Dementia

Topic information	
Topic title	*Dementia – Working Age and 65+*
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Executive summary

Introduction

Dementia encompasses a range of brain disorders resulting in a progressive and severe loss of brain function. It affects over 5% of people over 65. The number of people living with dementia in Nottingham will reach over 4,000 by 2035, almost doubling from 2017. Dementia has superseded cardiovascular disease as the leading cause of death.

This needs analysis considers dementia of all causes. There is significant overlap with the Carers and Care Homes JSNAs, and there is signposting to these where appropriate.

The Department of Health's Living Well With Dementia (2009) strategy on dementia provides a framework through which this needs analysis will be conducted. The Prime Minister's Challenge on Dementia 2020 requires action on 5 themes: global leadership, risk reduction, healthcare, social action and research.

Unmet need and gaps

1. There remains poor awareness of dementia risk factors among the general public – *see section 4, Prevention*. Although there are many existing interventions and services that target dementia risk factors locally, the links between these risk factors and dementia are not made explicit.
2. Uptake of NHS Health Checks overall remains poor – *see section 4, Prevention*. The 40- to 64-year-old age group has not been sufficiently targeted. The dementia component within the NHS Health Check targets only people over 65, despite there being evidence that risk factor modification should occur in early life.
3. Current local Memory Assessment Services are not accredited by the Memory Services National Accreditation Programme (MSNAP) – *see section 5, Diagnosis*.

4. BME groups continue to experience inequities in access to diagnostic services and consequently social support – *see section 2, Diversity*.
5. Following diagnosis, there are few options for support for BME groups which are sensitive to specific cultural needs. This is a pertinent issue as people from BME groups are more likely to develop dementia at a working age.
6. Although the number of people with dementia using inpatient services in Nottingham is reducing, it is not reducing as quickly as the national benchmark – *see section 2, Severity*. There needs to be greater work to understand what more can be done to reduce utilisation of inpatient services by people with dementia, to meet the national benchmark.
7. There is poor awareness that dementia is a terminal illness – both in the general public and among health professionals – *see section 5, Dying*. Consequently, advance care planning and access to palliative care services is limited. This has shifted dementia deaths from the community to the hospital.
8. The performance of community services in reducing admissions to hospital is not being measured.
9. Information about available services and support is needed on paper and verbally through formal and informal networks.
10. Data regarding service utilisation is not shared with commissioners.

Recommendations for consideration by commissioners

1. Commissioning should reflect NHS England's Well Pathway for Dementia and Nottingham City's Dementia Framework for Action
2. Map service provision currently available in the city to identify gaps and areas of duplication
3. Train GPs and healthcare workers across the city regarding risk factors for dementia and interventions that can prevent dementia.
4. Increase uptake of diagnostic services in BME groups, possibly through the use of community outreach programs
5. Increase rates of diagnosis of dementia subtypes / information sharing with community care providers to assist targeted care provision
6. Develop a robust plan to generate evidence showing a reduction in hospital admissions due to dementia following the provision and development of community dementia services
7. Increase choice and control in care homes for service users
8. Increase percentage of care homes rated 'Good' or 'Outstanding' by the Care Quality Commission from 45.3% to 60% by 2019
9. Form a City-wide joint approach to supporting people with dementia
10. Increase learning for family carers, supporting carers to understand the different types of dementia, support self care
11. Continue to develop local services to meet standards for Nottingham City to achieve dementia-friendly status
12. Develop a dementia-friendly employer framework and encourage organisations to sign up to committed actions
13. Write sustainable development plans that specifically consider dementia
14. Provide specialist end-of-life care for people with dementia through palliative care services integrated in the community
15. Educate health professionals and the public that dementia is a terminal illness

What do we know?

1) Who is at risk and why?

Dementia encompasses a range of brain disorders resulting in a progressive and severe loss of brain function. The most common types of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Non-modifiable risk factors are increasing age, female sex and genetic differences. Over 1 in 20 people aged over 65 are diagnosed with dementia, with 2 in 3 being female (Alzheimer's Society, 2015). Modifiable risk factors include lifestyle (smoking, overweight and obesity, physical inactivity), socioeconomic class, social isolation, mental health, stress and cognitive activity.

Estimates indicate that over a third of dementia cases are preventable (Livingston *et al.*, 2017). Cognitive problems occur more frequently in people of lower socioeconomic class with lower educational attainment (Ott *et al.*, 1995). Head injury increases the risk of dementia, and the severity of injury correlates with the magnitude of increased risk (Hugo and Ganguli, 2014). People with mental health problems (depression, anxiety and post-traumatic stress disorder) are at a higher risk of developing dementia.

Although most dementia is diagnosed in later life, a subgroup of dementias are early onset in nature – by definition those diagnosed before the age of 65. These tend to have a stronger genetic contribution. Patients with Down syndrome may develop dementia between 30-40 years of age. Black and other minority ethnicity (BME) groups are more likely to develop early-onset dementia (Personal Social Service Research Unit, 2007). However, the effect of an ageing population may diminish this association (House of Commons All-Party Parliamentary Group on Dementia, 2013).

The Prime Minister's Challenge on Dementia 2020 requires action on 5 themes: global leadership, risk reduction, healthcare, social action and research (Department of Health, 2015).

What is the impact on health and well-being?

The cognitive decline in dementia is progressive and irreversible. Most people live 10 years after diagnosis (Xie *et al.*, 2008). The loss of function affects people diagnosed with dementia, their family and friends, and society at large.

