

Dementia Prevention in Southwark

Southwark's Joint Strategic Needs Assessment

Healthcare Public Health

Southwark Public Health

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GATEWAY INFORMATION

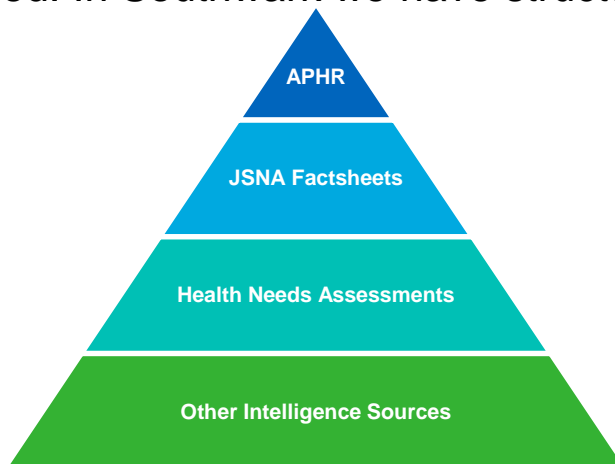
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Health Needs Assessments form part of Southwark's Joint Strategic Needs Assessment process

BACKGROUND

The Joint Strategic Needs Assessment (JSNA) is the ongoing process through which we seek to identify the current and future health and wellbeing needs of our local population.

- The purpose of the JSNA is to inform and underpin the Joint Health and Wellbeing Strategy and other local plans that seek to improve the health of our residents.
- The JSNA is built from a range of resources that contribute to our understanding of need. In Southwark we have structured these resources around 4 tiers:



Tier I: The Annual Public Health Report provides an overview of health and wellbeing in the borough.

Tier II: JSNA Factsheets provide a short overview of health issues in the borough.

Tier III: Health Needs Assessments provide an in-depth review of specific issues.

Tier IV: Other sources of intelligence include Local Health Profiles and national Outcome Frameworks.

- This document forms part of those resources.
- All our resources are available via: www.southwark.gov.uk/JSNA

This needs assessment aims to understand the local impact of dementia and promote healthier behaviours

AIMS & OBJECTIVES

The aim of this project is to better understand the negative impact of dementia and promote healthier behaviours across our local population.

- This health needs assessment addresses **Phase 1** of this project which investigates the local health needs and the impact of dementia while exploring the evidence base.

The specific objectives of Phase 1 are to:

- Describe the policy and strategic context including NICE guidelines on dementia care, and NHSE dementia care pathway implementation guidance
- Update our knowledge around modifiable risk factors to dementia
- Describe the local picture in terms of early identification, assessment, diagnosis and treatment of dementia in primary care
- Describe evidence-based public health interventions to (i) reduce the negative impact of the disease through both prevention and early detection, and (ii) Identify examples of good practice in dementia care at the national/regional/local level

This work will inform Phase 2 of the project including mapping of local services and dementia care pathways to enhance management and care services in Southwark.

- Public Health will support the development of future plans and actions addressing dementia prevention by offering insight regarding best practice according to the evidence base and recommendations to improve prevention and integrate care locally.

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Dementia is a clinical syndrome characterised by difficulties with one or more areas of mental function

INTRODUCTION

Dementia is defined as a significant loss of cognitive abilities to the extent that it interferes with social or occupational functioning affecting each individual differently.

- 'Dementia' is a clinical syndrome (group of symptoms) characterised by difficulties with one or more areas of mental function.
- These areas may include memory, language, ability to complete activities of daily living, behavioural changes including self-neglect and out of character behaviour and psychiatric problems.

Dementia is a progressive and largely irreversible condition and can be caused by several different disease processes.

- 50-70% of cases are due to Alzheimer's disease, which is a poorly understood neurodegenerative disease with genetic, medical and behavioural risk factors.
- Other forms of dementia include vascular dementia, dementia with Lewy bodies, Picks diseases, Creutzfeldt-Jakob disease and dementia associated with brain injury or medical conditions. These forms of dementia can co-exist with Alzheimer's disease and many share similar risk factors.

Due to the loss of cognitive functions, dementia can lead to a reduced quality of life, ill-health and premature mortality.

- Because they are less able to perform activities of daily living, persons with dementia often require additional community support and long term care.

References

1. Alzheimer's Society: Dementia UK Report (2014).
2. NICE Guidance Dementia, disability and frailty in later life (2015). <https://www.nice.org.uk/guidance/ng16>

Age is the most significant non-modifiable risk factor for the development of dementia

INTRODUCTION – RISK FACTORS

Several non-modifiable risk factors for dementia exist, the most significant being age.



- **Above the age of 65**, a person's risk of developing Alzheimer's disease or vascular dementia doubles approximately every 5 years. It is estimated that dementia affects one in 14 people over 65 years old, and one in six over 80 years old.



- Alzheimer's disease is known to be more common in **women**, even when adjusted for greater life expectancy of women.



- International research has demonstrated differences in rates of diagnosis between certain **ethnic groups**. Evidence indicates people from South Asia and people of African or Afro-Caribbean origin seem to develop dementia more often.



- Whilst more than 20 genes have been identified to not directly cause dementia, there is a clear pattern of **inheritance** of dementia in affected families.

References

1. Dementia UK: The Full Report, Alzheimer's Society (2007).
2. Risk Factors for Dementia: Factsheet 450LP (2016).

A range of modifiable risk factors for dementia are already the subject of public health initiatives

INTRODUCTION – RISK FACTORS

Several modifiable risk factors for dementia have been identified and are already the subject of public health initiatives.

- The robustness of the evidence and communality of risk factors, however, can make it difficult to distinguish the relative importance of individual factors.

Smoking

Physical Inactivity

Type 2 diabetes

Hypertension

Depression

Social isolation

Poor diet

Obesity

Excessive alcohol

Head injury

Lack of secondary education

Specific disease-related conditions

Hyperlipidemia

Cardiovascular disease

Additionally, the Lancet Commission for Dementia prevention, intervention and care found **hearing loss to be an important mid-life risk factor.**

- Hearing loss may have a greater impact than just sensory loss, but in fact add to the cognitive load or lead to stress, social disengagement or depression, further contributing to cognitive decline. It has been suggested hearing-aid usage is protective for risk of dementia, however further research is needed.

References

1. The Lancet Commission for Dementia Prevention, Intervention and Care (2017).
2. Risk Factors for Dementia: Factsheet 450LP (2016).

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Ambitions set by the Prime Minister and NHS highlight dementia prevention and care as a national priority

NATIONAL POLICY CONTEXT

England has had a long standing commitment to improve the awareness, diagnosis, healthcare and quality of life for people with dementia and their carers.

- Following the first national strategy of its kind in 2009, the Prime Minister's Challenge on Dementia 2015 aimed to drive up healthcare quality, create dementia-friendly communities and further research across the dementia landscape.

Building on ambitions of outlined in 2015, the Prime Minister's Challenge on Dementia 2020 reaffirmed the nation's commitment to carers and people with dementia and established a range of new goals for dementia care from diagnosis through end of life.

- In addition to creating supportive and inclusive environments, the challenge emphasizes the need to develop research, raise awareness, and coordinate care with a trained workforce.

Furthermore, the NHS Five Year Forward View, recognises dementia as a priority area with a specific aim to diagnose more people with dementia earlier to allow treatment to help slow the progression of the disease.

- To achieve this, the NHS Five Year Forward view aims to provide a consistent standard of care for patients and to support clinicians or advisors, with proper care plans developed in partnership with patients and families.

References

1. Living Well with Dementia – A National Dementia Strategy, 2009.
2. Prime Minister's Challenge on Dementia, 2012.
3. Prime Minister's Challenge on Dementia, 2020.
4. NHS Five Year Forward View 2014.

NICE has produced guidance addressing mid-life approaches to delay or prevent the onset of dementia

NATIONAL POLICY CONTEXT

NICE has produced a guideline addressing mid-life (adults aged 40-64 years) approaches to delay or prevent the onset of dementia, disability and frailty later in life.

- The aim is to delay the onset of disease progression to increase the amount of time that people can be independent, healthy and active in later life.

The focus of the NICE guideline is on changing specific modifiable risk factors and behaviours that can reduce the risk of dementia disability and frailty.

The recommendations for promoting healthy lifestyles span healthy weight advice, smoking cessation and alcohol consumption.

- Although there are already numerous policies and guidelines in place to address the recommended healthy behaviours, dementia, disability and frailty are often not associated with these conditions as potential consequences.

Organisations can support individuals to achieve healthy lifestyle behaviours by promoting and encouraging opportunities for behaviour change.

- Providing access to services and sharing information about the risk factors of the disease are key ways to operationally engage in dementia prevention activities.

References

1. NICE Guidance Dementia, disability and frailty in later life [NG16] (2015).

NICE has also produced guidance focused on person-centred care for the person living with dementia

NATIONAL POLICY CONTEXT

In addition to the NICE Guideline produced to support the agenda of ‘delaying or preventing the onset of dementia, disability and frailty later in life’, NICE has also produced a guideline for ‘assessment, management and support for people living with dementia and their carers’.

- The aim is to improve care provided to people living with dementia by making recommendations on training staff and helping carers.

The focus of the NICE guideline is on delivering best-practice person-centred care to people living with dementia and their families and carers.

The recommendations highlight the need to involve patients and carers in decisions about care, which should be coordinated by a single named health or social care professional. Some of the specific recommendations include:

- An individual **care plan** should be created and reviewed once a year.
- Special measures should be taken to ensure **communication** is optimised, and interventions should focus on promoting overall wellbeing as well as the cognitive and non-cognitive symptoms of dementia.
- Use of **pharmacological agents** in treatment of dementia should supplement holistic care.
- Special consideration should be placed on management of **medical co-morbidities** given the communication and physical barriers patients can face.

References

1. NICE Guidance Dementia, disability and frailty in later life [NG97] (2018).

England has pioneered strategic policy for dementia prevention and care

POLICY CONTEXT: SUMMARY

England has had a long standing commitment to improve the awareness, diagnosis, healthcare and quality of life for people with dementia and their carers.

- After developing the first national strategy on dementia, the Prime Minister's Challenge on Dementia 2015 and 2020 aimed to drive up healthcare quality for people living with dementia, create dementia-friendly communities, support carers and further research across the dementia landscape.
- Additionally, the NHS Five Year Forward View, recognises dementia as a priority area with a specific aim to diagnose more people with dementia earlier to allow treatment to help slow the progression of the disease.

NICE has produced guidelines addressing mid-life (adults aged 40-64 years) approaches to delay or prevent the onset of dementia, disability and frailty later in life as well as for assessment, management and support for people living with dementia and their carers.

- Although there are already numerous policies and guidelines in place to address the recommended healthy behaviours, dementia, disability and frailty are often not associated with these conditions as potential consequences.
- The focus of these guidelines is to promote the delivery of best-practice person-centred care to people living with dementia and their families and carers.

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Whilst dementia prevalence is lower in Southwark, the rate of new diagnoses is similar to London and England

THE LOCAL PICTURE

There are currently 850,000 people living with dementia in the UK, and it is the leading cause of death in England and Wales.

