Sutton Joint Dementia Strategy
2025 -2030

Sutton

NHS
South West London

Sutton
age UK

NHS
South West London and
St George's Mental Health
NHS Trust

SUTTON
PRIMARY CARE
NETWORKS
INTEGRATING
& INNOVATING

SUTTON CARERS CENTRE

Dementia UK
Admiral Nurses
Helping families face dementia

NHS
Epsom and St Helier
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1. Foreword

“ I welcome this strategy that builds on the previous work undertaken. I am pleased that the strategy has been co-produced with stakeholders, including those with lived experience and carers. Their voices will be integral in the delivery of this strategy and key to ensuring all those living with dementia in Sutton are supported to live well.”

-**Councillor Marian James**, Lead Member for People,
Sutton Council

“As someone who has worked in dementia care in Sutton for 30 years, I am very pleased to see the focus on dementia through the careful development of this joint strategy, which includes, most importantly, the learning from Sutton residents who have lived experience of dementia or of being a carer. There is new hope in terms of risk reduction and the future development of effective treatments, but this strategy gives important guidance for the here and now.”

-Dr Deborah Stinson, Consultant Psychiatrist, Sutton Older People’s Community Mental Health Team (OPCMHT)

“This strategy represents the partnership's unwavering commitment to supporting individuals living with dementia and their families, ensuring dignity, respect, and access to the best possible care within our community."

-**Sandra Howard,** Director, Adult Social Care and Safeguarding,
Sutton Council

“I welcome the development of this strategy. It is critical that we work across health and care in Sutton to support those with dementia and those who care for them. This is not about creating new services, but making sure we connect and collaborate effectively. We must also review our focus on preventing dementia, reflecting that a lot of the risk factors are the same as other causes of ill health.”

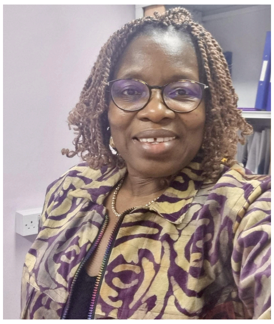
-**James Blythe**, Managing Director, Epsom and St Hellier’s University Hospitals NHS Trust.

“I am pleased to endorse the Dementia Strategy. It recognises the contribution people with dementia make to their families, friendships, and communities and we want to support them to continue to do so.
We also recognise this is not the experience for others where symptoms have progressed making it difficult to remain independent and active in their communities. Through this strategy and our collective efforts across the partnership we want to ensure we do all we can to deliver personalised care, supporting people to live and age well, accessing the support they need to remain independent for as long as possible”.

- **Dr Dino Pardhanani,** Clinical Director, Sutton Place, South West London Integrated Care Board

“As a strategic delivery partner and representative of the voluntary and community sector, we are proud to have had involvement in the development of this strategy and look forward to seeing the strategy actions being delivered.”

- Hilary Dodd, Acting CEO, Age UK Sutton



Quote Pending

-**Dr Shade Ajayi-Obe,** Chair of the Board of Trustees,
Sutton Carers Centre

"By bringing together the voices of professionals, carers, and—most importantly—people with lived experience, we are setting a clear direction for how we can improve care, coordination, and outcomes. This strategy is a meaningful step towards building a more connected, compassionate, and proactive approach to dementia support across our borough which as the Chief Operating Officer for Sutton Health and Care- instrumental in the delivery of this offer - is welcome.”

-**Lucy Botting,** Chief Operating Officer, Sutton Health and Care

“'This is an exciting bespoke strategy for local people with dementia. i a, pleased to see the extent of co-production throughout the strategy and how this will shape our services.”
-**Imran Choudhury,** Strategic Director of Public Health and Wellbeing, Sutton Council

“Alzheimer’s Society is pleased to have been involved in supporting the development of Sutton’s Dementia Strategy. As the biggest health and social care challenge we face in this country, we welcome Sutton’s drive towards ensuring residents with dementia can access an early and accurate diagnosis and are supported along their dementia journey with good quality care and support. We also applaud the focus on supporting family and friends caring for those with dementia, (without whom the system would be totally overwhelmed) and to the extent to which people living and affected by dementia have helped to shape this strategy.”

“We eagerly await seeing how the strategy is brought to life over the next five years, as actions are put into place to enable Sutton residents with dementia and carers to live more fulfilled lives, access the help they need and become more closely connected to their local communities.”

- **Tim Baverstock,** Head of Local Systems Influencing, Alzheimer’s Society

“We saw many professionals- all seeking a diagnosis…it was emotionally exhausting. In the end, we were sent back to our GP.

When we achieved a diagnosis, getting involved with the various agencies became like a revolving door - repeating the same information, again and again. My head was spinning - who said what? What do I need to do next? We were completely overwhelmed. At this time there was no single point of contact- with an escalation route.”

“The new dementia hub would have provided us with a point of contact to speak to and ask where to find things. I would have been able to have a lunch break at work, instead of charging around looking for answers. Through a single point of contact I would have been able to find the best options for mum.”

-***Denise*** *- Sutton resident with lived experience of dementia*

2. Our Vision

Our vision, created by our partners, stakeholders and those with direct and lived experience is that through this strategy**:**

“We will support people affected by dementia to live well throughout their lives, receiving a timely diagnosis, and the right support at the right place and time. Together, we will develop Dementia-friendly communities with the person, their choices, dignity and what is important to them at its centre”.

3. Executive Summary

This strategy recognises that people with dementia are an integral part of our community. They can lead full, positive lives and actively participate in and contribute to society. This document sets out shared aspirations and actions to enhance the overall support available to people living with dementia across Sutton to help them stay connected, well and living independently for as long as possible.

The development of this strategy has been supported and overseen by the local health, care and voluntary organisations that make up the Sutton Place Partnership. It has been further shaped by - and priorities set through - invaluable contributions from local stakeholders, community groups and residents who generously shared their time and lived experiences of dementia.

We also acknowledge that this strategy comes at a time of change for NHS England, the wider health sector and potentially in the delivery of local health services. In response, this strategy aims to strengthen collaboration between health, social care, community and voluntary sectors to provide coordinated support to people with dementia, their families, friends, and carers.

A key focus for this strategy is to work with Sutton’s local communities to ensure that prevention messaging, information about dementia, post-diagnostic support and subsequent care reviews are delivered in a way that is accessible, inclusive and welcoming to everyone. This includes ongoing and meaningful collaborations between strategy partners and people with dementia, their families and carers to create more dementia-friendly places, activities and environments to support living well with dementia across the borough.

The **five key priorities** framing this strategy are:

- **Preventing Well** - Up to 45% of dementia cases may be preventable through lifestyle changes (Lancet Commission, 2024). This priority focuses on promoting actions that can help prevent, delay, or reduce the risk of dementia for adults in Sutton. We will ensure these prevention messages are accessible, inclusive, and culturally appropriate, enabling everyone to make informed choices about their health.
- **Diagnosing Well** - Ensuring that people are able to recognise the early signs and symptoms of dementia and know where to turn for support. We are committed to improving access to timely, accurate diagnoses, alongside the provision of clear, accessible information and effective signposting at every stage of the diagnostic process.
- **Living Well** - Supporting people diagnosed with dementia to remain active, connected, and independent within their communities. This means working across health, social care, and voluntary sectors to provide meaningful opportunities and activities that promote wellbeing and reduce social isolation.
- **Caring Well** - Acknowledging and respecting the unique insight, experience, and expertise of family members looking after people with dementia and dementia carers. We will support them in their caring role by ensuring they have access to the right information, resources, and services to sustain their wellbeing and continue providing care with confidence and dignity.
- **Dying Well** - supporting people with dementia and their carers to plan for the later stages of life, including end-of-life care. We aim to ensure that individuals are able to express their wishes and, wherever possible, receive care in their preferred place, with dignity, compassion, and appropriate support.

The partners of the strategy aim to the best use of available resources ensuring that they are focused where they can have the best effect. We also intend to link this strategy to others aiming to improve associated outcomes and care and support services as well as local health and care programmes, examples include Sutton’s:

    - Adult Social Care Prevention Strategy
    - Joint Carers Strategy
    - Health and Care Strategy
    - Mental Health Partnership
    - Integrated Neighbourhood Teams
    - Our collective community-based care and support-based commissioning plans

Examples of areas where these strategies share purpose and common aims are social isolation/loneliness, keeping people healthy and well for as long as possible, social prescribing and commitments to work on a neighbourhood or community-based level.

Engagement activities with stakeholders, people with dementia, their carers, and community engagement activities further influenced our approach and commitment to improving the quality of life for people with dementia, their families and carers. They also helped us to identify possible community-based interventions and new ways of working to improve access to support for people with dementia (such as Sutton's new Dementia Hub, launched in April 2025, currently delivered by Age UK Sutton, our Voluntary Community Sector partner).

This combined approach will also be used going forward to co-produce this strategy's Delivery Plan (Appendix 1) and establish the metrics to measure our activities through an Dementia Strategy Outcomes Framework with additional guidance from Alzheimer's Society London.

This is Sutton's first Joint Dementia Strategy. Over the next 5 years, we hope to continue to work together, and where possible develop new programmes and pathways that are built on collaboration, best practice and evidence with direct input from people with dementia, their families/friends and carers across Sutton's local communities and cultures.

While we cannot change the way formal treatment is delivered and every case is unique, this strategy sets out how we will work together to help improve everyday experiences in life and when accessing support and care for people with dementia in Sutton.