Cognitive	Emotional	Physical	Practical	Social
Memory loss Word-finding difficulty Poor concentration Difficulty recognising people and places Easily confused	Loss of self-esteem Loss of confidence Depression Irritability Mood swings Frustration with self and others	Problems eating and swallowing Dehydration Malnutrition Incontinence Constipation Pressure sores Insomnia	Difficulty completing activities of daily living Difficulty keeping safe (e.g. gas, ironing, kettles) Difficulty managing money	Physical, emotional and economic pressures on carers Social isolation Loss of independence

Cognitive

Many of the early symptoms of dementia are cognitive. For the most part, forgetfulness and getting easily confused go unnoticed. As the disease progresses, people with dementia often experience word-finding difficulty and difficulty recognising familiar people and places. People with dementia may even forget where they live.

Emotional

Because of the cognitive symptoms of dementia, people with dementia may become frustrated with themselves and others. They often lose confidence and withdraw from social activities. This can often result in depression. In the later stages of the disease, people with dementia lose the ability to follow social cues. They may exhibit inappropriate social responses and aggression. An emerging problem in care homes and acute care settings is the overuse of chemical sedatives, despite legislation protecting the autonomy and independence of people with dementia (Parsons *et al.*, 2012).

Physical

People with dementia commonly develop problems with continence and constipation. This can be due to a primary effect of the disease, secondary to immobility, or a side effect of medications. People with dementia may develop swallowing difficulties, which puts them at risk of dehydration, malnutrition and aspiration pneumonias.

Practical

People with dementia often have trouble with fine motor coordination. As the disease progresses, they require progressively more help with activities of daily living: for example, getting dressed, taking medicines and mobilising. People with dementia may turn on a gas cooker and forget to turn it off again.

Social

Carers of people with dementia most strongly feel the burden of the disease. The physical and psychological health of carers is poor. For a more detailed overview of the health risks of being a carer, see the Carers JSNA.

There is no dementia screening programme in the UK. However, timely diagnosis provides the following benefits:

- Advance care planning encompassing medical, financial, social, housing, driving and end-of life care
- Access to information and support
- Review of physical health and co-morbidities
- Access to peer and carer support
- A cost effective way to reduce admissions to residential care (Banerjee and Wittenberg, 2009)

Carers JSNA - http://nottinghaminsight.org.uk/themes/health-and-wellbeing/adults/carers-2017/

2) Size of the issue locally

The prevalence of dementia in Nottingham City (5.4%) is significantly higher than the East Midlands region (4.4%) and England overall (4.3%) (Public Health England, 2017). Although the incidence of dementia is falling in England and Wales, the number of people living with dementia in Nottingham is likely to increase due to the aging population. Males aged 75-79 are likely to experience the largest growth of people with dementia (43%) between 2017 and 2025 (Office for National Statistics, 2016b).

Diversity

One-third of people in Nottingham identify as being from an ethnic minority group (Office for National Statistics, 2011). People from BME communities are less likely to present to diagnostic services and less likely to receive support once they do (House of Commons All-Party Parliamentary Group on Dementia, 2013). However, nationally the burden of dementia in BME communities is poorly understood. More research is needed locally and nationally to characterise the disease burden.

Demography

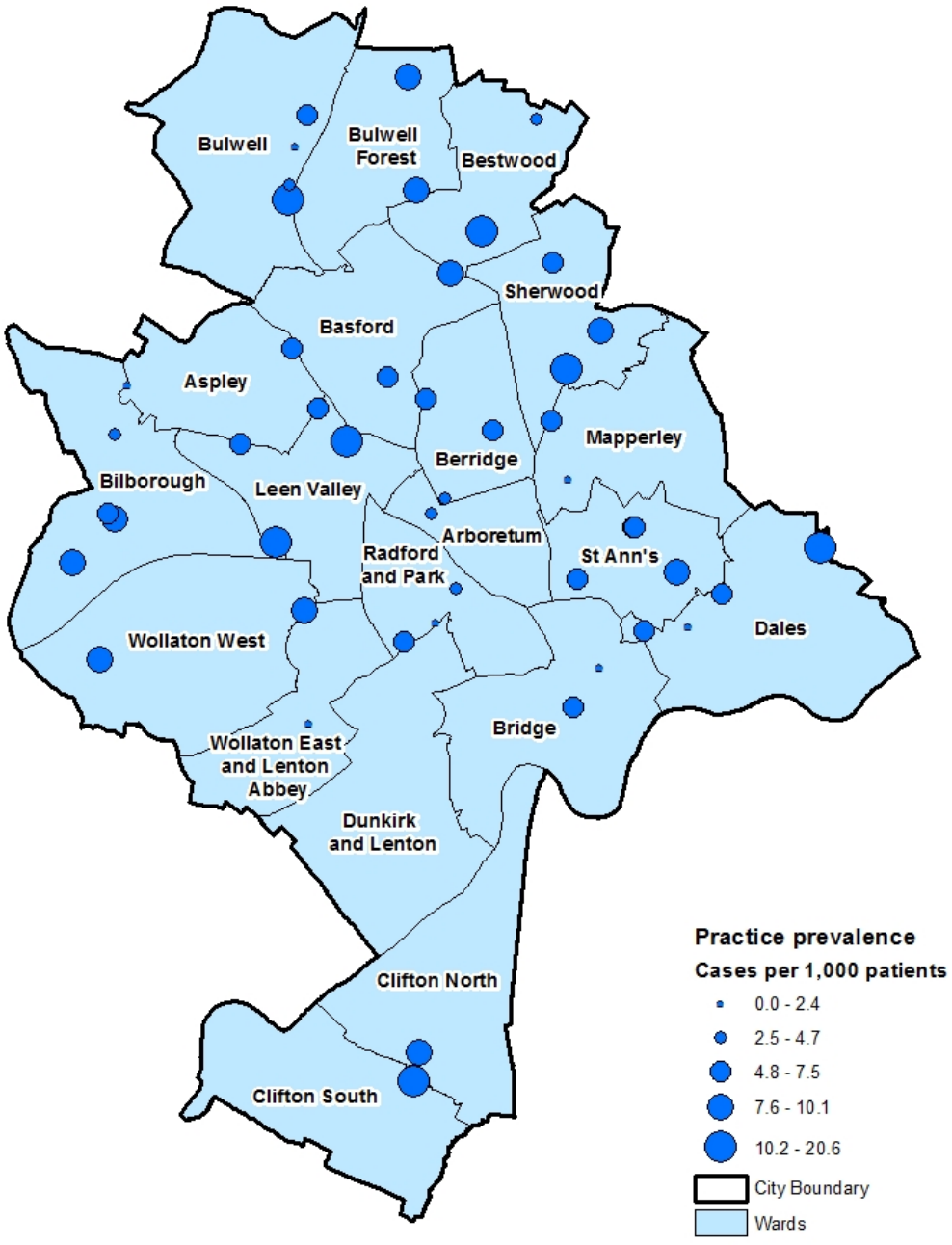
In 2017, Nottingham had nearly double the age-standardised prevalence of early-onset dementia (4.87 per 10,000) compared to the rest of England (2.94 per 10,000). One explanation could be due to the diverse local population, as there is a greater representation of BME individuals in people with early-onset dementia.