- 12% of all deaths registered in 2016 were due to dementia, and 15.6% of female deaths were attributable to dementia and Alzheimer's disease.

Dementia has a greater impact on women as the prevalence among women is higher than men and the majority of carers are women.

- In England, 65% of people living with dementia are women, compared to 35% men.
- 60-70% of carers for people with dementia are women, and 20% of those carers have changed their employment from full-time to part-time status.

For the over 65+ population in Southwark, 1,016 (3.6%) people have a recorded prevalence of dementia, which is significantly lower than the London (4.5) and England (4.3) values.

- However, the rate of new dementia diagnoses for the over 65 population in Southwark (10.7 per 1,000 population) is similar to the rate for both London (10.3 per 1,000 population) and England (11 per 1,000 population).

References

1. Prince, M et al. (2014) Dementia UK: Update Second Edition
2. Deaths registered in England and Wales (series DR): 2016.
3. Women and Dementia: A Marginalised Majority by Alzheimer's Research UK
4. Public Health Outcomes Framework (2019).

As residents age, the overall prevalence of dementia is expected to increase in Southwark

THE PICTURE IN SOUTHWARK

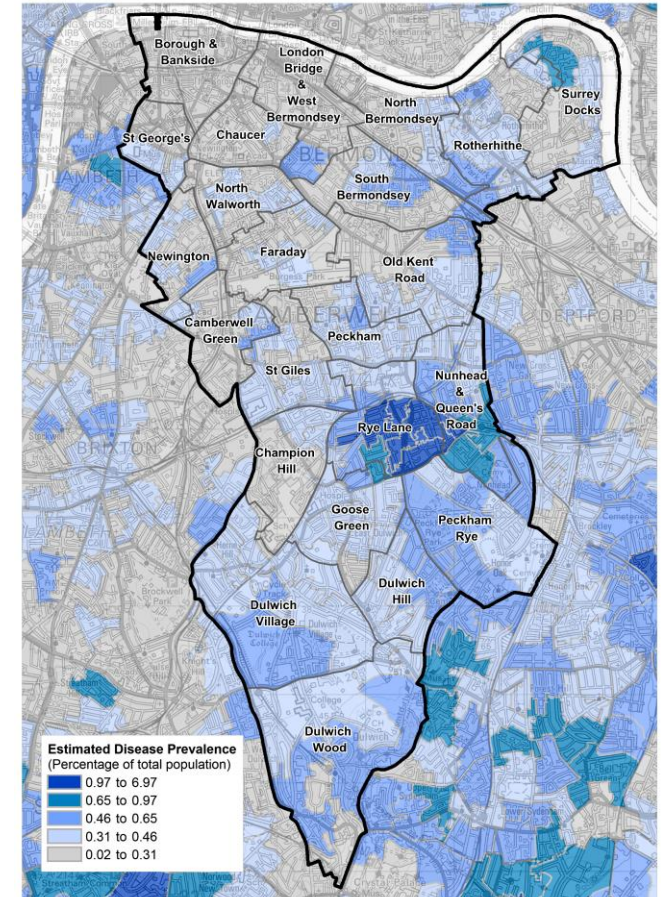
Rye lane has the highest estimated prevalence of dementia in the borough.

- The southern half of the borough has more areas of higher dementia prevalence, suggesting areas that should be prioritised for dementia friendly communities.

The population of Southwark is set to continue to grow, increasing by 20% to over 370,000 in 2026.

- Growth is set to continue across almost all areas of the borough in the next decade. In particular, redevelopments around Old Kent Road, South Bermondsey and Elephant and Castle, will lead to significant population increases in these communities.
- Additionally, the number of people aged 65 and over will increase by 13,700 by 2030, with increases across the borough. As a result we can expect the overall prevalence of dementia to increase.

Local neighbourhood all-ages dementia prevalence, 2017/18 (%)



References

1. Map source: House of Commons Library (Disease prevalence in England: local estimates), 2019
2. Overview of Southwark's Population. Southwark's JSNA. (2018).

It is estimated 336 people are living in Southwark without a diagnosis of dementia

THE PICTURE IN SOUTHWARK

Research shows a timely diagnosis of dementia can have a significantly positive impact on a person's quality of life.

The diagnosis rate for Southwark as of May 2019 is 78.5%, which is the 8th highest diagnosis rate in London.

- Despite the ranking, it is estimated **336** persons are living with dementia in Southwark without a diagnosis.
- Furthermore, as of April 2019, **65%** of all diagnoses had an ethnicity of 'Not Defined' indicating data collection can be improved.

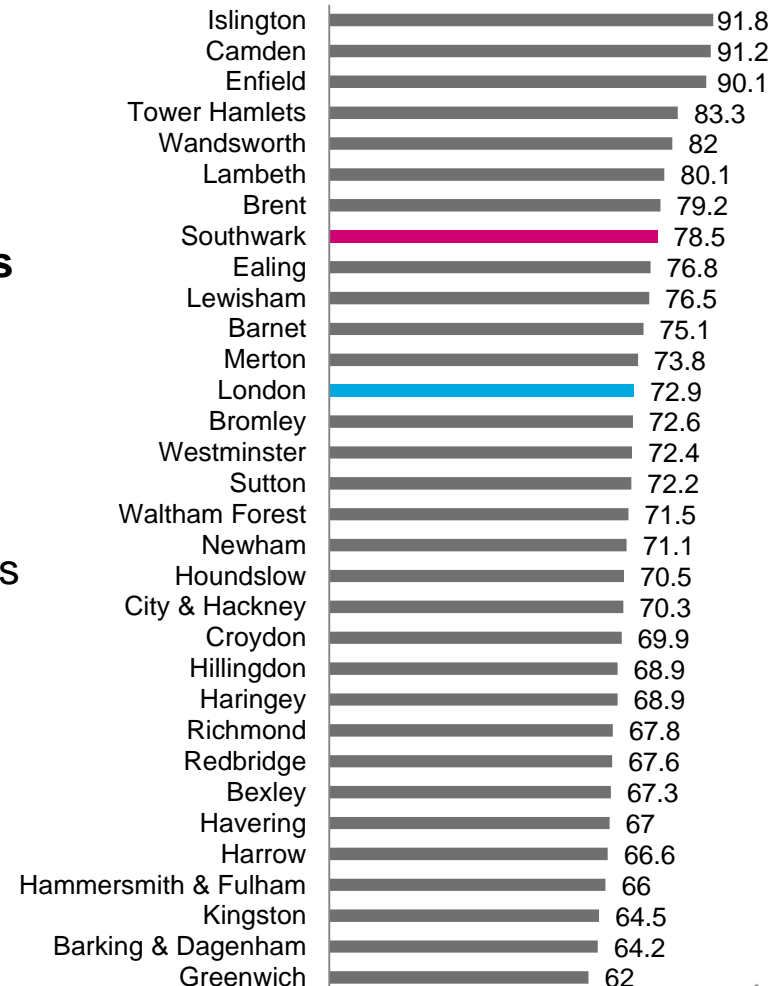
Guidance has been developed for GPs to improve dementia coding across clinical systems.

- Non-diagnosed patients are missing the opportunity for early intervention emphasising the need for continued action.

References

1. Public Health Outcomes Framework (2019).
2. NHS – London Clinical Networks, Dementia Clinical Leadership Group (2019).
3. NHS Digital – Recorded Dementia Diagnoses April 2019.

Dementia Diagnosis Rate Across London, May 2019 (%)



Southwark has one of the highest emergency admissions rates for people aged 65+ living with dementia

THE PICTURE IN SOUTHWARK

Southwark has one of the highest rates of emergency admissions in London for persons aged over 65 years with a diagnosis of dementia (See APPENDIX 1).

- With a rate of 5958 per 100,000 people aged 65+ with dementia, Southwark is significantly higher than the London (4,356) and England (3,609) values indicating many local residents with dementia are requiring acute care services.

The percentage of admissions related to dementia increases with age for the 65+ population.

- 6% of admissions for the 65-74 age group were related to dementia, compared to 15% for the 75-84 age group and 31% for the 85+ age group.

The dementia admission rate also increases with age for the over 65+ population in Southwark.

- The dementia admission rate for the 85+ population in Southwark (22,982 per 100,000), is more than 3 times greater than the 65-74 and 75-84 population rates combined (7,281 per 100,000).

References

1. Public Health Outcomes Framework (2019).
2. HDIS.

Females in the 85+ age group represent a large proportion of dementia admissions

THE PICTURE IN SOUTHWARK

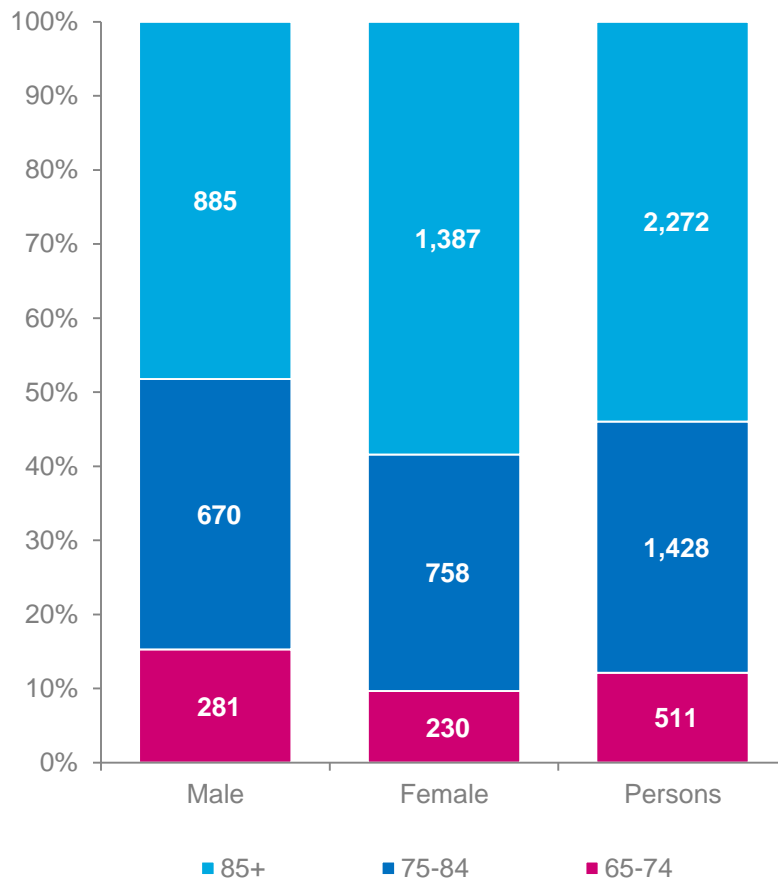
Over half (54%, 2,272) of persons aged 65+ admitted for dementia, are patients in the 85+ age-band.

- Because age is the most significant risk factor for developing dementia, it is unsurprising the 85+ age group represents the largest proportion of admissions.

Females in the 85+ population represent a third (33%, 1,387) of all 65+ dementia admissions, and 61% for those aged 85+.

- Interestingly, however, there is a greater proportion of males diagnosed with dementia in the 65-74 age group (15% of males aged 65+) and the 75-84 age group (36%) compared to the corresponding age groups for females at 10% and 32%, respectively. This may be attributable to the fact that more females are living to ages of 85+ than males.