The Sutton Place Partnership
- London Borough of Sutton
- NHS South West London ICB
- Sutton Primary Care Networks
- Epsom and St Helier Hospitals NHS Trust
- Sutton Health and Care
- South West London and St George's Mental Health NHS Trust
- Age UK Sutton
- Sutton Carers Centre
- Community Action Sutton
- Together for Sutton

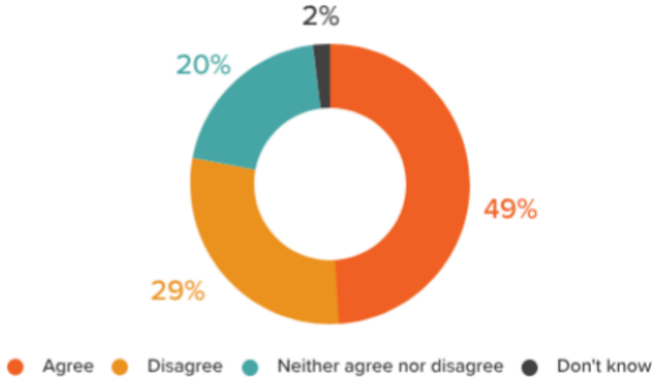
Public attitudes towards dementia

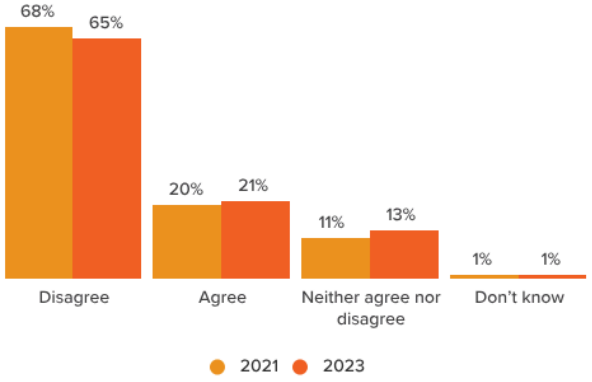
(extracts from Alzheimer's Research UK)

'Dementia is the health condition I fear most'

Half (49%) of UK adults say that dementia is the health condition they fear getting in the future most.

Older adults (57% of those aged 65 or over) and people who know someone who has been diagnosed with the condition (55%) are more likely to agree that dementia is the health condition they fear most, reflecting findings from 2021.



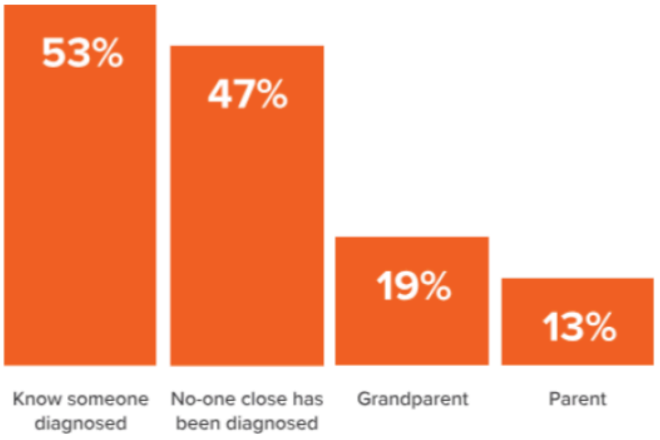


Dementia is not an inevitable part of getting older

Dementia is not a normal part of ageing but is caused by diseases, including Alzheimer's, that affect the brain. The majority of people (65%) correctly disagree with the statement 'dementia is an inevitable part of getting older', but 21% agree and 13% neither agree nor disagree.

More than half of us have been affected by dementia.

The Monitor reveals that more than half (53%) of the UK public know someone who has been diagnosed with the condition. This is most often a grandparent (19%) or parent (13%).



4. Introduction

Dementia - a definition

The World Health Organisation, (WHO) defines dementia as "a syndrome that can be caused by a number of diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. While consciousness is not affected, the impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation."

The WHO continues: "Dementia has physical, psychological, social and economic impacts, not only for people living with dementia, but also for their carers, families and society at large. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care." (WHO, 2024).

While dementia is more common in older people, it can also affect younger adults. This is known as young-onset dementia, and it can bring unique challenges for those diagnosed.

Each person's experience of dementia is different. Many people with dementia continue to contribute positively to their families, friendships, and communities - staying active and engaged. However, for others, the symptoms can make even basic daily tasks very difficult. Some individuals live alone or rely on a sole or an occasional carer, increasing the risk of social isolation and loneliness. Recognising the diversity of experiences living with dementia is key to providing support that is responsive, compassionate, and person-centred.

Dementia in Sutton

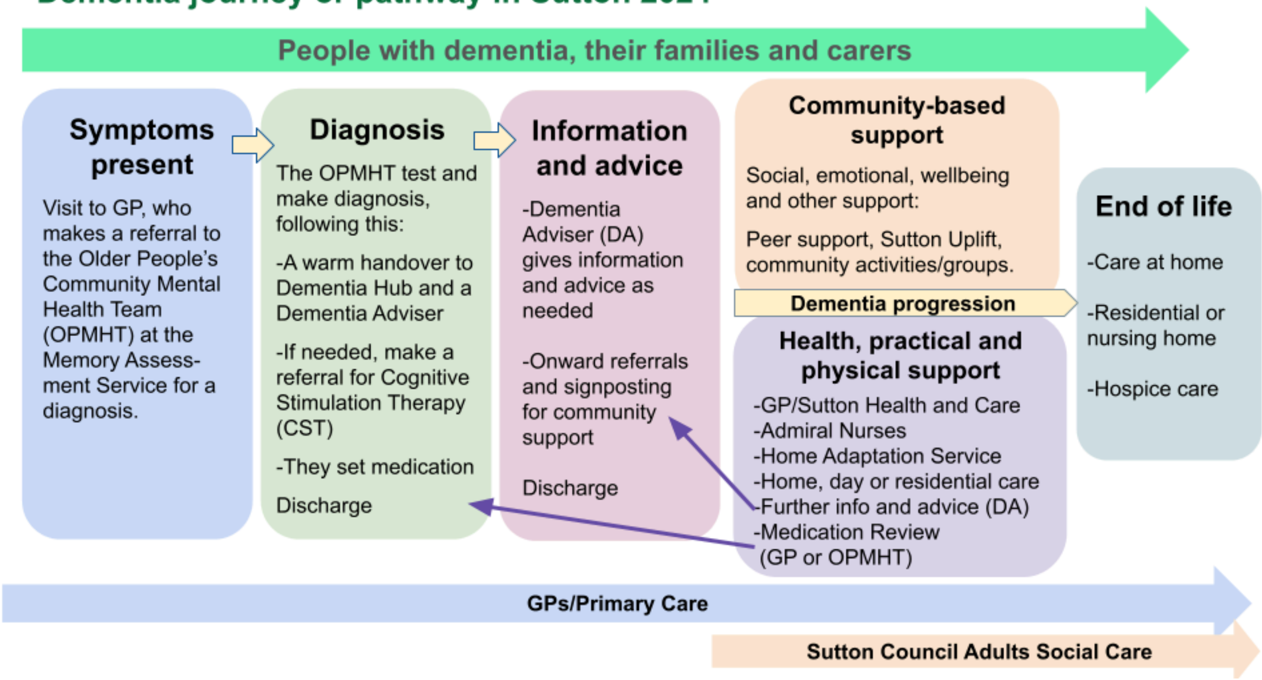
Dementia is an area of increasing focus for all of us. As people are living longer, we are seeing a steady rise in the number of individuals affected by dementia, and those diagnosed at a younger age. Local data highlights the importance of proactive planning and responsive support services. In Sutton:

- An estimated 2,107 people aged 65 and over are living with dementia in Sutton. However, only 1,559 of those individuals (around 74%) have a recorded diagnosis.
- In 2022/23, Sutton's Quality and Outcomes Framework (QOF) data reported a dementia prevalence rate of 0.7% across all age groups. This is in line with the England average (0.7%) and slightly higher than the South West London average (0.6%).

- ➔ A gradual increase in early-onset dementia (diagnosed in people under 65) is projected between 2023 and 2040, rising from 55 to 60 cases, which reflects a 9.09% increase.
- ➔ The most notable growth is expected among people aged 50–59 and 60–64, with younger age groups remaining relatively stable.
- ➔ For those aged 65 and over, the number of people with dementia is projected to rise by 39.8% between 2023 and 2040—from 2,431 to 3,389 individuals.
- ➔ The most significant increase will occur in the 90+ age group, where dementia incidence is expected to rise by 83.7% in men and 41.6% in women.

As projections show that Dementia will be most notable for people aged 50-59 and 60-64 between 2023 and 2040, a collaborative service response for professionals, those on dementia journeys, their carers and the wider community underscores this strategy.

Dementia journey or pathway in Sutton 2024



People with dementia, their families and carers

Symptoms present

Visit to GP, who makes a referral to the Older People's Community Mental Health Team (OPMHT) at the Memory Assessment Service for a diagnosis.

Diagnosis

The OPMHT test and make diagnosis, following this:

-A warm handover to Dementia Hub and a Dementia Adviser

-If needed, make a referral for Cognitive Stimulation Therapy (CST)

-They set medication

Discharge

Information and advice

-Dementia Adviser (DA) gives information and advice as needed

-Onward referrals and signposting for community support

Discharge

Community-based support

Social, emotional, wellbeing and other support:

Peer support, Sutton Uplift, community activities/groups.

Dementia progression

Health, practical and physical support

-GP/Sutton Health and Care
-Admiral Nurses
-Home Adaptation Service
-Home, day or residential care
-Further info and advice (DA)
-Medication Review (GP or OPMHT)

End of life

-Care at home

-Residential or nursing home

-Hospice care

GPs/Primary Care

Sutton Council Adults Social Care

Aims and objectives

As the first Joint Dementia Strategy for Sutton, we sought the views and experiences of people with dementia, their families and carers as well as the teams providing care and support. Community and stakeholder engagement shaped this strategy's 5 Key Priorities. The aim was to ensure that how we developed each one to reflect not only the ideas and examples of best practice shared with us, but also proven, evidence-based approaches and suggestions from the people delivering dementia support to improve everyone's experience.

Specific examples within this strategy that reflect these engagement activities include: a collaboration to share resources to create a single point of contact for post-diagnosis support, wellbeing check-ins with carers during dementia care reviews and developing toolkits for local heritage-based groups to help keep people with dementia and their unpaid carers involved in local activities, reducing their risk of social isolation and loneliness.