Deprivation

Income deprivation affects 25% of people aged over 60 in Nottingham (Kirk, 2017). While Nottingham still ranks 8th most deprived district in England, the number of people aged over 60 affected by income deprivation has fallen by 3.5% since the last JSNA. Socioeconomic status may indirectly increase the risk of dementia through inequalities in cardiovascular risk (Marmot *et al.*, 1997). Socioeconomic status may create inequalities in dementia death

through life course events such as leaving full-time education at an earlier age (Russ *et al.*, 2013).

In Nottingham, dementia is more prevalent in its more deprived neighbourhoods, with the highest numbers of dementia patients per GP practice seen in the most deprived districts.



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Figure 1. Distribution of dementia patients by GP practice, weighted by practice size. (Source: David Millington, NCC, NHS digital dementia diagnosis workbook, March 2017)

Severity

The proportion of people with dementia in Nottingham using inpatient services has fallen between 2012 to 2016. However, it has fallen at a slower rate than the national average. At present 58% of people diagnosed with dementia in Nottingham use inpatient services compared to 54% nationally. This may indicate poor engagement with community services locally compared to the rest of England. Furthermore, in the same time period, there has been a shift of dementia death from the community into the hospital (Public Health England, 2017).

The reasons for this are not clear, as although the residential care and nursing home bed capacity of 74.2 beds per 100 persons registered with dementia in Nottingham is higher than the national average of 69.2, Nottingham has much higher rates of adults requiring home care services (1,279 per 100,000 in Nottingham vs 1,110 per 100,000 in England), which may suggest greater care needs locally (Public Health England, 2017). See the Carers JSNA 2017 for more detail.

Loneliness

A State of the Nation report by Alzheimer's Society conducted in partnership with Ipsos MORI found that public attitudes to dementia still marginalise people with dementia and their carers (Alzheimer's Society, 2017). Loneliness is a risk factor for developing dementia, and it is also detrimental to quality of life. Social isolation remains a prominent issue for people with dementia, with 55% of people with dementia feeling lonely and 83% of carers feeling socially isolated due to their caring responsibilities (Alzheimer's Society, 2012; Carers UK, 2014). More work is needed to shift public attitudes. Ensuring the City achieves dementia-friendly status forms an important first step to improving the experience of people with dementia.

Notable changes in need since the last JSNA

1. The dementia diagnosis rate has continued to improve. In Nottingham, 83% of people aged over 65 who should receive a diagnosis of dementia are correctly diagnosed with dementia (Public Health England, 2017). This is higher than the England benchmark (67%), and an improvement from 2014 (57%).
2. The prevalence of dementia in people aged over 65 in Nottingham has reduced from 6.5% in 2013 to 5.4% in 2017. However, the number of people with dementia will continue to rise due to the increasing older population.
3. There are a number of activities to raise awareness of dementia and encourage engagement among BME communities, including visits to faith organisations. This may change the demography of service users accessing diagnostic services.
4. The aging workforce and rising retirement age will increase the number of people with dementia and their carers who continue to work. Engaging local businesses to provide dementia-friendly workplaces will form an important theme for improving dementia services.

3) Targets and performance

I. Primary care – QOFs
   A. The percentage of patients with a new diagnosis of dementia recorded in the preceding 1 April to 31 March with a record of full blood count, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded between 12 months before or 6 months after entering on to the register
   B. The percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months

II. Secondary care and social care – PHOF
   A. Age-standardised rate of hospital admissions
   B. Residential care and nursing home bed capacity
   C. Residential care and nursing home bed quality
   D. Delayed transfer of care
   E. Age-standardised rate of mortality

Primary care

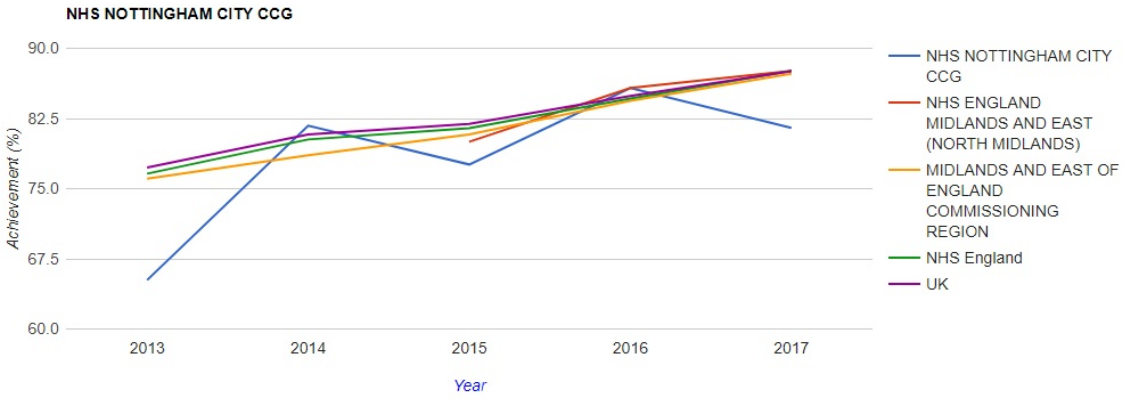


Figure 2. The percentage of people who have completed investigations to exclude alternative diagnoses to dementia. (Source: QOF database)

I. A. The percentage of people who have completed investigations to exclude alternative diagnoses to dementia has fallen to 81.5% in 2017 compared to 87.6% in the rest of England.

