

Dementia

Summary

- Dementia describes a set of symptoms which includes memory loss, mood changes and problems with communicating and reasoning.
- Dementia is not just part of growing old. It is caused by diseases of the brain, the most common of which is Alzheimer's.
- People with dementia can live well with their dementia provided they and their carers have good, timely and person centred advice, support and care within a non- stigmatising and understanding community.
- One in six people over 80 and one in 14 people over 65 have a form of dementia. Prevalence is higher in women in the older age groups.
- There are estimated to be over 18,000 people with dementia in Hampshire, but only 8,695 people on GP dementia registers.
- The number of people with dementia in Hampshire is predicted to increase by over 30% from 18,323 in 2012 to 24,042 in 2020.

Recommendations

- Prevention – link to prevention programmes for cardiovascular disease.
- Support the development of Hampshire Dementia Alliance with a Hampshire County Council member champion.
- Health and Wellbeing Board support for the development of dementia friendly communities through the Joint Health and Wellbeing Strategy.
- Clinical Commissioning Groups continue to support GPs to diagnose dementia early by commissioning relevant support and memory clinic services.
- Better hospital care – more holistic and integrated approach to people with dementia in acute hospitals.
- Support carers and their specific needs.
- Further develop the specialised end of life care for this group of people.

1. Introduction

The term dementia describes a set of symptoms which includes memory loss, mood changes and problems with communicating and reasoning. Dementia is not just part of growing old. It is caused by diseases of the brain, the most common of which is Alzheimer's. People with dementia can live well with their dementia provided they and their carers have good, timely and person centred advice, support and care within a non- stigmatising and understanding community.

Nationally we know that:

- There are currently 800,000 people with dementia in the UK.
- There will be over a million people with dementia by 2021.
- Two thirds are women.
- The prevalence of dementia is closely associated with age.
- People from all ethnic groups are affected by dementia.
- One third of people over 95 have dementia.
- 60,000 deaths a year directly attributable to dementia.

Dementia

- Delaying the onset by 5 years would halve deaths directly attributable to dementia.
- The financial cost is over £20 billion a year.
- Family carers save the UK over £10 billion a year.
- At least two thirds of people living in care homes have a form of dementia.
- Two thirds of people with dementia live in the community.
- Only 43% of people with dementia ever receive a diagnosis.
- The UK is in bottom third of European performance in terms of diagnosis and treatment of dementia.

1.1 The causes of dementia

1.1.1 Alzheimer's disease accounts for 62% of all dementia and is caused by changes in the structure of the brain and a shortage of important chemicals that help with transmission of messages.

1.1.2 Vascular dementia accounts for 17% and is caused by problems in the supply of blood to the brain, commonly caused by a stroke or a series of small strokes.

1.1.3 Mixed dementia (10%) is a type of dementia where a person has a diagnosis of both Alzheimer's disease and vascular dementia.

1.1.4 Dementia with Lewy bodies (4%) is one of the less common forms of dementia, and it is caused by irregularities in brain cells. It leads to symptoms similar to Alzheimer's disease and Parkinson's disease.

1.1.5 There are many rarer conditions that can lead to dementia or dementia-like symptoms, including Corticobasal degeneration and Creutzfeldt-Jakob disease. Fronto-temporal dementia (2%) is rare when all ages are taken into account but relatively common in people under 65, it is a physical disease that affects the brain.

1.2 Risk Factors

Factors associated with increased risk of developing dementia include high blood pressure, high body mass index (BMI), smoking and possibly diabetes. This highlights the overlap with cardiovascular disease, so earlier interventions to improve cardiovascular health such as stopping smoking, a healthy diet and regular physical activity can all help to reduce the risk of developing dementia.

Alcohol intake may be linked to the development of dementia in as many as 10-24% of cases in the UK. Binge drinking and increased consumption may result in earlier development of serious memory problems.

The direct costs of dementia (Alzheimer's Disease) alone exceed the total costs of stroke, cancer and heart disease in cost of illness studies.

Dementia

2. Level of need in the population

There are estimated to be over 18,000 people with dementia in Hampshire and is most common in older people. One in six people over 80 and one in 14 people over 65 have a form of dementia. Prevalence is higher in women in the older age groups (table 1).

Table 1: Prevalence of dementia by age and sex

Age group	Prevalence of dementia	
	% Male	% Female
65-69	1.5	1.0
70-74	3.1	2.4
75-79	5.1	6.5
80-84	10.2	13.3
85-89	16.7	22.2
90+	27.9	30.7

2.1 Community Mental Health Profiles

The Community Mental Health Profiles 2013¹ estimate the overall prevalence of dementia in adults (18+) from NHS data. The rate in Hampshire at 0.65% is significantly higher than the England average of 0.53%. This is not surprising as Hampshire has a greater proportion of residents in the “older old” age groups compared to the England average; and as table 1 shows the prevalence of dementia is much higher in these groups.