Southwark admission by age-band (2015-18), percentage



References

1. HDIS.
2. Overview of Southwark's Population. Southwark's JSNA (2018).

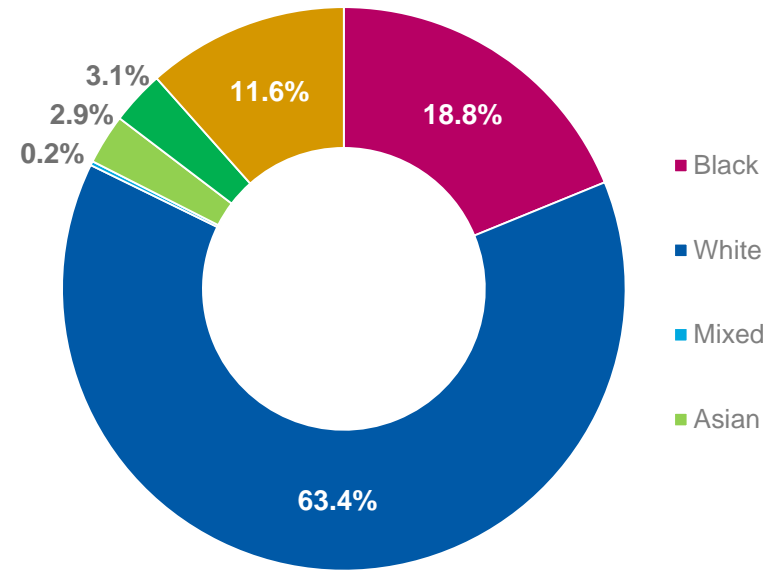
Local dementia admissions for the 65+ population reflect the population distribution by ethnicity

THE PICTURE IN SOUTHWARK

The white ethnic category represents the majority (63%) of dementia admissions for the over 65+ population in Southwark.

- The black ethnic group accounted for almost a fifth (18.8%) of dementia admissions among patients aged 65+.
- Despite the high prevalence of dementia admissions among the black and white ethnic groups, this largely reflects the demographic population distribution by ethnicity and therefore **dementia prevention initiative should not target a particular ethnic group.**

Southwark admissions for 65+ by broad ethnic category (2015-18), %



Ethnicity	Dementia Admissions Percentage	Population percentages (70+) - JSNA Demography Factsheet
Black	18.8%	21.1%
White	63.4%	68.8%
Mixed	0.2%	1.9%
Asian	2.9%	6.2%
Other	3.1%	2.1%

References

1. HDIS.

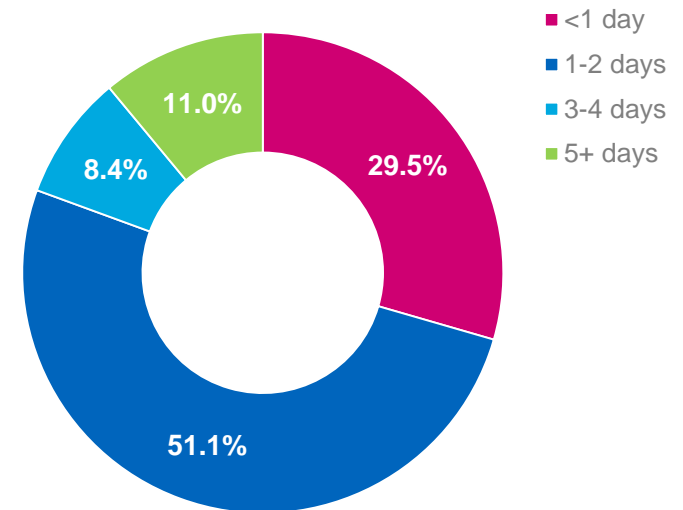
In Southwark, 81% of emergency hospital admissions for dementia were discharged in less than three days

THE PICTURE IN SOUTHWARK

34.8% of emergency inpatient admissions for people with dementia aged 65+ in Southwark stayed for one night or less, which is significantly higher (worse) than for London (30.2%) and England (28.9%).

- Furthermore, in Southwark 80.6% of hospital admissions for dementia were discharged in less than 3 days.
- Whilst longer hospital stays for older people have been linked to worse health outcomes and an increase in care needs upon discharge, changes in the surrounding environment can lead to increased anxiety and stress for both dementia patients and their cares, and therefore short stays should be avoided if possible.

Southwark patients length of stay for emergency admissions related to dementia (2015-18), %



The evidence (from a qualitative review) showed that even small practice changes could have a positive impact in reducing a *delayed discharge* for people living with dementia following an acute hospital stay.

- Minor improvements across rehabilitation practices, obtaining a clinical history, documentation, joint working and supporting family involvement have the potential to result in a timely discharge.

References

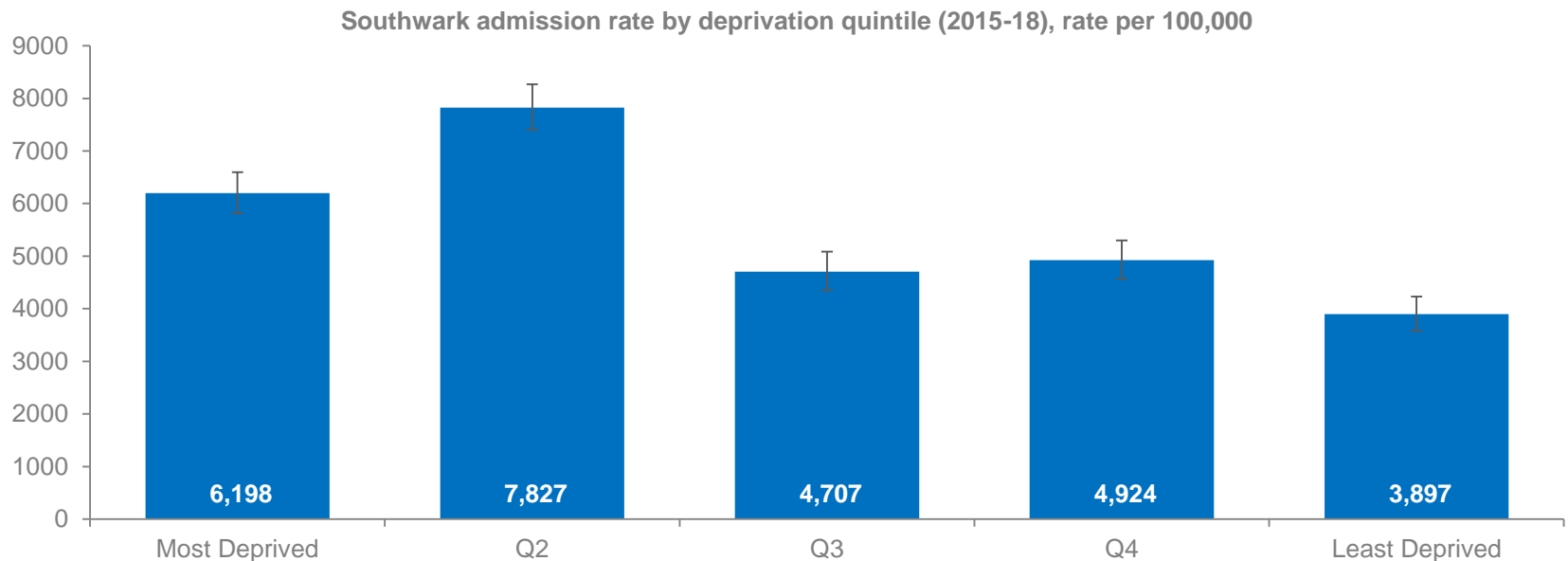
1. Public Health Outcomes Framework (2019).
2. NHS: Identifying factors contributing to acute hospital delayed discharge for people living with dementia (2018). www.londonscn.nhs.uk/wp-content/uploads/2018/02/dem-DC-dec18.pdf

The dementia admission rate is lowest in the least deprived quintile

THE PICTURE IN SOUTHWARK

The dementia admission rate for the population aged 65+ in the most deprived quintile (6,198 per 100,000), is 1.6 times greater than the admission rate in the least deprived quintile (3,897 per 100,000).

- There is no clear correlation between deprivation level and dementia admission rates; the highest rate (7,827 per 100,000) relates to the second most deprived quintile indicating dementia prevention initiatives should be delivered universally.



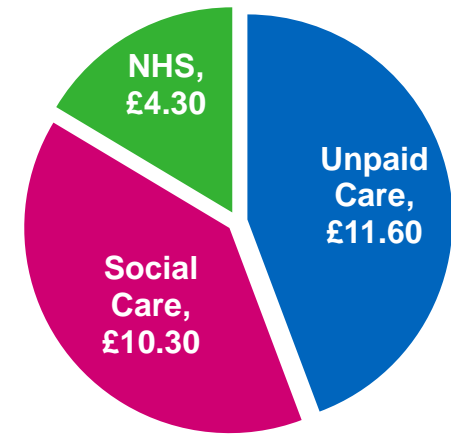
The cost of dementia extends well beyond the direct price of healthcare services

THE COST OF DEMENTIA

The estimated cost of dementia care across the UK exceeds £26 billion each year, which is equivalent to £32,250 per person annually.

- Of the £10.3 billion spent on social care, more than half (£5.8 billion) is privately funded, accounting for 23% of the total cost of dementia.
- In addition to the cost of direct healthcare services, it is estimated by 2030, dementia will cost companies more than £3 billion as an additional 33,000 people are expected to leave employment to care for people with dementia.

Estimated Cost of Dementia Care Across the UK, £billion



Estimates project delays in onset of disease could result in a considerable amount of savings for the NHS.

- If prevention methods and behaviours delayed the onset of disease by 12 months, it is estimated this would save the UK approximately £1.5 billion per year. A delayed onset of as much as 36 months would save the UK an estimated £4.9 billion per year.
- Although cost data is not available for Southwark, these estimates indicate dementia prevention has the potential for both a clinical and financial benefit.

References

1. Alzheimer's Society – Dementia UK Update (2014).
2. Prime Minister's Challenge on Dementia, 2020.
3. Knapp, M et al. Scenarios of Dementia Care: What are the Impacts on Cost and Quality of Life? (2014).

Despite higher activity levels, Southwark residents increase risk from unhealthy diets and excess weight

RISK FACTORS IN SOUTHWARK: ACTIVITY & DIET

Physical inactivity and an **unhealthy diet** are major lifestyle behaviours contributing to an increased risk of developing dementia.

Only 50.5% of adults meet the recommended '5-a-day' on a 'usual day', compared to 54% of Londoners and 55% across England.

- Southwark residents consume an average of 2.5 and 2.6 portions of fruits and vegetables each day, similar to London and England levels, indicating most are not meeting recommended dietary intake levels.

74% of Southwark adults (18+) are physically active whilst only 16.8% of Southwark adults are inactive (less than 30 minutes of activity per day).

- Despite the higher level of activity compared to London and England, because activity levels decrease with age it is important to ensure activity is maintained throughout the life course.

Furthermore, overweight and obesity (excess weight) increase a person's risk of developing a range of medical conditions and diseases including type 2 diabetes, hypertension and hyperlipidemia, which in turn increase a person's risk for dementia.

