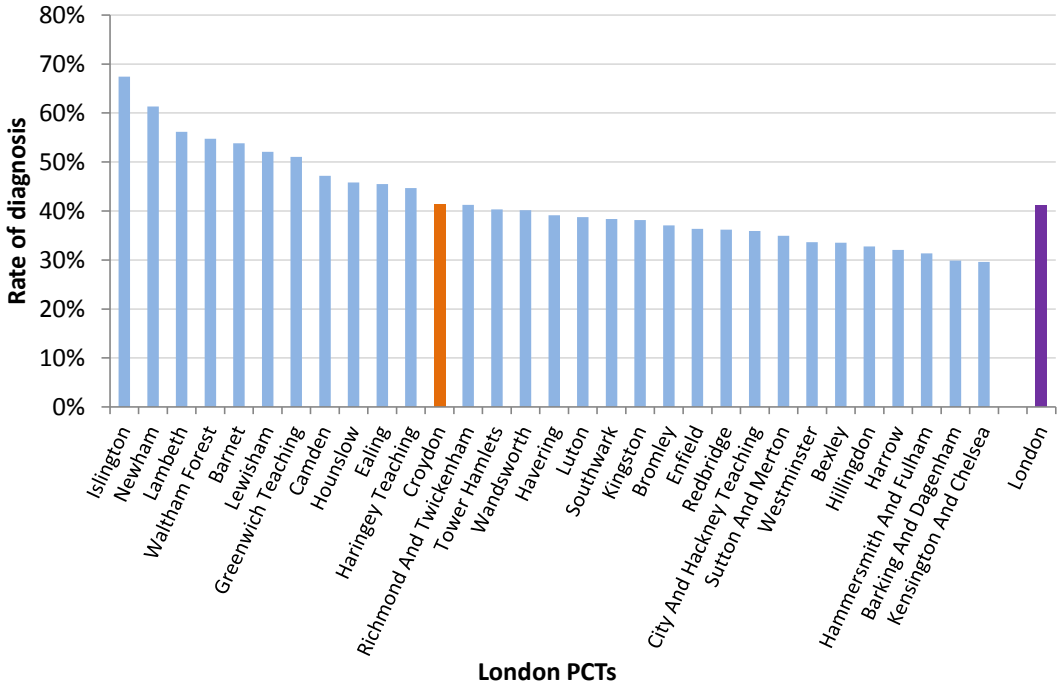
Estimated Need 2011 (see Table 1)	3,283
Primary care dementia register 2010/11	1,416
Those living with dementia without a diagnosis	1,867 (3,283 - 1,416)
Croydon: Diagnosis rate	43% (1,416/3,283)

Source: POPPI, Quality and Outcomes Framework 2010/11 and Alzheimer's society

Note: Rate of diagnosis = Proportion of the estimated numbers with dementia, that have been diagnosed.

Figure 8 shows that Croydon's diagnosis rate is similar to the average London rate but that there is scope for Croydon to improve – one third of London boroughs have a better diagnosis rate, with areas such as Islington and Newham having rates of 67% and 61% respectively.

Figure 8 Estimated rates of diagnosis, London Primary Care Trusts, 2011



Rate of diagnosis = proportion of the estimated numbers with dementia, that have been diagnosed

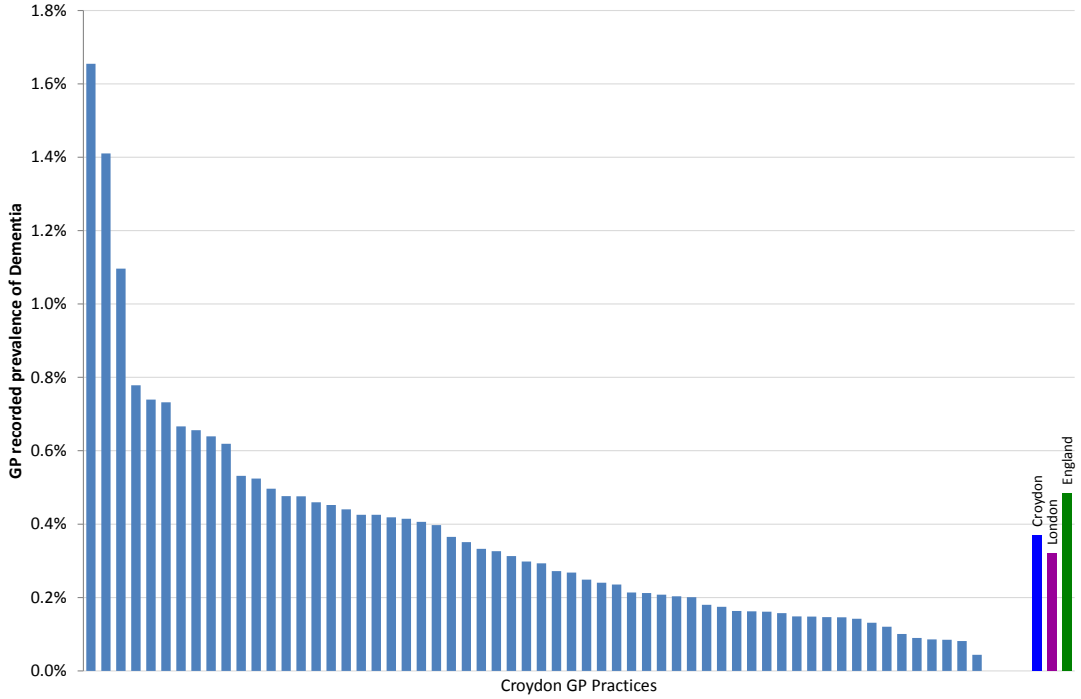
Source: Mapping the dementia gap, Alzheimer's society

Variation in practice prevalence

Practice prevalence is the number of people who are registered with a GP practice who have a diagnosis of dementia. Figure 9 shows that Croydon has a practice prevalence slightly above the London average but lower than the England average (Croydon 0.37%; London 0.32%; England 0.48%).

There is a tenfold variation in practice prevalence within Croydon. Whilst some variation may be explained by differences in age structure etc., in order to improve early diagnosis, all practices, especially those with low prevalence, could look to increase their diagnosis rate.

Figure 9 Prevalence of Dementia on QOF diseases registers (all ages), by Croydon General Practices, 2010/11

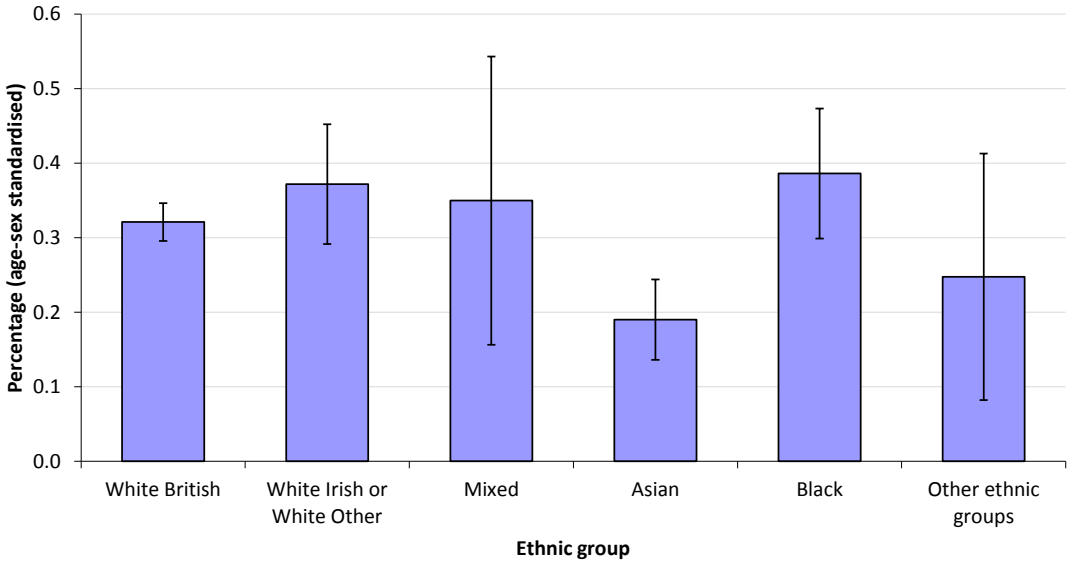


Source: NHS Information centre for health and social care

Variation in prevalence by ethnicity

Figure 10 shows that people from Asian groups are 60% less likely to have a diagnosis of dementia than the white British population – a finding that is statistically significant (Asian prevalence 0.19%; white British prevalence 0.32%). It may be that there are cultural differences that lead to inequalities in access to a dementia diagnosis for Asian groups. The size of the older BAME population in Croydon is growing faster than the older white population and Croydon should look to understand these differences and reduce inequalities in access.

Figure 10 GP recorded dementia prevalence (age-sex standardised) by ethnic group, Croydon, as at 31 Mar 2011



Source: Croydon general practice data

Summary of section 4.3: Early diagnosis and interventions

- Early diagnosis and intervention improves quality of life, reduces behavioural problems and it delays or prevents unnecessary admissions into care homes and hospital.
- The Croydon memory service assesses and diagnoses dementia where appropriate. Numbers seen by the service are growing, and the service is widely recognised as a highly innovative and effective service. It works across health, social care and the voluntary sector
- Early intervention works best when integrated and Croydon should ensure that agencies work together effectively.
- Only two fifths (43%) of people with dementia receive a diagnosis in Croydon, a rate that is similar to the London average but still leaves room for improvement. In primary care, there is a tenfold variation in the proportion of people with a diagnosis of dementia.
- In primary care, people from Asian groups are 60% less likely to have a diagnosis of dementia than the white British population. This may be a sign of inequality of access and needs exploring.
- Croydon should seek to improve its diagnosis rate, in particular in primary care practices with lower rates and in Asian groups

4.4 Better care at home or care home

People with a diagnosis of dementia can live with the condition for seven to twelve years after diagnosis. As the disease progresses, the support they and their carers need will change and typically become more complex, involving a range of agencies. Whether they remain in the community or live in a care home, those with dementia need support in navigating through the services within the system. The section considers the gaps and assets in a number of these services used by people living with dementia.

4.4.1 Reviews within primary care

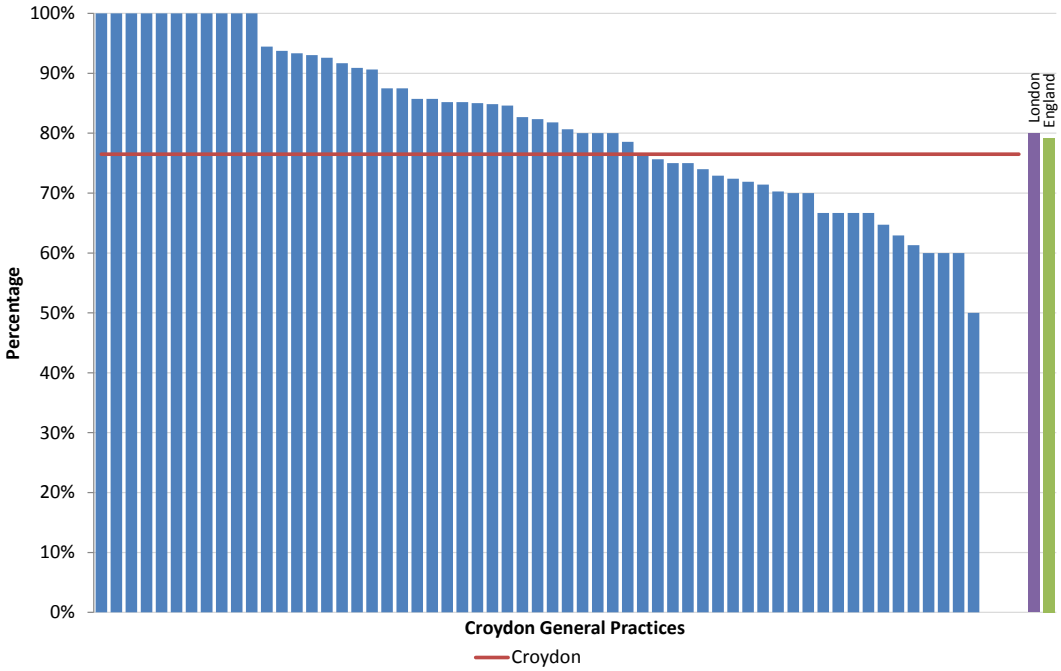
People with dementia and their carers should have their physical and mental health needs reviewed in primary care on a regular/annual basis.[34] Where many agencies are involved in their care, there should also be a review of communication between health, social care and non-statutory sectors.