2.2 Prevalence information from general practice

GPs register the number of people with dementia as part of the Quality Outcomes Framework (QOF) data collection. The figures are dependent on how individual practices identify patients and record information. Less than half the estimated number of people with dementia are recorded on the registers.

In 20011/12 there were 8,695 people on the GP registers in Hampshire, a prevalence rate of 0.7%.

Figures 1 and 2 show how the prevalence of dementia as recorded by GPs varies by CCGs and local authorities in Hampshire. Rates are higher in East Hampshire (0.8%), Gosport (0.8%) and the New Forest (0.9%); and lower in Hart (0.4%); Basingstoke and Deane (0.4%) and Rushmoor (0.4%).

¹ <http://www.nepho.org.uk/cmhp>

Dementia

Figure 1: prevalence of dementia in Hampshire by CCG, 2011/12

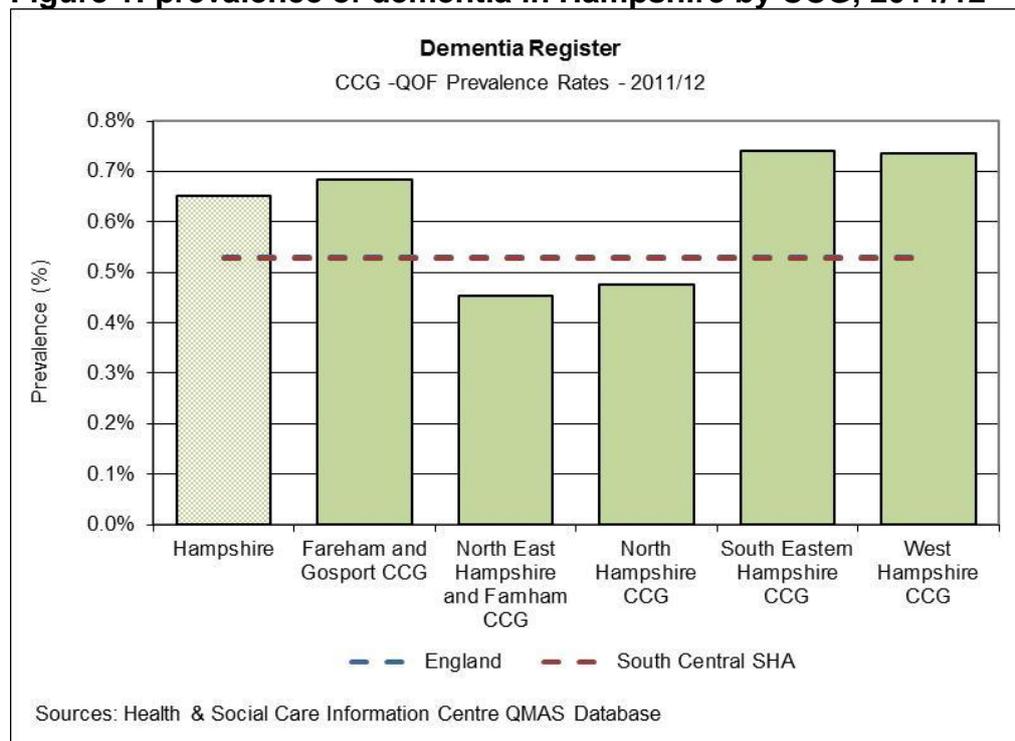
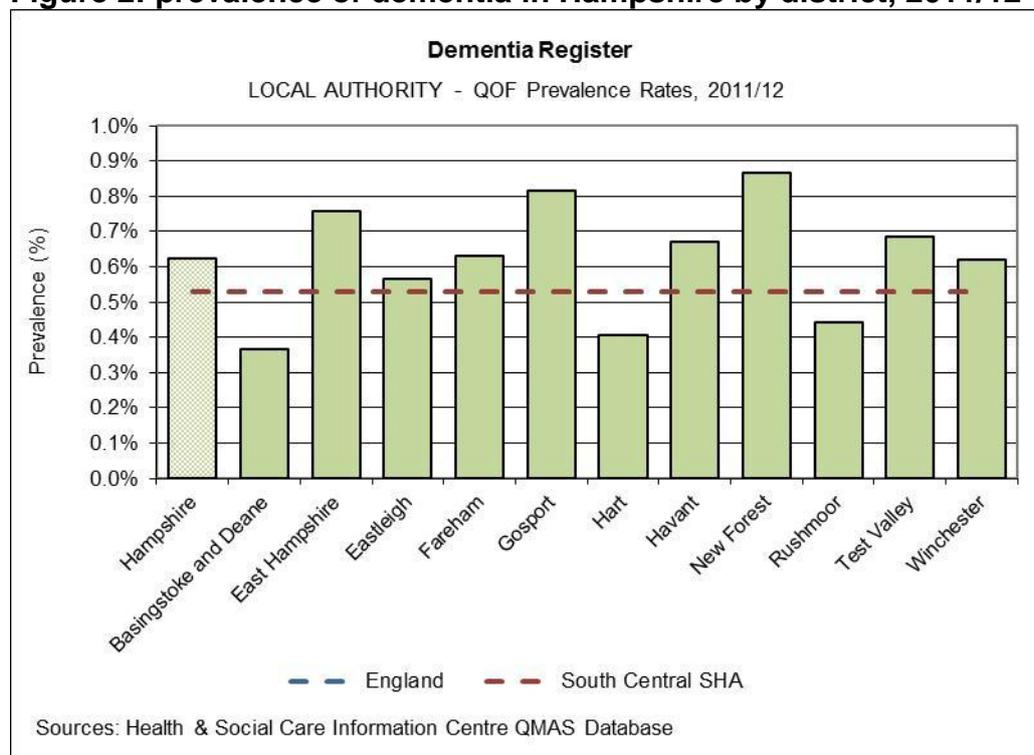


