

Swindon's Joint Strategic Needs Assessment

Bulletin 2: Dementia



Key Points:

- The JSNA provides evidence to help us understand the health and wellbeing needs of people with and at risk of dementia in Swindon.
- Dementia causes damage to the brain affecting people's cognitive ability and over time day to day functioning. The most common types of dementia are Alzheimer's Disease and vascular dementia.
- Although 1 in 6 people over 65 are estimated to develop dementia at some stage, this means 5 out of 6 will not.
- There are about 29,000 people over 65 in Swindon of which over 2000 people are estimated to have a type of dementia. Under half of these have a formal diagnosis. 986 were on a GP dementia register in 2011/12.
- Dementia is a very individual disease - experience depends on the type, severity, and support available. About half of people with dementia have mild dementia.
- The biggest risk factor for dementia is age. Promoting general good health – not smoking, maintaining a healthy weight, avoiding high blood pressure or high cholesterol - is also thought to be important.
- Swindon's older population is forecast to increase (which will mean more people with dementia in future years).
- In Swindon there are some very good services provided by the statutory and voluntary sector but there is also room for improvement.
- The JSNA makes fourteen recommendations – these are set out on pages 7 & 8.

What is Joint Strategic Needs Assessment?

Joint Strategic Needs Assessment (JSNA) helps us to understand:

- what we know about the current health and wellbeing needs of local people;
- how their needs are being met;
- what we think their future needs are likely to be; and
- how their needs can be best met.

Understanding Swindon's changing population, the factors that affect health and wellbeing, the town's assets and the implications for future services are vital in setting priorities and planning future services.

The JSNA process involves many different partners and is overseen by Swindon's Health and Wellbeing Board.

The Dementia JSNA

Dementia causes damage to the brain resulting in a progressive decline in more than one area of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. It affects people differently depending on the type of dementia, stage of illness and the individual affected.

People are more likely to have a type of dementia as they get older although it can affect people under 65, which is known as early onset dementia.

As more people live longer, the number of people with dementia is likely to increase. It is estimated that one in 14 people over 65 years of age and one in six people over 80 years of age in the UK has a form of dementia.

Dementia is a priority for the current government with action developed from the National Dementia Strategy and the Prime Minister's challenge which aims to make a real difference to the lives of people with dementia and their families and carers.

Some key themes emerged locally but are also reflected nationally:

- dementia is a very individual disease - experience depends on the type, severity, and support available
- people do not want to be defined by dementia but acknowledged as a valuable and respected member of the community
- people with dementia want to do normal things in an age friendly environment
- increasing awareness is key in all aspects of day to day life whether people care for, provide services for, or live next to people with dementia
- carers are central to supporting people with dementia
- other support when needed should come from health, social care and the voluntary sector working together.

In this JSNA process, we have found many examples of good practice in Swindon. This bulletin aims to provide an opportunity to build on this.

How many people in Swindon have learning disabilities?

Estimating the number of people with dementia is difficult as over 50% are not diagnosed. People who have been diagnosed via a formal assessment at a memory clinic are usually then registered on the GP practice dementia register. There were 986 people on GP dementia registers in Swindon in 2011/12 (including Elm Tree practice which is outside the Borough boundary).