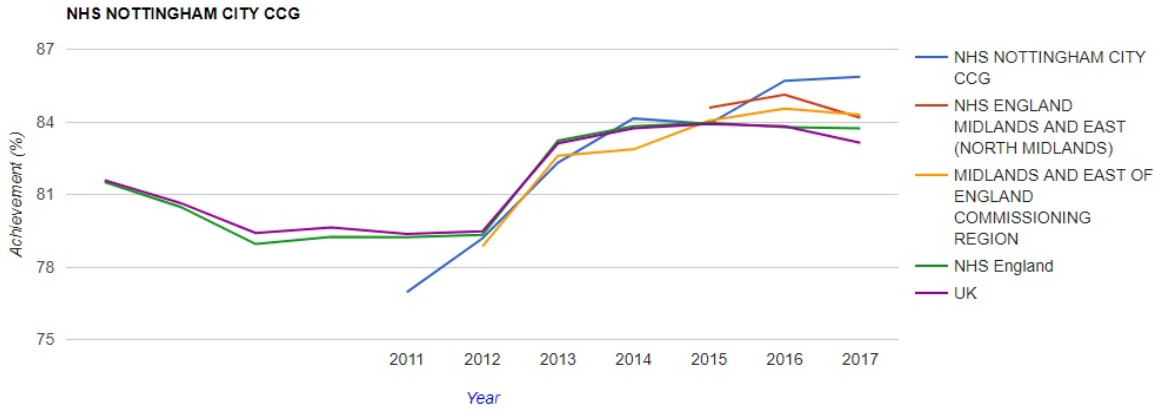


Figure 3. The percentage of people with dementia whose GPs have reviewed their care plans in the past 12 months. (Source: QOF database)

I. B. The percentage of people with dementia whose GPs have reviewed their care plans in the past 12 months has improved from 77.0% in 2011 to 85.9% in 2017 (NHS England, 2017). This supersedes the rest of England, where only 83.7% of people with dementia have had a care plan review in the past 12 months.

Secondary Care - Hospital admissions

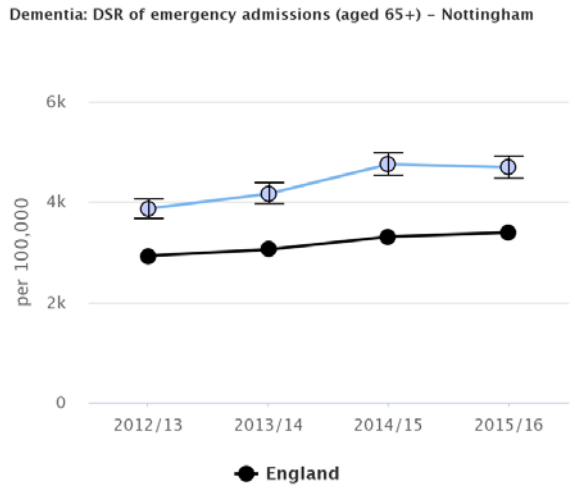


Figure 4. The age-standardised rate of hospital admissions in people with dementia aged over 65. (Source: PHOF)

II. A. The age-standardised rate of hospital admissions in people with dementia aged over 65 in Nottingham was 4,689 per 100,000 in 2016. In the rest of England it was 3,682 per 100,000. Furthermore, these admissions tend to be longer than in the rest of England. Only 21.2% of hospital admissions in Nottingham for people with dementia aged over 65 were short-stay admissions (1 night or less), compared to 28.3% in the rest of England.

Social care

II. B. and C. In 2017, Nottingham had a higher capacity of residential care and nursing home beds (74.2 per 100 people with dementia) than the rest of England (69.2 per 100 people with dementia). However, there is room for improvement in the quality of these services. Only 45.3% were rated 'Good' or 'Outstanding' by the Care Quality Commission, compared to 59.7% in the rest of England and 62.6% in the East Midlands region.

Name	A) Awaiting completion of assessment	B) Awaiting public funding	C) Awaiting further non-acute NHS care	Di) Awaiting residential home placement or availability	Dii) Awaiting nursing home placement or availability	E) Awaiting care package in own home	F) Awaiting community equipment and adaptations	G) Patient or family choice	H) Disputes	I) Housing – patients not covered by NHS and Community Care Act	O) Other	Total
England	19,946	4,747	27,953	18,283	21,558	31,667	3,869	16,390	1,572	5,410	905	152,300
Nottingham	92	0	748	55	18	175	32	196	57	62	2	1,437

Table excerpt from: NHS England Delayed Transfers of Care Data January 2017-18 (NHS England, 2018)

II. D. In the period January 2017 to January 2018, there were 1,437 delayed transfer of care (DTOC) days in Nottingham. Delays resulting from awaiting residential care accounted for fewer DTOC days than the national benchmark, reflecting the higher residential care bed capacity in Nottingham than the rest of England. However, the proportion of DTOC days attributable to awaiting home care packages was twice the national benchmark.

While the data shown are not specific to dementia, carers of people with dementia account for 11% of all the carers in the UK (Nottingham City Council, 2017). Furthermore, nationally people with dementia face twice as long a delay compared to those without the condition (Alzheimer's Society, 2016). Therefore, a significant proportion of the City's DTOC days are likely to be attributable to dementia.