Figure 2: prevalence of dementia in Hampshire by district, 2011/12



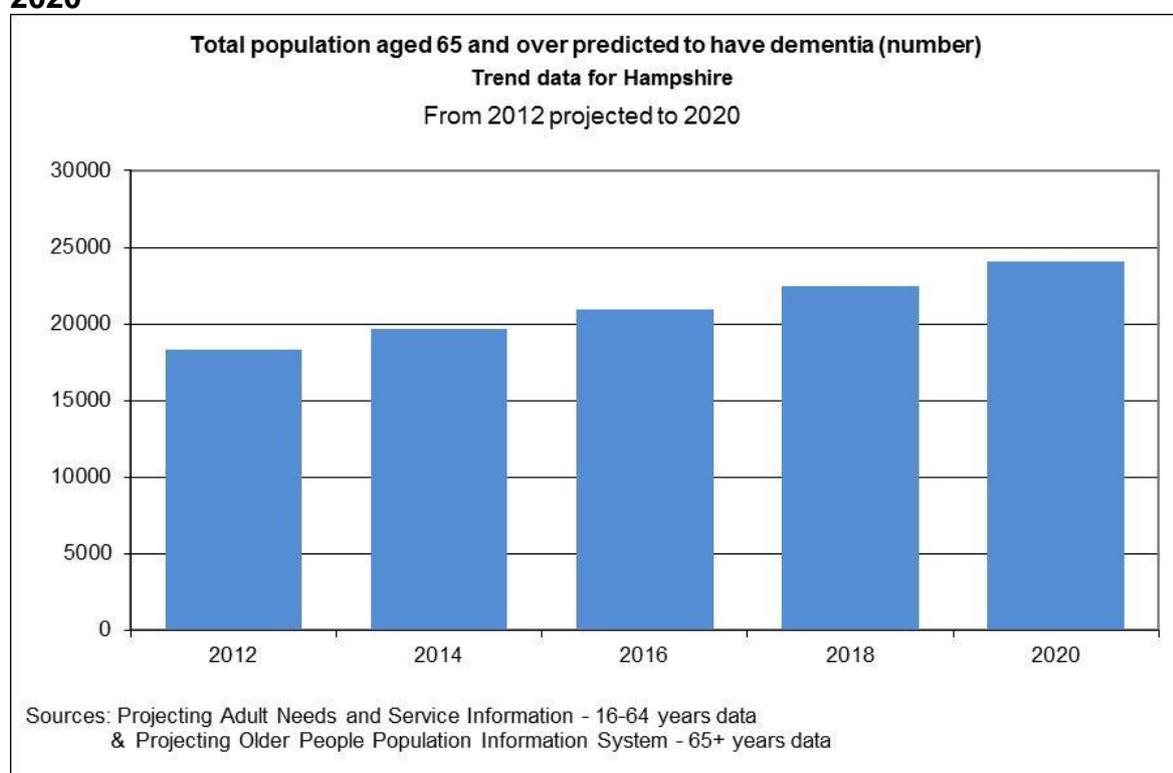
Dementia

3. Projected service use and outcome

If nothing else changes and the prevalence rates of dementia remain the same, then the increasing longevity of the population will mean that there will be a considerable increase in the number of people with dementia over the next decade.