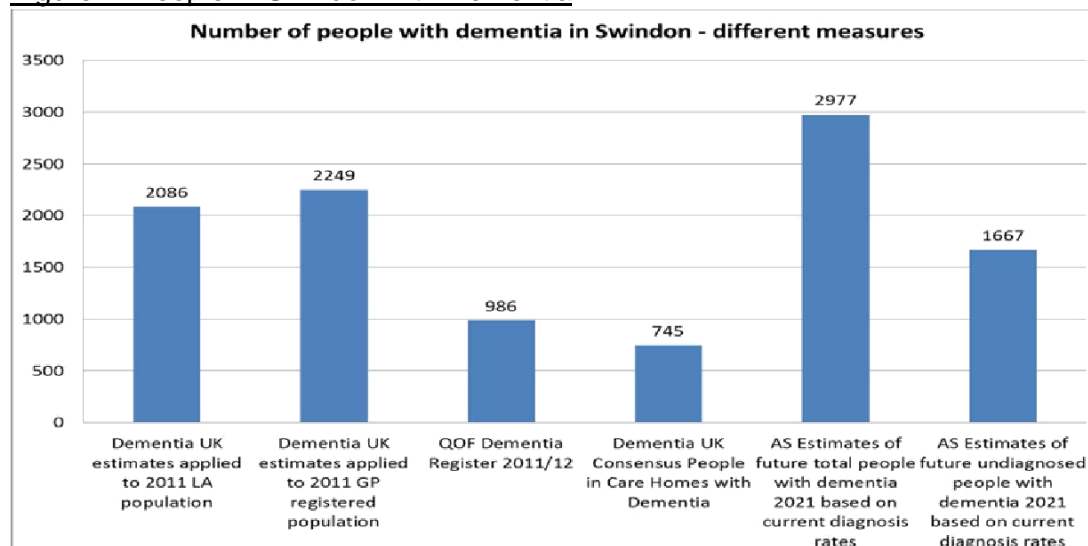
Research suggested people wait an average of three years after first symptoms before contacting their GP. Under-diagnosis is highest amongst people with mild dementia.

A national consensus exercise was done in 2007 by Dementia UK to estimate the actual number of people with dementia. This used agreement between experts in dementia to estimate how many people may have dementia but not be diagnosed. Combining diagnosed and undiagnosed people with dementia gave a more accurate picture.

Using the Consensus estimates, there are about 2035 people aged 65 and over with dementia in Swindon, nearly half of whom are over 85. This is about 7% of the total population over 65. Estimates suggest there are about 50 people with early onset dementia.

Different types of dementia affect different parts of the brain which means people have different symptoms and behaviours.

Figure 1. People in Swindon with Dementia



The main types are Alzheimer's Disease (affecting two thirds of people with dementia) and vascular dementia (affecting one in five people with dementia).

Over half of people have mild dementia where people have some memory problems, but can cope with day to day living. Moderate dementia is where people may have reduced reasoning and confusion and often need some support with personal care due to memory loss, and affects one in three people with dementia. People with severe dementia (which ranges from 6% of those age 65 to 74, to almost one in four of those over 95) often need constant support. In Swindon it is estimated that 1147 people have mild dementia, 668 have moderate dementia, and 271 have severe dementia.

Understanding and supporting people with a number of different illnesses is important. Research estimates two thirds of people with dementia have three or more other conditions. People with dementia often have high levels of depression and an increased risk of falling.

People with dementia are more likely to die in a care home and less likely to die in a hospice.

National research suggests there is no apparent link between risk of dementia and deprivation or social economic status.

Diagnosis rates are often lower in Black and Ethnic Minority communities: however specific figures are not available for Swindon.

There is no local data available for travelling communities, nor for lesbian, gay, bisexual or transgender (LGBT) groups. However older LGBT people may face particular challenges if they need residential care or when caring for a loved one with dementia as there may be less understanding amongst older generations.

What are the risk factors for dementia?