Mortality

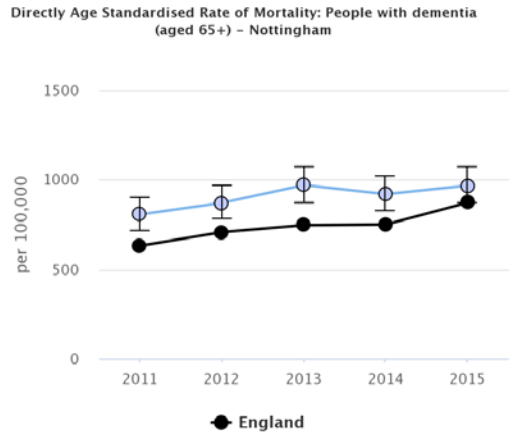


Figure 5. The age-standardised mortality rate of people with dementia. (Source: PHOF)

II. E. The age-standardised mortality rate of people with dementia in Nottingham (968 per 100,000) is higher than the rest of England (873 per 100,000), but the gap has reduced over the past 5 years.

4) Current activity, service provision and assets

Most people diagnosed with dementia are older and have multiple concurrent physical health problems. Service provision, therefore, must adopt an integrated care model. There is a broad spectrum of service providers, including the NHS, social care, independent and third sector provision. The NHS England Well Pathway for Dementia provides a five-step framework for services: preventing well, diagnosing well, supporting well, living well and dying well (NHS England, 2015a).

Prevention

NHS Health Check

Launched in 2009 and updated in 2013 to include a dementia awareness component for people aged over 65, NHS Health Checks are an opportunity for primary prevention through education and risk factor modification. People over the age of 65 receive a leaflet explaining dementia. Awareness of dementia risk factors is low in lay people and easily amenable to

change (Alzheimer's Research UK, 2017). Coverage of NHS Health Checks is poor nationally (9%) and worse locally (4%) (Public Health England, 2017).

In addition to the NHS Health Checks, there are local interventions and services targeted toward lifestyle modification, which may reduce the local burden of dementia. These include adult weight management services, smoking cessation services, the diabetes prevention programme, healthy eating and physical activity guidelines for care homes among others.

In 2017, Alzheimer's Research UK funded the first projects through the Prevention and Risk Reduction Fund to national research centres. The projects collectively seek to identify a feasible strategy to identify people at higher risk of developing dementia and deliver a targeted intervention to lower their risk.

Alzheimer's Research UK - https://www.alzheimersresearchuk.org/grants/prevention-risk-reduction-fund/

Diagnosis

Primary Care

The GP Dementia toolkit developed by Alzheimer's Society has been implemented in all GP practices. NICE Guidelines for dementia ensure a consistent approach to exclude other causes and referral to specialist memory assessment services. GPs continue to support people with dementia through annual reviews.

Secondary Care

Nottinghamshire Healthcare NHS Trust provide specialist dementia care through the Mental Health Service for Older People (MHSOP). Services include memory assessment clinics, community mental health, cognitive stimulation therapy, inpatient dementia care, specialist dementia outreach and rapid response liaison psychiatry. Silver Birch ward provides multidisciplinary dementia assessment and intervention, with enhanced staffing levels that shorten lengths of stay. The focus is on managing people within the community and avoiding hospitalisation. The Working Age Dementia Service provides both specialist assessment and care plans for people under 65 suspected or confirmed to have dementia.

Support

Adult Social Care

Nottingham City Council commissions a range of services aimed to maximise the ability to people with dementia to live independently. These services include Advocacy, Meals at Home, Carer Support and Telecare. POhWER delivers advocacy services including IMCAs and IMHAs for people with dementia.

POhWER - https://www.pohwer.net/nottingham-city

Care Services and Homes

Nottingham City Council commissions and provides a range of care services for people with dementia and their carers. The Nottingham Health and Care Point provides a phone service that allows people living with dementia and their carers to request an assessment of

circumstances from Adult Social Care Services. The provision of service ranges according to need from dementia day centres, telecare, respite care, home care, residential homes and care homes.

Community care services support people with dementia with basic activities of daily living in their own home.

Care Choices maintains a list of social care services produced by Nottingham City Council, including services for carers. A directory of private sector dementia day centres is maintained by Housing Care. The Marcus Garvey Day Centre caters for the needs of older Afrocarribean citizens with dementia. The Jack Dawe service initially provided specialist home care services for people with dementia, but has expanded to cater to people with different diagnoses.

Nottingham's City Care Homes Vanguard is a three-year programme of work that ends in March 2018, aiming to improve the experience of care within the care home sector by providing dementia training for 100 care home staff, pioneering telemedicine-enabled laptops and integration with the specialist Dementia Outreach Team.

Housing Care **-** http://www.housingcare.org/service/list/s-131-day-centres/l-456-nottinghamshire.aspx

Care Choices - http://www.carechoices.co.uk/welcome-nottingham-city-council/

Nottingham City Care Homes Vanguard - http://www.nottinghamcity.nhs.uk/news-projects/integrated-care/care-homes-vanguard.html

Nottinghamshire Help Yourself - http://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/results.action?districtcovered=9&qt=dementia&sorttype=distance&directorychannel=0&sr=10&nh=10

Working Age Dementia Service - https://www.nottinghamshirehealthcare.nhs.uk/working-age-Dementia-service

University of Nottingham Centre for Dementia

A research centre chaired by Professor Tom Dening is investigating ways to improve communication with care home residents with dementia and hearing loss.

http://www.nottingham.ac.uk/research/groups/dementia/index.aspx

Living

Voluntary organisations

Third sector organisations provide important support for patients, carers, family and friends of people with dementia. Alzheimer's Society and Age UK provide services including dementia cafes, information programmes, activity groups, money advice, legal advice, welfare benefits, community care, housing options and links to local services. There is even 24/7 support available online through a comprehensive information bank on Dementia UK

and the Alzheimer's Society forum. The Radford Care Group provides regular training courses to support carers of people with dementia.