Figure 11 shows that in 2010/11 Croydon had a review rate slightly lower than both the London average and the England average (Croydon 77.8%; London 79.9%; England 79.2%). Some practices reviewed all of their patients however, the ten worst performing practices in Croydon only reviewed between 50% and 66% of their patients in the past 15 months.

It is recommended that Croydon works to improve the quality of care in poorer performing GP practices and ensures that all those with dementia and their carers have their needs regularly assessed.

[34] Quality and Outcomes Framework for 2012/13

Figure 11 Percentage of dementia patients whose care has been reviewed in the past 15 months, Croydon General Practices, 2010/11



Source: NHS Information centre for health and social care

4.4.2 Social care support

Social care provides support to people to allow them to lead independent lives and/or improve the quality of their lives. For those in the community, social care interventions include home care, day care, meals, equipment and adaptations to their homes. Those with higher need may live in a residential or nursing care home. Carers may be offered respite, information, advocacy and support.

The Croydon social care system does not have a comprehensive dementia register. Some people receiving social care may have a diagnosis of dementia but this may not be known to the people providing social care. Without a register shared between health and social care, it is not possible to understand fully the care that people with dementia and their carers are receiving or to assess whether needs are met equitably.

Those aged 65+ and classified as having a mental health problem provide a rough proxy for a dementia register. In this category, 24% of people are recorded as having dementia. In all other categories, less than 3% are recorded as having dementia (Table 5).

In total, 5.4% (283 of the 5,194) of clients aged 65+ receiving social care support in Croydon are recorded as having dementia, representing a major underestimate. National figures estimate that more than 60% of people aged

65+ in care homes have dementia[35] however, Croydon data record only 14% of people in Local Authority funded residential or nursing care homes as having dementia. This suggests that less than a quarter of people with dementia in care homes are known to social services as having a diagnosis.

Table 5 Services provided or commisioned by Croydon council, by client type, 2010/11

Item	Total	No. with dementia	%
Clients aged 65+ receiving services provided or commissioned by the local authority	5194	279	5.4%
Those with learning disability	60	0	0.0%
Those with mental health problems	647	158	24.4%
Physical disability, Frailty and/or temporary illness	4470	121	2.7%
Other vulnerable people	16	0	0.0%
Substance misuse	1	0	0.0%

Source: SWIFT extract 2011, Croydon Council

In 2009/10, Croydon had a relatively low proportion of social care clients receiving self-directed support (SDS) at 5.9% (see Figure 6). Data for 2010/11 shows that that this proportion increased to 20%.[36] We do not have information on the proportion of people with dementia/caring for someone with dementia who receive SDS. SDS can help social care users to personalise and manage their condition and Croydon should increase the number of people with dementia and their carers who are offered SDS.

Carers

Approximately 1,118 people in Croydon are registered as carers within adult social care, although it is believed that this is an underestimate since

- some packages of care for carers are recorded against the client rather than the carer
- anecdotally some assessments are not entered onto the social care system

It is recommended that Croydon considers setting up a comprehensive dementia register in social care. This would help to look at changing needs and how / whether they are being met in the most effective and cost effective way as well as identifying social care inequalities.

4.4.3 Older Adult Community Mental Health Teams

Community Mental Health Teams (CMHT) for Older Adults provide community-based assessment, treatment and care for people, aged 65+, who

[35] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London
[36] Croydon 2011/12 JSNA Overview chapter

have mental health problems. The multidisciplinary team includes psychiatrists, psychological therapists, mental health nurses, social workers and occupational therapists that specialise in older adult mental health care.

A large proportion of the resources of the more specialist older adult Community Mental Health Team (CMHT) service is devoted to those with dementia. Table 6 shows that approximately half the clients referred to the older adult CMHT in 2011 had a primary diagnosis of dementia. Those with dementia have a longer median[37] length of stay than those without dementia. (Median length of stay for dementia patients was 8 months; other than dementia patients, median length of stay was 5 months).

Table 6 Caseload by latest primary diagnosis, Croydon mental health teams, January to December 2011

Last primary diagnosis	Nos	% of caseload
Dementia	947	52%
Other	880	48%
Total	1827	100%

Source: South London and Maudsley Mental Health Trust

Of the 947 episodes of care for dementia, 52% had a discharge date and for this group the median length of stay was eight months (interquartile range[38] of 2 to 21).

Of the 880 episodes of care for diagnoses other than dementia, 51% had a discharge date and the median length of stay was five months (interquartile range of 1 to 12).

The mental health teams provide consultant input to the continuing care beds at Amberley Lodge but increasingly the mental health teams are being asked to provide input to the care homes in the borough. Given the size of the care home market in Croydon this is becoming a capacity issue for the service.

Table 7 shows numbers in the CMHT by mental health cluster. HoNOS (Health of the Nation Outcome Scales) is used to measure the health and social functioning of people with severe mental illness.[39] HoNOS PbR is the name given to the scales that underpin Payment by Results (PbR) for mental health in England. The HoNOS PbR scores are used to help allocate people to one of 21 mental health clusters used in mental health PbR. Looking at

[37] Median is the middle value of a set of values in a dataset that are arranged in ascending order. It is preferable to use the median rather than the average for a set of values that may have extreme values or outliers at either end of the range such as in the case of length of stay in hospital.

[38] The interquartile range shows the minimum and maximum values or the range of values of the middle two quarters of the ordered dataset.

[39] http://www.rcpsych.ac.uk/training/honos.aspx

level of need (high/severe, medium, low), the table shows that where a need level is assigned, patients with dementia are more likely to have moderate need than people with non-dementia diagnoses.

Table 7 Croydon Mental Health Teams caseload by HoNOS cluster value, 2011

Latest HoNOS Cluster Value	Dementia		Non-dementia	
	nos	%	nos	%
19: Cognitive Impairment or Dementia Complicated (Moderate Need)	397	42%	63	7%
20: Cognitive Impairment or Dementia Complicated (High Need)	151	16%	9	1%
18: Cognitive Impairment (low need)	115	12%	61	7%
21: Cognitive Impairment or Dementia (High Physical or Engagement)	106	11%	7	1%
3: Non Psychotic (Moderate Severity)	18	2%	134	15%
11: Ongoing Recurrent Psychosis (Low symptoms)	5	1%	75	9%
2: Common Mental Health problems (Low Severity with greater need)	5	1%	57	6%
1: Common Mental Health Problems (Low Severity)	4	0%	55	6%
14: Psychotic Crisis	2	0%	7	1%
4: Non-psychotic (Severe)	2	0%	52	6%
12: Ongoing or recurrent Psychosis (High Disability)	1	0%	54	6%
6: Non-Psychotic Disorder of Over-valued Ideas	1	0%	8	1%
7: Enduring Non-Psychotic Disorders (High Disability)	1	0%	26	3%
0: Variance	0	0%	14	2%
10: First Episode Psychosis	0	0%	6	1%
13: Ongoing or Recurrent Psychosis (high symptom and disability)	0	0%	30	3%
15: Severe Psychotic Depression	0	0%	7	1%
16: Dual Diagnosis	0	0%	2	0%
17: Psychosis and Affective Disorder - Difficult to Engage	0	0%	6	1%
5: Non-Psychotic Disorders (Very Severe)	0	0%	6	1%
8: Non-Psychotic Chaotic and Challenging Disorders	0	0%	1	0%
9: Substance Misuse	0	0%	1	0%
(blank)	139	15%	199	23%
Grand Total	947	100%	880	100%

Source: South London and Maudsley Mental Health Trust

4.4.4 Voluntary Sector

The voluntary sector provides a huge range of services for those with dementia, a full list is found in Appendix 4. A particular strength of the voluntary sector is that services may support a person with dementia and/or their carer throughout the course of their illness potentially acting as a navigator through the system. The Alzheimer's Society in Croydon is the largest provider of voluntary sector services for people with dementia and their carers in Croydon. Demand for their services is greater than their current capacity. They deal with over 400 queries per quarter and provide 1-2-1 support to over 75 people with dementia and their carers. The carer's information service is in touch with 225 carers of people with dementia.

4.4.5 Care homes

Partly due to historical reasons, Croydon has the largest number of care homes in London. In the 1980s, Croydon had a large number of mental health/learning disability institutions and building costs were lower in Croydon than in the rest of London. Overall, there are 180 care homes in Croydon and a further 200 within five miles of Croydon. Numbers will change as care homes merge or split. Approximately half are wholly or partly for people with

dementia and/or people aged 65+. Many of the people living in Croydon care homes are originally from out of the borough, but will be registered with a Croydon GP. A map of Croydon showing the location of care homes is shown in Figure 12.

Summary of section 4.4: Better care at home or care home

- People with dementia can live with the condition for seven to twelve years after diagnosis. The support that they and their carers need will change and become more complex. It can be difficult to navigate through the wide range of services.
- Although the physical and mental health needs of people with dementia and their carers should be reviewed annually in primary care, in the poorer performing practices, less than two-thirds of people received a review. Croydon should reduce this variation in primary care quality.
- The Croydon social care system does not have a comprehensive list of people with dementia. Some people receiving social care have a diagnosis of dementia that is not known to the people providing social care. This limits our understanding of social care support provided and our ability to plan services.
- The primary care register of people with dementia should be shared with social care.
- Croydon should increase the number of people with dementia who are offered self-directed support in order to help client manage their condition.
- Half of the people in contact with the older adult Community Mental Health Team (CMHT) service have a primary diagnosis of dementia. This group stays with the team longer
- Croydon has more care homes than any other London borough. It has approximately 180 care homes of which half completely or partly specialise in care of people aged over 65 or people with dementia.

4.5 Better care in hospital

The care of people with dementia in general hospitals is a priority for the government. The National Dementia Strategy[40] found:

- Up to 70% of acute hospital beds are currently occupied by older people and up to one half of these may be people with cognitive impairment, including those with dementia and delirium.
- People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation.