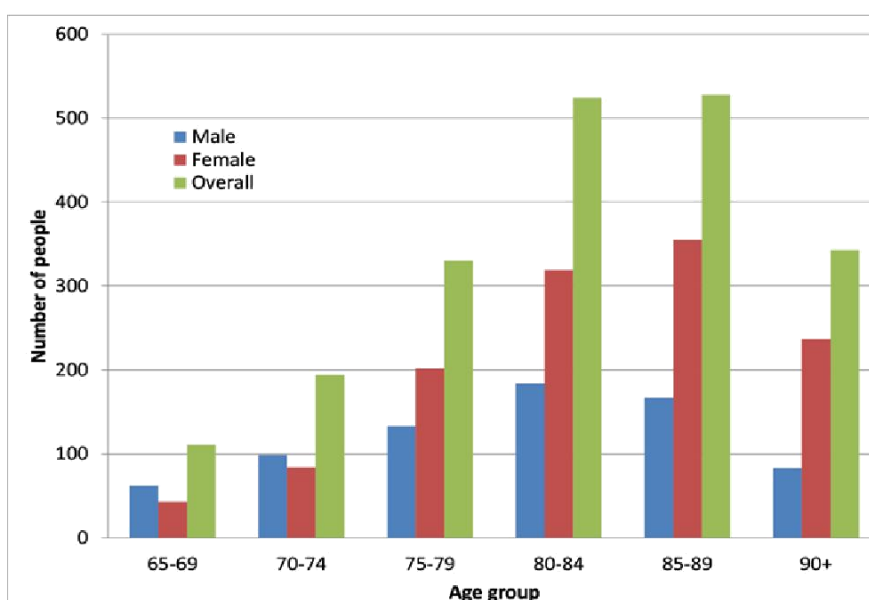
There is no single risk factor for dementia. The risk of getting a type of dementia increases as people get older.

Mild Cognitive Impairment (MCI) is not part of the dementia diagnosis but can cause some memory and recall problems as people get older. It is included in the dementia JSNA as a risk factor as about half of people with MCI are estimated to develop dementia. Many people with MCI will not access diagnostic services nor need additional support.

Scientific evidence for what causes different types of dementia is inconclusive but the following may increase the risk:

- the presence of a particular gene
- having another neurological condition
- a history of stroke or transient ischaemic attack (TIA)
- high blood pressure, diabetes, and / or high cholesterol
- lifestyle factors such as smoking, excess alcohol and / or obesity
- being socially isolated

Figure 2. Expected number of people in Swindon with dementia over 65 (Source: Dementia UK 2007 Consensus Report estimates applied to 2011 Swindon Census Data)



Research is mixed on whether increased physical activity or types of diet specifically reduce the risk of dementia. However, a healthy lifestyle is recommended to promote independence as people get older.

People with a learning disability are at risk of developing Alzheimer's Disease earlier than the rest of the population.

What services do people use?

In Swindon services for people with dementia are delivered via local GP practices, Swindon Borough Council, Avon & Wiltshire Mental Health Partnership Trust (AWP), Great Western Hospitals Trust, SEQOL community services and voluntary organisations.

Contact with services usually starts when someone approaches their GP with concern about their memory. After checking for other causes, they are then referred to the memory clinic for assessment. Following diagnosis, people can access a mix of voluntary, community and primary care services depending on their needs, providing psychological, social and physical support as the illness progresses. Some people will move to residential or nursing care at some stage, and a small number with challenging behaviour access in-patient care at the Victoria Centre.

Getting a timely diagnosis is important. There have been long waiting lists for assessment at the memory clinic but measures are in place to address this. Consideration is being given to community based memory services and dementia support at practice level in Swindon.

There were about 2200 Swindon hospital admissions to Great Western Hospital between 2009 and 2012 with a primary or secondary diagnosis of dementia accounting for over 32,000 bed days. 38% of people had more than one admission during this time and 4% had five or more. The most common cause of admission was for urinary tract infection.

After people are diagnosed, support includes services such as Think Again for those recently diagnosed, and Forget-Me-Not for people with early onset dementia; both of which are recognised as examples of good practice and highly valued.

On-going support is available through Alzheimer's Society services (Singing for the Brain and the monthly Memory Café – both of which are well attended and valued) and support offered by the Carers Centre which includes peer support.

Swindon Borough Council commissions a range of social care support including residential care, home care and day services. Social services data identified 330 people over 65 with mental health problems living in residential or nursing care homes who are funded by Swindon Borough Council. The number of people cared for by the local authority with dementia is increasing.