- Half of Southwark residents aged 18+ are classified as overweight or obese. Whilst significantly lower than regional and national values (56% and 62%, respectively), a large proportion of adults entering older ages will be of unhealthy weight.

References

1. Public Health Outcomes Framework (2019).
2. Active Lives Adult Survey – May 17/18 Report (2018).

Despite a falling smoking prevalence in Southwark, local smoking-attributed mortality is higher than average

RISK FACTORS IN SOUTHWARK: SMOKING

Smoking tobacco significantly increases the risk of developing dementia and especially **Alzheimer's disease** in older adulthood.

- The significant harmful effects on the cardiovascular and respiratory systems can also lead to medical conditions increasing the risk of developing dementia.

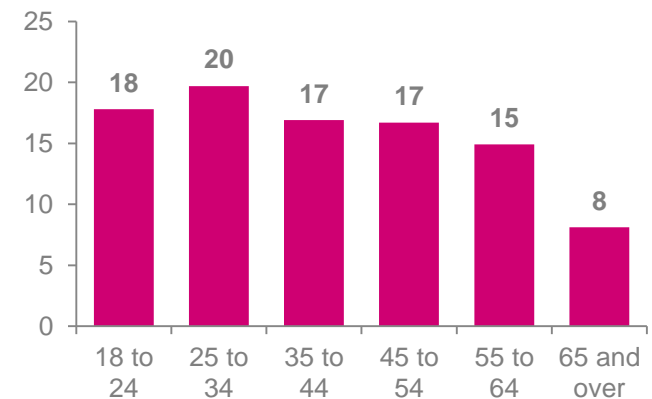
Estimates suggest over 30,000 (12%) smokers currently live in Southwark, a prevalence relatively lower than London and England (15%), and each year almost 270 people in Southwark die from smoking related illnesses.

- Since 2012, great strides have been made in reducing the prevalence of adult smoking, yet smoking-attributable mortality remains above London and England averages.

National models show smoking prevalence reduces with age, however it is possible the impact is already realised by older adulthood.

- Effective tobacco control should continue to support residents to stop smoking at all ages.

Figure 4: National smoking prevalence by age group, 2017



References

1. Public Health Outcomes Framework (2019).
2. Risk Factors for Dementia: Factsheet 450LP (2016).
3. Smoking in Southwark. Southwark's JSNA (2019).

Southwark has the second highest rate of alcohol dependency in SE London for those aged 35 and over

RISK FACTORS IN SOUTHWARK: ALCOHOL

Regular alcohol intake above the NHS recommended levels increases a person's risk of developing dementia.

- Furthermore, a prolonged period of excessive alcohol consumption may lead to a range of cardiovascular medical conditions and increases the risk of developing Korsakoff's syndrome and alcoholic dementia.

According to national profiles, highest levels of alcohol consumption were among those aged 45-64 years, and those aged 55-64 were most likely to be drinking at higher or increasing risk levels.

- Additionally, fewer older adults aged 65 years reported abstaining from alcohol completely.

Similar to national trends, Southwark males aged 35-54 had the highest proportion classified as alcohol dependent.

- Southwark has the second highest rate of alcohol dependency in South East London for those aged 35 and over.
- If behaviours of alcohol dependency continue, this has the potential to have a significant impact on dementia disease progression

References

1. Risk Factors for Dementia: Factsheet 450LP (2016).
2. Statistics on Alcohol, England (2018).
3. The Impact of Alcohol in Southwark – Southwark JSNA (2017).

People affected by dementia have a higher risk of feeling lonely and being socially isolated

RISK FACTORS IN SOUTHWARK: SOCIAL ISOLATION & LONELINESS

People affected by dementia have a higher risk of being socially isolated and lonely than other social groups.

- **Social isolation** refers to the inadequate quality and quantity of social relations with other people at the different levels where human interaction takes place (individual, group, community and the larger social environment).
- **Loneliness** is subjective, unwelcome feeling of a lack or loss of companionship.

Over a third (35%) of people with dementia interviewed as part of Turning Up the Volume report said they have felt lonely recently.

- Furthermore, a third of people with dementia said they had lost friends following a diagnosis. Whilst the reasons for this were manifold, some people reported this was due to friends requiring more assistance moved to new neighbourhoods, sheltered accommodation or a care home.
- Stigma around dementia also resulted in people affected by condition to become more isolated.

Research suggests that some people living with dementia have poor experiences when coming into contact with people outside their immediate social circle, causing them to want to withdraw from society.

References

1. Perlman & Peplau (1981). Toward a Social Psychology of Loneliness.
2. Alzheimer's Society – Tackling Loneliness in People Living with Dementia. (2018).

For Southwark residents, dementia prevention and an early diagnosis could enable independent living for longer

THE PICTURE IN SOUTHWARK: HOUSING

The national approach is to support independent living for those with dementia in their own homes for as long as possible and currently it is estimated in England one third of people affected by dementia live in residential care.

- People with dementia living in care homes, however, have an increased likelihood of being admitted to hospital for avoidable conditions such as urinary infections, dehydration, and pressure sores.

For the 65+ population in England, dementia was the most common health condition requiring long term support for specialist housing in 2015/16.

- In Southwark, the 65+ population size is set to increase by 35% over the next 10 years and the 'very old' (90+) population is also expected to rise.
- It was estimated that local specialist accommodation utilisation will increase by 13% as the likelihood of individuals requiring support with activities such as washing, dressing and having additional co-morbidities will increase.

The current quality rating of residential care and nursing home beds for adults aged 65 years and over in Southwark is 44.4, which is significantly lower than that for London (48.9) and England (68.2).

- This indicates there are an insufficient number of beds for all CQC residential care homes and nursing home to account for all persons in Southwark with a registered diagnosis of dementia.
- Delaying the onset of dementia through prevention and an early diagnosis could reduce the negative impact of disease and enable these individuals to live independently for longer.

References

1. Prime Minister's Challenge on Dementia, 2020.
2. SALT data, 2015/16.

A projected increase in the 65+ population in Southwark may lead to a higher prevalence of dementia locally

THE LOCAL PICTURE: SUMMARY

For the over 65+ population in Southwark, 1,016 (3.6%) people have a recorded prevalence of dementia, and it is projected the number of residents aged 65 and over will increase by 13,700 by 2030, and we can therefore expect the overall prevalence of dementia to increase.

- It is estimated 336 persons are living with dementia in Southwark without a diagnosis.

Southwark has one of the highest rates of emergency admissions in London for persons aged over 65 years with a diagnosis of dementia.

- Females in the 85+ age group represent a large proportion of dementia admissions.
- In Southwark, 81% of hospital admissions for dementia were discharged in less than 3 days.

The estimated cost of dementia care across the UK exceeds £26 billion each year, which is equivalent to £32,250 per person annually.

- Although cost data is not available for Southwark, these estimates indicate dementia prevention has the potential for both a clinical and financial benefit.

Smoking, alcohol intake, activity, diet, loneliness and social isolation are all important risk factors to consider in the context of dementia prevention.

- The focus of dementia prevention should be on strategies to decrease the onset of dementia and furthermore delay the deterioration that ensues. This could reduce the impact of disease and enable these individuals to live independently for longer.

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Commitments laid out in the Prime Minister's Challenge 2020 are actioned to a range of partners across England

THE NATIONAL RESPONSE

Although the nation has seen significant progress with regards to dementia care and service provision, the Prime Minister's Challenge 2020 encourages agencies to build upon the momentum to achieve more.

- To meet the over 50 commitments set out in the Challenge, **the Prime Minister's Challenge 2020 Implementation Plan** identifies the specific actions and partner organisations that will achieve the goals.
- Across each of the four themes, **risk reduction, health and care, awareness and social action, and research**, the collaborative, cross-sector response delivered through the Implementation Plan will bring the nation closer to achieving the Challenge vision of England being the best country in the world for dementia care, support, research and awareness.

One of the key priorities set out in the Challenge and Implementation Plan is the delivery of a Well Care Pathway for dementia.

- This pathway describes an overarching framework for coordinating and improving the experience of health and social care from diagnosis through to end of life through five main stages:

Preventing Well

Diagnosing Well

Supporting Well

Living Well

Dying Well






- Local pathways should align with the Well Care Pathway for dementia with the aim of reducing fragmentation and poor coordination.

References

1. Prime Minister's Challenge on Dementia 2020 – Implementation Plan (2016).

The NHS Well Pathway for Dementia describes best practice for coordinating care from diagnosis to end of life

THE NATIONAL RESPONSE

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
<p>PREVENTING WELL</p>  <p>Risk of people developing dementia is minimised</p>	<p>DIAGNOSING WELL</p>  <p>Timely accurate diagnosis, care plan, and review within first year</p>	<p>SUPPORTING WELL</p>  <p>Access to safe high quality health & social care for people with dementia and carers</p>	<p>LIVING WELL</p>  <p>People with dementia can live normally in safe and accepting communities</p>	<p>DYING WELL</p>  <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾, BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾, Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽⁶⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾, Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>
<p>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</p>				
<p>RESEARCHING WELL</p> <ul style="list-style-type: none"> • Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change. • Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries. 				
<p>INTEGRATING WELL</p> <ul style="list-style-type: none"> • Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care. 				
<p>COMMISSIONING WELL</p> <ul style="list-style-type: none"> • Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice. • Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources. 				
<p>TRAINING WELL</p> <ul style="list-style-type: none"> • Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community. • Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes. 				
<p>MONITORING WELL</p> <ul style="list-style-type: none"> • Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each. • Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation. 				

References

1. NHS England Well Pathway for Dementia

A good quality diagnosis and a streamlined dementia pathway are strategic priorities in the borough

THE LOCAL RESPONSE

Southwark's Joint Mental Health and Wellbeing Strategy 2018-2021 specifically identifies priorities for older people in the borough.

- One of the aims of the strategy is to support older people living with functional and organic mental health conditions to experience the best possible health outcomes inclusive of those with dementia-related needs.

Key areas of action outlined in the strategy are to ensure everyone receives a good quality dementia diagnosis and is supported by a streamlined dementia pathway across the Southwark CCG and Southwark Council.

- Importantly, this commitment also includes supporting residents under 65 years of age experiencing symptoms or early signs of dementia to enable and encourage independent living and retained employment.

There are already a number of initiatives in place addressing dementia prevention that complement the Strategy and can be divided into three areas across the Well Pathway:

- **Primary prevention:** reducing or avoiding the occurrence of a disease through lifestyle changes and healthy behaviours (**preventing well**)
- **Secondary prevention:** Early diagnosis and treating conditions before they cause significant ill health (**diagnosing and supporting well**)
- **Tertiary prevention:** Reducing the negative impact of an existing disease through restoring function and reducing complications (**living and dying well**)

References

1. Southwark Joint Mental Health and Wellbeing Strategy (2018 – 2021).

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Less than 10% of Southwark residents receiving an NHS Health Check are given dementia risk reduction advice

PRIMARY PREVENTION – NHS HEALTH CHECKS

The NHS Health Checks programme offers all people between the ages of 65-74 years receiving a health check information and advice on dementia.