The National Audit Office has estimated the excess cost to be more than £6 million per year in an average general hospital.[41]

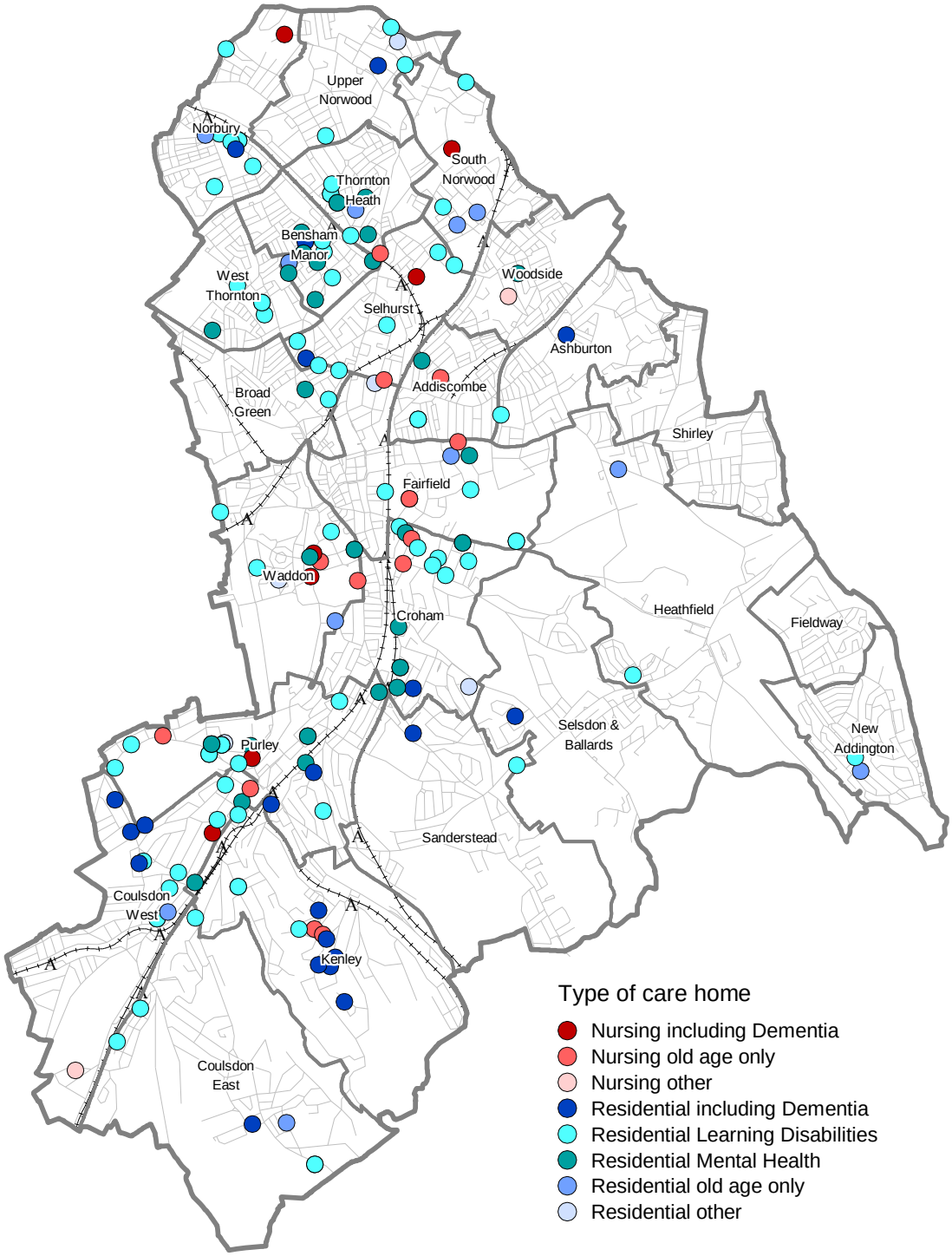
The first National Audit of Dementia took place in 2010[42] and looked at the quality of care received by people with dementia in general hospitals. It found that there were low levels of performance, and no hospital met all of the essential standards. There was wide variation on key standards, for example, nationally, 70% of patients received a nutritional assessment, however this ranged from 3% to 100% between participating hospitals. It also found that there was little correlation between policy and practice. For example, 96% of hospital assessment procedures included assessment of nutritional status. However, only 70% of patient case notes showed that an assessment of nutritional status had been carried out.

The audit showed that performance in CUH (Croydon University Hospitals Trust) was similar to that of London Trusts overall. However this was worse than the England average.[43] It found that in Croydon

- There were no dementia policies in place.
- Recognition and assessment of memory problems was better than average in the elderly care, but not in other specialities such as general medicine and surgery.
- There was no named discharge coordinator.
- There was no centralised paperwork for documenting discussions with patients and relatives about care and discharge.

[40] Department of Health (2009) *Living well with dementia: a National Dementia Strategy,* London: The Stationery Office
[41] Ibid.
[42] Royal College of Psychiatrists (2011). *Report of the National Audit of Dementia Care in General Hospitals*. Editors: Young J, Hood C, Woolley R, Gandesha A and Souza R. London: Healthcare Quality Improvement Partnership.
[43] Royal College of Psychiatrists (2011). *Report of the National Audit of Dementia Care in General Hospitals – core audit report for Mayday University Hospital*

Figure 12 Map of care homes in Croydon



Source: Care Quality Commission

Some of these issues have subsequently been addressed, for others, work is on-going. Guidelines for dementia and delirium have been developed; a clerking proforma is also now in use to help with assessment and recognition.

Older adults who are inpatients in CUH have access to the older adults psychiatric liaison service, a specialist support service that provides mental health assessments, and advice in relation to treatment and management. Dementia, delirium and cognitive impairment account for half of the referrals to this service. In 2011, there were 487 referrals. Dementia and Alzheimer's were the most common diagnoses, accounting for almost one third (31%) of referrals. A further 15% had a diagnosis of delirium, and 4% had cognitive impairment.[44]

Whilst the liaison service can provide specialist advice, the care of people with dementia in hospital should not be a specialist skill. Dementia is more common in general hospital than in the community – an estimated 30% of older people in general hospital have dementia.[45]

CUH guidelines for delirium suggest that on admission, all inpatients should be assessed for confusion, delirium and cognitive impairment[46]. This may enable the right support to be given to people who have dementia even if they do not have a diagnosis of dementia.

Recording of dementia as a secondary diagnosis is low in CUH. Over the three years 2009 to 2011, only 5.4% (approximately 3,000 / 60,000) of admissions in people aged 65+ living in Croydon had a secondary diagnosis of dementia.[47] This is one sixth of the expected percentage of 30%[48] and may reflect low levels of diagnosis in the community and/or failure to communicate or record existing diagnoses to hospital settings.

Admissions with a primary diagnosis of dementia are uncommon in general hospital settings. Over the three years 2009 to 2011, only 0.2% (approximately 130/60,000) of admissions in people aged 65+ living in Croydon had a primary diagnosis of dementia. Admissions with a primary diagnosis of dementia to Croydon's main psychiatric hospital (SLaM) are common, making up one third (31%) of all admissions under the older people CAG (clinical academic group) over the three calendar years 2009 to 2011.

[44] Data supplied by the Older Adults Psychiatric Liaison Service
[45] Royal College of Psychiatrists (2005). Who Cares Wins: Improving the outcome for older people admitted to the general hospital. London: RCPsych.
[46] Croydon Health Services 2011. Guidance on the Management of Delirium in Adults, ,
[47] Secondary User Services (SUS) admission to general hospitals with any secondary diagnosis code of F00-F03 or G30
[48] Royal College of Psychiatrists (2005). Who Cares Wins: Improving the outcome for older people admitted to the general hospital. London: RCPsych

Reasons for admission

Nationally, the top five reasons why carers report people with dementia are admitted to hospital are:[49]

- Following a fall 14%
- Broken/fractured hip or hip replacement 12%
- Urine infection (including urinary tract infection) 9%
- Chest infection 7%
- Stroke/minor stroke 7%

This is mirrored locally to some extent. Table 8 shows that diagnoses related to falls, urine infections and chest infections are among the most common reasons for admission where a high proportion (>10%) have a secondary diagnosis of dementia. It may be that hip fractures do not appear in this list because of coding issues. Efforts should focus on keeping people out of hospital where possible

Table 8 Top nine reasons for admission where >10% have a secondary diagnosis of dementia, Croydon acute hospitals Jan 2009 – Dec 2011

Primary diagnosis	No of admission	Proportion with secondary diagnosis of dementia
Other disorders of urinary system	1346	20%
Pneumonia, organism unspecified	876	17%
Syncope and collapse	755	12%
Unspecified acute lower respiratory infection	564	18%
Senility	522	16%
Other symptoms & signs involving cognitive function and awareness	311	22%
Open wound of head	299	24%
Cellulitis	299	11%
Acute renal failure	219	14%

Source: Secondary User Service data for Croydon hospitals excluding South London and Maudsley Mental Health Trust.

Efforts to improve care for people with dementia in general hospitals should focus on

- An on-going programme of audit of practice against national and local standards laid down for example in CUH guidelines on dementia and delirium and in the use of the clerking proforma.
- Promoting good practice in elderly care across the whole Trust. Consider developing standardised, centralised paperwork for recording discussion with patients and relatives.

[49] Alzheimer's society (2009) *Counting the Cost*

- Regular training of all staff in assessing, treating and managing people with dementia regardless of their presenting condition.
- Discharge planning for those with dementia / impaired cognitive impairment. Consider a specialist nurse who can advise on discharge of people with complex needs.
- Closer working with other agencies such as the voluntary sector and primary care to provide integrated support, and to good follow up after discharge

The introduction in April 2012 of the new national CQuINs for dementia[50] will provide an incentive for hospital providers to deliver improved care. The CQuINS have three main aims:

- Identifying people with dementia – members of staff will ask members of the family or friends of a person admitted to hospital if the patient has suffered any problems with their memory in the last 12 months
- Assess people with dementia – if there is evidence to suggest a problem with their memory, that person will be given a dementia risk assessment
- Refer on for advice – a referral would be made for further support either to a liaison team, a memory service or a GP.

Summary of section 4.5: Better care in hospital

- Dementia is much more common in general hospitals than in the community – an estimated 30% of older people in general hospital have dementia.
- People with dementia in general hospitals have worse outcomes – they stay in hospital longer, are more likely to die and are more likely to be discharged to a care home
- In caring for people in hospital who have dementia, there are low levels of performance across the whole country - no hospitals are meeting all of the essential standards. Croydon performs about average for London and slightly worse than England.
- Whilst there are specialist services in Croydon University Hospital (CUH), the care of people with dementia in hospital should not be a specialist skill because it is so common.
- Recording of dementia as a secondary diagnosis in CUH is low. One in twenty admissions in people aged 65+ have dementia as a secondary diagnosis, approximately 1/6 the expected percentage.

[50] http://dementia.dh.gov.uk/introducing-the-national-dementia-cqin/

- CUH guidelines suggest that on admission, all inpatients should be assessed for confusion, delirium and cognitive impairment so that everyone can receive the right support even if they do not have a diagnosis of dementia

- Efforts to improve care for people with dementia in general hospitals should focus on:
  - Audits of practice against guideline standards
  - Regularly train staff to help and support people with dementia or cognitive impairment even if they don't have a diagnosis of dementia
  - Early planning for discharge – consider a specialist nurse to advise on the discharge of people with complex needs
  - Closer working with other agencies such as the voluntary sector and primary care to support dementia during the admission and afterwards

4.6 Appropriate use of antipsychotic medication

Antipsychotic medication is one of a number of interventions for behavioural and psychological symptoms in people with dementia. In 2009, it was estimated that 180,000 people with dementia (approximately 25%) were being prescribed antipsychotics and that two-thirds of the prescribing was unnecessary. Antipsychotics can cause harm – it is estimated nationally that that there are 1,800 excess deaths and 1,620 additional strokes each year as a result of the prescribing of antipsychotics to people with dementia[51]

In late 2010 the Care Services Minister, Paul Burstow, called for a 66% reduction in prescribing of antipsychotics to people with dementia by November 2011. A continued commitment to reducing prescribing of antipsychotics was made in the NHS Operating Framework 2012/13.

Estimates suggest that Croydon has relatively low levels of antipsychotic prescribing. Analysis of Croydon's general practice data found that approximately 12% of patients with dementia had been prescribed an antipsychotic in the previous 12 months, less than half the national figure of 25% although these estimates were made at least two years apart.

[51] Department of Health (2009) *The use of antipsychotic medication for people with dementia: Time for action,* London: The Stationery Office

Table 9: Estimate of number of people with dementia in Croydon who are prescribed antipsychotics

Patients with dementia diagnosis or prescribed anti-dementia drugs in last 6 months	932
Patients with a typical antipsychotic drug prescribed in last 6 months	41
Patients with an atypical antipsychotic drug prescribed in last 6 months	72
Either typical or atypical antipsychotic drug prescribed in last 6 months	113 (12%)

Source: Croydon General Practice database Feb 2012

Note that Table 9 is an underestimate of both the number with dementia and the number being prescribed antipsychotics. This is because of local variation in coding practices.

A National Dementia and Antipsychotic Prescribing audit is underway and a more accurate estimate will become available in the next few months. This primary care audit aims to assess the levels of antipsychotic prescribing in people with dementia. It will cover patients with dementia that live either in their own homes or in a care home.

There are a number of initiatives that are taking place/have taken place in Croydon to reduce antipsychotic use and improve knowledge and skills in this area.

