

Southwark dementia prevention awareness and welcome pack

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- 2. Key messages from the dementia prevention needs assessment**
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Dementia is a clinical syndrome characterised by difficulties with one or more areas of mental function

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.

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

Symptoms of dementia include:

Loss of memory - for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day

Mood changes - particularly as parts of the brain that control emotion are affected by disease

People with dementia may also feel sad, frightened or angry about what is happening to them

Communication problems - a decline in the ability to talk, read and write. In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

Who is affected?

- **Dementia can affect anyone, anywhere**
- **One in three people over the age of 65 will develop dementia** but people as young as 40 have been diagnosed.
- **Two-thirds of dementia case are women**, this could be due to the lack of oestrogen after the menopause.
- **Family members and close friends are often affected** by the progress of a loved one's dementia due to little help and lack of understanding.
- **Carers can be overworked** and dementia sufferers distressed as there is an insufficiently support and resources

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>

What causes dementia?

DIFFERENT TYPES OF DEMENTIA

There are a number of different diseases and conditions that can cause dementia, including:

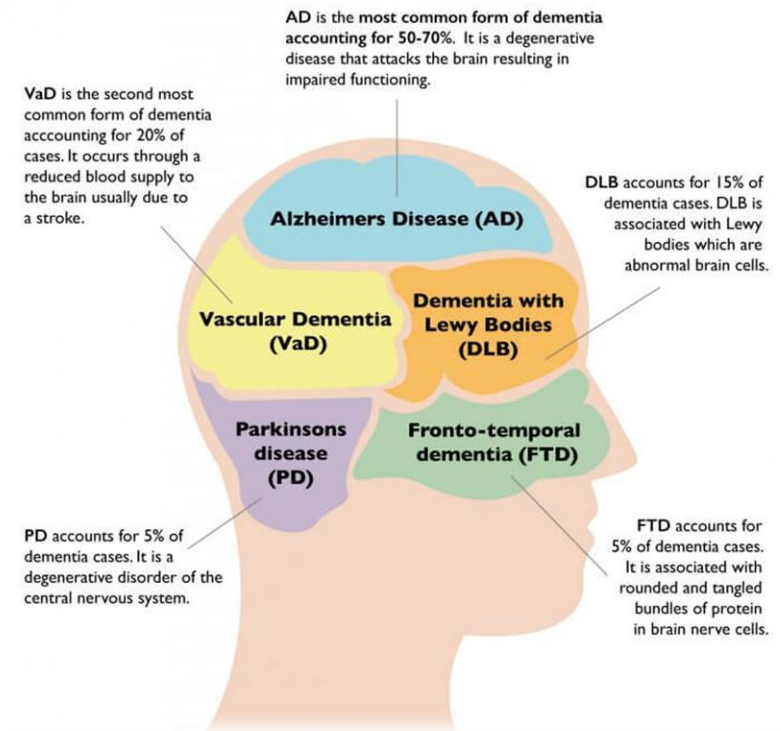
Alzheimer's disease (AD) is the most common cause of dementia. A person with AD is likely to experience severe memory loss and become increasingly frail. They may have difficulty eating, swallowing and experience loss of communication skills such as speech.

Vascular dementia is caused by strokes (or small vessel disease) which affects the supply of oxygen to the brain. It can cause communication problems, stroke-like symptoms and acute confusion.

Fronto-temporal dementia is a rare form of dementia affecting the front part of the brain. In the early stages, personality and behaviour are more affected than memory.

Dementia with Lewy bodies - gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of the brain tissue. Memory, concentration and language skills are affected. This type of dementia has symptoms similar to those of Parkinson's disease.

50-70% of dementia cases are due to Alzheimer's disease, which is a poorly understood neurodegenerative disease with genetic, medical and behavioural risk factors.