- According to the NHS Health Checks Best Practice Guidance,
 - **Everyone who has received an NHS Health Check** should be made aware that the **risk factors** for CVDs are the same as those for dementia through the messaging: “what is good for your heart is good for your brain”
 - **Everyone aged 65-74** who has received an NHS Health Check should be made aware of the **signs and symptoms** of dementia and be signposted to memory services if this is appropriate.

There is a significant discrepancy between those receiving a Health Check and those also receiving advice on dementia.

- Whilst it is unclear how accurately this information is captured in clinical systems, data indicates only **3.6%** of residents aged 65-74 receiving a Health Check were offered information about dementia, although some advice was also given to younger age groups (ages 40 – 64).
- Specifically for pharmacies, **10 out of 159 (6.3%)** patients aged 65+ who had their health checks in the past five years were provided dementia advice, although according to the system, the option to document advice is communicated is only available for patients aged 65+.

There is a clear opportunity to improve dementia risk reduction messaging and advice across all ages through the NHS Health Checks.

References

1. Southwark NHS Health Checks (2019).

The Healthy Weight Strategy sets a framework for taking a whole systems approach to tackling obesity

PRIMARY PREVENTION – HEALTHY WEIGHT

The Southwark Healthy Weight Strategy 2016-2021: Everybody's Business sets a framework for taking a whole systems approach to tackling obesity in the borough.

- This framework commits to both universal and targeted services that are evidence-based, family focused and across the life course.
- The strategy priorities target **people** (maternity and early years, children and young people, adults) and **places** (the obesogenic environment) in Southwark.

Because obesity is so complex, there are several other Southwark strategies and plans in place that contribute to the aims of the healthy weight strategy, including:

- **The 2019 Food Security Action Plan** promoting healthy eating and a balanced diet at all income levels
- **The 2019 Movement Plan - Setting a Direction for Travel:** The plan recognises the need to create streets that are nicer for walking and cycling and are more accessible and healthier in order to make activity easier for all residents.
- **Active Southwark - Sport and Physical Activity Strategy 2019-2023:** This strategy encourages sport and physical activity for adults and children through a range of opportunities across the borough.

All of these initiatives promote dementia risk reduction by helping to address inactivity, unhealthy eating and obesity in Southwark.

References

1. Southwark Council. Everybody's Business: Southwark Healthy Weight Strategy 2016-2021.

As part of a local strategic response Southwark has adopted a new approach to tobacco control

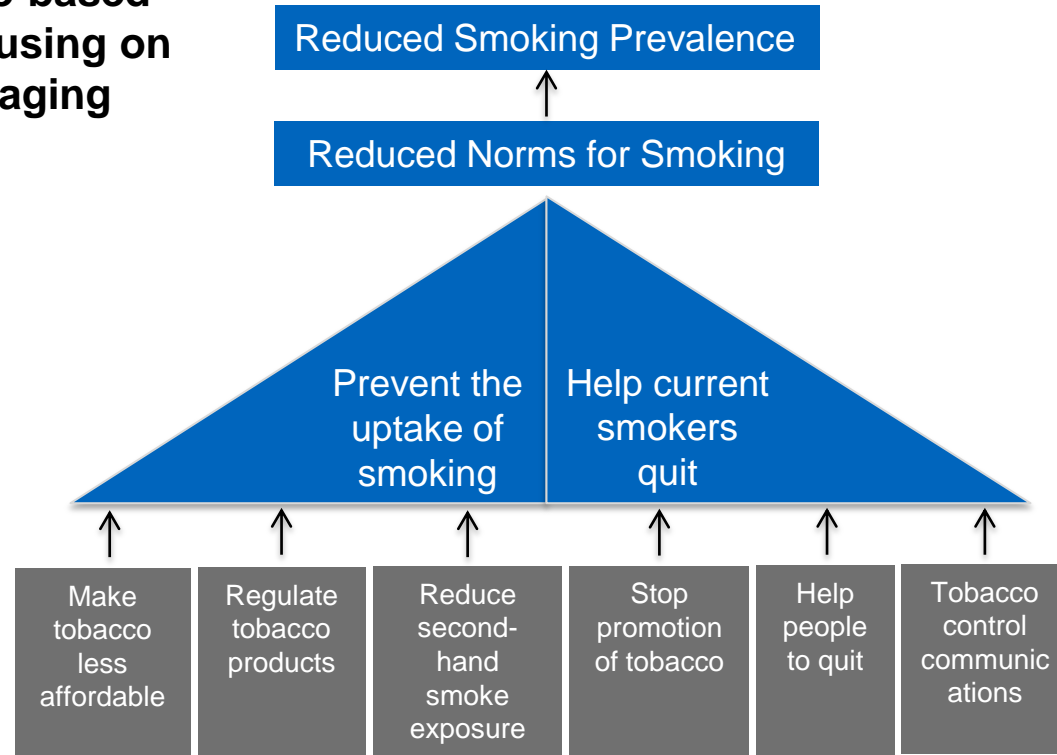
PRIMARY PREVENTION – SMOKING CESSATION

Southwark has developed an evidence-based approach to local tobacco control focusing on both preventing of uptake and encouraging cessation.

- A broad local and regional partnership support system is in place to facilitate action through combined resources.

Smoking cessation, even if later in life, has been shown to benefit overall health and may also reduce the risk of dementia.

- Despite a lower prevalence locally, smoking prevention and cessation messaging should continue to be promoted throughout Southwark.



References

1. Public Health Outcomes Framework (2019).
2. Smoking in Southwark. Southwark's JSNA (2019).

The Southwark Alcohol Action Plan sets out clear objectives for addressing alcohol reduction in the borough

PRIMARY PREVENTION – ALCOHOL REDUCTION

Following the Southwark Alcohol Strategy (2013-2016), the Southwark Alcohol Action Plan (2017 – 2020) was established to take forward three key objectives:

1. Establish safe, sensible drinking as the norm
2. Protect families and the wider community
3. Provide high quality treatment

To achieve these objectives, Southwark addresses alcohol reduction in several ways:

- **CGL Southwark** provides an open access, confidential support service for adults (aged 25 and above), living with or affected by drug or alcohol issues.
 - Recovery is underpinned in all aspects of treatment delivery and is presented as a visible, attainable and desirable outcome to all.
- Southwark currently enforces three **Cumulative Impact Zones** (CIZs) in areas considered 'saturated' by alcohol outlets: Borough Bankside, Peckham and Camberwell
 - CIZs empower local licensing authorities to better control the number and type of licenced outlets as well as impose more restrictive conditions upon alcohol licences
- Since 2011 the Director of Public Health (DPH) has been granted statutory powers to influence **local alcohol licensing** where applications impact any licensing objectives:
 - Prevention of crime and disorder
 - Protection of public safety
 - Prevention of public nuisance
 - Protection of children from harm

References

1. The impact of alcohol in Southwark. Southwark's JSNA. 2017.

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Local stakeholders identified a need for a Dementia Care Pathway specific to Southwark

SECONDARY PREVENTION: THE LOCAL DEMENTIA PATHWAY

Recognising the need for a localised understanding of service provision, Southwark CCG and Southwark Council worked with stakeholders to develop a local Dementia Care Pathway.

- The local vision for the Southwark Dementia Care Pathway is for all people living with dementia and their carers to live in dementia friendly communities where they feel empowered and know where to go to seek information, advice and help.
- The pathway should also ensure that patients and carers have access to care and support that enables them to live well at home for as long as possible and to die with dignity.

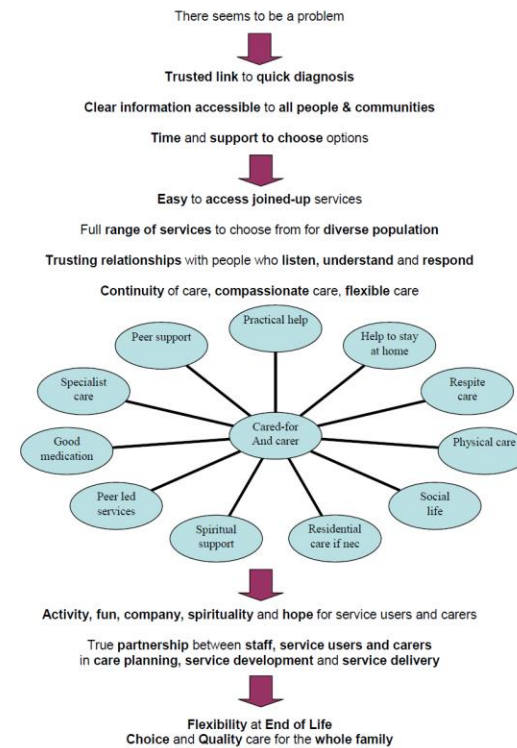
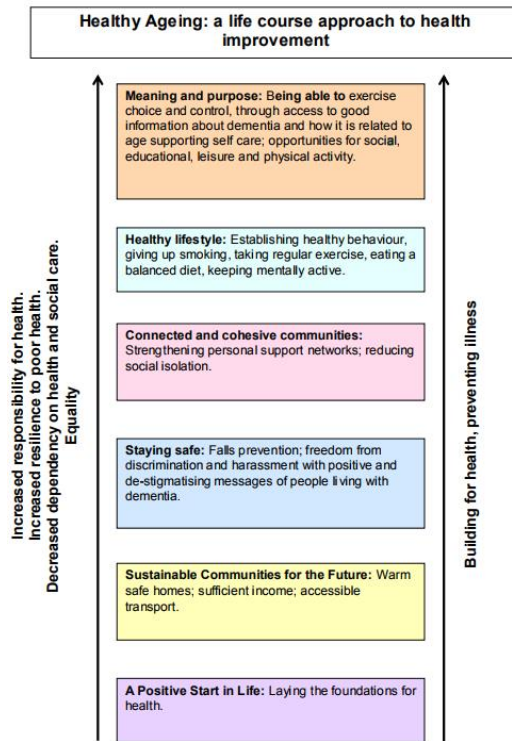
Because the pathway was never fully implemented, a task and finish group was established in 2018 to reinvigorate the Southwark Dementia Care Pathway.

- The task and finish group identified four areas of opportunity for local improvement in line with the NHS Well Pathway:
 - Preventing Well
 - Living Well
 - Supporting Well
 - Dying Well

The Task and Finish group explored two existing models of care to inform the Southwark pathway

SECONDARY PREVENTION: THE LOCAL DEMENTIA PATHWAY

The Bristol Dementia Care Pathway (left) takes a life course approach to healthy ageing with support from primary care, whilst the Lewisham Dementia Care Pathway (right) highlights person centred care for both the patient and the carer.



References

1. Dementia Partnerships. Accessed from: <https://dementiapartnerships.com/wp-content/uploads/sites/2/nhs-bristol-dementia-care-pathway.pdf>
2. Lewisham's Joint Strategic Needs Assessment. Accessed from: http://www.lewishamjsna.org.uk/sites/default/files/documents/Dementia_v01.doc

Provision and services were identified to be integrated into the local dementia pathway

SECONDARY PREVENTION: THE LOCAL DEMENTIA PATHWAY

Local provision and appropriate services were identified to be integrated into the pathway.

- These and other services should be mapped onto and implemented across the stages of the Well Pathway for Dementia.