Some people with dementia will not need social care and some of those receiving social care aged over 65 with mental health needs will not have dementia. There are also people over the age of 65 with dementia who are funding their own support and who may not be in contact with agencies in Swindon.

The National Institute for Health and Clinical Excellence (NICE) recommends

- people with dementia have a named person who supports them to develop a care plan and acts as a single point of contact across all organisations
- consistent and stable staffing, retaining a familiar environment, and minimising relocation can help people retain independence
- interventions such as reminiscence therapy, multisensory stimulation, animal assisted therapy and exercise can help with anxiety and depression

In Swindon there are some very good services and pockets of good practice. It was identified that more needs to be done to improve the interaction between services.

Carers play a crucial role in supporting people with dementia and helping people maintain independence. Nationally it has been estimated that carers for people with dementia save the UK £8bn a year. However, caring can also impact on the health and well-being of the carer. Recognising the value of carers and providing appropriate support is vital.

Supported housing provision is currently being reviewed: there are currently 57 sheltered housing and 4 extra care housing schemes in Swindon. There is much good practice about the planning and design of housing for people with dementia which can inform future developments.

What could the future look like?

Swindon's population is forecast to increase faster than average, both overall and in older age groups. The number of people with dementia in Swindon is estimated to increase by about 700 by 2020 due to the increase in population of those over 65 based on current prevalence rates.

There will be more older people living alone over the next 20 years. However, older people living alone will not necessarily increase the risk of dementia or demand for services as it may encourage people to maintain independence.

The number of people aged 65 and over providing unpaid care to a partner, family member or other person is forecast to increase by 60% between 2012 and 2030, with a doubling in the number of carers who are aged over 85.

The cost of dementia is significant. The JSNA report offers some illustrative scenarios to look at the financial impact of:

- Delaying the onset of the disease (i.e. time to mild stage)
- Delaying transition between stages
 - Extending time in mild stage
 - Delaying progress to severe stage when residential care is most likely to be needed
- Increased life expectancy

Estimating the number of people with dementia is difficult as it depends not only on the number of older people but also on the risk factors for dementia and the outcomes of on-going scientific research into drugs that could prevent or slow down the disease. However for planning services understanding possible future scenarios is very important.

Figure 3. Number of people estimated to have dementia, diagnosed and undiagnosed (2012) for Swindon and Comparator areas