Nottingham is a member of the Dementia Action Alliance. Through Dementia Friends training, it raises dementia awareness and encourages dementia-friendly practices among a wide range of agencies such as the police and local shops. Multi-sensory gardens provide stimulation for people living with dementia.

Dementia-friendly activities include:

- Physical activities – health walks and dementia-friendly swimming provided by Alzheimer's Society, "On the Ball" football project work
- Library resources – "memory packs" and "Reading Well" books for dementia
- Museum resources – reminiscence groups
- Art activities – dementia-friendly performances at the Theatre Royal and Singing for the Brain by Alzheimer's Society

Improving Dementia Education and Awareness (IDEA) is a website operated by Nottingham's Centre for Dementia providing a range of national and international courses for people living with dementia and their carers aimed at improving their quality of life.

Age UK – https://www.ageuk.org.uk/

Alzheimer's Society – http://www.alzheimers.org.uk/

Dementia UK – https://www.dementiauk.org/

Dementia Action Alliance – https://www.dementiaaction.org.uk/local_alliances/651_nottinghamshire_dementia_action_alliance

IDEA - https://idea.nottingham.ac.uk/

Radford Care Group - http://www.radfordcaregroup.org.uk/dementia-care-nottingham/

Dying

Commissioned by Nottingham City CCG, community nurses from CityCare attend to any person with nursing needs. Haywood House, Cedar House and John Eastwood House offer hospice care to patients with dementia. The National SWAN initiative aims to improve end-of-life care in acute settings for patients and carers.

5) Evidence of what works

Prevention

There is sufficient evidence that the incidence of dementia can be reduced by increasing physical and mental activity and reducing cardiovascular risk factors (smoking, diabetes, hypertension, obesity) (National Institute for Health and Care Excellence, 2015). Simply increasing knowledge of the relationship between risk factors and dementia increases the motivation to adopt a healthier lifestyle in people at risk of developing dementia (Alzheimer's Research UK, 2017). However, there will be little to no effect on prevalence until at least

2040. Therefore, the return on investment of mid-life approaches to primary prevention is a long-term return over 20 years (Wittenberg, Karagiannidou and Knapp, 2017).

There is no evidence that modifying alcohol, diet, air pollution and social isolation in mid-life prevents dementia. In designing a risk reduction strategy, it is important to consider not only the relationship between risk factors and dementia, but also the prevalence of each risk factor within the local population.

NICE guideline on prevention - https://www.nice.org.uk/guidance/ng16

Diagnosis

Dementia is diagnosed using formal cognitive testing instruments, such as the Mini Mental State Examination (MMSE), the 6-Item Cognitive Impairment Test (6-CIT) or the General Practitioner Assessment of Cognition (GPCOG). Various combinations of deficits in attention and concentration, orientation, memory, language or executive function constitute the syndrome of dementia. Structural imaging, for example MRI or CT, are used to exclude other pathologies and establish the subtype of dementia. Rarely, PET may be used to differentiate Alzheimer's disease from other types of dementia.

NHS England has evaluated the cost effectiveness of several models of dementia assessment and diagnosis but does not give preference to any (NHS England, 2015b). Dementia assessment and diagnosis in Nottingham City is within a specialist care managed service with primary care support. The target waiting time of 6 weeks is being met in the City. The Memory Services National Accreditation Programme (MSNAP) sets national standards that local providers need to meet. At present, no local service has been accredited.

NICE guideline on assessment and support - https://www.nice.org.uk/guidance/cg42

Support

There remains only partial evidence on the most effective ways to treat dementia. NICE guidelines recommend a combination of pharmacologic and non-pharmacologic approaches (National Institute for Health and Care Excellence, 2006).

Non-pharmacologic approaches to supporting people with dementia include Cognitive Stimulation Therapy (CST). In the later stages of the disease, challenging behaviour may be reduced by aromatherapy, animal-assisted therapy and therapeutic use of music or dancing.

Alzheimer's disease is the only form of dementia with a specific disease-modifying drug therapy for its cognitive symptoms. However, the drug does not cure the disease – only relieve its symptoms and slow progression. Two-thirds of antipsychotic drug prescriptions for challenging behaviour may be inappropriate, and it is a national priority to reduce their use (Department of Health, 2009).

As there is no cure for dementia, national and local strategies aim to increase the quality of life of people with dementia and their carers. Improvements in quality of life have been demonstrated through the provision of a specialist Dementia Support Worker (Goeman, Renehan and Koch, 2016). The Dementia Support Worker acts as a single point of contact for people with dementia and their carers, providing information and increasing access to local services, particularly for people in hard to reach groups. In the City, Alzheimer's Society provide access to a Dementia Support Worker through their Dementia Support Service.

One-third of people with dementia live in care homes, and two-thirds of care home residents have dementia (Alzheimer's Society, 2014). Features of a good care home have been

identified by Healthwatch: staff who have time to care for residents, personalisation, and an environment that encourages feedback (Healthwatch, 2017).

Monitoring and evidencing the performance of community and care home services has emerged as a local priority.

Living

Creating dementia friendly communities changes perceptions of dementia and promotes inclusivity across society. Over 300 community and business organisations have committed to dementia friendly practices through the 'Take a Seat' initiative (Centre For Ageing Better, 2017). Currently 18% of people with dementia aged under 65 continue to work (Alzheimer's Society, 2015). Dementia friendly practice in the workplace enables employers to acknowledge the skills and experience of people with dementia and encourages their continued contribution.

The IMAGINE arts project has explored the interaction between older people with dementia and technology (City Arts, 2016). Researchers at the Centre of Dementia Research are extending the project to explore how technology can enable the continued employment of people with dementia.