Forty one Croydon GP practices have been offered training on 'Best Practice in antipsychotic prescribing, review and discontinuation for people with dementia'. This training is delivered by a consultant Old Age Psychiatrist as part of a local incentive scheme.

A care homes local enhanced service (LES) was run in 2011/12 with GPs that undertook a full review including a medication review for their patients resident in care homes. The scheme is continuing. The review was undertaken during a 'grand round' with the GP, a prescribing adviser and a senior nurse. Between May 2011 and Sept 2012:

- 17 care homes (14 nursing /3 residential) participated in the grand round.
- 19 GP practices signed up to the scheme
- 500 patients had an initial multidisciplinary review and at least one follow up
- 1728 Pharmacist initiated medicines interventions were made (average: 3 per person)

From May 2011 to March 2012, 14% of all antipsychotics prescribed were stopped completely and a further 28% had reduced doses i.e. antipsychotic medication was stopped for eight people out of 43 who were on antipsychotics and the dose reduced for a further 12 people.

Croydon care homes are also supported by the multidisciplinary Care Support Team. This team works closely with care homes and care agencies within Croydon, and offers training and support on all areas of care including dementia care. In 2011/12 the following dementia specific training was delivered:

- 40 people attended three full days of Person-centred dementia care training.
- A further 44 people from 5 organisations (4 care homes and 1 assisted living centre) attended a two hour session on understanding dementia.

In order to reduce the use of antipsychotics and improve awareness and skills, additional support is needed to develop non-drug based interventions for individuals. There needs to be on-going training to staff in primary care and in care homes and on-going medication reviews of those on antipsychotics.

Summary of section 4.6: Appropriate use of antipsychotic medication

- Antipsychotic medication can help treat behavioural and psychological symptoms in people with dementia. But it can cause harm and is sometimes given inappropriately –nationally there are an estimated 1,800 excess deaths and 1,620 extra strokes each year because of antipsychotics
- Croydon has relatively low levels of antipsychotic prescribing – estimated at 12% (in 2012) compared to the national figure of 25% (in 2009). A prescribing audit is underway that will give us a better understanding and more accurate figures.
- Croydon piloted a care home Local Enhanced Service that stopped or reduced the dose of antipsychotics in almost half of people reviewed although not all care homes were involved. Croydon also provides training to GPs and to staff in care homes.
- To reduce use of antipsychotics further and improve skills and awareness, Croydon should develop more non-drug interventions that manage behavioural and psychological symptoms, provide on-going training for staff in primary care and care homes and continue to review regularly the medication of those prescribed antipsychotics.

5 Data limitations

5.1 Limitations of the healthcare data

A search of the national repositories of data revealed little published data on care and services specific to Dementia.

In this situation we used some locally collected data (e.g. Croydon General Practice data); however care must be taken in the interpretation of these. Locally collated information could vary nationally in terms of the method of collection, reporting mechanisms, methods of analyses, completeness, accuracy, etc. and should therefore be used with caution when making comparisons.

In cases where nationally published data is available (for instance, care related to older people), data may be a couple of years behind. There is an inevitable time lag between the submission of local data and when this data is published or made available nationally.

Most local prevalence figures are estimates which have been derived by applying modelled prevalence figures to local populations.

Although published nationally, mortality data also has its limitations. Mortality rates are produced using data where the cause of death is listed as either Dementia or Alzheimer's disease. However, this does not take into account cases where Dementia or Alzheimer's disease was also present as a contributory factor but not the main cause of death

There is evidence that SLaM (South London and Maudsley Mental Health Trust) admissions data from SUS (Secondary User Service) is incomplete. E.g. In the three years 2009-11, SUS shows 1 admission where dementia was the primary diagnosis, while a local extract obtained directly from SLaM shows 91 admissions where dementia was the primary diagnosis.

5.2 Limitations of the social care data

Dementia data is only reported in one social care return (Referrals, Assessments and Packages of Care (RAP)) and is a subset of mental health as a client type. Not all tables capture Dementia as a client type.

Dementia information is captured on Croydon's management information systems only if this information is provided at contact/referral and at assessment or review. The social care system also relies on this information being provided by our partner's systems that do not capture information in the same way or at the same level.

In most cases Dementia is recorded as a client type which is a subset of primary client type. The primary client type of mental health or physical disability / frailty and/or temporary illness takes priority.

Summary of section 5: Data Limitations

- A search of the national repositories of data revealed little published data on care and services specific to Dementia.
- Locally collated information may vary from national collections in terms of reporting mechanisms etc. and may not be directly comparable.
- There is evidence that SLaM (South London and Maudsley Mental Health Trust) admissions data from SUS (Secondary User Service) is incomplete.
- Nationally published data may be a few years out of date – local data tends to be more timely.
- Dementia information is captured on Croydon's social care systems only if it is provided at contact/referral and at assessment or review.

6 Views of stakeholders

The views of people delivering services and providing support to people with dementia, and the views of those with dementia are vital in shaping and developing services and identifying the strengths and weaknesses of care. Their opinions and experiences can inform an understanding of the needs of people with dementia and their carers and how they are being met. Dementia patients, and their carers, should be given an active role in the care and support they receive and in informing how services are delivered and commissioned.

Carers have a central role. Two thirds of people who have dementia live in the community and many rely on unpaid care provided by friends, family and neighbours. Carers are the most important resource for people with dementia and without this unpaid support, health and social care services would be overwhelmed. Good support for carers can reduce or delay admission to care home.[52] However the caring role places a burden on the health and quality of life of the carer themselves. The National Dementia Strategy outlines the importance of carers to people with dementia.[53]

We explored the views of people with dementia, their carers and other stakeholders in three ways:

- **Views collected by services and local networks**. Rapid assessment of the views of people with dementia and their carers collected regularly or one-off by providers, partnerships and networks.
- **National surveys / indicators**. Findings from national surveys and relevant national indicators.
- **Stakeholder consultative meeting**. We held a stakeholder consultative meeting to gather views on assets and gaps in dementia care, comment on interim findings and make recommendations for development

6.1 Views collected by services and local networks

We asked providers from the statutory and voluntary sector whether they collect information routinely about the experiences and views of people who use their services. We asked about formal service evaluations, consultations, focus groups or research that had been carried out regarding dementia care in Croydon in the last three years. We contacted the following strategic partnerships, networks and voluntary sector organisations:

[52] Banerjee S et al., Predictors of institutionalisation in people with dementia. Journal of Neurology, Neurosurgery and Psychiatry, 2003; 74: 1315–1316

[53] Department of Health (2009) *Living well with dementia: a National Dementia Strategy,* London: The Stationery Office

- South London and Maudsley – memory service, liaison and participation leads
- Croydon University Hospital (CUH) clinical leads and the Patients Advice and Liaison Services (PALS)
- Croydon Council – complaints, commissioning managers, Customer service and strategy teams
- Strategic partnership groups and networks: Carers Partnership Group, Older peoples partnership group, Physical disability partnership group, Croydon's Older Peoples Network (OPeN), Croydon's Shadow Health Watch
- Umbrella voluntary organisations - BME forum, Croydon Voluntary Action, Voluntary Sector Service Providers for Older People (VoSSPOP), Carers' Information service, Croydon Neighbourhood Care Association, HealthWatch
- Some providers and voluntary sector organisations– Crossroad, Heavers Resource Centre, Fellows Court, Marsh and Willow Day services, Alzheimer's Society, Mind in Croydon, Rethink, Imagine, Age UK, OPEN

We found that only a handful of services collect qualitative information routinely from people with dementia and their carers about the care provided.

The Croydon Memory service gathers service user and carer feedback as part of the Memory Services National Accreditation (MSNAP) programme. The MSNAP report highlighted that feedback from service users and carers was very positive, particularly around the assessment and communication of the diagnosis.

Some comments include:

> *"The diagnosis was given to me in a professional and courteous fashion." (Service user)*

> *"Over all we received a very good service. It could have been quicker but it was worth the wait as the tablets are really helping." (Carer)*

Heavers Resource Centre and Fellows Court (care home and day care centre) conducted a customer satisfaction survey in December 2010. The feedback from service users and carers was generally positive.

> *"The staff are nice and the people are lovely"*

> *"We could have more social activities for service users and tenants."*

Croydon's Shadow HealthWatch prioritised dementia as a topic for 2012. They intend to carry out a survey of service user and carer views, and visit care homes. The outcome of this work could inform the dementia strategy.

A systematic approach to collecting the views of people with dementia and their carers is needed across all services. Carers' services should collect the condition of those who they are caring for.

6.2 National surveys / indicators

There are no national surveys or indicators that focus exclusively on people with dementia and/or their carers. There is information however, about carers in contact with social services. The first national user experience survey of adult carers caring for adults known to Councils was carried out in 2009. Nationally, 60% of councils took part in the voluntary survey, including Croydon. Approximately one quarter of respondents reported that they were caring for someone with dementia (Croydon 27.6%, England 26.4%).[54]

Compared to England, carers in Croydon report lower levels of satisfaction with the support they receive (Table 10). This may be in part because the response rate in Croydon was lower (Croydon 30% response rate, England 40%). However these differences were statistically significant.

Table 10 Carer satisfaction in Croydon and England, 2009/10

Item	Croydon	England
Extremely satisfied with the support or services the carere and the person cared for have received from social services in the last 12 months	9.2%	17.5%
"Some always got back to me" - most closely describes how quickly social services have responded to queries or questions in the last 12 months	42.0%	61.8%
Found it "very easy" to get the support or services needed as a carer in the last 12 months	14.5%	23.8%

Source: The NHS Information Centre - Personal Social Services Survey of Adult Carers in England - 2009-10

Carers are entitled to receive an assessment of their needs or a review quite separately from those they look after, and to receive a specific carer's service, or advice and information. The Croydon JSNA overview chapter finds that the proportion of those who choose to do so increased slightly, from 12.7% as it was in 2009/10 to 14.9% in 2010/11.[55] This remains a low proportion and below the average for London.

[54] The NHS Information Centre - Personal Social Services Survey of Adult Carers in England - 2009-10

[55] Croydon JSNA Overview chapter 2010/11 and see section 4.2

This could partly be explained by the fact that support provided by the voluntary and community sector is not formally captured through a separate assessment and subsequent provision of a service for many, but commissioners and strategy managers will want to investigate whether need is being met.

Croydon has developed an action plan for information and advice to ensure the public can identify and access local options for meeting their care and support needs. An enhanced website, with clear signposting to resources across the borough, is now available.[56]

6.3 Stakeholder consultative meeting

A stakeholder consultative meeting was held in early March. It had two aims:

- To gather the views of attendees on the assets and gaps in care for people with dementia and their carers.
- To give attendees the opportunity to comment on interim findings and inform the final findings of this JSNA

Over thirty people attended from across the system including primary and secondary care clinicians, commissioners, public health analysts, carers, managers, service providers including representatives from secondary care, the private sector and the voluntary sector.

Stakeholders identified assets and strengths in the care provided to people with dementia:

Early diagnosis and intervention

- Croydon memory service
- Croydon mental health teams long term care planning
- Liaison service (early diagnosis)

Better care at home and or the care home

- Training programme to support staff learning in care homes
- Clinical reviews in care homes means antipsychotic prescribing in Croydon is reducing.

Better care in the hospital

- Low antipsychotic prescribing
- Dedicated in patient provision through psychiatric liaison service
- Joint working to assist discharge process
- Staff awareness and knowledge of dementia care

[56] http://www.croydon.gov.uk/healthsocial/carers/

- Referrals to Mental Health Older Adults team are picked up and actioned quickly.
- Links with voluntary sector
- Increased awareness of legal framework to evidence and support decision i.e. best interests.

Support for carers

- Voluntary sector support
- POP bus
- Personal budgets
- Support groups for carers
- Secondary services

Stakeholders discussed the ways in which services could / should be developed. The full list of recommendations identified by the attendees is given in Appendix 5.