Across Sutton's Place Partnership (Council, NHS and Primary Care Networks and the local voluntary and community sector) there is also a growing approach to deliver care and support through neighbourhood or community-based models. We aim to build upon and strengthen this collaboration to deliver this strategy. This includes shared objectives to increase our collective cultural/community competency to respect different concepts around ageing and care, implementing new training programmes for community and heritage-based groups to support people with dementia and improving access to support through designing informational resources with local communities.

The following themes underpin each of the 5 Key Priorities and reflect what people told us across engagement activities:

- **The role and importance of community.** Local voluntary, community, heritage-based and faith-based community groups were consistently mentioned as important sources of support for people with dementia, their families/friends and carers. These are valued, trusted sources for signposting, health and wellbeing activities and staying connected to society. They are crucial partners within this strategy to help people overcome language and cultural barriers to help ensure health equity and increased accessibility of Sutton's dementia care and support services and activities.
- **Prevent, reduce, delay.** 45% of dementia cases are preventable. This figure is highly significant and presents us with an opportunity to improve individual lives and reduce demands on health and social care. There are also areas where the same lifestyle changes recommended to reduce the risk of developing dementia also lower the risk of developing other long-term health conditions. They also help to reduce reliance upon high intensive and costly health services, the number of avoidable hospital admissions and support the overall wellbeing and independence for people diagnosed with dementia.

  Participants in community engagement activities across age and heritage-groups consistently asked for information, tips and things they could do for themselves, their loved ones and within their social groups to prevent dementia.
- **Early diagnosis of dementia.** We aim to challenge urban myths and beliefs that dementia only happens later in life. We will build upon current dementia prevention messaging to include recognising its signs and symptoms at earlier in adulthood. The early diagnosis of dementia not only helps to improve overall

health outcomes, but also provides more time for advanced care planning and decision-making across each person’s dementia journey.

- **Contingency and advanced-care planning** and preparing for changes over the course of a dementia journey. This includes ensuring that carers are confident with respite care choices and the cared for are well looked after in their absence, people with dementia put relevant legal documents into place at the right time for them, and there are resources to help inform decisions around transitioning to residential care or preparing for the end of life. Contingency planning for people with dementia can help them to stay independent, living well and to be supported in the community for as long as possible.
- **Co-production and hearing the voices** of those with lived experience and that these help shape what we do. This includes developing new programmes, reviewing or improving existing support and creating new resources for people with dementia, their families and their carers across local cultures and communities. This further ensures that the voices, wishes and preferences of people with dementia, their families and carers shape care and support plans.
- **Training and Tool-kits.** Community and stakeholder activities both showed a desire for training to better understand and prevent dementia, supporting people with dementia (including professional carers and front line workers) and resources for community and heritage-based groups to recognise signs of dementia and associated loneliness/isolation. Carers and community groups especially asked for resources to help people experiencing neurological based symptoms or distress or anxiety compassionately.
- **Collaboration and sharing resources**. Many of the priorities and themes within this strategy link to other partner strategies for specific groups or people (for example, Carers and people with Learning Disabilities), health and wellbeing (Mental Health, Falls Prevention, End of Life), Public Health campaigns (healthy lifestyles, loneliness/isolation, Cardiovascular disease prevention) and service delivery models such as hospital discharge teams, social care support, community mental health, Integrated Neighbourhood Teams (bringing together community services and primary care to support local delivery of a wide range of health and care services).

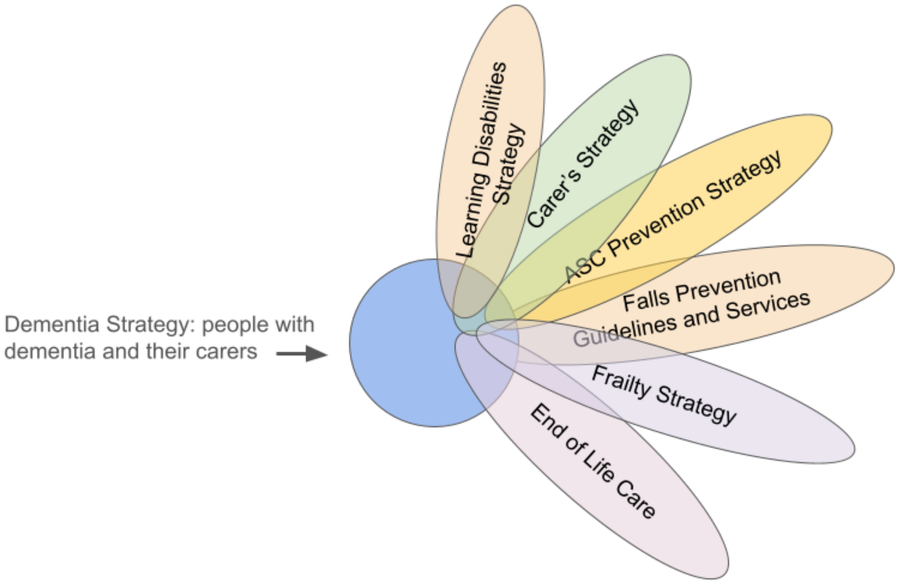
  We also hope to bring together voluntary sector resources across Sutton to enable a smoother connection and pathway and increasing access to national resources through Age UK (National), Alzheimer's Society, Carers Trust and Carers UK to support the strategy and people affected by dementia.

  Through strengthening these links to deliver and promote community-based support for people with dementia and their carers we also contribute to our shared commitment to keep Sutton’s residents healthy, well and living independently in their own lives.

An example of this is the new Dementia Hub model which provides a vehicle for improved collaboration through the triage of post-diagnosis dementia support referrals, joint working across voluntary sector, health and social care teams to provide a single point of access for people with dementia to access the right level of support at the right time to meet their individual needs. Support at the Dementia Hub is provided by Age UK Sutton and the Admiral Nurses, who provide specialist dementia support for people with dementia and their carers.

Sutton Carers Centre are wider partners of the Dementia Hub and also an important resource for Sutton's carers, linking the Dementia and Carers Strategies' aims to support the families, friends, and unpaid carers looking after people with dementia.

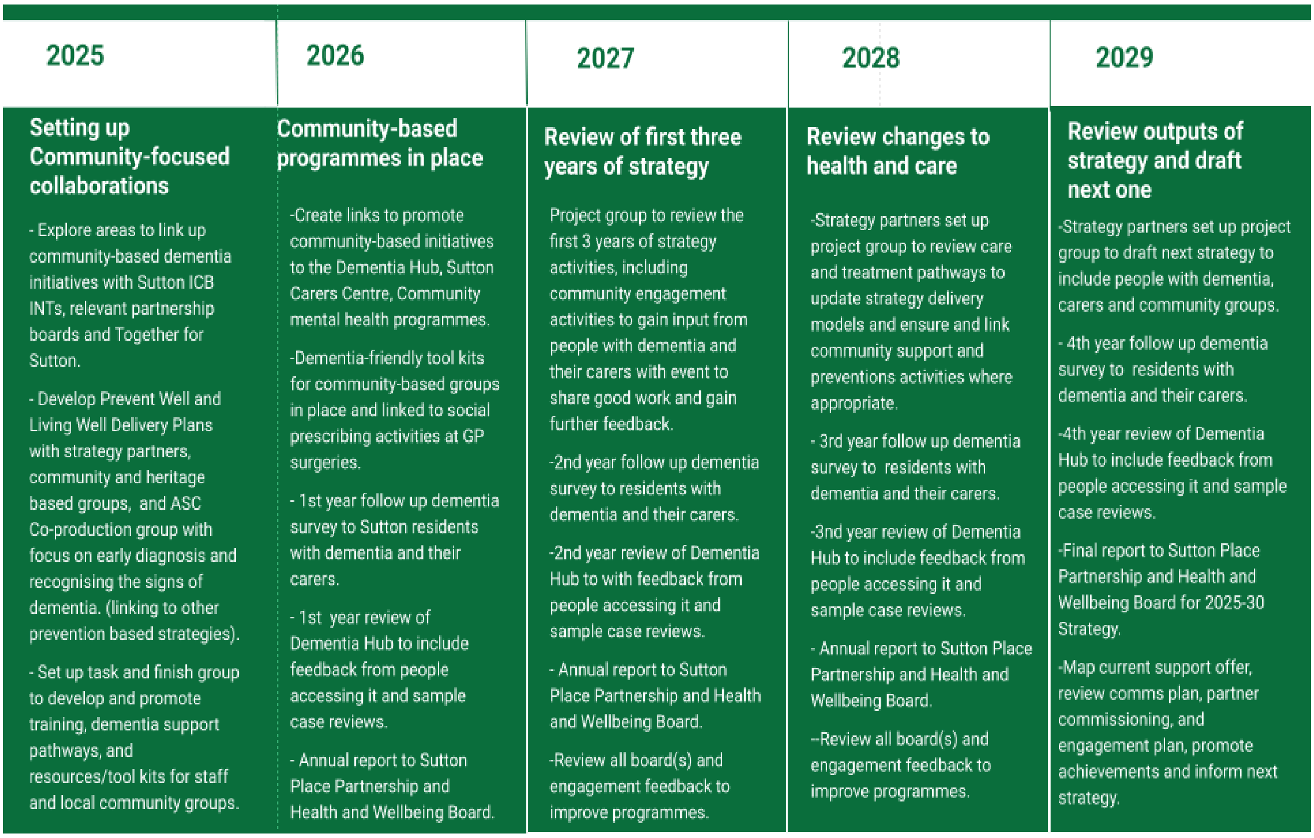
Partnership strategies and services linked to the Joint Dementia Strategy