The number of people with dementia is predicted to increase by over 30% from 18,323 in 2012 to 24,042 in 2020 as demonstrated in figures 3, 4 and 5 and table 2. Rushmoor has lowest overall estimated numbers and the New Forest the highest based on its population and the predicted increase in the number of older people. All local authority areas in Hampshire have a greater percentage increase in the number of men with dementia than women – presumably as male life expectancy increases and so age specific prevalence rates increase. This predicted increase is highest in Winchester for men and highest in Hart for women.

Figure 3: projected estimates of dementia in people age 65+ in Hampshire to 2020



Dementia

Figure 4: trend in number of people age 65+ projected to have dementia by district, 2012 to 2020

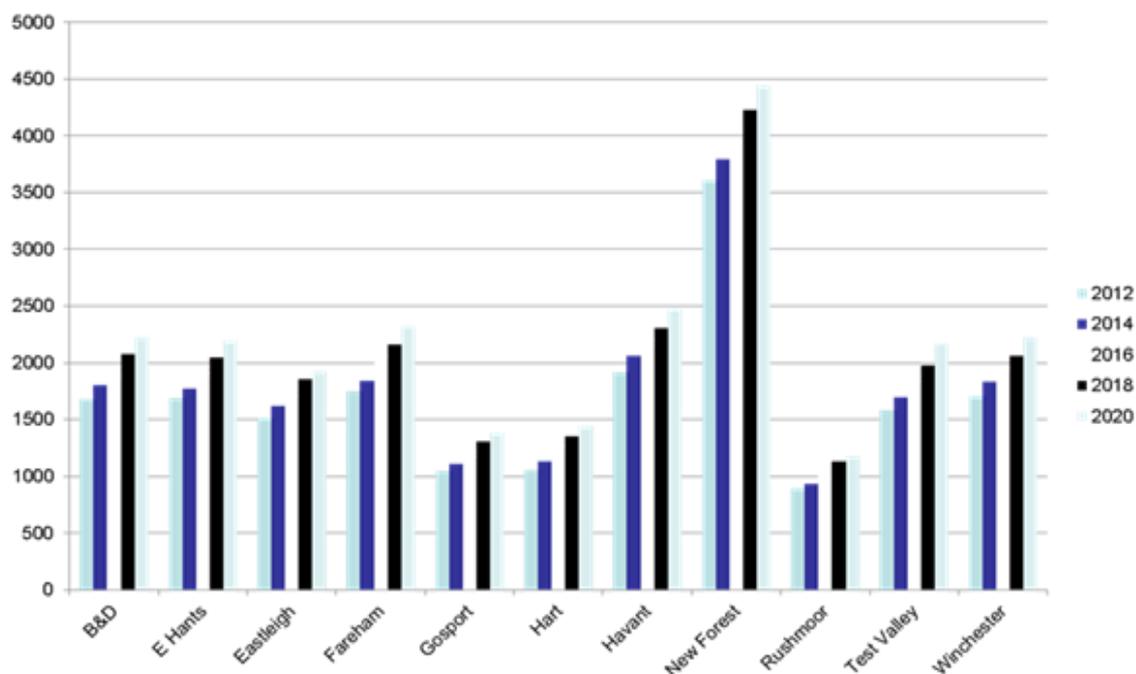


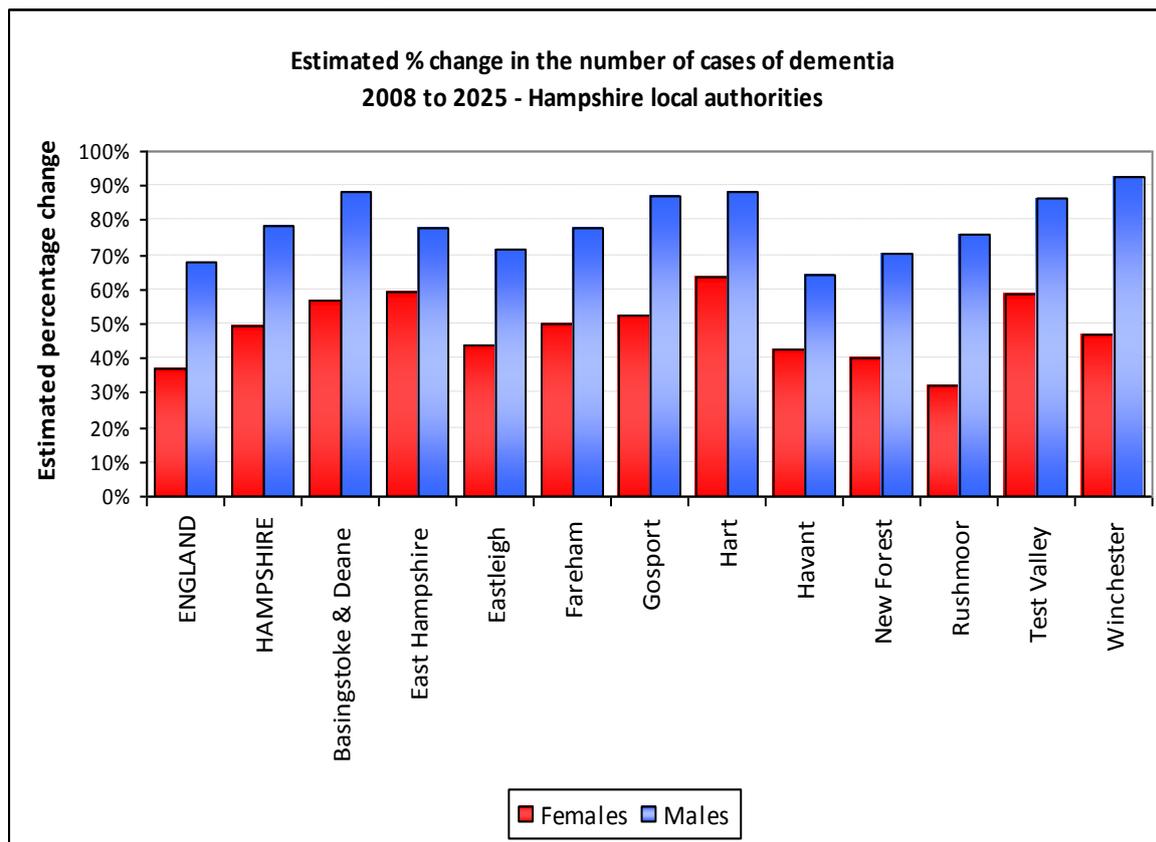
Table 2: trend in number of people age 65+ projected to have dementia by district, 2012 to 2020

Local authority	Total population aged 65 and over predicted to have dementia (number)				
	2012	2014	2016	2018	2020
Basingstoke and Deane	1,682	1,798	1,873	2,074	2,219
East Hampshire	1,685	1,774	1,883	2,046	2,188
Eastleigh	1,513	1,621	1,722	1,856	1,927
Fareham	1,747	1,841	2,038	2,159	2,320
Gosport	1,049	1,108	1,191	1,305	1,380
Hart	1,053	1,134	1,245	1,355	1,445
Havant	1,915	2,062	2,177	2,302	2,480
New Forest	3,609	3,791	3,977	4,227	4,444
Rushmoor	1,580	1,693	1,854	1,974	2,167
Test Valley	1,580	1,693	1,854	1,974	2,167
Winchester	1,706	1,835	1,927	2,064	2,223
Hampshire	18,323	19,667	20,922	22,464	24,042

Source: Projecting older people population information system (POPPI)

Dementia

Figure 5: estimated % change in number of dementia cases by district, 2008 to 2025



Source: Estimating the future number of cases of dementia in England (NEPHO / Mental Health Observatory)

4. Current services in relation to need

The previous section showed that as Hampshire’s population becomes older there will be an increasing number of people with dementia with all the implications that has for individuals, families, services and the wider community.