What Croydon should be aiming for:

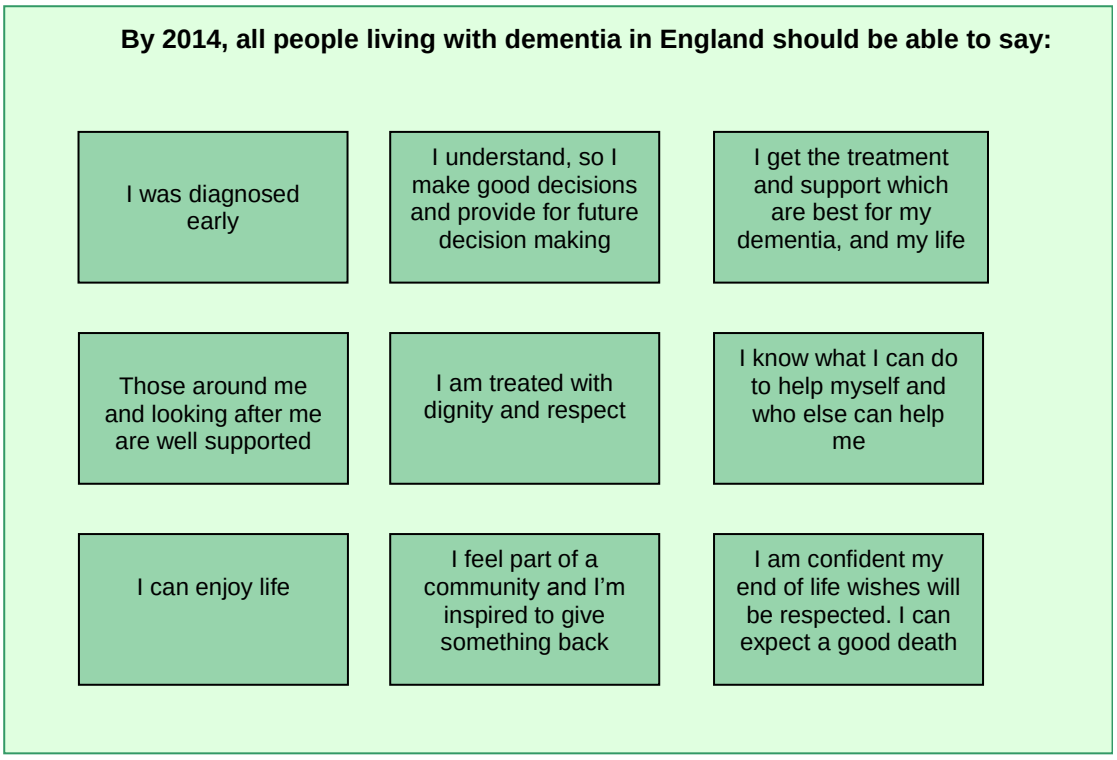
Stakeholders reported that while many of the services are good and well regarded, there is a need for greater integration between them.

Stakeholders identified the following priorities:

- ***Integrated pathway***: develop clear pathways of care from early detection through to end of life across health, social care and the voluntary sector. This should include out of hours support, joined up services and easy access to self-directed support. At the centre of the system should be the needs of the person with dementia and the carer
- ***Information***: develop comprehensive accessible information for everyone including people with dementia, their carers, providers of care and those making referrals. Consider a single point of access to information and a single directory of services.
- ***Navigation.*** identify ways for people with dementia and their carers to navigate through the system
- ***Outcomes:*** focus on outcomes based on the experiences of people with dementia and their carers: providers should collect the views of people with dementia and their carers systematically. Carers services should collect the condition of those who they are caring for
- ***Carers***: improved recognition and support for carers
- ***Mental well-being:*** Reduce fear and stigma of dementia
- ***Hospital care:*** Improve dementia care in hospitals using successful models in other areas.

The government identified nine outcomes desired by people with dementia and their carers (Figure 13). All dementia services in Croydon should aspire to deliver these outcomes by 2014

Figure 13 Draft syntheses of the outcomes desired by people with dementia and their carers



Source: Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (Sept 2010)

Taking into account the information gathered about the views of stakeholders, it is recommended that Croydon ensures the following:

1. All services providers (statutory and voluntary sector) need to improve the information they hold on the dementia patient experience. A more co-ordinated approach to capturing the overall experiences of people with dementia and carers who use their services is required. Information should be collated and published in a useable and accessible format, in order to assess effectively how people experience services in Croydon.

2. All providers of dementia care should commit to greater engagement of people with dementia and their carers in an explicit and planned way to inform service provision. This should provide real and meaningful continued involvement in the process of decision-making, and should not be limited to 'one off' events.

3. To ensure the right balance of services across the whole pathway, commissioners should consider undertaking a survey of the views and experiences of people with dementia and their carers in Croydon.

Summary of section 6: Views of stakeholders

- The views of people delivering services and providing support to people with dementia and the views of those with dementia are vital in shaping and developing services and in identifying the strengths and weaknesses of care
- Carers have a central role. Without this unpaid support health and social care services would be overwhelmed and good support for carers can reduce or delay admission to care home
- Only a handful of Croydon services collect information routinely about the experience and views of people with dementia and their carers.
- Compared to England, carers in Croydon report lower levels of satisfaction with the support they receive and are less likely to seek advice and information
- Many of the services that Croydon provides are good and are recognised as being assets in dementia care.
- Stakeholders identified the following priorities to improve dementia care in Croydon:

  - ***Integrated pathway:*** develop clear pathways of care from early detection through to end of life across health, social care and the voluntary sector. The needs of people with dementia and their carers should be at the centre
  - ***Information***: develop comprehensive accessible information for everyone; people with dementia, their carers, providers of care and those making referrals. Consider a single point of access to information to develop a shared understanding of what is on offer
  - ***Navigation***: identify ways for people with dementia and their carers to navigate through the system
  - ***Outcomes***: focus on outcomes based on the experiences of people with dementia and their carers
  - ***Carers***: improve the recognition and support for carers
  - ***Mental well-being***: reduce fear and stigma of dementia
  - ***Hospital care***: improve dementia care in hospitals using successful models in other areas

- Croydon should encourage all services providers (statutory and voluntary sector) to improve the information they collect about the experiences of people with dementia and carers.
- All providers of dementia care should commit to greater engagement of people with dementia and their carers in an explicit and planned way to inform service provision
- Croydon should consider undertaking a survey of the views and experiences of people with dementia and their carers in Croydon.

7 Cost

NHS spend on dementia can be estimated through national programme budget data collected by the DH.[57] Based on the 2010/11 programme budget for Croydon, NHS Croydon spends £10 million on services for those with organic mental disorders, a category that includes dementia. The average spends on organic mental health disorders per weighted head of population increased fourfold between 08/09 and 09/10, from £7 to £29. This increase may be due to improvements in the data quality.

Table 11 NHS spend per head of weighted population in Croydon and total spend, 2007/08 to 2010/11

Programme Budgeting categories	Spend per weighted head of population (£s)				Total Spend (£millions)
	2007/08	2008/09	2009/10	2010/11	2010/11
All Programme Budgeting categories	1,399	1,478	1705	1785	585.5
Mental health (category 5)	185	206	216	206	67.6
5a Substance Misuse	18	21	21	17	5.6
5b Organic Mental Disorders	5	7	29	31	10
5c Psychotic Disorders	8	8	10	48	15.7
5d Child and Adolescent MH Disorde	13	14	15	14	4.6
5x mental health disorders (other)	140	156	141	97	31.7

Source: SPOT tool and Department of Health Programme Budgeting PCT Benchmark Tool

Table 12 shows that Croydon council spent approximately £5.3 million on mental health for older people of which £3.5 million (66%) went on residential care.

Dementia costs are wider than NHS and social care costs and include, for example, self-funded accommodation costs and costs of unpaid care. It has been estimated that the average costs per annum per person with late onset dementia in 2007 was £25,472.[58] We estimate that there are currently 3,283 people in Croydon living with dementia. Applying these costs, we estimate that the total annual cost to Croydon of people with dementia is £83 million.

[57] http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programme budgeting/index.htm

[58] Knapp, M., Prince, M. et al., (2007) Dementia UK. Alzheimer's Society: London

Table 12 Croydon LA expenditure on mental health – older adults

Service Type	Service	£s (000s)
Home Care	Home Care Service - Older People	146
Home Care	Assistive Technology and Telecare - Older People	1
Day Services	Specialist day/resource centres - older people	418
Residential	Care home (with nursing) - older people	1,800
Residential	Care Home – Older People	1,763
Specialist Service	Memory Assessment Service - Older People	51
Specialist Service	Integrated Community Mental Health Team - Older Peopl	422
Special Groups	Services for young people with dementia	82
Support Services	Self-help and Mutual Aid Group (for older people)	96
Carer's Services	Carer's Support Service - Older People	76
Carer's Services	Carer's Support Group - Older People	44
	Total	**4,899**
	Indirect Costs	434
	Grand Total	**5,333**

Source: Croydon Council Mental Health Finance Map 2010/11

Summary of section 7: Cost

- NHS Croydon spends about £10 million per year on people with "organic mental disorders", some of whom will have dementia
- Croydon council spends about £5.3 million on mental health for older people per year.
- The total annual cost to Croydon of people with dementia is estimated at £83 million.

8 Recommendations

Key Recommendations

1. ***Services should be developed to meet future needs***. Need for dementia care in Croydon is higher and will continue to be higher than many other London boroughs over the next decade. There will be a relatively large number of older people from BAME (Black Asian Minority Ethnic) groups. Croydon should develop dementia services to meet the growing needs of its population.

2. ***The views of people with dementia and their carers should be used as outcome measures*** Croydon should collect and use the views and experience of people with dementia and their carers to develop services and measure their quality. All providers should capture the experiences of those who use their services in a systematic way and use them to develop and deliver services. Croydon should consider undertaking a survey of the views and experiences of people with dementia and their carers in Croydon

3. ***Support to carers should be increased***- Croydon should improve support to carers through regular assessment, information, advice, training, respite and peer support. Providers of dementia care should commit to greater engagement of people with dementia and their carers in an explicit and planned way to inform service provision, service development and decision making. Involvement should be on-going and meaningful.

4. ***The early diagnosis rate for dementia should be increased***. Only two fifths of people with dementia in Croydon have a diagnosis. Croydon should take steps to increase the proportion of people who receive a diagnosis, particularly in Asian communities.

5. ***The needs of people with dementia and their carers should be regularly reviewed***. Croydon should ensure that people with dementia and their carers have their mental and physical needs regularly assessed in primary care. Croydon should reduce primary care variation in the proportion of patient reviewed every year.

6. ***Services for dementia in Croydon should be integrated*** Croydon should develop clear pathways of care from early detection through to end of life across all agencies including health, social care and the voluntary sector. SDS (self-directed support) can help people with dementia and

their carers to manage and personalise their support and Croydon should seek to improve the take up of SDS.

7. ***Access to information about services should be improved and navigation through services should be made easier***. Croydon should develop comprehensive accessible information for everyone: people with dementia, their carers, providers of care and those making referrals. Consider a single point of access to information to develop a shared understanding of what is on offer with a single phone number. Where possible, build on existing initiatives such as the Carer's hub. Bring together the many existing online directories of advice into a single website. Croydon should find ways to help people with dementia and their carers to navigate through the system and obtain the right support and care.

8. ***Awareness and skills of workforce should be increased*** Croydon should continue to provide training and support for people who work in primary care, secondary care, care home staff and other agencies.

9. ***Care for people with dementia in general hospitals should be improved*** Croydon should focus on audits, staff training, and promoting good practice across the Trust, discharge planning, use of specialist advice and closer working with other agencies.

10. ***Antipsychotic prescribing should be reduced*** Croydon should develop more non-drug interventions to help manage behavioural and psychological symptoms, provide on-going training for staff in primary care and care homes and continue to review regularly the medication of those prescribed antipsychotics

11. ***Data quality should be improved*** Croydon should improve the information it holds about dementia care. For example, service providers should systematically collect information about dementia patient experience. The primary register of people with a diagnosis of dementia should be shared with social care. Carers' services should collect the condition of those who they are caring for.