SLaM Memory Service

- 5 FT community practitioners
- 4 PT community practitioners
- 1 PT manager (nurse)
- 1 FT asst. psychologist
- 1 consultant 2 sessions/week
- 1 FT CNS 2 sessions/week
- 1 FT admin
- 1 Dementia advisor

Alzheimer's Society

- 3 x Dementia Support Workers
- 1x DAA Coordinator
- Daffodil Dementia Café
- Primrose Dementia Café
- £22K towards Approved Social Worker function

Prescribing

- For patients with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor

Psychoeducation for Carers

- Offer carers of people living with dementia a psychoeducation and skills training intervention

Specialist Investigations

- For young onset dementia

Care Planning & Care Coordinators

- Providing people living with dementia with a single named professional who is responsible for coordinating their care

Care & Support Plan

- Care coordinator should develop a care and support plan

Cognitive Stimulation Therapy

- Offer group cognitive stimulation therapy to people living with mild to moderate dementia

Staff Training

- Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia

Non dementia pathways were developed to support patients with cognitive impairment but without dementia

SECONDARY PREVENTION: NON DEMENTIA PATHWAYS

Non dementia pathways were developed by the NHS Dementia Clinical Leadership Group to support commissioners and clinicians in directing services for patients presenting with memory complaints due to non dementia causes.

- A 2016 London memory service audit found 43% of patients referred to a memory clinic were not given a diagnosis of dementia.
- Even without a diagnosis of dementia, it is equally important that persons with cognitive problems receive quick access to relevant interventions.

Non dementia pathways describe the primary care, memory assessment services (MAS) triage and MAS assessment and diagnosis for patients experiencing several types of cognitive conditions:

- Mild to moderate depression and/or anxiety
- Cognitive concerns in the context of alcohol misuse
- Mild cognitive impairment (MCI)
- Functional cognitive disorder (FCD)

The intention of the non dementia pathways is to initiate treatment for patients experiencing cognitive problems and potentially delay the onset of dementia.

References

1. Non dementia pathways, Guidance from the London Dementia Clinical Network (2018).

Social prescribing has the potential to support by promoting wellbeing in people living with dementia

SECONDARY PREVENTION – SOCIAL PRESCRIBING

Social prescribing (SP) is a means of enabling primary care services to refer patients with social, emotional or practical needs to a range of non-clinical services, and by 2023 all GPs will be able to refer through SP.

- Prescriptions can include referrals to everything from arts groups and volunteering to activities that involve physical exercise, such as gardening and dance clubs, or services that can provide help and advice with issues such as debt, benefits and housing.
- NHS England estimates that 60% of CCGs have already commissioned some form of SP.

Although lots of social prescribing has grown organically across Southwark, the Primary Care Networks, in partnership with Community Southwark, are working to co-design and develop a more coordinated model of social prescribing in the borough.

- The initial focus will be on supporting people with long-term conditions, with a view to developing an evidence base for expanding to other population groups.
- The model will be designed through a series of SP network workshops with residents, local voluntary and community sector representatives and health and care professionals.

Whilst more research is needed, preliminary results found an average of 28% fewer GP consultations and 24% fewer attendances at A&E in instances where the social prescribing connector service was working well.

- To develop the body of knowledge on effective social prescribing, the government pledges to create a national database of social prescribing schemes and launching an online platform for commissioners and practitioners.

References

1. Apter, C. Mental Health Today: The benefits of social prescribing – and a word of warning.
<https://www.mentalhealthtoday.co.uk/news/awareness/the-benefits-of-social-prescribing-and-a-word-of-warning>

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Dementia awareness and social action is essential for people with dementia to live more fulfilling lives

TERTIARY PREVENTION: COMMUNITY

In 2014 Public Health England (PHE) and Alzheimer's Society launched major campaign promoting Dementia Friends.

Dementia Friends learn more about the lived experience of a person with dementia, converting that understanding into action for a more inclusive environment.

- The aim of this social movement is to enable people living with dementia to live more independent lives within their own communities.
- The Alzheimer's Society has set a target of reaching four million Dementia Friends by 2020.

Dementia Friendly Communities can be specially recognised as working to help people live well with dementia and feel supported to continue in day-to-day activities they enjoy.

In an attempt to make the borough a place where ageing is positively celebrated and embraced, in 2015 Southwark became the first and only London borough to join the WHO Global Network as 'Age Friendly'.

- The aim is to deliver a fairer future for all older residents so that they can make a better life and age well locally.

References

1. Prime Minister's Challenge on Dementia, 2020.
2. WHO: Age Friendly World (2015).

Dementia prevention could delay the onset of disease and result in more residents living at home for longer

TERTIARY PREVENTION: HOUSING

Locally the ambition for the Southwark Housing Strategy to 2043 is: *“to become an age friendly and dementia friendly borough, providing homes and neighbourhoods that will support people to live long, healthy, happy lives in their own communities”*.

- To achieve this Southwark has committed to developing a Centre of Excellence for people living with dementia and associated complex needs and building a standard of lifetime homes that are age friendly and dementia friendly.

With an expected increase in the ‘very old’ (90+) population across Southwark, it is likely that more individuals will require support with activities of daily living such as washing, dressing and cooking and may require accommodation in care homes.

- Although there is increased focus on supporting people with dementia to live in their own homes, the level of support required may be very expensive and result in negative cost.
- Delaying the onset of dementia and the ensuing gradual deterioration could reduce the negative impact of disease and enable these individuals to live independently for longer and thus more efforts should be aimed at dementia prevention.



References

1. Southwark Council – Southwark Housing Strategy to 2043.

Already a range of initiatives are in place that address primary, secondary and tertiary dementia prevention

THE LOCAL RESPONSE: SUMMARY

There are already a number of initiatives in place addressing dementia prevention that complement the Strategy

Primary prevention:

- The NHS Health Checks, the Southwark Healthy Weight Strategy 2016-2021, the borough's approach to smoking cessation and the Southwark Alcohol Action Plan are all existing initiatives that address dementia prevention.

Secondary prevention:

- Recognising the need for a localised understanding of service provision, Southwark CCG and Southwark Council worked with stakeholders to develop a local Dementia Care Pathway.
- Implementation of the local Dementia Care Pathway should continue with the identified local provision and services being mapped onto and implemented across the stages of the Well Pathway for Dementia.

Tertiary prevention:

- Dementia awareness and social action is essential to support people with dementia to live fulfilling lives.
- Whilst care homes are available to provide comprehensive support for residents requiring assistance with activities of daily living, delaying the onset of dementia and the ensuing gradual deterioration could reduce the negative impact of disease and enable these individuals to live independently for longer and thus more efforts should be aimed at dementia prevention.

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There is a continued need to expand the evidence base investigating dementia treatment and prevention

THE EVIDENCE BASE

There is a continued need to expand the evidence base investigating dementia treatment and prevention through high quality research.

- The multiple risk factors contributing to dementia means that most prevention trials have been inconclusive, however it is thought that integrated, multifaceted approaches to dementia prevention are more likely to lead to successful outcomes.

Antihypertensive medication	Although no single study has shown effectiveness of pharmacological blood pressure control, a meta-analysis of available data showed that a target blood pressure of <150/90 mmHg for those >60 years is protective.
Other medication	Trials involving NSAIDs, oral hypoglycaemics, oestrogen HRT, vitamins, & statins have not shown any protective benefit for risk reduction for dementia. Combined HRT may have a protective effect in a subgroup of women, although the long term multisystemic effects of hormonal therapy is still under investigation.
Mediterranean diet	Good evidence shows that a Mediterranean diet can improve cognitive outcomes, although the incidence of dementia does not suggest that it could prevent the dementia syndrome.

References

1. Mukaetova-Ladinska, M. Age and aging collection: Treatments in dementia (2019).

There is a continued need to expand the evidence base investigating dementia treatment and prevention

THE EVIDENCE BASE

Cognitive training	Evidence from a meta-analysis suggests engagement in mentally stimulating activities throughout the life course can be protective against dementia. Other studies have shown that targeted training in a single cognitive domain can be helpful in sustaining improvement in that domain as well as generalised cognitive improvements. However, there remains insufficient evidence that non-targeted cognitive training interventions could be effective on a population scale.
Physical activity	There are a number of studies looking at targeted physical activity interventions and dementia risk, although there is overall insufficient evidence that any single physical activity based intervention can reduce dementia risk.
Social engagements	There is a lack of evidence that social interventions can prevent dementia, despite good evidence showing association between social isolation and risk of dementia.

References

1. Mukaetova-Ladinska, M. Age and aging collection: Treatments in dementia (2019).

A range of pharmacological and non-pharmacological interventions have been linked to dementia treatment

THE EVIDENCE BASE: SUMMARY

A range of pharmacological and non-pharmacological interventions have been linked to support treatment and prevention of cognitive and behavioural sequelae related to dementia.

Dementia treatment options remain limited, with known dementia treatments having diminishing efficacy after the first few years.

- Dementia prevention is playing an increasingly important role through the exploration of the impact certain lifestyle habits, such as healthy eating, have in successful aging.
- Furthermore, it is unclear how the treatment of dementia-associated risk factors affect cognition and behaviour in people already living with dementia.

Significant improvements over recent decades have led to more readily available treatment options and widespread dementia screening in routine assessments resulting in a 'dementia-friendly' clinical culture and society.

- Despite these strides, much is still unknown about the long-term effect of treatment of older people and prevention through risk factor reduction.

Dementia research is a key element of the Prime Minister's Challenge on Dementia, and by collating new and existing data on dementia through the PHE Dementia Intelligence Network, public health agencies will have a better understanding of prevalence and how it affects the population.

References

1. Mukaetova-Ladinska, M. Age and aging collection: Treatments in dementia (2019).
2. Dementia Data Catalogue (2016).

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Dementia is the most feared disease among adults aged over 55 years

COMMUNITY & STAKEHOLDER VIEWS

Dementia is the most feared disease among the 55+ population and 62% of those interviewed believe a diagnosis of dementia means 'life is over.'

- Most people's concerns exist around their identity, ability to function, and roles and relationships with family members and the wider community.
- Despite the fear, 73% of UK adults reported they would want to be told in midlife about their personal risk of developing dementia, indicating there is an opportunity for more information sharing about dementia risk reduction and normalizing the conversation around the condition.

Interestingly, whilst one in five UK adults believe that dementia is an inevitable part of aging, 40% of people reported they would adopt a healthier lifestyle to reduce their risk of developing dementia, demonstrating a real opportunity for behaviour change.

- Furthermore, almost a third of people incorrectly believed that medicines were available to slow the progression of the disease.

Almost half (48%) of UK adults were not able to identify any risk factors for dementia demonstrating the need to improve communications and messaging around dementia risk reduction.

References

1. Dementia Attitudes Monitor (2019)
2. "Over half of people fear dementia diagnosis, 62 per cent think it means 'life is over' " study; Dementia Awareness Week 15th-21st May 2016 from the Alzheimer's Society

The Dementia Statements describe the rights of all people living with any form of dementia

COMMUNITY & STAKEHOLDER VIEWS

Following the launch of the National Dementia Strategy in 2009, the National Dementia Declaration was published further the commitment by communities and organisations supporting dementia care.