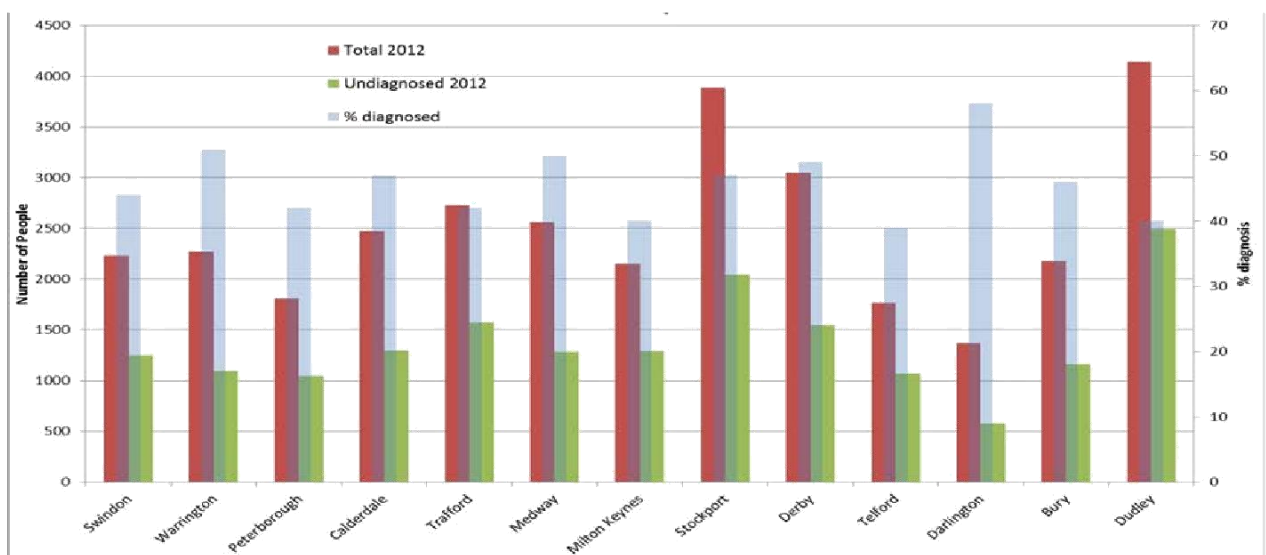


Figure 4. Forecasts of people living in a care home with or without nursing (all people aged 65 and over not just dementia)

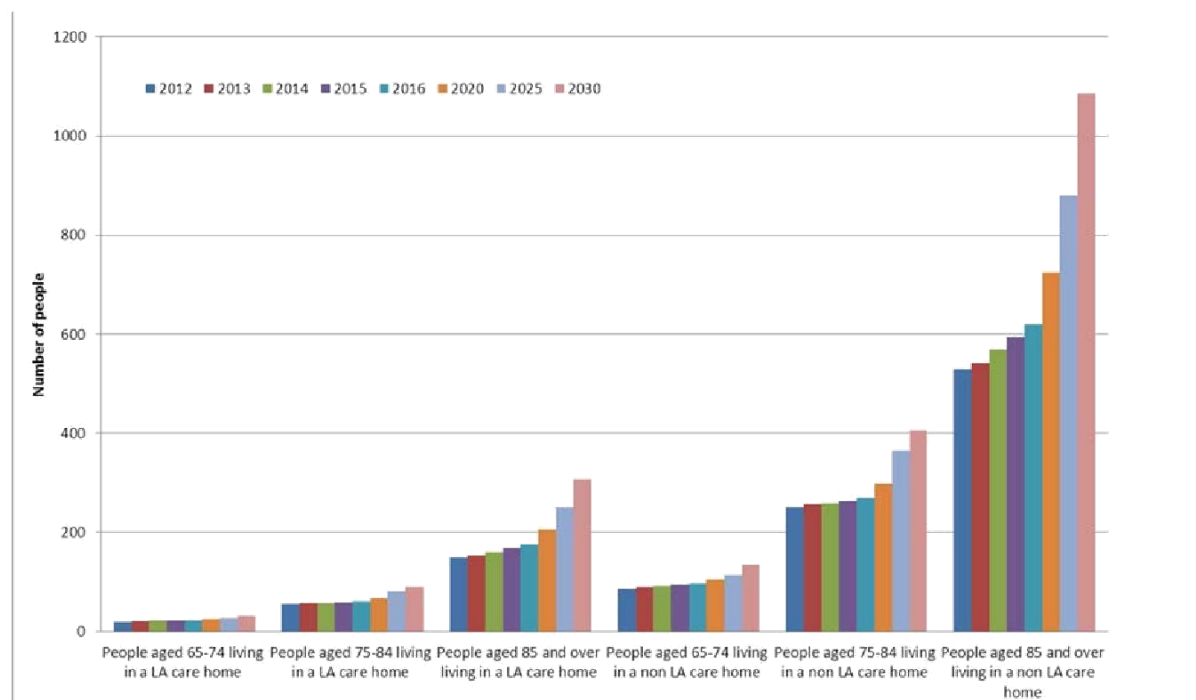
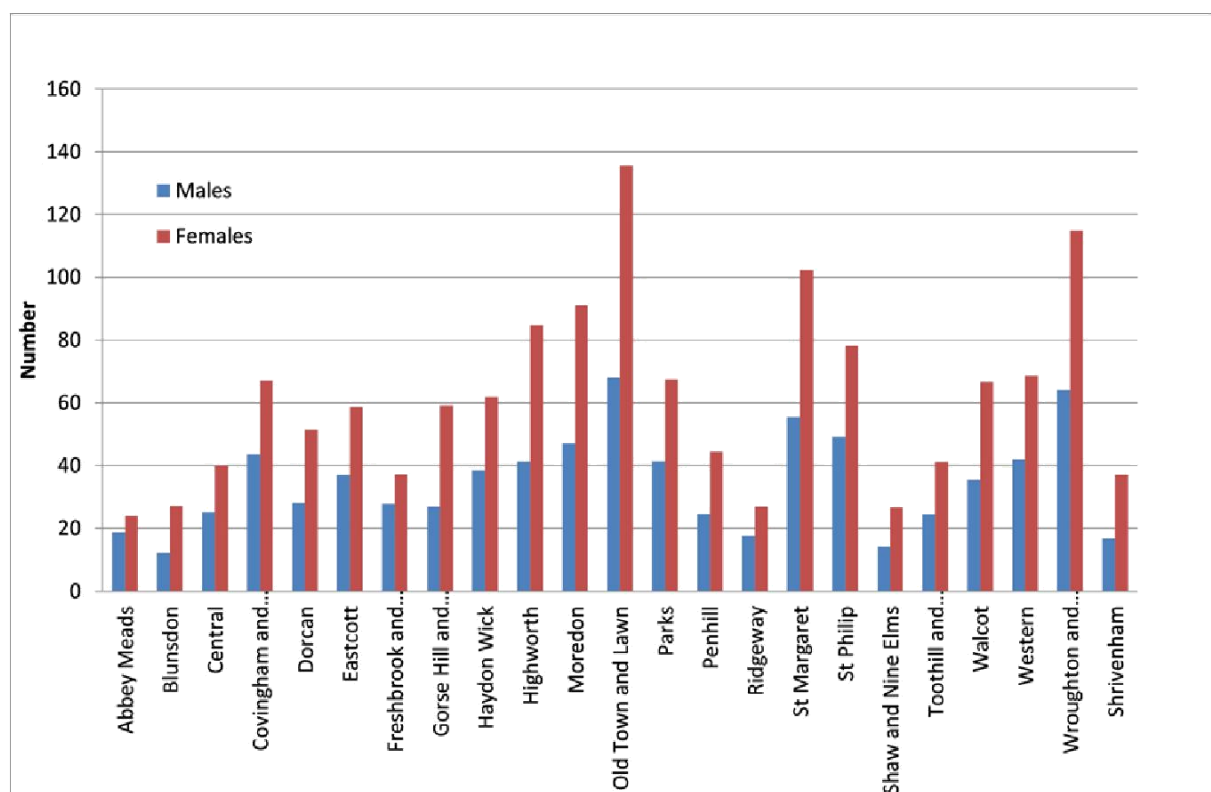