12. ***Recommendations from this needs assessment should now be addressed in the forthcoming local dementia strategy***. Croydon should now ensure that the recommendations from this needs assessment are taken forward in the forthcoming strategy and that SMART (specific, measurable, achievable, realistic, and time-bound) targets and goals are developed to address the identified gaps and issues.

9 Appendices

9.1 Appendix 1 Terms and definitions used this chapter

Acronyms

BAME - Black Asian and Minority Ethnic

CMHT – Croydon Mental Health Team

CPA – Care Programme Approach

CQC – Care Quality Commission

CUH – Croydon University Hospital

EMI - Elderly Mentally Infirm

ICD - International Classification of Diseases

HoNOS – Health of the National Outcome Scales

JSNA – Joint Strategic Needs Assessment

LES – Local Enhanced Service

MCI – Mild Cognitive Impairment

MHOA – Mental Health Older Adults

NAO - National Audit Office

NICE - The National Institute for Health and Clinical Excellence

PbR – Payment by Results

QOF - Quality and Outcomes Framework

SDS – Self Directed Support

Definition of Dementia

The International Classification of Diseases (ICD) codes are the standard diagnostic codes used by clinicians. In the analyses presented within this chapter, the term ‘dementia’ is used to cover ICD10 codes ranging from F00 to F03 and including G30, which cover Dementia in Alzheimer’s disease, Vascular Dementia, Unspecified Dementia and a code for Alzheimer’s disease itself. However, different data sources use different combinations of these codes and do not always include all of the above; therefore a brief note under each table or chart has been provided to highlight this. The full list of codes is shown in Table 13.

Table 13 ICD10 Codes for Mental Health

ICD10 code3	ICD10 code4	Chapter	Block	Description3	Description4
F00	F000	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in Alzheimer's disease	Dementia in Alzheimer's disease with early onset
F00	F001	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in Alzheimer's disease	Dementia in Alzheimer's disease with late onset
F00	F002	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in Alzheimer's disease	Dementia in Alzheimer's disease, atypical or mixed type
F00	F009	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in Alzheimer's disease	Dementia in Alzheimer's disease, unspecified
F01	F010	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Vascular dementia of acute onset
F01	F011	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Multi-infarct dementia
F01	F012	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Subcortical vascular dementia
F01	F013	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Mixed cortical and subcortical vascular dementia
F01	F018	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Other vascular dementia
F01	F019	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Vascular dementia	Vascular dementia, unspecified
F02	F020	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in Pick's disease
F02	F021	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in Creutzfeldt-Jakob disease
F02	F022	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in Huntington's disease
F02	F023	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in Parkinson's disease
F02	F024	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in human immunodef virus [HIV] disease
F02	F028	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Dementia in other diseases classified elsewhere	Dementia in other specified diseases classified elsewhere
F03	F03X	Mental and behavioural disorders	F00-F09 Organic, including symptomatic, mental disorders	Unspecified dementia	Unspecified dementia
G30	G300	Diseases of the nervous system	G30-G32 Other degenerative diseases of the nervous system	Alzheimer's disease	Alzheimer's disease with early onset
G30	G301	Diseases of the nervous system	G30-G32 Other degenerative diseases of the nervous system	Alzheimer's disease	Alzheimer's disease with late onset
G30	G308	Diseases of the nervous system	G30-G32 Other degenerative diseases of the nervous system	Alzheimer's disease	Other Alzheimer's disease
G30	G309	Diseases of the nervous system	G30-G32 Other degenerative diseases of the nervous system	Alzheimer's disease	Alzheimer's disease, unspecified

9.2 Appendix 2 Key documents and timeline

2006 – Dementia Guidelines.

The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint Clinical Guideline on the management of dementia

February 2007

Dementia UK published by the Alzheimer's Society presented information on prevalence, numbers with dementia, and costs.

July 2007

Improving services and support for people with dementia. National Audit Office (NAO) published the findings of its review of dementia services. It was critical about the quality of care received by people with dementia and their families.

January 2008

House of Commons Public Accounts Committee (PAC) published a report on dementia services in January 2008 after considering the NAO report. Its comments and recommendations were consistent with those of the NAO report and with earlier reports on the changes that were needed.

February 2009 – Living well with dementia: A National Dementia Strategy, Department of Health

It identified three themes:

1. Raising awareness and understanding: increasing public and professional awareness of dementia and developing an informed and effective workforce for people working with dementia.

2. Early diagnosis and support: good quality early diagnosis, and intervention for all; good quality information for those with dementia and their carers, which enables continuity of support and advice and planning for the future.

3. Living well with dementia: improving the quality of care for people with dementia in all care settings including nursing and residential care homes; respite care/short breaks; intermediate care, general hospitals and in their own homes.

And it identified 17 key objectives grouped largely within these three themes

November 2009 – Antipsychotic medication report

This highlighted the overuse of antipsychotic medication for people with dementia. It estimated that 180,000 people with dementia were being prescribed antipsychotics and that two-thirds of the prescribing was unnecessary. It also estimated that there are 1,800 excess deaths and 1,620 additional strokes each year as a result of the prescribing of antipsychotics to people with dementia[59]

June 2010 - NICE Quality Standards for Dementia

10 quality standards published

Sep 2010 - Quality outcomes for people with dementia:

Building on the work of the National Dementia Strategy, this was the Department of Health's revised, outcomes focused implementation plan. It supported the national strategy and identified four themes:

1. Good quality early diagnosis and intervention for all - Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.

2. Improved quality of care in general hospitals - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co-morbidity with general medical conditions is high, people with dementia stay longer in hospital.

3. Living well with dementia in care homes - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

4. Reduced use of antipsychotic medication - There are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription.

[59] The *use of antipsychotic medication for people with dementia: Time for action* Department of Health (2009

July 2011 – Dementia Commissioning pack launched.

The pack provides a set of tools and templates for health and local authority commissioners, helping them to design services that are suited to local needs and are cost effective.

December 2011 - Common and complex: Commissioning effective dementia services in the new world.

This document by the Alzheimer's society makes recommendations to the government and NHS about meeting the challenges of dementia commissioning

November 2011 - The Operating Framework for the NHS in England 2012/13

Dementia and the care of older people and carers are two of four areas that the operating framework says require particular attention during 2012/13

NHS, Public Health and Social Care outcomes frameworks

Care of people with dementia and their carers forms part of the government outcomes frameworks for the NHS, public health and adult social care.

- NHS outcomes framework: Domain 2 – enhancing quality of life for people with long term conditions.
- Public Health Outcomes framework: Domain 4 Healthcare public health and preventing premature mortality
- Adult social care outcomes framework: All four domains:
    - Domain 1: Enhancing quality of life for people with care and support needs
    - Domain 2: Delaying and reducing the need for care and support
    - Domain 3: Ensuring that people have a positive experience of care and support
    - Domain 4: Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm

9.3 Appendix 3 Croydon dementia key dataset chart footnotes

1. Proportion of population aged 65+, Mid-2010, Source: Office for National Statistics mid-2010 population estimates (http://www.ons.gov.uk/ons/rel/pop-estimate)

2. Proportion of population aged 65+ from BAME groups, 2011, Source: GLA 2009 Round Ethnic Group Projections - SHLAA (revised) (http://data.london.gov.uk/datastore)

3. Projected proportion of population aged 65+ from BAME groups, 2021, Source: GLA 2009 Round Ethnic Group Projections - SHLAA (revised) (http://data.london.gov.uk/datastore)

4. Projected increase in people aged 65+ living alone, 2011-2030, Source: POPPI based on General Household Survey data applied to ONS population projections. (http://www.poppi.org.uk/)

5. Proportion of people aged 65+ with late onset dementia, 2009, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

6. Projected increase in number of people with dementia, 2009-2021, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london needs assessment 2011)

7. Proportion of the estimated numbers of people with dementia that have been diagnosed and are on the Quality and Outcomes Framework disease register, 2010/11, Source: Mapping the dementia gap, Alzheimer's Society (http://alzheimers.org.uk/)

8. Proportion of dementia patients that have had their review in the last 15 months year, 2010/11, Source: Quality and Outcomes Framework (http://www.ic.nhs.uk/the-quality-and-outcomes-framework-2010-11)

9. Cost of prescribing per estimated case of dementia year (Drug groups included: Donepezil Hydrochloride, Galantamine, Memantine Hydrochloride, Rivastigmine), 2009/10, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

10. Numbers of places in care homes per 1,000 people with dementia, 2005/06, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

11. Percentage increase in people aged 65+ living in care homes, 2011-2030, Source: POPPI based on General Household Survey data applied to ONS population projections. (http://www.poppi.org.uk/)

12. Percentage increase in people aged 65+ providing unpaid care, 2011-2030, Source: POPPI based on General Household Survey data applied to ONS population projections. (http://www.poppi.org.uk/)

13. Residents aged 65+ supported by the local authority to live in mental health care homes (rate per 100,000 residents supported), 2010/11, Source: National Adult and Social Care Information System (NASCIS) (https://nascis.ic.nhs.uk/)

14. Residents aged 65+ supported by the local authority to live in care homes (rate per 100,000 residents supported), 2010/11, Source: National Adult and Social Care Information System (NASCIS) (https://nascis.ic.nhs.uk/)

15. New Mental health assessments for people aged 65+ as a proportion of dementia prevalence, 2008/09, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

16. Social care users for Mental Health as a proportion of late onset dementia prevalence, 2008/09, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

17. Social care users for dementia as a proportion of late onset dementia prevalence, 2008/09, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

18. Hospital admissions for primary diagnosis of dementia, Rate per 1,000 people with dementia, (ICD10 codes used included F00, F01, F02, F03, G30, F059 and G318), 2009/2010, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

19. Inpatient admissions for primary or secondary diagnosis of dementia, rate per 1,000 people with dementia (ICD10 codes used included F00, F01, F02, F03, G30, F059 and G318), 2009/10, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

20. Old age psychiatric patient spells including CPA review as a proportion of dementia prevalence, 2009/10, Source: London Needs Assessment 2011 (http://www.london.nhs.uk/london dementia needs assessment 2011)

9.4 Appendix 4 Description of services for people with dementia and their carers (written by Anne Mbonu and Jan Saines)

Services commissioned by NHS Croydon

Primary Care: Dementia Registers and Reviews

Most people with mental health conditions in late life are never seen by a specialist service, mainly being seen in General Practice. General Practitioners (GPs) are well placed to identify later-life mental health conditions early, to provide people and their families with information and to organise further investigation, treatment and support when necessary.

The National Service Framework for Older People (Department of Health, 2001) required PCTs to ensure that every general practice was using a protocol agreed with local specialist services for the diagnosis, treatment and care of older adults with depression or dementia by April 2004. Physical investigations and cognitive testing instruments are included in many protocols for the treatment of people with Alzheimer's disease, facilitating both early detection of cognitive impairment in primary care and rapid access to anti-dementia drugs.

The Quality and Outcomes Framework (QOF), used by GPs and PCTs to assess performance under the new General Medical Services contract, provides useful information on services provided by GPs. Two new dementia indicators for General Practice were introduced for 2006 and GPs are now required to have dementia registers and to record the number and proportion of people seen from the register in the previous 15 months.

The QOF requires a face-to-face review of people on the dementia register, focusing on support needs of the patient and their carer. In particular, the review should address four key issues:

- An appropriate physical and mental health review for the patient
- If applicable, the carer's needs for information commensurate with the stage of the illness and his/her and the patient's health and social care needs
- If applicable, the impact of caring on the carer
- Communication and co-ordination arrangements with secondary care (if applicable).

The review should also assess for physical ill health. Patient assessments should therefore include the assessment of any behavioural changes caused by:

- Concurrent physical conditions (e.g., joint pain or intercurrent infections)

- New appearance of features associated with dementia (e.g., wandering) and delusions or hallucinations due to the dementia
- Depression should also be considered since it is more common in people with dementia than those without.