Strategy Implementation Timeline

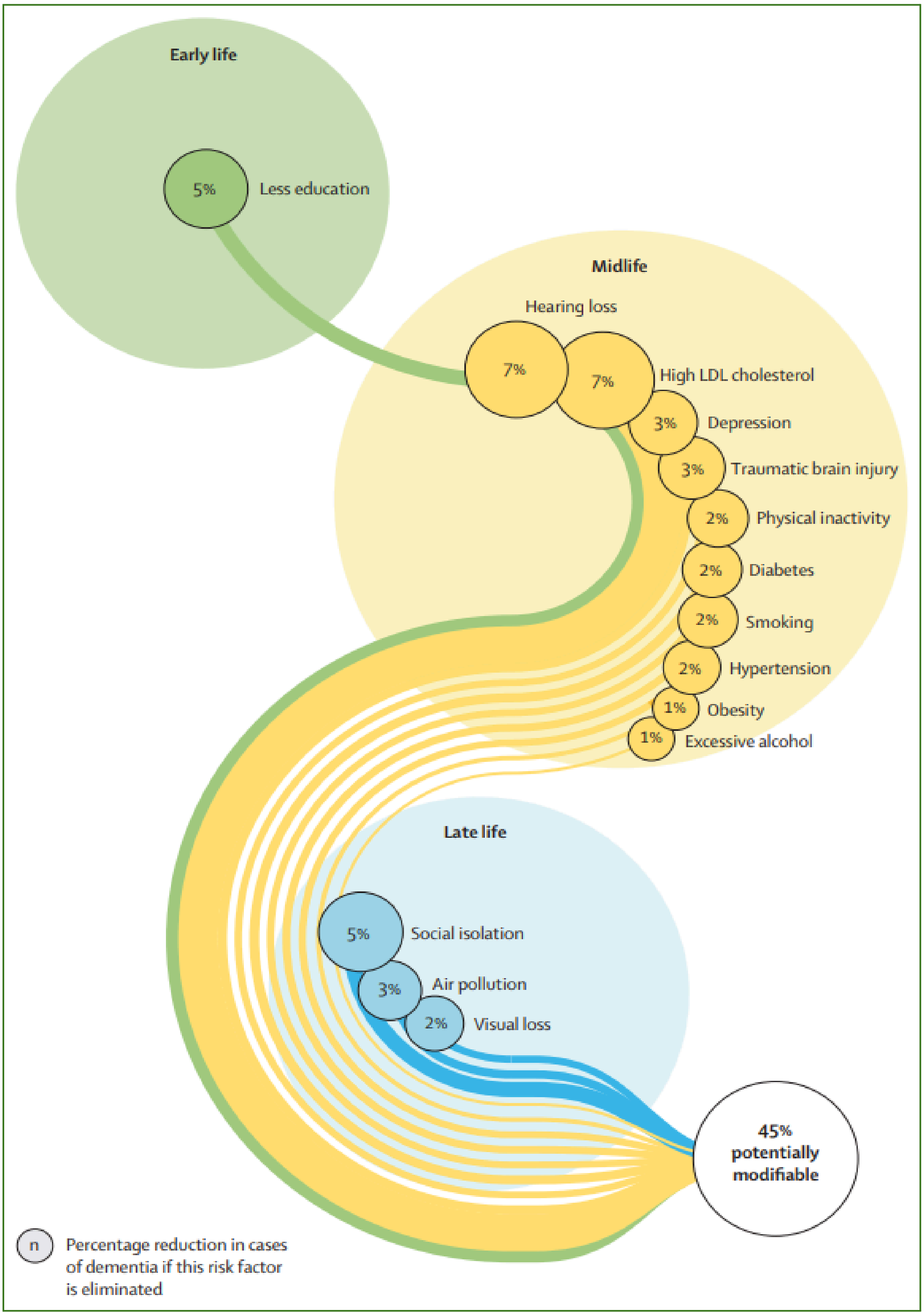
The following table set out the indicative timeline to deliver this strategy. The first three years will be used to agree, set up and carry out community-based interventions within this strategy, co-produced with people with dementia, their families and carers. It will also see the partners of this strategy identify areas for further collaborations to increase dementia awareness, prevention and early diagnosis and improve access to support across dementia journey pathways, increase our collective cultural competency and build upon the Dementia Hub model. The draft High-level Delivery Plan is attached as Appendix 1.

In our third year, strategy partners will review the progress of the strategy alongside anticipated changes to health and care to identify new opportunities to improve dementia support to Sutton's residents and also make adjustments where needed. Years 4 and 5 will continue an annual review and refresh cycle for the strategy and lay the groundwork to develop the next strategy anticipated to be in place for 2030.



2025	2026	2027	2028	2029
Setting up Community-focused collaborations	**Community-based programmes in place**	**Review of first three years of strategy**	**Review changes to health and care**	**Review outputs of strategy and draft next one**
- Explore areas to link up community-based dementia initiatives with Sutton ICB INTs, relevant partnership boards and Together for Sutton. - Develop Prevent Well and Living Well Delivery Plans with strategy partners, community and heritage based groups, and ASC Co-production group with focus on early diagnosis and recognising the signs of dementia. (linking to other prevention based strategies). - Set up task and finish group to develop and promote training, dementia support pathways, and resources/tool kits for staff and local community groups.	-Create links to promote community-based initiatives to the Dementia Hub, Sutton Carers Centre, Community mental health programmes. -Dementia-friendly tool kits for community-based groups in place and linked to social prescribing activities at GP surgeries. - 1st year follow up dementia survey to Sutton residents with dementia and their carers. - 1st year review of Dementia Hub to include feedback from people accessing it and sample case reviews. - Annual report to Sutton Place Partnership and Health and Wellbeing Board.	Project group to review the first 3 years of strategy activities, including community engagement activities to gain input from people with dementia and their carers with event to share good work and gain further feedback. -2nd year follow up dementia survey to residents with dementia and their carers. -2nd year review of Dementia Hub to with feedback from people accessing it and sample case reviews. - Annual report to Sutton Place Partnership and Health and Wellbeing Board. -Review all board(s) and engagement feedback to improve programmes.	-Strategy partners set up project group to review care and treatment pathways to update strategy delivery models and ensure and link community support and preventions activities where appropriate. - 3rd year follow up dementia survey to residents with dementia and their carers. -3nd year review of Dementia Hub to include feedback from people accessing it and sample case reviews. - Annual report to Sutton Place Partnership and Health and Wellbeing Board. --Review all board(s) and engagement feedback to improve programmes.	-Strategy partners set up project group to draft next strategy to include people with dementia, carers and community groups. - 4th year follow up dementia survey to residents with dementia and their carers. -4th year review of Dementia Hub to include feedback from people accessing it and sample case reviews. -Final report to Sutton Place Partnership and Health and Wellbeing Board for 2025-30 Strategy. -Map current support offer, review comms plan, partner commissioning, and engagement plan, promote achievements and inform next strategy.

"...addressing most risk factors in mid-life (18-65) had the greatest impact in delaying or preventing the onset of dementia later in life. In early life (0-18), less education was found to have the greatest impact, while social isolation, air pollution and vision loss were found to have a more significant impact on risk in late life (65+)." (Alzheimer's Disease International, 2024).



5. Priority 1: Preventing Well

We have an opportunity within this strategy to help reduce the number of people diagnosed with dementia within Sutton in the years to come. Recent health evidence shows that approximately **45%** of dementia can be prevented or delayed.

STEPS TO A HEALTHIER BRAIN

DO NOT SMOKE
If you smoke, quitting is one of the best things you can do for your brain health.

PROTECT YOUR HEAD
Wear a helmet during sports or when riding a bike.

STAY SHARP
Keep challenging your brain throughout your life and stay socially connected.

LOOK AFTER YOUR HEART
Keep physically active, maintain a healthy weight, and try to limit alcohol to under 14 units per week.

TAKE CARE OF YOUR HEARING AND VISION
Get your eyes and ears tested regularly, and wear a hearing aid if you've been given one.

MANAGE UNDERLYING CONDITIONS
Take steps to prevent or manage high blood pressure, high cholesterol and diabetes.

Adapted from The Lancet standing commission on dementia prevention, intervention and care, 2024.

Actions on lower steps are linked to a greater proportion of dementia cases.

ALZHEIMER'S RESEARCH UK FOR A CURE

Registered charity numbers - 1077089 & SC042474

What research tells us

In 2020 the Lancet Commission on Prevention, Intervention and Care issued a report that said up to 40% of dementia cases may be preventable by addressing 12 lifestyle-related risk factors.

In 2024, the Lancet Commission added 2 new risk factors—bringing the total to **14 modifiable risks**, raising the percentage of dementia that was preventable to **45%**.

The report also stressed that health and social care should be ambitious about preventing dementia, and:

- ➔ **We should start early** - prevention should begin in childhood and continue throughout life.
- ➔ **Combine efforts** - many people have multiple risk factors, so a mix of diet, exercise, social connection, hearing care, and managing health conditions is most effective.
- ➔ **Our genes aren't our destiny** when it comes to our health - even people with a family history can lower their risk with healthy lifestyle choices.

There are also notable health inequalities when it comes to dementia:

- ➢ Women are nearly twice as likely to die from dementia as men. 46,000 vs 24,000 deaths in 2020. (Alzheimer's Research UK, 2022).
- ➢ Black and South Asian communities face earlier diagnosis and death from dementia. (Mukadam et al, 2022).
- ➢ People with learning disabilities are at much higher risk— 13% of those aged 60–65 are affected (vs 1% in the general population) and 50% of people with Down's syndrome will develop dementia as they age. (National Institute on Aging, NIH, 2020).

Early onset dementia

Taking action to prevent dementia needs to start as early as possible. The Projecting Adult Needs and Service Information (PANSI) data for Sutton predicts that there will be a gradual increase in the number of early onset dementia cases in Sutton between 2023 and 2040.

- ➔ For males aged 30-64 a rise from 32 to 35 or a 9.38% increase.
- ➔ For females in the same age group, an increase from 23 to 25 or an 8.70% increase.
- ➔ This means an overall increase from 55 adults in 2023 to 60 in 2040 or 9.09%.
- ➔ The biggest increases are seen in the 50-59 and 60-64 age groups, with younger age groups staying relatively stable.