Dying

Dementia is now the leading cause of death in England and Wales, superseding even ischaemic heart disease (Office for National Statistics, 2016a). The UK remains a global leader in palliative care due to continued investment, training, public awareness and medication availability (The Economist Intelligence Unit, 2015). Community-based palliative care reduces hospital admissions (Spilsbury *et al.*, 2017). However, advance care planning in people with dementia remains poor, mainly due to poor awareness that dementia is a terminal illness (University College London News, 2017).

To be consistent with the government's commitment, high quality end-of-life care must be person-centred, reflect individual needs, choices and preferences, and acknowledge that those needs will change as the disease progresses (Department of Health, 2016).

6) What is on the horizon?

Number of people living with dementia in Nottingham

	2017	2020	2025	2030	2035
<65	64	67	70	69	66
65+	2,740	2,853	3,135	3,563	4,146

Table formed using prevalence rates from Dementia UK: The Full Report (Alzheimer's Society, 2007) applied to Office of National Statistics population projections.

The number of people living with dementia in Nottingham is predicted to exceed 4,000 by 2035.

By 2020, the Prime Minister's Dementia Challenge intends for 50 percent of people in the UK to live in dementia-friendly communities. The University of Nottingham is already a recognised dementia-friendly community, and the agenda for Nottingham City to gain recognition as a dementia-friend community is actively being championed by the Dementia Action Alliance.

Research

Potential drugs for dementia have had limited success (Wise, 2017). Over 400 clinical trials have failed to identify a new drug treatment for dementia, leaving dementia with the highest failure rate of any disease area for potential drug candidates: 99.6%, compared with 81% for cancer (Cummings, Morstorf and Zhong, 2014). The emphasis for research, therefore, has shifted to prevention.

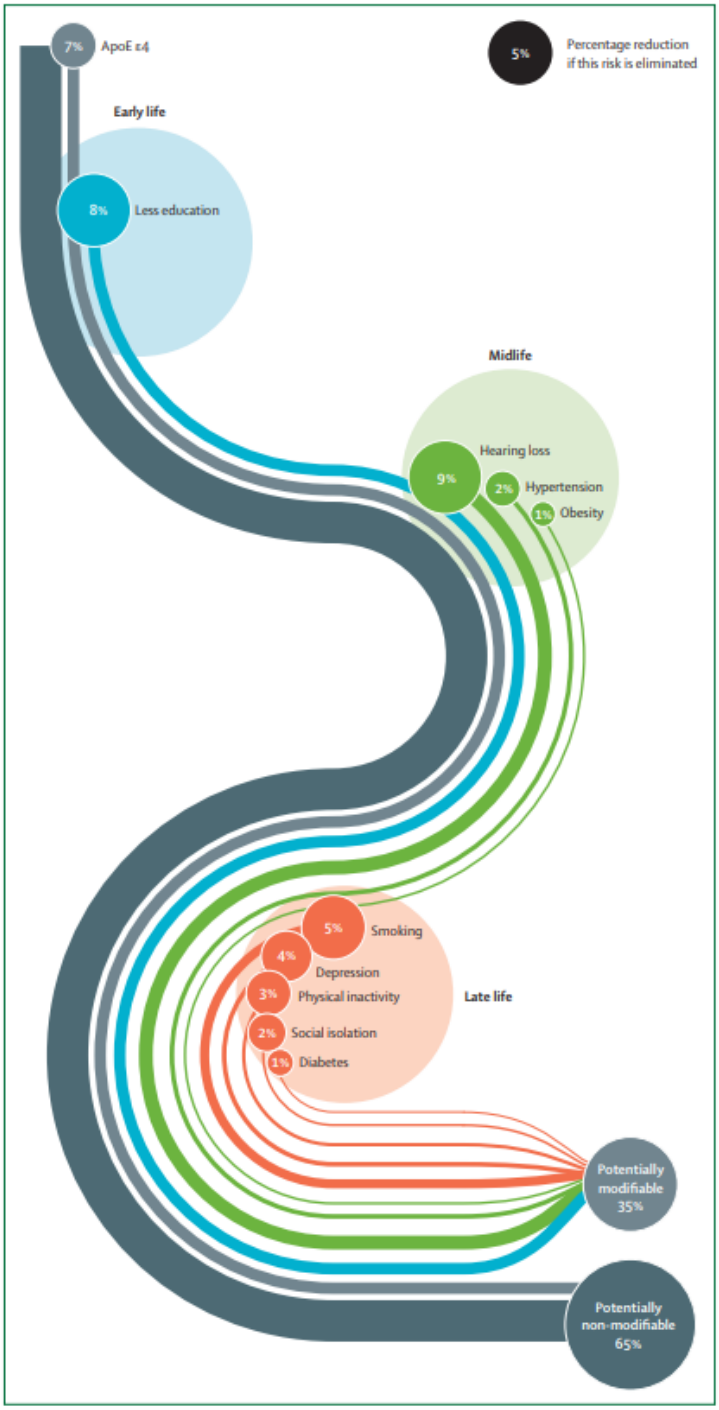


Figure 6. Infographic depicting a life-course model for dementia, and the relative risk attributable to each risk factor (Livingston *et al.*, 2017)

Funded through the Prevention and Risk Reduction Fund by Alzheimer's Research UK, researchers at the University of Manchester are developing a tool to predict an individual's risk of dementia from information readily available on GP records. If successful, this tool will enable a targeted approach to intervention, similar to the Q-RISK score for cardiovascular disease.

Service Provision

The Care Homes Vanguard has identified a number of ways technology can be used to provide a more synchronised service between care sectors. Before the end of the project in March 2018, they intend to enable care home staff to access electronic patient records of held by GPs on SystemOne and develop clear information sharing policies between care providers.

The Fix Dementia Care campaign is a national initiative by Alzheimer's Society that seeks to address the unequal delay in care faced by people with dementia and financial burden on their carers (Alzheimer's Society, 2016).