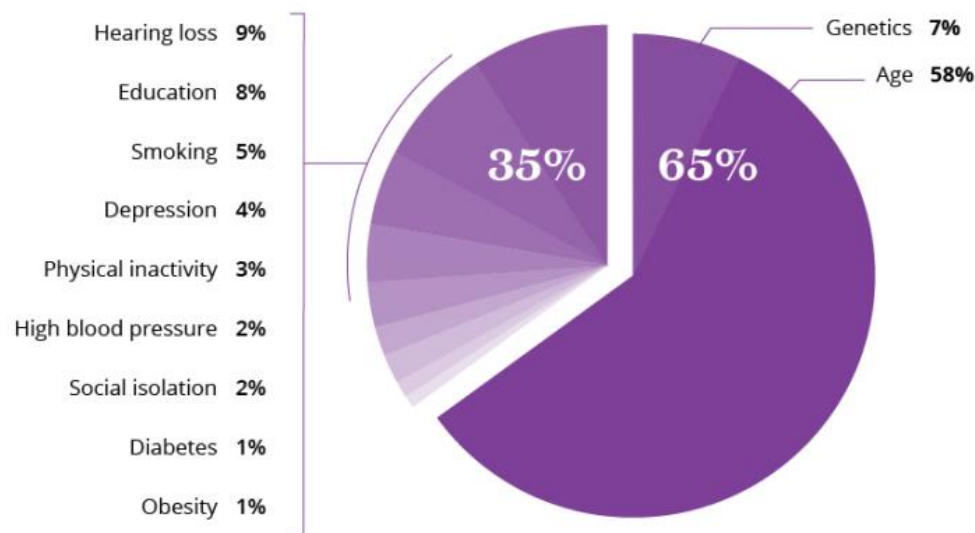


A range of modifiable risk factors for dementia are already the subject of public health initiatives

RISK FACTORS IN POPULATION

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. **Age is the biggest risk factor for dementia.** By 2040, nearly 1 in 4 people in the UK (24.2%) will be aged 65 and over.



At least **35%** of dementia risk may be within individual's control.

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

Living a healthier life could reduce the influence of factors like genetics and age

References

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

Despite higher activity levels, Southwark residents increase risk from other unhealthy behaviours

RISK FACTORS LOCALLY

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

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). Activity levels decrease with age, so it is important to ensure activity is maintained throughout the life course.

Overweight and obesity (excess weight) increase a person's risk of developing a range of medical conditions and diseases, which in turn increase a person's risk for dementia.

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

Regular alcohol intake above the NHS recommended levels increases a person's risk of developing dementia. Southwark has the second highest rate of alcohol dependency in SE London for those 35 and over. Local data also show an increase in alcohol related hospital admissions in the over 65 age group.

References

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

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Taking actions to close the gaps in our knowledge and improve dementia care locally

KEY MESSAGES (1): FOCUS ON PREVENTION AND QUALITY OF CARE

Improving dementia prevention through:

- A significant increase of the risk reduction advice offered to those over 50 years old as part of the **NHS Health Check**
- Behavior change approaches highlighting the evidence and the importance of **adopting a healthier lifestyle in particular in mid-life**

Improving diagnostic rates and early detection through:

- Ensuring the number of **people with dementia known to services** is as close as possible to those of the total need in Southwark – including those with mild/moderate dementia (that are less likely to be known to services)
- Improving the **GP dementia registers – that** will help identify more people with dementia which will enable them to access our services earlier
- Ensuring that **public information dementia campaigns** are being run locally to encourage people to come forward for help (if they or someone they care for has symptoms)

Improving the quality of care through:

- **Better care plans** – ensuring that everyone in the dementia register have a detailed care plan and is it reviewed once/year
- **Improving Dementia practice learning** through developing a dementia learning resource that will promote excellence (support all staff working with people with dementia, their family and carers).



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

KEY MESSAGES (2): FOCUSING ON THE LOCAL RESPONSE

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.

There are already a number of initiatives in place addressing dementia prevention – links available below:

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

Secondary prevention:

- **Recognising the need for a localised understanding of service provision**, our health and social care teams worked with various stakeholders to develop a local Dementia Care Pathway.
- **Implementation of the local Dementia Care Pathway**

Tertiary prevention:

- **Dementia awareness and social action** is essential to support people with dementia to live fulfilling lives.
- Whilst moving to a care home **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.

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The importance of information and support for people with dementia and carers

“Involving people with dementia and carers in developing dementia services can often be a tick-box exercise with no real meaning. I am fortunate as I live in an area that puts me and my wife and people like us at the centre of everything that concerns dementia. ... in fact, I am busier now than when I was working! ***Doing ‘with’ rather than doing ‘to’*** is vitally important to ensure services are developed that people with dementia and their families not only want and need, but deserve and expect.”