Early Onset Dementia Predictions for Sutton

Group	2023	2025	2030	2035	2040
Males 30 - 39 yrs	<5	<5	<5	<5	<5
Males 40 - 49 yrs	<5	<5	<5	<5	<5
Males 50 - 59 yrs	17	17	17	18	18
Males 60 - 64 yrs	11	12	12	12	12
Total males	**32**	**33**	**33**	**34**	**35**
Females 30 - 39 yrs	<5	<5	<5	<5	<5
Females 40 - 49 yrs	<5	<5	<5	<5	<5
Females 50 - 59 yrs	11	11	11	12	12
Females 60 - 64 yrs	7	7	7	7	7
Total females	**23**	**23**	**24**	**24**	**25**
Persons 30 - 39 yrs	<10	<10	<10	<10	<10
Persons 40 - 49 yrs	<10	<10	<10	<10	<10
Persons 50 - 59 yrs	28	28	28	30	30
Persons 60 - 64 yrs	18	19	19	19	19
Total Persons 30 - 64 years	**55**	**56**	**57**	**58**	**60**

Source: PANSI: Projecting Adult Needs and Service Information

These numbers are likely to be underestimations because early identification of dementia figures comes from people accessing health services and there are likely to be many adults under 65 years who do not seek help.

Through targeted comms focusing on prevention, we can also significantly help to keep individuals and their families from experiencing all that goes with dementia and also significantly reduce dementia-related hospital admissions and demands upon health and social care services. The Alzheimer's Society (2024) estimated that the economic impact of dementia in the UK in 2021 was £42.5b. This figure is expected to increase to over £90b by 2040.

What people told us

In focus groups and community engagement activities helping to shape this strategy, questions about how to prevent dementia became a main focus of conversation. In addition to participants asking for guidance or 'how-to's', many times the question aimed at group facilitators evolved into wider discussions about the types of local activities people did to stay active, suggestions for YouTube and Tik Tok videos featuring people with dementia sharing their tips for brain health and requests for training or workshops to learn more and offers to participate in further co-production activities to develop prevention programmes.

What we aim to do

This strategy places a key focus upon giving people the information they need in order to make early lifestyle choices to help stay healthy and well for as long as possible. We also aim to work together and link our combined prevention programmes and strategies to share resources and increase access to information and support for people to develop their own healthy lifestyle habits to stay healthy, well and living independently for as long as possible. This includes:

- ➔ Collaborating across health and social care partners to link healthy lifestyle and ill-health prevention messaging using targeted comms and a range of media to support an overall ‘what’s good for the heart is good for the brain’ campaign outlining the 14 modifiable risk factors for dementia.

- ➔ Creating any new dementia prevention programmes and promotional resources with local community and heritage-based groups to make sure they are accessible and support different abilities, local languages, and respect cultural concepts for aging, health and caring.

- ➔ Map current partnership commissioning and community-based programmes to identify opportunities for targeted interventions for groups of people with a higher risk for dementia and brain health targeted activities over the lifespan of this strategy.
- ➔ Explore ways dementia prevention programmes can support and increase access to take up of support offered through local GP surgeries, Integrated Health Teams and Public Health such as social prescribing, smoking cessation services, community-based activities programmes and vision and hearing checks.

6. Priority 2: Diagnosing Well

Receiving a timely diagnosis of dementia is a crucial step for individuals to understand where they are in their dementia journey and what their future may look like. An early diagnosis allows people to have meaningful conversations with family and friends, explore ways to potentially slow the progression of symptoms and begin planning for both current and long-term care and support needs.

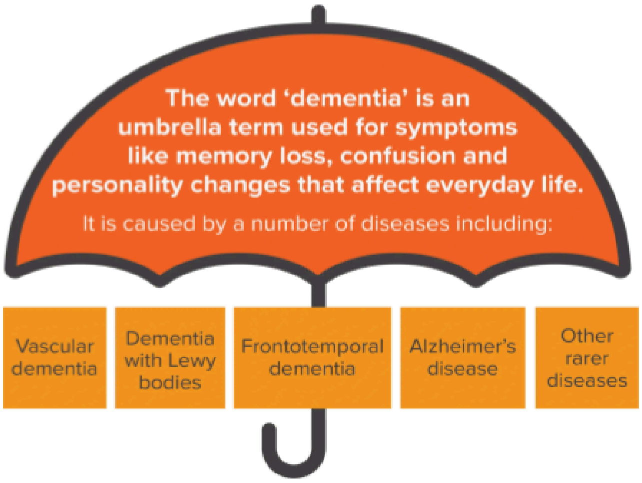
NHS England has set a national target for individuals to receive a dementia diagnosis within six weeks of discussing symptoms with their GP. In Sutton, we are performing strongly against this target with 85% of people receiving their diagnosis within six weeks of being referred to a Memory Clinic by their GP.

Through this strategy, we aim to ensure that more people can recognise the signs and symptoms of dementia, feel encouraged to speak to their GP at an earlier stage and are referred through for a Memory Assessment quickly and efficiently once the possibility of dementia is identified. Additionally, we are committed to providing personalised post-diagnosis support to help individuals, their families, and carers better understand the specific type of dementia involved and navigate the next steps in care and support in a way that respects their personal preferences and needs.

What people told us

Stakeholder groups emphasised the important need for people to consult their GP or main health professionals at the very earliest signs of symptoms associated with dementia.

There is an opportunity to discuss brain health alongside cardiovascular health in the standard aged 50+ health checks, but as mentioned in our Prevent Well priority, early onset dementia cases are predicted to rise. Collaborating on campaigns to recognise the signs and symptoms of dementia and asking for a dementia diagnosis earlier in adulthood was frequently suggested as a priority for this strategy.



The word 'dementia' is an umbrella term used for symptoms like memory loss, confusion and personality changes that affect everyday life.

It is caused by a number of diseases including:

Image: Alzheimer's Research UK, Getting a Dementia Diagnosis

In community and heritage-based focus groups, many attendees told stories about how they or others in the group had recognised symptoms in other members who lived alone and supported them in receiving a diagnosis. Knowing what to look for often came from their own experiences caring for or supporting family or friends with dementia.

Across groups there was also a general concern for people living alone who do not have a family member or friend to help notice symptoms, such as: memory loss, increasing anxiety and unexpected issues with coordination.

Creating resources that explain the symptoms of dementia as something different to the expected signs of aging, support varying cultural concepts around wellbeing and respect potential stigma around discussing mental health was suggested. This was seen as a positive step to increase early diagnosis within Sutton’s ethnic minority communities. It also was seen to contribute to feeling more confident and secure in discussing brain health with their GP or requesting a formal diagnosis.

In peer groups and interviews with people with dementia, their families and carers, attendees shared their own experiences, examples of best practice and their ideas to improve diagnosis and post-diagnostic support:

- GPs talking through the standard approaches to receiving a diagnosis and timelines for confirming a result was mentioned as helpful.
- Post diagnosis, initial help from the Memory Assessment Service or an Age UK Sutton Dementia Adviser to understand their dementia and what happens next was mentioned as invaluable support at the start of a dementia journey.
- Carers in the final round of focus groups told us that signposting for follow-up support after diagnoses made in hospitals (vascular dementia) wasn’t as consistent as those being made through the Memory Assessment Service. They suggested a consistent approach across all dementia diagnostic services.
- For families and carers understanding dementia, the steps in the diagnosis process and respecting their input and views when the person with dementia discusses symptoms with their GP was included in feedback. This general point about recognising the role of carers in decision-making is also a priority within Sutton’s Carers Strategy 2025-2030.

Recognising the potential signs of dementia, asking for a diagnosis and thinking about how a positive diagnosis will impact quality of life can be overwhelming for anyone. This strategy aims to support people to consult their GPs at the earliest sign of the symptoms of dementia and that they receive a timely diagnosis when referred to the Memory Clinic.

Case study:

“My dad clearly struggled to manage the stresses of his job, watching him go to work every day almost in tears was horrible. But without a diagnosis, a lot of people can’t retire early or benefit from schemes they have been paying into all their lives. “… Alzheimer’s is never fun. But understanding what it is and being able to deal with it would make it a lot less painful.”

- Zac Sherwani, son of gold-medal winning Olympian Imran Sherwani. Imran lives with early-onset Alzheimer’s disease. (Alzheimer’s Research UK, 2024)

What we aim to do

- Collaborate with community and heritage-based groups to develop resources to recognise the signs and symptoms for dementia, the process and steps to receiving a diagnosis that are culturally sensitive, accessible and available in multiple formats for people with learning disabilities and sensory impairments.
- Dementia Awareness training for community groups put into place to support Prevent Well messaging includes resources to help identify and support members of their community throughout the diagnosis process and understand what help is available and where.
- Encourage earlier conversations about the possible signs of dementia in adults under 65 years of age. Work with health partners and Sutton residents to identify opportunities to promote the benefits of an early diagnosis and how to ask for one.
- Respect and include the views of family members and carers where possible throughout the diagnosis pathway. That they are informed about their diagnosis and are offered post-diagnostic support in a way that is right for them.

  The new Dementia Hub arrangements include a warm handover from the Memory Assessment Service (MAS) to the Hub and access to a Dementia Adviser within a week after someone is told they have dementia, offering additional support to their family and carer if needed.
- Work with the Dementia Hub to identify diagnosis points in local hospitals (outside of the Memory Assessment Service) to improve signposting to the Dementia Hub and explore options to include a warm handover.
- People with dementia receive reviews in timeframes appropriate for their own needs and evolving dementia journey.

Preventing Well to Diagnosing Well

Once a person experiences symptoms or recognises that they may be at risk of dementia, they should contact their GP.

Early diagnosis helps to improve overall health outcomes, gives more time for advanced care planning and decision-making across each person's dementia journey.

Their GP will talk to them about their symptoms and ask about any others they may be experiencing.

To make a formal diagnosis for dementia, they will refer the person to the **Memory Assessment Service or MAS**. The MAS is located within the Older People's Community Mental Health Team, or OPCMHT.

The MAS gives the diagnosis. People with a positive diagnosis:

- Receive a Dementia Hub referral for ongoing support. (Their family and/or carer too).
- If treatment is needed, a referral for the appropriate service.
- Are issued prescriptions for any medications they may need.

7. Priority 3: Improving post-diagnosis support - the Dementia Hub

The Dementia Hub, a key initiative developed as part of this strategy, is reshaping the borough's post-diagnosis support offer. It was put into place through collaboration between the Integrated Care Board (ICB) and Sutton Council in response to feedback from people with dementia, their families, friends and carers.