Locally we have relied on the national policy to inform the development of the *Joint Hampshire Commissioning Strategy for Older People’s Mental Health 2008-13*. The accompanying action plans describe local approaches and service developments to date and this is currently being refreshed.

4.1 Dementia Friendly Toolkit

A pilot project to develop dementia friendly communities was undertaken in North East Hampshire in 2011. A result of this pilot was that in spring 2012 Hampshire County Council published a toolkit for businesses and organisations to help them think about how to become more dementia aware and friendly.²

² <http://www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-toolkit.htm>

Dementia

This toolkit is one of the initiatives being introduced by the County Council to help improve the quality of life for people living with dementia and their carers intended to help our communities to become more inclusive.

Given the expected increase in the numbers of people with dementia over the next twenty years, local authorities have an important role in helping to develop dementia friendly communities that will support people in their homes and neighbourhoods.

Hampshire County Council has commissioned a one year project to widen the further development of dementia friendly communities across Hampshire.

4.2 Community and voluntary groups

There are many voluntary and community groups offering invaluable advice, support and care to people with dementia and their carers eg Alzheimer's Cafes. It is important to involve local groups in the development and commissioning of local care pathways. As part of the project to develop dementia friendly communities, a local Hampshire Dementia Action Alliance is being developed to help champion work to raise awareness. Through this and the national Alzheimer's Society campaign local people are being encouraged to learn more about dementia and share their knowledge with others as dementia friends or champions.