7) Local Views

Radford Care Group

The Radford Care Group is a charity that primarily runs a day care centre for older people in Nottingham. In addition, they host a regular information programme for people living with dementia and their carers. Through formal and informal consultation with service users, they have identified the following shortcomings of dementia care in Nottingham:

- Support services are inconsistent, disjoint and unreliable.
- Most information is provided online, for which access is limited for people with dementia and their carers
- Providing information about support services at the time of diagnosis is overwhelming; information should be given after a short break following diagnosis
- Social workers and community care services increasingly conduct their assessments via phone. These result in inaccurate and inappropriate referrals.
- Both patients and staff feel there is a greater need for culturally sensitive diagnostic tools and support services.

Healthwatch

Healthwatch is a national advocate for service users of health and social care, with multiple local offices. Healthwatch regularly produce national and local themed reports examining service users' perceptions of care. Healthwatch Nottingham have identified the following needs from people living with dementia:

- Patients and carers want more control and choice about how care is delivered
- Care home residents want to go out more to visit the local area
- Inconsistent levels of dementia training among staff

Healthwatch Care Home - http://www.healthwatch.co.uk/resource/whats-it-live-care-home-findings-healthwatch-network

Healthwatch Home Care - http://www.healthwatch.co.uk/news/Home-care-services-what-people-told-Healthwatch

Healthwatch Dementia Services - https://www.healthwatch.co.uk/resource/dementia-services-findings-healthwatch-network

Healthwatch Nottingham - http://hwnn.co.uk/wp-content/uploads/2016/12/Insight-Report-Dementia-diagnosis-1.pdf

What does this tell us?

8) Unmet needs and service gaps

Prevention

1. There remains poor awareness of dementia risk factors among the general public (Alzheimer's Research UK, 2017) – *see section 4, Prevention*. Although there are many existing interventions and services that target dementia risk factors locally, the links between these risk factors and dementia are not made explicit.
2. Uptake of NHS Health Checks overall remains poor – *see section 4, Prevention*. The 40- to 64-year-old age group has not been sufficiently targeted. The dementia component within the NHS Health Check targets only people over 65, despite there being evidence that risk factor modification should occur in early life.

Diagnosis

3. Current local Memory Assessment Services are not accredited by the Memory Services National Accreditation Programme (MSNAP) – *see section 5, Diagnosis*.
4. BME groups continue to experience inequities in access to diagnostic services and consequently social support – *see section 2, Diversity*.
5. Following diagnosis, there are few options for support for BME groups which are sensitive to specific cultural needs. This is a pertinent issue as people from BME groups are more likely to develop dementia at a working age.

Support

6. Although the number of people with dementia using inpatient services in Nottingham is reducing, it is not reducing as quickly as the national benchmark – *see section 2, Severity*. There needs to be greater work to understand what more can be done to reduce utilisation of inpatient services by people with dementia to meet the national benchmark.
7. Information about available services and support is needed on paper and verbally through formal and informal networks.

Living

8. For Nottingham to achieve dementia-friendly status, local authorities must review existing healthy living plans and ensure the built environment, commissioned services and local businesses reflect the specific needs of people living with dementia.

Dying

9. There is poor awareness that dementia is a terminal illness. In the general public, a survey conducted during Dementia Awareness Week showed that only 18% of over 4,000 survey respondents correctly identified dementia as a terminal illness. (Alzheimer's Society, Saga Homecare and YouGov, 2012). Among health professionals, a cohort study of people with advanced dementia in Greater London found that only 34% were referred to palliative care and only 40% had a recorded preferred place of death (Sampson *et al.*, 2017). Evidence suggests that lack of advance care planning is a national trend. This has shifted dementia deaths from the community to the hospital.

9) Knowledge gaps

1. At present, the performance of primary care services are measured by only four Quality Outcome Framework indicators relevant to Dementia, two of which are used in the Assessment Framework for Clinical Commissioning Groups. There are no data to evidence which community services effectively reduce hospital admissions. Increasing the number of indicators being measured would CCGs to deliver against them.
2. Data regarding service utilisation is not shared with commissioners.

What should we do next?

10) Recommendations for consideration by commissioners

Recommendations		Leads			
Theme	**Action**	**Local authority**	**Service providers**	**CCG**	**NHSE**
Prevention	1. Commissioning should reflect NHS England's Well Pathway for Dementia and Nottingham City's Dementia Framework for Action.	x	x	x	x
	2. Map service provision currently available in the city to identify gaps and areas of duplication.	x			
	3. Train GPs and healthcare workers across the city regarding risk factors for dementia and interventions that can prevent dementia.		x	x	
Diagnosis	4. Increase uptake of diagnostic services in BME groups, possibly through the use of community outreach programs		x	x	
	5. Increase rates of diagnosis of dementia subtypes / information sharing with community care providers to assist targeted care provision		x		x
Support	6. Develop a robust plan to generate evidence showing a reduction in hospital admissions due to dementia following the provision and development of community dementia services	x	x	x	
	7. Increase choice and control in care homes for service users		x		
	8. Increase percentage of care homes rated 'Good' or 'Outstanding' by the Care Quality Commission from 45.3% to 60% by 2019		x		
Living	9. Form a City-wide joint approach to supporting people with dementia	x	x	x	x
	10. Increase learning for family carers, supporting carers to understand the different types of dementia, support self care.		x	x	
	11. Continue to develop local services to meet standards for Nottingham City to achieve dementia-friendly status	x	x		
	12. Develop a dementia-friendly employer framework and	x	x		

	encourage organisations to sign up to committed actions				
	13. Write sustainable development plans that specifically consider dementia	x	x		
Dying	14. Provide specialist end-of-life care for people with dementia through palliative care services integrated in the community		x	x	
	15. Educate health professionals and the public that dementia is a terminal illness	x	x	x	x

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