The hub provides a single point of contact for accessing tailored, specialist dementia support. People can self-refer or contact the Hub at the right time for them by phone, email or in-person at Sutton's Memory Assessment Service.

How to contact the Dementia Hub

Tel: 020 4551 7337

Email: dementiahub@ageuksutton.org.uk

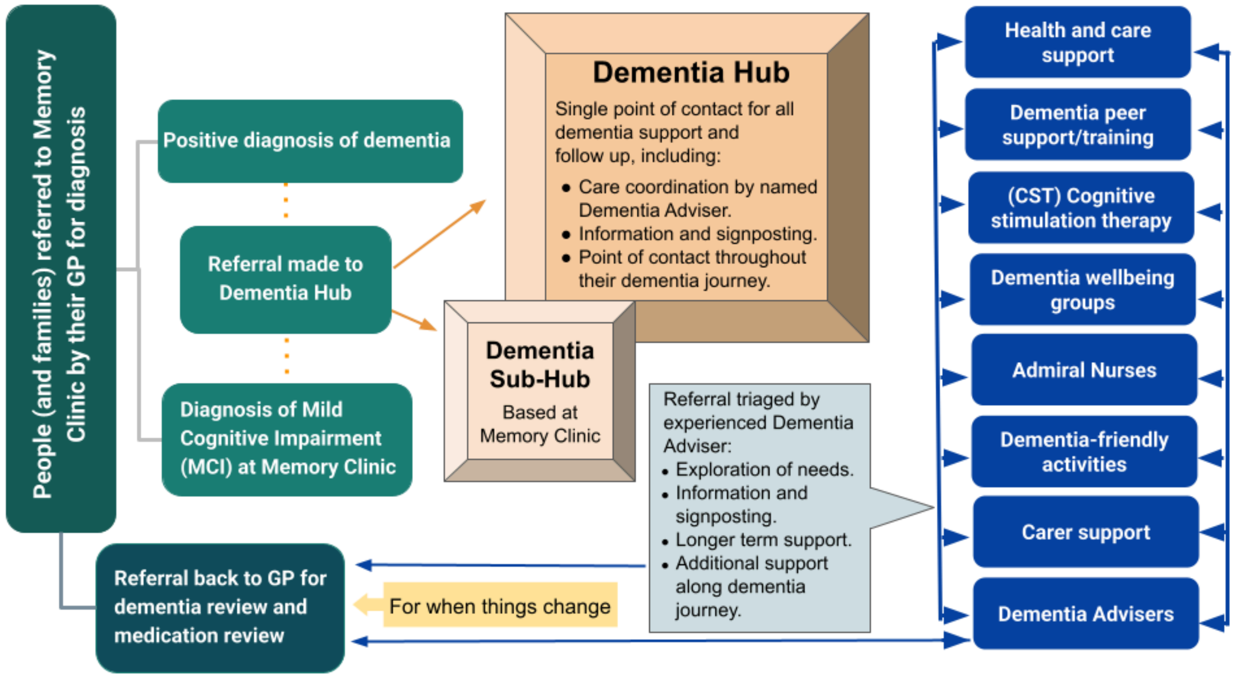
Age UK Sutton's main helpline: 020 8078 0002

Services are primarily delivered by Age UK Sutton, who oversee the Dementia Adviser teams, alongside the Admiral Nursing Service, who provide expert support to families and carers.

The Dementia Hub model was informed by strategic partnership mapping of Sutton's current dementia support pathways (see Appendix 7) and shaped with insights from professionals delivering local dementia care and support services. Launched in April 2025, the Dementia Hub aims to deliver a more coordinated, person-centred approach to improving post-diagnostic dementia support. Its core purposes are to:

- Provide bespoke post-diagnostic support to people with dementia, their families, and carers - responding to their individual needs at each stage of their dementia journey.
- Maintain a consistent Dementia Adviser service, offering individuals the option of a named or specific adviser for ongoing support.
- Offer accessible information and advice about dementia to all Sutton residents.
- Accept and respond to referrals from a range of sources, including the Memory Clinic, GPs, self-referrals, community health teams, and voluntary sector organisations.
- Support improved access to and delivery of care reviews, where appropriate.
- Facilitate connections to community-based programmes aligned with 'Living Well' and 'Preventing Well' principles, promoting holistic support and wellbeing.
- Enhance safeguarding and wellbeing, especially for self-funding adults and carers who do not qualify for subsidised support, ensuring equitable access to advice and guidance.

Dementia Hub Model



The Dementia Hub (Age UK Sutton and the Admiral Nurse service) are also important partners in developing additional resources for community-based initiatives included within the ‘Prevent Well’, ‘Diagnosing Well’ and ‘Living Well’ priorities. With this, work towards building upon the cultural competency of health and social care front line workers providing support to people with dementia and their carers will also be shared with the Dementia Hub.

An example of this was a recent focus group informing this strategy with the Hong Kong community that also promoted local support, answered questions about recognising the signs of dementia with Dementia Hub advisers and Sutton Council social care staff who speak Cantonese. In addition to raising awareness of local services, we received valuable feedback and insight about traditional views on caring, aging, and where participants were looking to find out about local health and social care services.

8. Priority 4: Living Well

“Dementia can affect all aspects of a person’s life as well as those around them. If you have been diagnosed with dementia, it’s important to remember that:

- You’re still you, even though you have problems with memory, concentration and planning.
- Everyone experiences dementia differently.
- Focusing on the things you can still do and enjoy will help you to stay positive.

With the right help and support when you need it, many people can - and do - live well and independently with dementia for several years.” (NHS Living well with dementia, 2024).

The partners of this strategy aim to support people with dementia to live well in Sutton. Early on in someone’s dementia journey, this support could be aimed at staying healthy, well, and connected to the people and places they enjoy. As their dementia progresses, support can include adaptations around the home, help with everyday tasks such as housework and technology to help people with dementia live independently and safely.

As part of this strategy, we also aim to support the family members and carers to live well with dementia. The “Caring Well” priority within this strategy includes additional support and is intended to complement Sutton’s Carers Strategy, approved in May 2025.

We also have aspirations through collaborative working to create new and link current support available to local community/heritage-based groups, social care, the Dementia Hub and Integrated Neighbourhood teams to support people living alone with dementia.

These are steps the NHS and dementia organisations recommend to live well with dementia:

- Staying social. Keeping local connections, catching up with friends and taking part in local dementia-friendly activities, including social and peer support groups, specialised cinema screenings and gentle exercise sessions. Community, heritage-based groups and memory cafés also provide shared experiences and help prevent social isolation and loneliness.
  Age UK Sutton and Sutton Information Hub can help you find local activities and events - many of which welcome family members and carers too.
- Telling others about your dementia (in your own time). Clear communication can help others provide better support. This includes letting them know what you may have trouble with such as following a conversation or not being able to drive. While this may change some relationships, new social connections can be formed through support groups and dementia-friendly activities.
- Looking after your health and wellbeing. Eating a balanced diet, regular exercise, getting good sleep, and staying hydrated are essential. Regular medical check-ups, including dental, eyesight, and hearing checks.

  Talking to your GP if you feel depressed, there are treatments that can help. It's also a good idea to keep them informed if you feel unwell. Especially for people with dementia who also have other longer-term health conditions.
- Contact Sutton Council's Adults Social Care team to find out available support to stay independent. This could include help making your home more dementia-friendly, help with a care and support plan if eligible and signposting to local activities. There are also assessments for carers to receive support too.

The Alzheimer's Society has made this video about living well with dementia.

What people told us

- People participating in community engagement activities told us that peer support groups and one-to-one sessions for people with dementia, families and carers were especially helpful to help maintain their wellbeing and also for signposting to any needed services. Feeling understood, welcomed and supported were frequently mentioned and the types of peer support included other people with dementia, people from the same background or heritage, carers and local community or leisure groups.

  Age UK Sutton, Sutton Carers Centre, Admiral Nurses and a number of smaller community groups were frequently mentioned.
- Regular, weekly dementia cafes, singing groups, walking groups, cooking activities, crafts and social activities organised by community groups were

mentioned as important to feeling more connected to their friends and neighbours. Many were attended by the person with dementia and carers.

- Many times conversations in community, heritage and faith-based groups included ideas for helping people living alone with dementia. Suggestions for buddy-schemes or dementia friends were specifically mentioned as was talking about ways the health and social care system could check in on or call people known to be on their own.

  Similarly to discussing dementia prevention, there was a willingness to learn more about dementia and supporting friends experiencing symptoms of dementia when taking part in activities or in other social situations such as going to church.

- Better day opportunities or safe activities with trained staff for people with progressive symptoms of dementia was highlighted as a need. Exploring ways to help people with memory loss and English as a second language or strong cultural identity was suggested.

- Health partners and Community Action Sutton gave examples of best practice for community-based activities as well as helped to identify programmes and services that could be linked to increase the overall ‘living well’ support available.

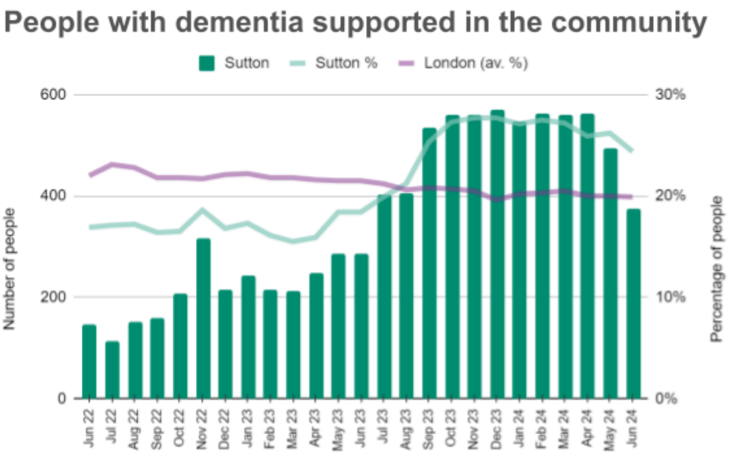
  This included guidance based on how to better engage Sutton’s communities to co-produce this strategy’s High-level Delivery Plan, create new local initiatives directly with emerging communities and expand signposting to care and support assistance.