Figure 5. Prevalence of late onset dementia based on Dementia UK estimates of diagnosed and undiagnosed people with dementia applied to 2010 ONS ward population



What do local people and organisations think?

As well as data, part of the needs assessment included discussions with both health and social care professionals, local voluntary sector organisations and attendance at local and national events involving people with dementia and carers.

There is a need to raise awareness and understanding

- about risk factors particularly around lifestyle behaviours
- for people working with people with dementia e.g. in care homes
- in the wider community, e.g. with retail, leisure, transport, public sector
- to ensure consistency amongst GPs

As part of the Prime Ministers Dementia Challenge businesses are being encouraged to sign up to the Dementia Action Alliance to commit to transforming the lives of people with dementia. Locally both Great Western Hospital Foundation Trust and Great Western Ambulance Service NHS Trust have signed up but other Swindon organisations could also sign up. The initiative also includes a focus on dementia friendly communities – which includes planning, signage, public toilets, clarity of information and advice as well as training and support. Great Western Hospital has developed a dementia strategy to support people with dementia who come into hospital.

As well as concern about the length of time from referral to diagnosis locally, there was also a perception that whilst support was very good directly after diagnosis there is then a gap. There was some concern about people who did not meet the threshold for dementia but still needed support due to problems with cognitive functioning as this was perceived to be a gap in support.