As the illness progresses, and more agencies are involved, the review should additionally focus on assessing the communication between health and social care and non-statutory sectors as appropriate, to ensure that potentially complex needs are addressed. Communication and referral issues highlighted in the review need to be followed up as part of the review process.

Croydon Memory Service/Early intervention

This service is provided by the South London and Maudsley Trust (SLaM). It was commissioned in 2003. The Croydon Memory Service provides early assessment; diagnosis and treatment for people aged 18+ who have memory problems that may be associated with dementia. It provides comprehensive assessments of people's cognitive abilities in general and their memory in particular in order to determine whether they are experiencing any memory impairment and whether this is greater than expected for their given age. People whose memory seems to be declining over a period of at least six months are eligible for referral to the Croydon Memory service by their General Practitioner.

Where applicable, a diagnosis of dementia is made and clients are offered the appropriate intervention to help minimise the problems caused by declining memory. These may include treatment with medication, talking therapies (both individual and group format) and attendance at day centres. Clients are followed up at clinically appropriate intervals and their therapy adjusted accordingly.

Clients are discharged from the service back to their General Practitioner or another appropriate service such as a Community Mental Health Team (CMHT) when they are no longer able to benefit from the interventions offered by the memory service.

The Department of Health (DOH) has provided additional £52,000 funding for the Croydon Memory Service. This money is to be used to deliver an enhanced memory service and is due to be transferred to Croydon Council by NHS Croydon by the end of the 2011/12 financial year.

Chelsham House, Bethlem Royal Hospital (Acute mental health in patients unit)

This service is provided by the South London and Maudsley Trust (SLaM). Chelsham House is a 30 bed acute admission and assessment mental health of older adults inpatient ward located at the Bethlem Royal Hospital. This

service is commissioned by NHS Croydon as part of the SLaM block contract. Adults over 65 years of age who have acute mental health problems are admitted to the unit for assessment and treatment following referrals from either the CMHT or Croydon University Hospital (admissions from Croydon University Hospital may be arranged via the Mental Health of Older Adults Liaison Service). During their in-patient admission, people will receive various assessments and interventions from psychiatrists, the nursing team, general physicians, occupational therapists, social workers and other clinically appropriate healthcare professionals. For some clients, the multi-disciplinary ward team may determine that they are eligible for NHS Continuing Healthcare, in which case a Continuing Care assessment using the national assessment template (the Decision Support Tool) will be completed and thereafter presented to the Continuing Care panel for ratification of the multidisciplinary team's recommendation. Such clients will usually be discharged to a Continuing Care placement funded by the NHS or receive a home care package if appropriate. Discharge planning occurs during the admission. Following the resolution of acute mental health problems, people are usually discharged home with notification sent to their General Practitioners. There is usually a follow up within 7 days of discharge and sometimes people are reviewed in the outpatient clinic after a clinically appropriate interval. The CMHT may also offer further input as appropriate. A significant number of people admitted to Chelsham house have a diagnosis of Dementia.

Mental Health for Older Adults (MHOA) Liaison Service at Mayday Hospital

This service is provided by the South London and Maudsley Trust (SLaM). This is a specialist mental health service for older adults provided by SLaM at Croydon University Hospital. This service is available to people aged 65+ who are admitted to a medical ward at Croydon University Hospital for a physical health problem such as a urinary tract infection, and who may experience mental health difficulties during their admission. Any such people are referred to the Liaison service, which provides mental health assessments, support and advice to the client and to the multi-disciplinary ward team to assist their clinical management of the client. If the multi-disciplinary ward team believe that the client may be eligible for NHS Continuing Healthcare on the basis of a primary mental health need, a referral is made to the liaison team, which will complete the Continuing Care assessment using the Decision Support Tool (DST), applying their particular expertise to the mental health domains of the DST; the assessment is then presented to the Continuing Care panel for ratification of its recommendation. The liaison team also supports the discharge planning process and liaises

with the CMHT and other community services as appropriate. A significant number of referrals to the liaison service are for people with dementia.

Community Mental Health Teams (CMHT) for Older Adults

This service is provided by the South London and Maudsley Trust (SLaM). There are 3 Community Mental Health Teams CMHTs) serving Croydon's population - the North, South and Central CMHTs each serving North, South and Central Croydon respectively. The CMHTs are integrated teams, consisting of psychiatrists who specialise in older adult psychiatry, community psychiatric nurses (CPNs), mental health support workers, psychologists, occupational therapists, care managers, support workers and administrators. People are usually referred to the CMHTs from primary care services, usually their General Practitioner. The teams serve people aged 65+ who are experiencing acute or relapsing mental health conditions and their carers, and also people under the age of 65 with progressive memory problems. Patients are initially seen in their own home or outpatient clinic by a team member who carries out an initial assessment. They are then offered appropriate follow-up, treatment and referral to other appropriate services. People are usually assigned a care coordinator with the CMHT and remain on the team's caseload until the resolution of their acute mental health problem at which point they are discharged back to the care of their General Practitioner or other relevant services. People may be referred to Chelsham house mental health in patient unit if their mental health deteriorates beyond the point that is manageable within the community. The CMHT is also able to perform continuing care assessments using the DST if deemed appropriate, and thereafter make recommendations to the Continuing Care panel.

MHOA Intensive Assessment Service (IAS)

This service is provided by the South London and Maudsley Trust (SLaM). NHS Croydon commissioned this service as a pilot from SLAM in September 2011. The service aims to provide a comprehensive mental health and continuing care assessment to people aged 65+ years with mental health problems (usually related to dementia) who are on admission to a medical ward at Croydon University Hospital, where there is a likelihood that they may be eligible for continuing care. The service is provided by a Consultant Psychiatrist led multidisciplinary team. This team provides comprehensive mental health assessments (including Continuing Care assessments using the DST) and appropriate interventions including medication where appropriate. People are referred to it by the MHOA Liaison Service at CUH. Whilst not formally known as an intermediate care service, it fulfils some of the functions of an intermediate care service in the sense that it caters to people who are medically fit for discharge from Croydon University Hospital, but who are experiencing some mental health problems that prevents them

from being discharged back to their usual place of residence. These mental health problems are typically not severe enough to warrant admission to Chelsham house mental health in patient unit. However, if a person mental health deteriorates whilst they are in the IAS, they are referred to Chelsham House mental health in patient unit. Other people are discharged to their previous place of residence following the resolution of their mental health problems, or otherwise admitted into NHS Continuing Healthcare for a primary mental health need if this is the recommendation of the MDT at the IAS to the Continuing Care panel.

Croydon Health Services – Croydon University Hospital (Acute General Hospital)

People in Croydon who have a diagnosis of dementia attend Croydon University Hospital (CUH) when they have a physical health problem. In some cases, dementia may complicate their medical treatment, in which case the medical team will refer individual cases to the Mental Health of Older Adults Liaison service. CUH has nominated a dementia lead clinician and has developed guidance on the management of Acute Confusional States (Delirium). This is helpful as people with dementia may develop acute confusional states when physically unwell, and this may complicate their care, prolonging their hospital length of stay and leading to delayed discharges.

A Dementia CQUIN (commissioning for Quality and Innovation) has been nationally mandated for 2012/13. NHS Croydon is in the process of developing this further in consultation with the appropriate stakeholders.

Croydon's Joint Community Learning Disability Team (JCLDT) – part of Croydon Health Services NHS Trust

The Croydon JCLDT provides services to people with learning disabilities who have been diagnosed with dementia. The team includes consultant psychiatrists and Learning Disability and General trained nurses, Dieticians and Speech and Language therapists. The team has a mental health pathway that incorporates a dementia pathway in place for people diagnosed with learning disabilities who subsequently develop dementia. People are referred to the team by their General Practitioner. They remain on the team's caseload for as long as the team's input is appropriate and beneficial.

NHS Continuing Healthcare

NHS Continuing Healthcare is provided for people whose care needs are predominantly health needs and who meet continuing care criteria for care funded fully by the NHS as defined in The National framework for NHS continuing healthcare and NHS-funded nursing care - July 2009. Examples of people meeting continuing care criteria would be those in the end of life stage

of dementia. In this case, they would be eligible on the basis of a primary mental health need.

Croydon has Continuing Care pathways for determining eligibility and providing assessment for continuing care. Where primary mental health needs e.g. dementia exist, people will be referred for a comprehensive assessment using the nationally mandated continuing care assessment tool – the Decision Support Tool (DST). The referrals can come from any concerned individual but the assessment must be carried out by qualified mental health clinicians and social work practitioners. The assessment is usually provided by the Intensive Assessment Service or Chelsham House mental health in patient unit (referrals from the MHOA Liaison Team) if the client is an in-patient at CUH or by the appropriate CMHT if the client is in a community location.

The completed assessment is then presented to Croydon's Continuing Care Panel for ratification and allocation of funding. An appropriate placement is then sought.

NHS Croydon has commissioned a block contract of 20 continuing healthcare beds from Care UK, a registered independent sector care home provider. These beds are provided at Amberley Lodge, Purley, which is a 60 bed unit providing NHS continuing care to the older adult population. Excluding the block contract of 20 beds with Care UK – Amberley Lodge, there are a further 98 people receiving NHS funded continuing healthcare in Croydon. These people are receiving care in spot purchased continuing healthcare beds in various Croydon homes. Majority of these people have a diagnosis of dementia.

Some older people with mental health needs opt to have their continuing care needs met in their own homes; Croydon PCT funds Home Care Packages for these individuals. This is more often the case if people have combined physical and mental health needs. Although this care is funded by the PCT, it can be provided by a combination of health and social care professionals.

Due to on-going demographic changes and the predicted rise in the incidence of dementia, we anticipate there will be growth in the number of people requiring NHS funded continuing healthcare.

Croydon has established joint commissioning agreements between health and social care and several services are jointly funded for example the Croydon memory service.

Independent Mental Capacity Advocacy (IMCA) Service

This service is jointly funded by health and social care and is well established in Croydon. It is provided by VoiceAbility, an independent charity. It supports people with dementia who lack the mental capacity to make decisions about

their treatment, hospital discharge plans and other aspects of their care. People are usually referred to this service by health and social care professionals within hospitals and residential or nursing care homes when important decisions about people's care need to be made. The service provides independent advocacy to clients, and also training to health and social care professionals.

POP STOP services

Following a successful application for funding from the Department of Health Partnership for Older People, Croydon now provides the POP STOP mobile service. Its need was identified by older people and carers at the open space event in 2005. The POP service was introduced in 2007. This takes a range of services directly to older people in their own communities. More frail older people are now helped to live independently, with appropriate support when they need it.

It brings together Croydon's health, local authority and other statutory and voluntary agencies and is available 7 days a week with a flexible timetable including evenings and delivers information, services and support right to people's doorstep.

It provides one point of access for health, social care, transport, benefits, housing, leisure, social participation, community safety and crime reduction interventions. It helps to address the needs of carers and the needs of people with long term conditions including dementia. It encourages greater involvement and participation of the community, voluntary sector and independent sector.

Older people have been helped to access £1.5 million in extra benefits through the POP service.

Services commissioned by Croydon Council

Housing Services

The Homes for the Future programme is the council's programme to modernise residential and day care services for older people in Croydon. It is funded through a £39 million private finance initiative source.

Extra care sheltered housing is also being developed to support people with higher care needs. Extra care sheltered housing provides a higher level of support to help people with their social care needs. "Homes for the Future" (New4Old) is a key partnership between the Council, Croydon PCT and South London and Maudsley NHS Foundation Trust to modernise local authority residential homes and develop extra care housing for older people.

Home Care Services

Social and nursing care, including palliative care, is available to support older people at home. This includes falls prevention and rehabilitation after falls.

Home care provides personal care to people living in the community. Care managers and social workers are responsible for assessing older people to see if they have significant social care needs and are eligible for home care. Independent home care agencies then provide the care in accordance with the person's care plan. Many of the people identified by the Older People's Care Management Team and the Community Mental Health Older Adults Team have personal care needs and are cared for in the community by home carers. As the carers usually visit people frequently, often on a daily basis, they are in a key position to monitor changes and deterioration in health. It is essential that home carers are trained to identify mental health needs so they can identify if their clients are developing memory problems or depression and can refer early to specialist services.