- Age UK Sutton and Sutton Carers Centre further outlined the importance of peer support, and suggested that in addition to commitments made through this strategy to keep current arrangements in place, that these groups could also be used for the training and tool kits requested by people with dementia and carers taking part in focus groups. These could include topics such as managing dementia symptoms and putting legal documents into place, find out about new tech solutions, etc.

Between July 2023 and October 2023, Sutton experienced large growth in the number of people with dementia being supported in the community, (from 287 people to 559 people).

Between June 2022 and 2024, London figures for the percentage of people supported in the community declined from 22% to 20%.

This is in contrast to an increase seen in Sutton, from 17% to 24% as noted above.



What we aim to do

- ➔ Maintain our commitments to the community-based peer support provision within commissioning arrangements such as the Dementia Hub. Explore adding specific topics to sessions such as managing symptoms, trying out new tech solutions and contingency planning/getting legal documents in order. This is linked to aims for topical workshops and training within the ‘Caring Well’ section of this strategy.
- ➔ Work with Together for Sutton and Sutton Council to create opportunities for communities and cultural groups to develop local activities to support people with Dementia, their family’s and and their carer’s overall health and wellbeing.
- ➔ Make sure that Dementia Hub has up to date information and signposting to support people with dementia and their carers with challenging health behaviours, for example smoking cessation, addiction services, etc.
- ➔ Ensure that care and support reviews are strength-based for as long as possible with opportunities to discuss staying active and signposting to healthy living resources for people with dementia. This also supports this strategy’s core principle that people have the necessary information to make decisions that are right for them and at the right time.
- ➔ Map and promote the current social and healthy lifestyles activities on offer for people with dementia, their families and carers. Co-produce any new resources.
- ➔ Support the further development of social prescribing resources at local GP surgeries to people with dementia, their families and carers.
- ➔ Work with health partners such as Public Health and Integrated Neighbourhood Teams (INTs) to develop resources to prevent social isolation and loneliness and promote local opportunities to help people stay connected to society.
- ➔ Develop dementia training and tool-kits for community, heritage and faith-based groups to make their social and leisure activities dementia-friendly and accessible. (with Age UK Sutton and INTs).
- ➔ Explore developing a Sutton-specific ‘Dementia-friendly’ status for local businesses, public areas, green spaces, cultural and leisure facilities.
- ➔ Support local asset mapping being done by the Integrated Care Board (ICB) to identify important community resources and identify opportunities to share available resources providing community-based activities and support.

9. Priority 5: Caring Well

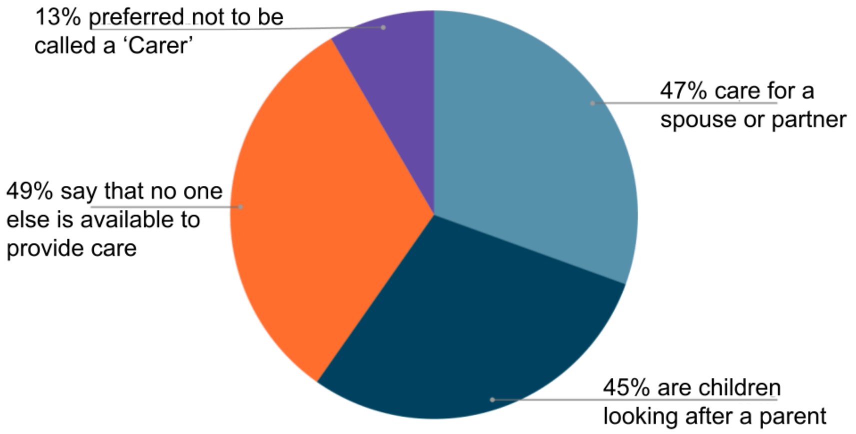
We know that many people with dementia are supported by unpaid carers—often immediate family members, good friends or neighbours —who play a vital role in helping them live at home and maintain the best possible quality of life. The support required can be complex and demanding, sometimes involving high levels of risk and responsibility. This can significantly affect a carer's emotional and physical wellbeing.

This priority builds on the core offer within Sutton’s Carers Strategy by providing **additional, targeted support for dementia carers**. Our aims are to:

- Recognise carers as *expert partners* in care planning and decision-making.
- Provide extra support for their **caring role**, tailored to the challenges of dementia care.
- Promote carers' **own health and wellbeing**, ensuring they are supported as individuals, not just as caregivers.

We fully acknowledge and respect the invaluable role that family members and carers play in supporting people with dementia. Through this strategy, we hope to enhance the support available to them—making it timely, meaningful, and sustainable.

As dementia progresses, carers often assume increasing responsibility. Many are older adults themselves and face considerable emotional, physical, and practical challenges. The **Dementia Carers Count Survey (2024)** report, *“What if… I’m not there to care,”* offers an important national context:



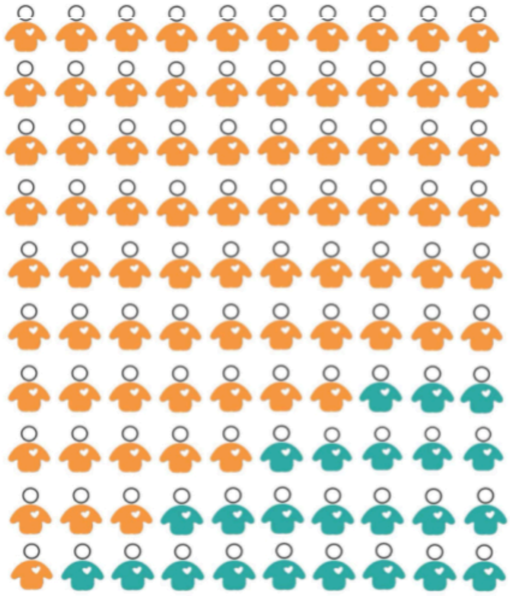
These figures reflect the intense, often isolating nature of dementia care. Many carers are doing this alone, with little opportunity for respite or personal time.

The **NICE Dementia Quality Standard** recommends that all dementia carers are offered education and skills training to support them in their role. As part of this strategy, there is consideration of what should be offered at different points of someone's dementia journey. For example, combined Life After Diagnosis (LAD) training for the person with dementia and their family or carer as part of post-diagnostic support, followed up with resources through the Carers Information and Support Programme (CRISP) a couple of months later with additional access to further training such as manual handling, managing progressive symptoms later on. This also includes helping to manage the emotional demands of care and coping with the stresses they bring.

By strengthening our support for dementia carers, we aim to improve not only the experience of caring, but also the outcomes for those living with dementia in Sutton.

We know that many people with dementia are being actively supported by unpaid carers, who make a significant contribution to people with dementia's ability to live at home and as well as possible. The level of support required for someone with dementia can be challenging and impact a carer's sense of wellbeing.

The aims of the Caring Well priority expand on the core carer's offer within Sutton's carers strategy to provide additional support for their personal wellbeing, are encouraged to have a Carer's Assessment to identify their own support needs, and ensure that they are recognised as 'expert partners' in decision-making and care planning for the person with dementia. We acknowledge and respect the important role family and carers play in supporting people with dementia and hope the support offered through this strategy helps them in themselves and their caring role.



76%

of dementia carers have **no** arrangements in place which outline what will happen if they cannot continue to care

What if…I'm not there to care? Dementia Carers Count (2024)

What people told us

Community engagement activities with dementia carers were done in collaboration with Sutton Carers Centre, Age UK Sutton and as part of conversations about dementia with local community and heritage-based groups. The views shared in these sessions also informed Sutton carer’s strategy. The feedback we’ve featured here helped shape the specific support recommendations for this strategy.

- Peer and one-to-one support was consistently mentioned as valuable and crucial for dementia carers. In addition to places known for providing this type of support such as Age UK Sutton and Sutton Carers Centre, Admiral Nurses and heritage and faith-based groups were also very important to dementia carers.

- Peer Support needs are different at various points in a carer’s dementia journey. look different depending on where someone is on their journey.

  This is the same for specialist support - early onset dementia peer support groups, day care/activities should be different to support carers looking after someone with later onset dementia.

- Carers who were immediate family members often did not think of themselves as a ‘carer’ and therefore not eligible for a carer’s assessment. This was not only because looking after a family member was a core cultural belief, but also for older married couples where caring for a spouse was felt to be a loving duty.

- Contingency planning was a major concern. Many dementia carers do not have someone to turn to for help and were concerned about paid-for replacement care being able to handle looking after someone with dementia. They also shared challenging experiences looking for bed-based care and good residential facilities they felt confident about using.

- Training for themselves as dementia carers and also for replacement or cover care was a common theme, especially for dementia carers looking after someone in the later stages of dementia.