Dr Trevor Jarvis, Dementia Ambassador and person living with dementia.

Information and practical support including healthcare and advanced care planning:

- People with dementia and their families and carers must receive sufficient information on their diagnosis.
- Accurate and up-to-date information should be made readily available in primary care through VCS organisations including Alzheimer's Society, who have published a 'dementia guide' for those who have recently been told that they have dementia.

References:

<https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf>

Improving the dementia awareness and early diagnosis remain important steps to treatment and care

DIAGNOSING DEMENTIA

Dementia is a profoundly life-changing condition and a diagnosis may well provide long-awaited answers for a failing memory, communication problems and changes in someone's behaviour.

A number of things may be needed to identify if a person has dementia.

These include:

- tests, for example the Mini Mental State Examination
- scans, for example a CT Scan (computerized axial tomography)
- personal history from person and the person's relatives

An early diagnosis opens the door to future care and treatment.

- It gives an opportunity to take medication which might help. There are some dementia medications which may slow down the course of Alzheimer's disease.
- It can help a person have an awareness of the likely progression of the disease
- A person can have greater awareness of what their diagnosis means to them
- Where the dementia has a genetic component this information could be helpful to other family members

Access appropriate care and treatment, including social services support and relevant benefits where appropriate.

References:

1. <https://dementiapartnerships.com/supported-well/learning-pathway/step-1/>

Supporting someone with dementia and their carers

HELP AND SUPPORT

Living with dementia can have a big emotional, social, psychological and practical impact on a person. Many people with dementia describe these impacts as a series of losses and adjusting to them is challenging. The way a person with dementia feels and experiences life is down to more than just having the condition. Other factors include the relationships the person has, their environment and the support they receive.

Helping someone with everyday tasks

- In the early stages of dementia, many people are able to enjoy life in the same way as before their diagnosis. But as symptoms get worse, the person may feel anxious, stressed and scared at not being able to remember things, follow conversations or concentrate.
- It's important to support the person to maintain skills, abilities and an active social life. This can also help how they feel about themselves.

How a carer can help

- A carer can help someone with dementia with everyday tasks, such as:
Shopping / laying the table / gardening / taking the dog for a walk
- Memory aids used around the home can help the person remember where things are.
- As dementia affects the way a person communicates, a carer will probably need to change the way they talk to and listen to the person they care for.

Useful links: [communicating with someone with dementia](#)

[Find out more about how to make your home dementia-friendly](#)

References:

<https://www.nhs.uk/conditions/dementia/carers/>

<https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia>

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Additional info/advice and dementia support locally

Southwark Dementia Action Alliance

- **Southwark Dementia Action Alliance (DAA) is a means through which all types of organisations and individuals can make a contribution to improve the lives of people with dementia and their families**, whether they live, work or enjoy the rich leisure, businesses, cultural or artistic resources in the borough.
- **Southwark DAA exists as a vehicle for organisations and individuals to work together to make Southwark a dementia friendly community**, where people living with dementia have the support they need to live their life to the full and remain a valued part of our community.

https://www.dementiaaction.org.uk/local_alliances/8628_southwark_dementia_action_alliance

Partnership Southwark links

- **SCCG** <https://www.southwarkccg.nhs.uk/get-involved/Shaping-services/Pages/Dementia%20services.aspx>
- **Partnership Southwark** https://www.southwarkccg.nhs.uk/our-plans/partnership-southwark/Documents/Partnership%20Southwark_%20August%202019.pdf

Other health promotion links

- **Alzheimer's society** <https://www.alzheimers.org.uk/about-dementia/types-dementia/alzheimers-disease>
- **Dementia UK** https://www.dementiauk.org/understanding-dementia/prevention-and-risk-factors/?gclid=EAIaIQobChMI7JyBx6fl6wIVdYBQBh28WwvXEAAAYAiAAEgLgmfD_BwE
- **Living well with dementia** <https://www.nhs.uk/conditions/dementia/living-well-with-dementia/>

Covid-19: Increased risk for people with dementia and other long-term conditions

APPENDIX: DEMENTIA AS A HIGH RISK GROUP

- **If a person with dementia does catch coronavirus, they are at higher risk of getting worse COVID-19 illness. The risk of severe symptoms rises steeply with age, and 9 in 10 deaths have been in people over 60. Most people with dementia and many older carers will fall into a higher risk group on age alone.**
- Long-term health conditions also significantly raise the risk of severe illness. Some of the more common of these – heart or blood vessel disease and diabetes – are more often seen in people with dementia.
- There is some evidence that dementia itself may add a further risk on top of age and these other health conditions, but this is not certain.
- It is not clear why, but men and people from black and minority ethnic (BAME) communities, with or without dementia, are also at increased risk. This link is not explained by age or long-term health conditions.