- Alongside the National Dementia Declaration the Dementia Action Alliance (DAA) was formed to unite businesses, organisations, carers and people living with dementia involved in sharing and delivering best practice.

In addition to promoting collaboration and action, the DAA established The Dementia Statements describing the rights of people living with dementia and their carers.

- These statements demonstrate the person-centred approach the DAA advocates for in dementia care and pathways.

The Dementia 'We' Statements

Independence: 'We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.'

Community / Isolation: 'We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.'

Carers: 'We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.'

Care: 'We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.'

Research: 'We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.'

References

1. Dementia Action Alliance – National Dementia Declaration for England: A call to action (2010).

Most people agree there is value in a person with dementia being given a formal diagnosis

COMMUNITY & STAKEHOLDER VIEWS

Care home staff highlighted the benefit of an accurate dementia diagnosis in providing care:

- *'We can help plan suitable activities for a resident if we know they have dementia.'*
- *'We can identify staff training needs when a diagnosis is made.'*
- *'It can help plan for hospital appointments and transfer if needed.'*

When residents of care homes were assessed for dementia the residents themselves and their families were often relieved when a diagnosis of dementia was not given.

- This demonstrates stigma and fear of dementia continues to exist within some communities.

There is widespread public support for people with dementia being given a formal diagnosis.

- 82% of UK adults and 67% of Southwark adults participating in a local survey agree that there is value in a person with dementia being given a diagnosis.
- 'Planning for their future', 'accessing treatments that could help' and 'accessing care that could help' were cited as the most common reasons why a diagnosis could be a benefit.
- *'We need to make the advantages of diagnosis clearer, not only to professionals but to the community.'*

References

1. NHS London Clinical Networks: Diagnosing dementia in care homes (2018).
2. Alzheimer's Disease International: World Alzheimer Report 2019 Survey (2019).
3. Dementia Attitudes Monitor (2019)

Local engagement highlighted gaps in dementia care from the perspective of patients and professionals

COMMUNITY & STAKEHOLDER VIEWS

Local engagement revealed it would be beneficial for carers, clinical practice staff, and people living with dementia themselves to have more access to:

- Information and advice about dementia;
- Befriending services;
- Dementia training and awareness raising; and
- Financial support services

Key themes highlighted gaps from the perspective of patient and carers as well as healthcare professionals and underscores the importance of a timely diagnosis, patient-centred care plans, and clear information on dementia-friendly services.

What patients & carers want:

A timely diagnosis, delivered in a sensitive way

Feel listened to and able to make decisions about their own care needs

Feel valued and understood

Supported to live well

Know that everything will be taken care of

Know loved ones will be supported

What professionals want:

Information and advice/training/awareness raising

Clarity over the right pathway

To understand benefits of diagnosis

Understand what support is available

References

1. Southwark CCG – Improving dementia services in Southwark – engagement results 2015-16.

Carers feel the impact of dementia through reduced quality of life and loneliness

COMMUNITY & STAKEHOLDER VIEWS

Carers in Southwark looking after people with dementia rate their own quality of life at 58%, which is similar to both regional and national reports.

- Carers self-assess their own quality of life through a series of indicators including occupation, control, personal care, safety, social participation and encouragement and support.
- The low quality of life score indicates the needs of carers are not fully met demonstrating the importance of including this group of people within the framework of care to support those affected by dementia.

Carers of people with dementia also experience loneliness.

- Currently three in five family carers say caring for someone with dementia has impacted their own health.
- 63% of carers say they have had no or not enough support.
- More than half of all carers who support someone with dementia for 20 hours or more a week said they felt lonely recently.
- *'Carers are losing their lives to caring. They need some me time; otherwise they are going to lose themselves.'*

Carers play a vital role in the care plan of a person living with dementia and this population should be a key consideration of the local Dementia Care Pathway.

References

1. Public Health Outcomes Framework (2019).
<https://www.alzheimers.org.uk/blog/tackling-loneliness-people-living-dementia>

Patients and carers want a timely diagnosis, patient-centred care plans and clear information on dementia services

COMMUNITY & STAKEHOLDER VIEWS: SUMMARY

Dementia is the most feared disease among the 55+ population and 62% believe a diagnosis of dementia means 'life is over.'

- Most people's concerns exist around their identity, ability to function, and roles and relationships with family members and the wider community.

The Dementia Statements describe the rights of people living with dementia and their carers and take a person-centred approach for in dementia care and pathways.

- This is of particular importance for carers in Southwark looking after people with dementia, who rate their own quality of life at 58%, which is similar to both regional and national reports.

There is widespread public support for people with dementia being given a formal diagnosis.

- Care home staff highlighted the benefit of an accurate dementia diagnosis in providing care by being able to plan suitable activities, conduct relevant training for staff and support with medical appointments and transfer.

Key themes following local engagement highlighted gaps from the perspective of patient and carers as well as healthcare professionals and underscores the importance of a timely diagnosis, patient-centred care plans, and clear information on dementia-friendly services.

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The aim of this project is to better understand the impact of dementia and promote healthier behaviours locally

SUMMARY

Dementia is a clinical syndrome characterised by difficulties with one or more areas of mental function and is defined as a significant loss of cognitive abilities to the extent that it interferes with social or occupational functioning affecting each individual differently.

- Age is the most significant non-modifiable risk factor for the development of dementia.
- Smoking, physical inactivity, poor diet, hypertension and social isolation are some of the modifiable risk factors found to be associated with the development of dementia.

England established the first national strategy on dementia in 2009, and the Prime Minister's Challenge on Dementia 2015 and again in 2020 was developed to drive up healthcare quality, create dementia-friendly communities and further research.

- Additionally, the NHS Five Year Forward View, recognises dementia as a priority area with a specific aim to diagnose more people with dementia earlier to allow treatment to help slow the progression of the disease.

NICE has produced guidelines addressing mid-life approaches to delay or prevent the onset of dementia, disability and frailty later in life and on the assessment, management and support for people living with dementia and their carers.

- The aim is to delay the onset of disease progression and increase independent living, healthy and active in later life.

Early diagnosis, management and integrated services will be of growing relevance to Southwark's aging population

SUMMARY (2)

Dementia prevalence is lower in Southwark yet the rate of new diagnoses is similar to London and England.

- The population aged 65+ in Southwark is projected to increase by 13,700 by 2030 which is expected to increase the overall prevalence of dementia across the borough.
- An estimated **336** persons are living with dementia in Southwark without a diagnosis.

Southwark has one of the highest rates of emergency admissions in London for persons aged over 65 years with a diagnosis of dementia.

- With a rate of 5958 per 100,000 people aged 65+ with dementia, Southwark is significantly higher than London and England indicating many local residents with dementia are requiring acute care services.

The percentage of admissions related to dementia increases with age for the 65+ population.

- 6% of admissions for the 65-74 age group were related to dementia, compared to 15% for the 75-84 age group and 31% for the 85+ age group.
- Females in the 85+ age group represent a large proportion of dementia admissions.

There are already a number of initiatives in place addressing dementia prevention that complement the Strategy and can be divided into three areas across the Well Pathway through **primary prevention (preventing well), **Secondary prevention** (diagnosing and supporting well) and **Tertiary prevention** (living and dying well).**

Increased access to information, services and training would benefit both local residents and professionals

SUMMARY (3)

There is a continued need to expand the evidence base investigating dementia treatment and prevention through high quality research.

- A range of pharmacological and non-pharmacological interventions have been linked to support treatment and prevention of cognitive and behavioural sequelae related to dementia.

Dementia is the most feared disease among the 55+ population and 62% believe a diagnosis of dementia means 'life is over.'

- Most peoples concerns exist around their identity, ability to function, and roles and relationships with family members and the wider community.
- Carers play a vital role in the care plan of a person living with dementia and this population should be a key consideration of the local Dementia Care Pathway.

Local engagement revealed it would be beneficial for carers, clinical practice staff, and people living with dementia themselves to have more access to:

- Information and advice about dementia;
- Befriending services;
- Dementia training and awareness raising; and
- Financial support services

This work will inform future plans and actions to address dementia prevention and care integration in Southwark

NEXT STEPS

The aim of Phase 1 of this project is to better understand the negative impact of dementia and promote healthier behaviours across the borough.

- The information and evidence provided in this needs assessment is intended to inform the Southwark Adult Social Care and Commissioning teams to develop and deliver the Southwark Dementia Care Pathway and more integrated local services locally.

The following next steps are recommended based upon the information gathered in this needs assessment:

- Given the range of modifiable risk factors related to lifestyle behaviours, it is imperative to continue delivering the message **‘what’s good for your heart is good for your head’** more widely.
- Ensure information and advice regarding dementia risk reduction and signs and symptoms of dementia is communicated to **all recipients** of an NHS Health Check.
- Strive for Southwark Council to become a **Dementia Friendly business** and work to develop more dementia friendly communities in the borough.
- Local NHS Trusts should implement recommendations to **reduce discharge delays** and prevent or minimise the need for acute care services.
- Emphasise the importance of the **Dementia Care Plan** from the moment of diagnosis as an important outcome measure for both the commissioning and adult social care teams and ensure people living with dementia and their carers are included in its development.

Find out more at
southwark.gov.uk/JSNA

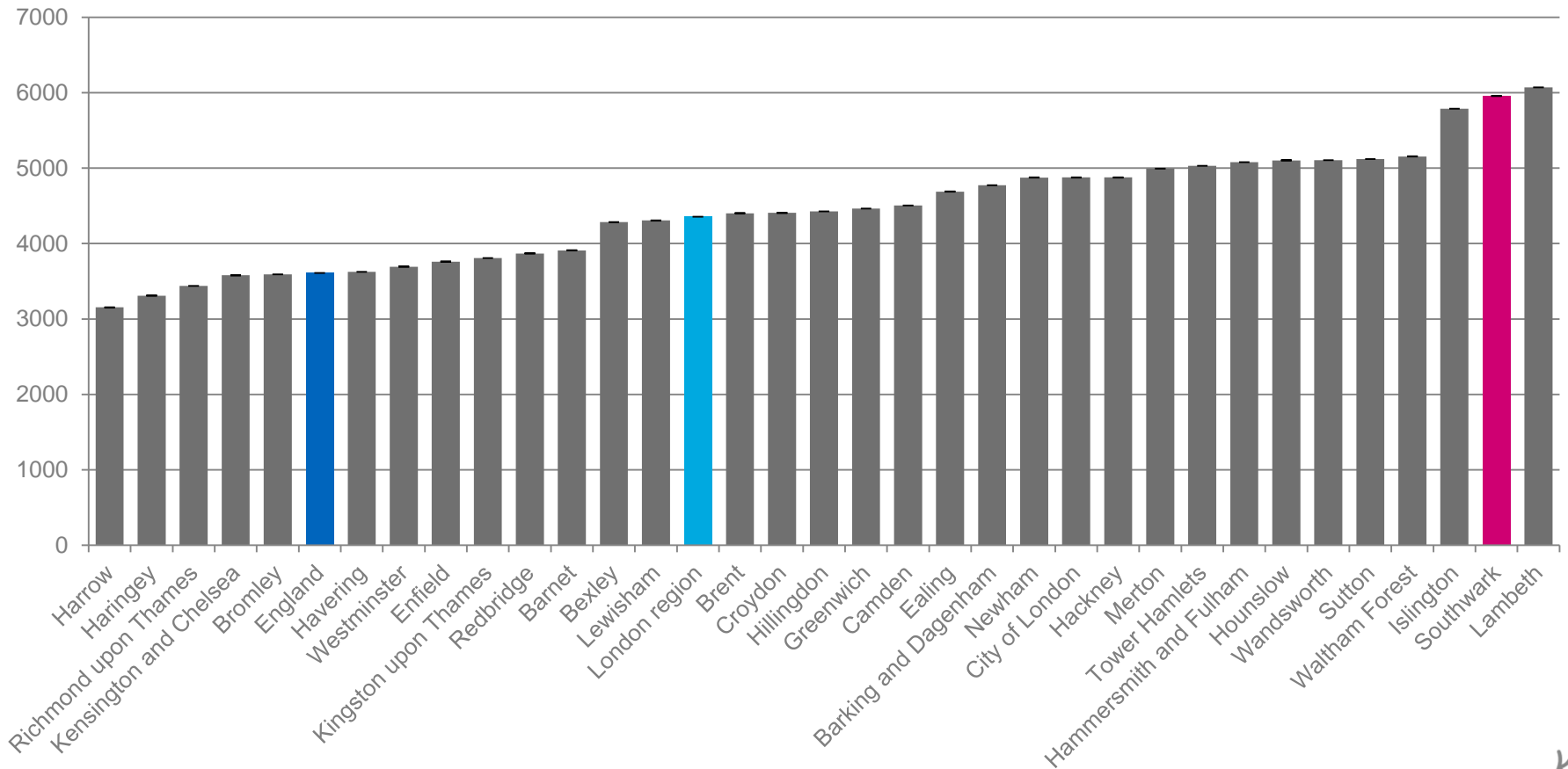
Healthcare Public Health Section
Southwark Public Health Division