4.3 Dementia advisors

The Hampshire Dementia Advisor Service opened on 1 October 2012. The service is currently provided by The Alzheimer's Society and Andover Mind. The service:

- is available to anyone in Hampshire with a diagnosis of dementia.
- is also available to people with a suspected dementia to help support them through the diagnostic process.
- focuses on wellbeing rather than illness.
- supports people to think about how they can come to terms with and live well with dementia.
- assist with health and social care support available to people with a diagnosed dementia and their carers.
- offer advice on state benefits and planning for the future.

4.4. Primary Medical Care

Early diagnosis of dementia to provide people with timely information and links to support is a key role for GPs. Less than half of all people with dementia receive a formal diagnosis at any time in their illness, meaning opportunities to minimise harm and promote good quality of life are lost. Often the diagnosis is made at a time of crisis, which could potentially have been avoided by earlier diagnosis and intervention. It may already be too late for the individual concerned to make their own choices about care.

An early diagnosis is helpful, because it:

- enables carers and people with dementia to be better equipped to cope with the disease progression.
- provides people with dementia with an opportunity to make decisions about their financial and legal affairs while they still have the capacity to do so.

Dementia

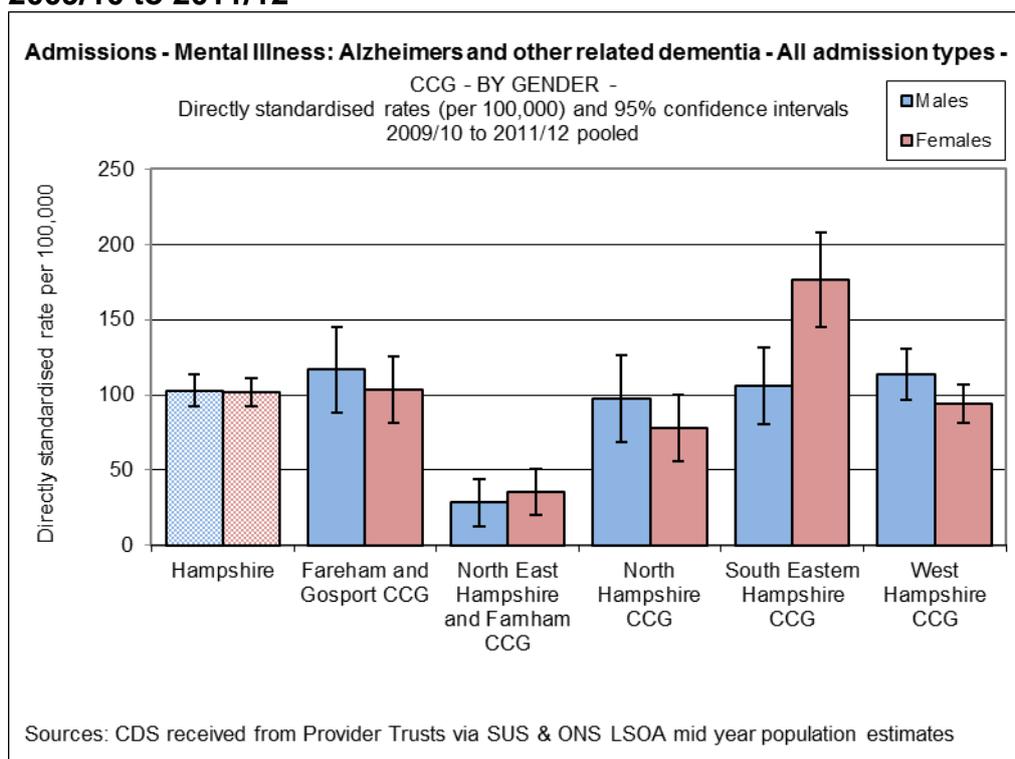
- gives people with dementia a better chance to benefit from available drug and non-drug therapies that may improve their cognition and enhance their quality of life.

One way to investigate the variation of diagnosed to undiagnosed patients is to look at the ratio of recorded to expected prevalence for dementia. The Community Mental Health Profile 2013 showed that for the year monitored (2010/11) Hampshire (0.45) was significantly better than the South East (0.40) and England average (0.42). This is still much lower than the best national rate of 0.69, and means that over half of the people with dementia remain undiagnosed; and there is considerable variation within practices in Hampshire.