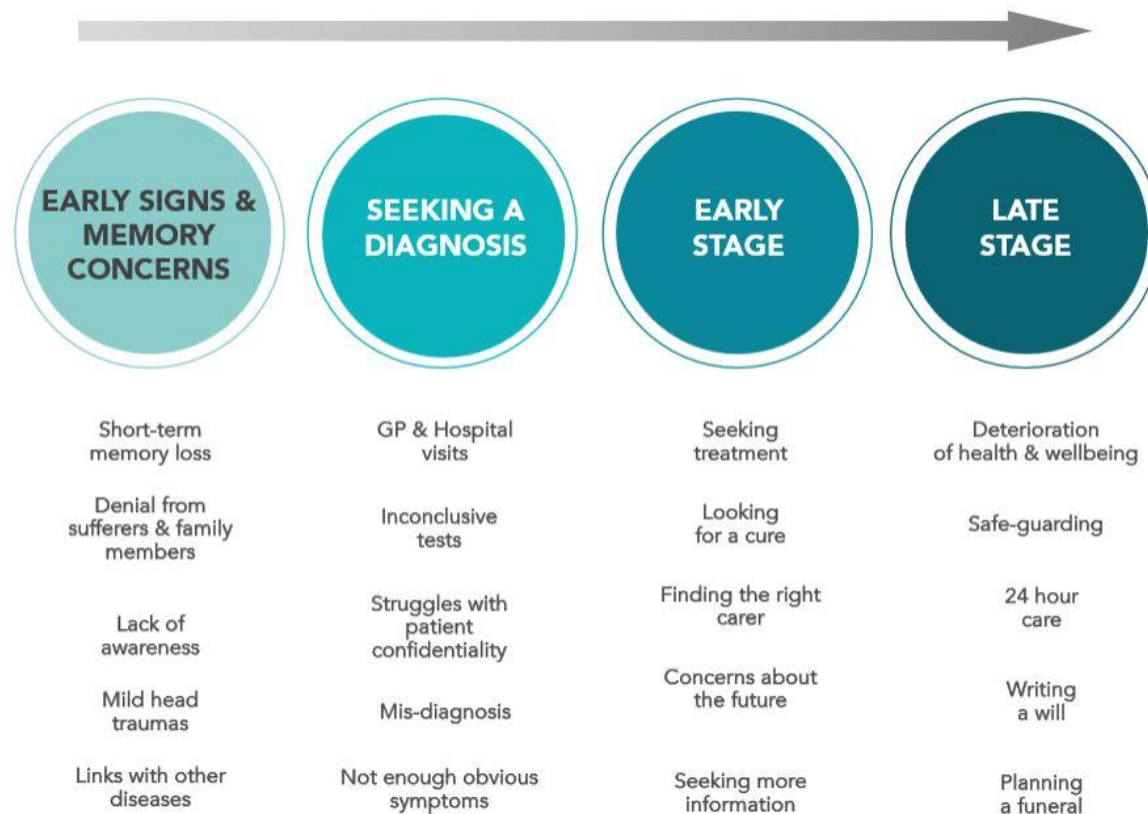
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<https://www.alzheimers.org.uk/get-support/coronavirus/dementia-risk#:~:text=If%20a%20person%20with%20dementia,risk%20group%20on%20age%20alons.>

Developing a dementia diagnosis journey to improve self-guided support

APPENDIX 2: DIAGNOSING WELL - MAPPING THE JOURNEY

Alzheimer's Society measured user experience to map out the needs of people affected by dementia, and create large-scale solutions



References:

1. <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/developing-new-services/mapping-diagnosis-journey>