There was some inconsistency in views of the level of formal assessment required before accessing social care, and whether social care needs to be accessed by the individual or carer or whether the GP could refer directly.

It was felt by both carers and voluntary sector staff that there was a gap in softer support e.g. places to go for coffee and a chat, social trips.

People also highlighted that there is a significant difference in the needs and interests of someone aged 55 with dementia compared to someone aged 90 and services should reflect this.

There was some concern that there should be better recognition of wider healthcare needs of both carers and people with dementia, and support for carers when their loved one dies.

Recommendations

This needs assessment identifies good practice in Swindon and supports further progress. Over recent years there has been a dementia strategy for Swindon and this JSNA should support and inform the refresh and refocus on that. A comprehensive, evidenced based dementia strategy and action plan is key to coordinating effort, ensuring that people are supported and cared for appropriately, maintaining independence for as long as possible but not reaching crisis point.

This JSNA will also inform work on-going by the NHS Swindon Clinical Commissioning Group, and the change programmes which are shaping the work of Swindon Borough Council and its partners.

The JSNA is about more than information. It should also identify priorities for action. The following recommendations are for action across organisations:

1. Establish a dementia steering group to take work in this area forward
2. Continue to develop a more detailed understanding of the role of carers and ensure the additional funding SBC are putting into caring services reflects carers' needs, recognising that people need different support at different times.
3. Ensure people with memory loss who do not meet the criteria for dementia have appropriate information about adopting a healthier lifestyle and coping independently
4. Encourage organisations to sign up to the Dementia Action Alliance and commit to the seven common principles defined by people with dementia and their carers:

- a. I have personal choice and control or influence over decisions about me
 - b. I know that services are designed around me and my needs
 - c. I have support that helps me live my life
 - d. I have the knowledge and know-how to get what I need
 - e. I live in an enabling and supportive environment where I feel valued and understood
 - f. I have a sense of belonging and of being a valued part of family, community and civic life
 - g. I know there is research going on which delivers a better life for me now and hope for the future
5. Work in partnership to improve the speed from referral to diagnosis
 6. Develop campaigns to ensure people are aware of the risk factors for dementia and in particular that lifestyle factors such as healthy eating, physical activity and not smoking can benefit cognitive ability as well as protecting against cardiovascular disease
 7. Encourage all staff working with the public, including GPs, to have dementia awareness training
 8. Investigate innovative approaches to developing dementia friendly and age friendly communities which can be included as part of housing and planning development
 9. Use the NICE quality standardsⁱ developed for social care settings and services working with and caring for people with dementia inform the commissioning of services
 10. Encourage people with dementia, even if they do not meet social care criteria, to have a named person (this may be a family member or someone from the voluntary sector) who supports them and acts as a single point of contact across organisations
 11. Encourage partnership working to promote independence for people post diagnosis
 12. Identify best practice for encouraging local businesses such as cafes, chemists, post offices and hairdressers to become dementia aware so people with dementia and carers know that they provide a supportive environment
 13. Work in partnership to consider opportunities to extend support for social activities and opportunities for people to benefit from others experiencing the same challenges, and reducing the risk of social isolation. This could include extending activities using volunteers such as Singing for the Brain to year round.
 14. Develop a briefing paper on best practice around supported and extra care housing for people with dementia to inform the planning and development of this type of housing in the future

Where to find more information

The full Dementia JSNA provides much more information on the issues covered by this bulletin (including full references). It can be found on Swindon's JSNA website: _

www.swindon.gov.uk/sc/sc-healthmedicaladvice/Pages/sc-jsna.aspx

The website includes a range of other documents about health and wellbeing in Swindon. If you have any queries (or would like to contribute to needs assessment activities in Swindon) please contact:

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This bulletin will be reviewed February 2015.

<http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30/introduction-and-overview>ⁱ