4.5 Hospital admissions for dementia

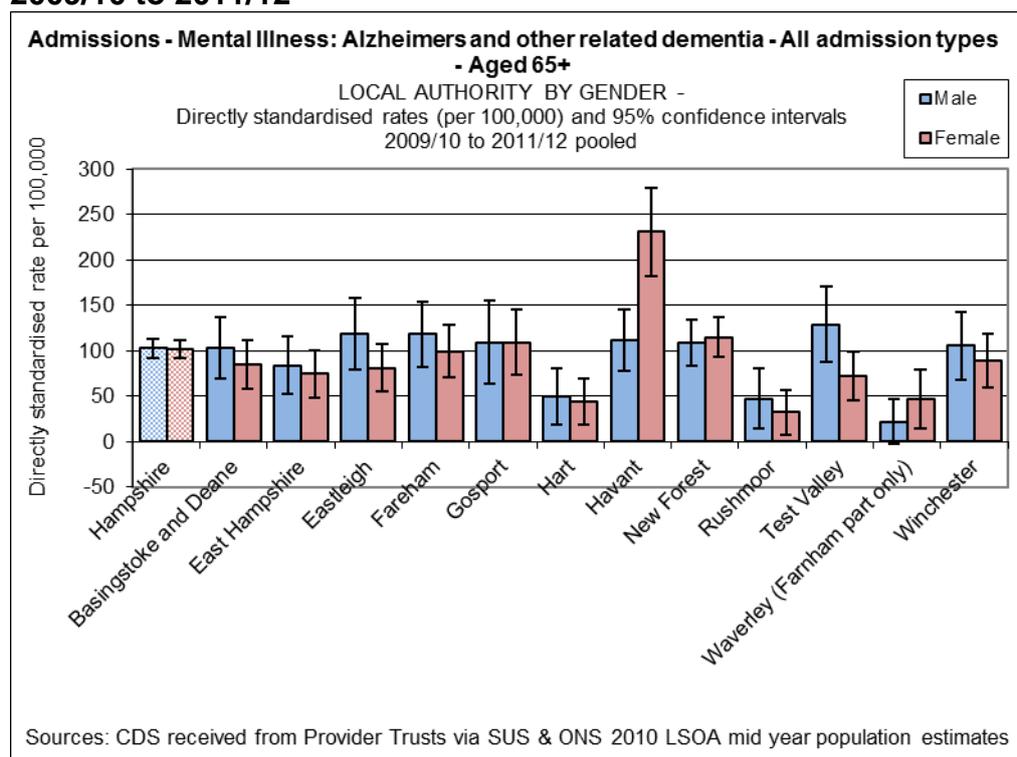
The Community Mental Health Profile 2013 shows that Hampshire has significantly higher directly standardised admission rates for Alzheimer's and other related dementia (2009/10 to 2011/12) at 105 per 100,000 population compared to the South East average of 53 and England average of 80 (figures 6 and 7). This could reflect the higher prevalence, better diagnosis, availability of community services or the admissions policies of local services.

Figure 6: hospital admissions for Alzheimers and other dementia by CCG, 2009/10 to 2011/12



Dementia

Figure 7: hospital admissions for Alzheimers and other dementia by district, 2009/10 to 2011/12



Admission rates are significantly higher amongst women in the South East CCG area, particularly Havant. They are significantly lower in North East Hampshire and Farnham CCG (Hart, Rushmoor and Waverly). This difference is due partly to different clinical practice by healthcare provider trusts.

4.6 Care in acute hospitals

Concern has been raised nationally about the care older people receive in hospital, especially those with multiple health problems including dementia.

A Care Quality Commission (CQC) report (March 2013) found:³

- In over half (78 out of 151) of primary care trusts, people with dementia in care homes were admitted to hospital for an avoidable reason significantly more than people without dementia.
- In almost all (96 per cent) of hospital trusts people with dementia stayed significantly longer than those without the condition after being admitted in an emergency. In three quarters (76 per cent) of trusts they stayed significantly longer when admitted for any reason.
- In 70 per cent of hospitals people with dementia were being readmitted significantly more than people without the condition.

³ http://www.cqc.org.uk/sites/default/files/media/documents/cqc_care_update_issue_2.pdf

Dementia

4.7 Prescribing of antipsychotic medication

Antipsychotic medication has been used inappropriately in the past to try and control some of the more challenging behaviour that people with dementia may present. These drugs can play a role in the treatment of people with dementia in certain well defined situations, but can cause harm if used outside agreed guidelines. Regular audits are being undertaken in hospital, care homes and primary care to review and improve local prescribing practice.

4.8 Carers Support

Families and friends provide the majority of care for people with dementia. It is vital that they receive the help and advice they need to maintain their own health and wellbeing, and continue caring for as long as they wish to.

5. User and provider views on dementia

The Alzheimer's Society⁴ and YouGov⁵ have been providing regular reports from surveys of people with dementia, their carers and the general population for a few years now. They provide a valuable insight into how well people are living with dementia, their experiences of services and inclusion in the community, and whether there have been any changes. These have highlighted the importance of raising the awareness of dementia in the general population; providing accurate and timely information to patients and carers; early diagnosis

Dementia 2013: The hidden voice of loneliness, the latest report commissioned by the Alzheimer's Society, found that many people with dementia and their carers are still not living well with the condition, and quality of life remains extremely varied.