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Southwark has one of the highest rates of emergency admissions for persons aged 65+ with dementia

APPENDIX 1

Rate of Emergency Admissions per 100,000 persons aged 65+ with any diagnosis of dementia, 2019



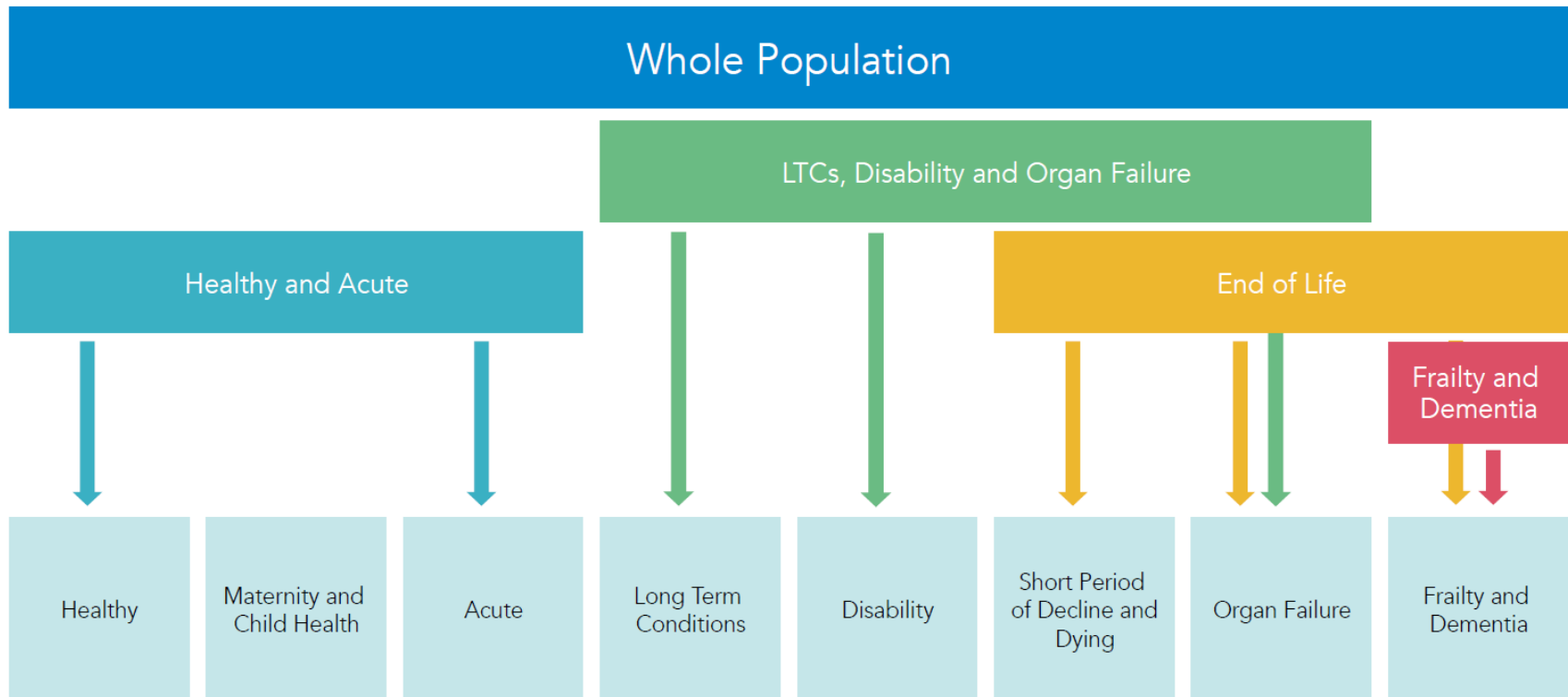
References

1. Public Health Outcomes Framework (2019).

The Bridges to Health and Wellbeing model takes a segmented approach to health care delivery

APPENDIX 2

The Bridges to Health and Wellbeing (B2HW) segments the population into eight distinct segments across the life-course.



References

1. National Collaborating Centre for Mental Health. The Dementia Care Pathway (2018).
2. Public Health England Strategic plan for the next four years: Better outcomes by 2020 (2016).

Recommendations for healthy lifestyle behaviours are often not associated with dementia risk reduction

NATIONAL POLICY CONTEXT

The recommendations for promoting healthy lifestyles span healthy weight advice, smoking cessation and alcohol consumption.

- Although there are already numerous policies and guidelines in place to address the recommended healthy behaviours, dementia, disability and frailty are often not associated with these conditions as potential consequences.

Awareness raising and information sharing are important to promote healthy lifestyles.

- Because non-modifiable risk factors also exist, it is important communicated messages are not stigmatising

A variety of health conditions and environmental factors can contribute to dementia.

- Some risk reduction behaviours may be more effective than others depending on the type of dementia.

NICE Recommendations for Promoting Healthy Lifestyles

1. Encouraging healthy behaviours
2. Integrating dementia risk reduction prevention policies
3. Raising awareness of risk of dementia, disability and frailty
4. Producing information on reducing the risks of dementia, disability and frailty
5. Preventing tobacco use
6. Improving the environment to promote physical activity
7. Reducing alcohol-related risk
8. Supporting people to eat healthily

References

1. NICE Guidance Dementia, disability and frailty in later life (2015). <https://www.nice.org.uk/guidance/ng16>

Service organisation and delivery can further support individuals to achieve healthy lifestyle behaviours

NATIONAL POLICY CONTEXT

Organisations can support individuals to achieve healthy lifestyle behaviours by promoting and encouraging opportunities for behaviour change.

- Providing access to services and sharing information about the risk factors of the disease are key ways to operationally engage in dementia prevention activities.

Already many organisations facilitate opportunities for employees or service users to promote health, but a greater emphasis needs to be on the relevance to dementia risk reduction.

- Linking the health-promoting behaviours to reducing the risk of dementia will help to raise awareness whilst also providing advice.

NICE Recommendations for Service Organisation & Delivery

1. Delivering services to promote behaviour change
2. Providing accessible services
3. Providing advice on reducing the risks of dementia, disability and frailty at every appropriate opportunity
4. Providing physical activity opportunities
5. Provide training
6. Leading by example in the public sector
7. Providing support in the workplace

References

1. NICE Guidance Dementia, disability and frailty in later life (2015). <https://www.nice.org.uk/guidance/ng16>

Good progress has been made on improving the health and care for people with dementia and carers

THE NATIONAL RESPONSE

Since the launch of the Prime Minister's Challenge on Dementia 2015, good progress has been made across healthcare, the community, research and international platforms:

Health & Care

- Greater awareness of risk management and reduction
- Improved diagnosis rates
- Greater identification & referral in hospitals
- More targeted inspection in hospitals
- A better aware, educated and trained workforce
- Better provision of post-diagnosis support
- Integrated care
- Care & support through the National Dementia Action Alliance
- Investment in dementia-friendly hospitals and care homes
- Greater support for carers
- Increased transparency of information for service improvement

Community

- Creation of a more dementia-friendly society
- More dementia-friendly communities
- Building a dementia-friendly generation
- Action by businesses and industry

Research

- World leading, major programmes of research and significant investment in infrastructure
- The UK a key player in the European Union Joint Programme – Neurodegenerative Disease Research (JPND)
- The increasing role of the charity sector
- Expansion of the dementia research workforce
- Greater participation of people with dementia in research
- Increased research in care homes

International

- Leading international collaboration across the world
- Establishment of the first World Dementia Envoy and World Dementia Council
- Action to accelerate progress on dementia research and the development of possible drugs
- World leading collaboration with regulators
- Launch of the first Global Alzheimer's and Dementia Action Alliance
- Bolstering human rights of those living with dementia
- Developing international standards of care for dementia
- The EU Joint Action on Dementia 2015-18

References

1. Prime Minister's challenge on dementia 2020.

A number of groups exist to support those living with dementia and their carers

COMMUNITY & STAKEHOLDER VIEWS



The five broad roles of the **Alzheimer's Society** reflect national guidance and local prevention interventions:

1. Informing people how to reduce their risk of developing dementia
2. Diagnosing dementia early
3. Supporting people to live well with the condition
4. Enabling dementia friendly communities
5. Monitoring and managing data



Public Health England has specifically recognised dementia as a major priority and incorporated the condition into their strategic plan.



The overarching aim of the **Dementia Clinical Leadership Group** is to provide leadership and advice to shape London's dementia services so that people with dementia receive an effective diagnosis, treatment and care.



The **Dementia Action Alliance** unites organisations across England committed to promoting the health and social care outcomes for people affected by dementia.

A number of groups exist to support those living with dementia and their carers

COMMUNITY & STAKEHOLDER VIEWS



To obtain more information about perceptions of dementia and to better understand lived experience of people living with the condition, the **Alzheimer's Disease International** has commissioned the London School of Economics to conduct the **World Alzheimer Report 2019 Survey: Your attitudes around Dementia**

- The survey will form the basis of a report to be published September 2019 and will be the largest worldwide survey of attitudes and beliefs around dementia.



Age UK offers both one-to-one and group support for people living with dementia and a free advice line for friends and family members.

- The classes offered include a range of activities including singing for the brain, dance for dementia, art for dementia and memory cafes.



In addition to providing information and fundraising opportunities around dementia awareness, Dementia UK also offers Admiral Nurses, specialist dementia support nurses to aid families facing the challenge of dementia.