Carer support services/initiatives

Croycare, launched in 2009, is an emergency service for carers, which provides up to 72 hours of care support should something happen to the carer. Over the past full year of operation, the number of carers registered for the Croycare service has increased from 110 to 228. Ten new carers' services (in relation to support, training, respite activities/breaks and peer support) delivered 4,051 breaks for carers, to enable them to live ordinary lives and manage their caring duties towards vulnerable people.

The Alzheimer's society works closely with the Memory service and provides advice and information on dementia and various aspects of caring to people with dementia and their carers, including:

- ***Dementia support*** - Provision of Outreach Support to people with dementia and their carers, via telephone support and one to one visits, giving information and advice, and emotional support. Monthly support groups,
- ***Carers' Assessment*** - Formal Carers Assessment by referral from Social Services, Memory Services and Community Mental Health Teams
- ***Forget-me-not Café*** - A cafe providing an opportunity for social interaction and activities for people with dementia, their carers, family and friends.
- ***Information and Advice*** - Providing telephone information and advice to people with dementia, their carers, family and friends. Providing information and advice at public events

- ***Peer Support Group*** – a set of Monthly held peer support groups for people with dementia, carers and young carers
- ***Training for Carers*** - Carers Information and support programme delivered periodically.

Preventive equipment and technology: Adaptations and Equipment

Croydon has a prize-winning Assistive Technology (Aztec) Project which installs assistive technology equipment packages to support people with dementia and their carers in their own homes and prevent long term residential or nursing placement. The Integrated Mental Health in Older Age Team delivers this project in partnership with the integrated Community Equipment Service and Croydon Careline. Between April and September 2006 an average of 129 calls per month were received activated by assistive technology devices to detect a range of problems including wandering, inactivity and gas leaks. The Aztec Centre has a Telecare dementia service for people with severe dementia.

Adaptive technology and aids in people's homes are also offered through CARELINE and the joint equipment service.

The Telecare in Homes for the Future project will help people in care homes who are at high risk of hospital admission with personalised care plans, information and education.

Croydon's Major Adaptations Unit adapts housing to meet people's needs to support them to live and remain in their own homes. People with mental health conditions in older age, who sometimes have co-existing physical health problems, may need to have their homes adapted to make them safe for living at home. Equipment can also be provided by the integrated Community Equipment Service to support people's care needs. The equipment store is open to the public one day a week for people to see what is available.

Croydon is one of the 11 local authorities that have been successful in obtaining funding for a self-assessment pilot project. The project focus is for the development of a fully accessible self-assessment tool and procedure for people to be able to independently determine their need for equipment and minor adaptations, to purchase equipment direct via the equipment store or via the online equipment store and to enable them, if they choose, to refer themselves for further Council services as appropriate.

Care Homes

There are 20 council accredited care homes specialising in the care of older people with mental health needs (elderly mentally frail, or EMF) in Croydon

with a total of 558 beds designated for those with dementia. Three of the residential homes are run by the Council and will be redeveloped as part of Homes for the Future (New4Old).

Under Health Flexibilities Legislation, Croydon Council and the PCT have entered into a partnership arrangement enabling the PCT to provide the governance for the nurses who will be employed in Council new care homes as part of the modernisation and redevelopment of the Council's residential care homes. This enables the Council to become a provider of nursing home beds and increase extra care sheltered housing provision in line with the strategic aim to reduce residential beds, supporting more people to live independently at home, and increase nursing bed provision.

There are also currently 5 private and voluntary run homes in the borough for older people with a past or present mental illness, with 105 beds.

As more people are supported to live independently at home for longer the point at which people will need 24-hour care and support in a care home will be later in their illness, when they are very frail and in need of high levels of care. For people with lower care needs, Homes for the Future (New4Old) will provide 32 one bed flats and 8 two bed flats together with small cluster communal lounges and kitchenettes and assisted bathrooms. For those with higher level needs Homes for the Future (New4Old) will increase the number of nursing home beds for older people with mental health needs at the 60 place Heavers Farm resource centre.

Extra Care Sheltered Housing

Heavers Court was opened in 2009. It provides residential care home services to people with Dementia. It is managed by Care UK. The Heavers residential and resource centre provides 100 extra home care and 106 day care places.

Croydon Council commissions a Care Home Support Team to provide training, advice and support to Croydon nursing and residential care homes.

Self-Directed Support

Direct payments are cash payments made to an individual directly, giving them the choice to buy and arrange their own social care services. Direct payments are intended to give an individual wider choice, control and flexibility to meet their individual social care needs. Direct payments can be used to buy services such as:

- Personal care: getting up, washing, dressing
- Practical tasks: preparing meals, shopping, housework

- Getting out and about: going to work, visiting a friend or relative, going to leisure activities
- Help for carers e.g. for breaks from caring.

People taking up direct payments are given the help to manage their direct payments - both in securing the services and the support they want the direct payments to provide, and in dealing with the finances.

Counselling and talking therapies

Some reablement fund money has been set aside for IAPT (increasing access to psychological therapies) in older adults

Equality/BME Services

BME Service Development Officers are employed by Croydon Adult Social services to support voluntary sector providers for BME elders.

Croydon Social Services commission a range of voluntary sector providers to support BME elders and also specific services to support BME elders with mental health conditions and their carers. An example is the Charisma day care service provided by Topcare.

Safeguarding

A Safeguarding Vulnerable Adults (SVA) Team and a Care Support Team were established in 2008 to support vulnerable people at risk of neglect or abuse and to support care homes and care agencies in improving their quality of care provision.

The establishment of a Safeguarding Adults Team has led to successful investigation of the highest number of allegations of abuse in London. Neither the council nor the NHS places anyone in a zero rated care home. Most domiciliary care providers are rated good or better by the care quality commission. All service providers for the council and NHS Croydon have to adhere to the multiagency Safeguarding procedures. Increasing numbers of staff in the statutory and non-statutory sector receive regular safeguarding training.

Croydon complies with the Deprivation of Liberty Safeguards (DOLS). This means that vulnerable older adults including those with dementia are not unnecessarily deprived of their liberty.

Advice and Information

Croydon Alzheimer's Society also offers a range of peer support services for people with dementia and their carers.

The Partnerships for Older People (POP) service provides information, advice and support to older people in their neighbourhood, helping them to live independently with appropriate support when they need it. The POP service is targeted at the over 55 population and tries to reach people who do not access services. Most services are offered direct from a mobile unit and advice is offered about other services. The aim is to prevent people allowing a condition to deteriorate to the point of needing intensive support or treatment. A 2009 evaluation found that the service was cost effective and well-liked by service users, but it recommended encouraging uptake in those aged 50 to 70, who were less likely to access the service.

Health and Wellbeing

Free swimming is available for those aged over 60 years across the borough. Active Lifestyles also provides a range of activities including walking and keep fit.

There is an Older Peoples Network (OPeN), which campaigns for older peoples interests.

End of Life care

Croydon Council have commissioned a pilot scheme operated by St Christopher's Hospice. Two nurses are currently working with four residential homes to enable service users to remain at home rather than being transferred to hospital at the end of their life. This project is now transferring to all residential homes and a social worker is being recruited to provide support planning.

DAY SERVICES

Day centres enable older people to remain in the community by maintaining or improving their quality of life or that of their carer through social contact and therapeutic activities. Day services also provide support in periods of personal stress thereby helping to reduce the likelihood of admission to hospital and avoiding or delaying the need for long term residential or nursing care. They aim to enhance the independence and social acceptance of service users and provide respite for carers through day support, respite care and carers groups. Croydon Council is currently working with Addington Heights to transform the use of Day Care facilities. This pilot which is OT led provides reablement facilities on discharge from hospital and includes activities of daily living, assessment for equipment and short stay for those who are not ready to return home due to risks or safety.

"Homes for the Future" (New4Old) aims to increase the amount of care provision for older people with mental health needs as below:

Heavers Farm Resource Centre provides a one-stop service for dementia sufferers and their carers and is a:

- 60 place resource centre for the care of older people with mental health needs
- 16 place early onset dementia support unit
- 15 place outreach service
- 24 place day activities centre to support mentally frail older people living at home

Coleby Court Extra Care Housing and Day Activities Centre (Physically Frail) has 32 one bed flats and 8 two bed flats. It is a 36 place day activities centre.

Langley Oaks Resource Centre - 40 place resource centre for the elderly mentally frail and a 16 place day activities centre.

Addington Heights - 18 place day care centre

Bensham - 25 place day care centre

Voluntary sector services

The Positive Ageing project from Age UK Croydon offers a variety of services for those aged 50 to 90. They include support to eat well, manage weight, and increase physical activity, falls prevention, advice on housing options and using arts and crafts to promote mental wellbeing. Some groups are coproduced by service users, set up initially by the service and then run by members, including lunch clubs and healthy eating clubs in sheltered housing.

Over 50 council supported lunch clubs, including the Neighbourhood Care Association lunch clubs, cater for those over 60, although some groups attract those aged 50 plus. These services provide befriending, advocacy, education, training and carers' respite

In March 2007 Croydon Council was awarded Beacon Status in the category "Increasing Voluntary and Community Sector Service Delivery", recognising the strong relationship that exists between the Council and the voluntary sector and the key contribution that the sector plays. Croydon has a diverse, flourishing voluntary sector that is made up of voluntary and community organisations, faith groups and social enterprises. For older people the voluntary sector is involved in five key areas:

- ***Community Involvement*** - The Voluntary Sector Service Providers for Older People (VoSSPOP) is an overarching body that represents voluntary organisations in Croydon which support older people by encouraging people to become involved in consultation and representing the interests of older people through events, networks and partnership groups.

- ***Advocacy, Advice, Training and Information*** - The Alzheimer's Society runs a programme to train recruits to offer information to people caring for those with dementia. It trains around 30 people a year.
- ***Respite*** - Short term breaks and respite care are provided for Croydon carers through Crossroads Carers. The respite breaks range from one hour to 24/7 care for a whole week to enable a carer to go on holiday. Between February 2011 and February 2012 a total of 2264 breaks were provided for carers looking after someone with dementia. The Alzheimer's Society also plays a key role assessing for and managing access to the respite beds at Amberley Lodge.
- ***Day Services*** - Croydon Neighbourhood Care Association groups also provide a large number of day services and luncheon clubs for older people with dementia.
- ***Practical help*** - Age Concern Croydon and Croydon Neighbourhood Care Association groups are key organisations in providing services such as minor repair work and health related activities. The Alzheimer's Society runs the Alzheimer Café attended by up to 100 carers. Six carer support groups offer a full programme of activities to improve the quality of life of carers and reduce the social isolation that can be a consequence of caring.

9.5 Appendix 5 Recommendations from the dementia consultative meeting attendees

At the dementia consultative meeting, attendees were asked to identify the three most important recommendations that the JSNA should make to improve dementia care in Croydon. They are listed below, grouped into themes

Integration / information / navigation

Greater links with the voluntary sector and understanding what individual voluntary sector organisations provide – not all the same!

Carer-centric service provision, how the system works and how to understand it simply

Improved out of hours – one stop dementia service

Simplification of personalised budget without means testing for basic support

Integrated, joined up services – focus on pathway mapping

Single point of access to information / advice about dementia services for everyone (people with dementia, carers, and professionals)

Early detection, simple, straightforward journey towards end of life care with an advocate along the journey

Support for carers

Improve recognition and support for carers (unpaid) including the social wellbeing of carers

Continuous engagement and involvement of carers – needs assessment, evaluation of service, identification of hidden carers, directory of services

Fear and stigma

Remove the fear and stigma of dementia

Hospital care

Improved dementia care in hospital using successful models in other areas e.g., Kings College Hospital dementia ward, Oxleas, SLAM learning disability

Outcomes based on experiences of people with dementia

Systematic collection of views of people with dementia and carers – can be used to measure outcomes