- 1/3 of people with dementia live on their own in the community.
- However only 23% of people think it is possible for people with dementia to live on their own.
- 24% of over 55s have felt lonely in the last month.
- 38% of people with dementia feel lonely.
- 62% of people with dementia living alone feel lonely.

See JSNA chapter on social isolation and loneliness in older people for more information.

National YouGov survey 2012 a poll, which questioned 4,276 UK adults over 18, found that those aged 55 or over are the most worried (66%) but dementia is even worrying over half of younger people aged 18 to 24 (61%). Women are much more concerned about dementia than men, with 70% worrying about the condition in some way, in comparison to 56% of men.

- 63% of UK adults say they are worried about dementia in some way.
- only 21% think they have a good knowledge of dementia.

⁴ <http://www.alzheimers.org.uk>

⁵ <http://cdn.yougov.co.uk>

Dementia

- less than a fifth (16%) of people want to know more about the condition.
- 25% of 18-24 year olds are keen to learn more compared to only 15% of people aged 55 or over.
- only 18% of people realise dementia is a terminal illness.
- just 6% of people have a plan in place if a family member were to develop dementia (this includes only 7 per cent of people aged 55 and over).

An earlier YouGov survey (2011) found that:

- 61% respondents thought that inclusion of people with dementia in communities was fairly bad or very bad.
- 58% thought quality of life for people with dementia was fairly bad or very bad.
- 52 % thought that care provided was fairly bad or very bad.
- 48% thought that access to services was fairly bad or very bad.

6. Evidence of what works

“What’s good for the heart is good for the head” (National Dementia Strategy)

There has been a perception that nothing can be done to prevent dementia. However there is a strong evidence base from population based cohort studies which suggests that better cardiovascular health, more education and higher levels of physical activity reduce the risk of dementia later in life.⁶

The following national and local strategies describe ways that people with dementia and their carers can have better quality of life and remain independent for longer. It is followed by descriptions of local projects that have been implemented to address this

Living well with dementia: A national Dementia Strategy (2009), set out a comprehensive approach to improve outcomes for people with dementia from raising awareness about dementia in the general population through to end of life care. This was further developed in Quality outcomes for people with dementia: Building on the work of the national dementia strategy which has a particular focus on:

- Good quality early diagnosis and intervention for all.
 - Only a third of GPs feel they have adequate training in diagnosis of dementia.
- Improved quality of care in general hospitals.
 - 40% of people in hospital have dementia.
 - The excess cost is estimated to be £6m a year in an average District General Hospital.
 - Co-morbidity is high, and people with dementia stay longer.

⁶ <http://www.alz.co.uk/research/world-report-2012>

Dementia

- Living well with dementia in care homes.
 - Dependency is increasing.
 - Behavioural disturbances are highly prevalent and often treated with antipsychotic drugs.
- Reduced use of antipsychotic medication.

The Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015 continued to raise the profile of dementia, particularly:

- Driving improvements in health and care.
- Creating dementia friendly communities that understand how to help.
- Better research.

NICE/SCIE dementia clinical guideline

NICE and SCIE have produced extensive evidence based guidelines and the first quality standard on best practice in the diagnosis, treatment and care of people with dementia and their carers. The version updated in 2011 now includes guidance about the use of drugs in mild and moderate dementia. (www.nice.org.uk - Quality Standards QS1 Dementia; QS30 Supporting people to live well with dementia; Clinical Guideline CG42 dementia; TA127 Donepezil, galantamine, rivastigmine and memantine in dementia).

Key recommendations include:

- Integrated working across all agencies.
- Memory assessment services at the point of referral for early diagnosis of dementia.
- Assessment, support and treatment for carers (where needed).
- Assessment and treatment of non-cognitive symptoms and behaviour that challenges.
- Dementia –care training for all staff working with older people.
- Improvement of care for people with dementia in general hospitals

7. Recommendations

- Prevention – link to prevention programmes for cardiovascular disease.
- Support the development of Hampshire Dementia Alliance with a Hampshire County Council member champion.
- Health and Wellbeing Board support for the development of dementia friendly communities through the Joint Health and Wellbeing Strategy.
- Clinical Commissioning Groups continue to support GPs to diagnose dementia early by commissioning relevant support and memory clinic services.
- Better hospital care – more holistic and integrated approach to people with dementia in acute hospitals.
- Support carers and their specific needs.
- Further develop the specialised end of life care for this group of people.