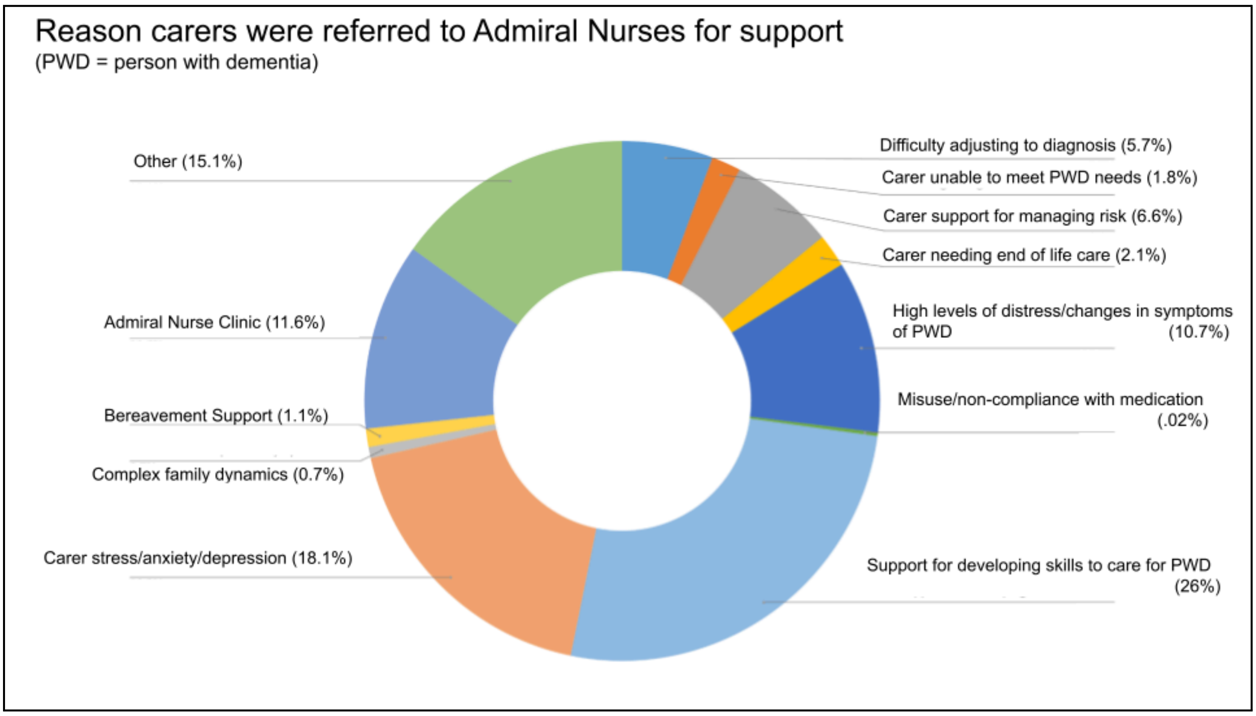
- Finding activities in earlier stages of dementia, day opportunities and residential care for later stages which were culturally sympathetic was mentioned especially for older adults experiencing cognitive and memory decline.

- Suicide prevention and access to enhanced access for formal mental health treatment was also a theme in 2 sessions where 50% of one group of dementia carers looking after people in advanced stages of the condition admitted to having thoughts of ending their lives on at least one occasion.

- Peer and professional advice and/or support in navigating the processes of putting Lasting Power of Attorney or Deputyship arrangements into place and coping with issues associated with using them was suggested. Carers in focus groups were having challenges with banks, complex issues when trying to change them, arranging a capacity assessment, and finding legal services.

- Carers and family members shared stories about the stress, uncertainty and anguish when the cared for person with dementia had wandered off or went missing. Carers discussed tracking devices and they were seen as useful, there were situations where they were taken off or left behind. Knowing where to turn, the relationship between hospitals and the police as well as using the 'This is Me' toolkit from Alzheimer's Society UK and the Herbert Protocol. It was suggested that these resources should be made available in advanced planning support sessions and a checklist of safeguarding tools was made available for carers.
- Carers acknowledged that the Memory Assessment Service shared contact information for local dementia support at the time of diagnosis. However people diagnosed in hospitals (vascular dementia) were often discharged without a review of next steps or signposting to support for themselves, family or carer.

The figures below reflect why a carer or family member looking after someone with dementia asked for specialist support from the Admiral Nurses team (now within the Dementia Hub) from April 2024 to March 2025. The Admiral Nursing team are Registered Nurses who provide specialist dementia care support to families affected by dementia and dementia carers with complex needs in Sutton. Families and dementia can self-refer and return to the team for support at any point in their dementia journey.



What we aim to do

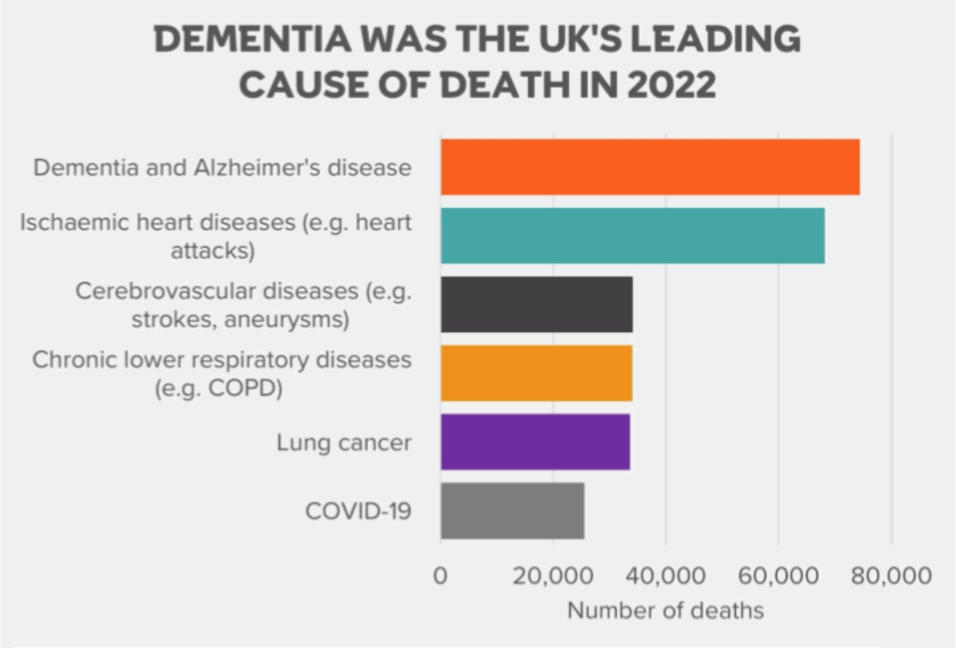
- ➔ Endeavour to continue the commissioning of peer and one-to-one support for dementia families and carers, co-producing any new initiatives with them and where possible, expand them to include more access to local activities.
- ➔ Create new workshops, training and peer support activities for people with dementia, their families and carers (and where appropriate, community groups) on topics suggested in carer engagement activities, such as: managing symptoms of dementia, advanced care planning and setting up and managing Legal Power of Attorney (LTA) and Deputyships. Link these new resources to the ‘New to Caring’ training offer for families and unpaid carers being put into place through the Carers Strategy and co-design new topics with direct carer input.
- ➔ Discuss ways to improve access to the capacity assessments often required as part of filing for an LTA or Deputyship with health partners and the Dementia Hub.
- ➔ Link the work being done in collaboration with the Sutton Adults Safeguarding Board to support contingency planning for carers as part of the Carers Strategy to also address specific dementia carer support/resources to put into place safeguard the person they look after if they are missing. Also produce, across all partner organisations, toolkits to support staff in their work with individuals and carers on both topics.
- ➔ Work with local Integrated Neighbourhood Teams (INTs), Together for Sutton and Sutton Council to improve outreach to dementia carers in cultural communities unaware of additional support via carers assessments, Admiral Nurses and the Dementia Hub.
- ➔ Link to activities under Sutton’s Mental Health Partnership (adults) to improve signposting to local mental health support services and join-up any new suicide prevention, social isolation/loneliness and emotional wellbeing campaigns to dementia carer support resources.
- ➔ Expand upon work being done under the carers strategy to improve access (through co-design and development) to improved respite care choices to include a focus on dementia to ensure that options for care include good quality, reliable and dementia-trained staff.
- ➔ Update the current Sutton Carers Offer with signposting and information about local dementia-friendly activities for people with dementia, their families and carers. This includes healthy living, wellbeing and leisure activities available through the Dementia Hub, social prescribing at local GP surgeries, Neighbourhood Teams and programmes commissioned by Sutton Council.

10. Priority 6: Dying Well

Dying well is a topic which many of us shy away from. Is it a good death when it comes too soon? How can I help my loved ones after I'm gone? How do I prepare if I am experiencing cognitive decline? In developing this strategy and its outcomes framework, we aim to provide support for people with dementia, their families and carers to start conversations about wishes, preferences and choices early in the individual's dementia journey. The goal is for decisions about end of life care to be known, understood and articulated before a potential future point where the person with dementia is unable to express them.

Advanced planning is also helpful in exploring associated risks that may go with care or treatment preferences and support staying independent for as long as possible. For dementia families and carers, advanced planning also helps make necessary legal and contingency arrangements for care (short term and longer term if needed). It also helps them know and respect the wishes of their loved ones with dementia if they are unable to articulate them directly when faced with care and support decisions during the later stages of dementia. Advanced care planning is a key element within overall care and support planning for each dementia journey.

Dying well also considers the people (loved ones and carers) around the person with dementia and whether they have the support necessary for their own health and wellbeing as well as in their caring role during the final stages of dementia. This includes access to effective choices for 'end of life' care services, whether these are for people with dementia remaining at home or bed-based or residential care. As much as what we aim to offer is about choice and availability, it's also about ensuring that these services are 'dementia sensitive' and culturally aware with the necessary skills and experience for compassionate, safe and reliable support.



Data sourced from the ONS website (England and Wales), National Records of Scotland and the Northern Ireland Statistics and Research Agency. Image: Alzheimer's Research UK

We are aligning our work within this priority of the strategy with the development of Sutton's End of Life strategy, building upon its goals and actions to make sure there is support available addressing the requirements of people with dementia and their families and carers.

What people told us

Within community conversations and one to one interviews about dementia, advanced care planning, knowing the later stage support wishes for the person with dementia and ensuring that required legal documents were in place was frequently offered as advice from people who had experienced the later stages of looking after someone with dementia, arranging end of life care and maintaining their own health and wellbeing.

Sessions with carers were filled with stories sharing the challenges of caring for someone with advanced stages of dementia, especially handling complex, advanced symptoms but also the emotional impact the experience had or was having on their own health and wellbeing. Many of the participants were older adults looking after their spouse or adult children taking care of their parent(s). Emotional support was provided by Sutton Carers Centre for these sessions.

Peer and one-to-one support appropriate to maintaining family/carer mental health and wellbeing during later stages of dementia, training or workshops on how to handle complex brain-based symptoms (seeing things that aren't there, severe anxiety, progressive memory decline), and support to help find reliable, safe short and longer-term respite care and bed-based or residential care were frequently mentioned as things that are or would be helpful.

What we aim to do

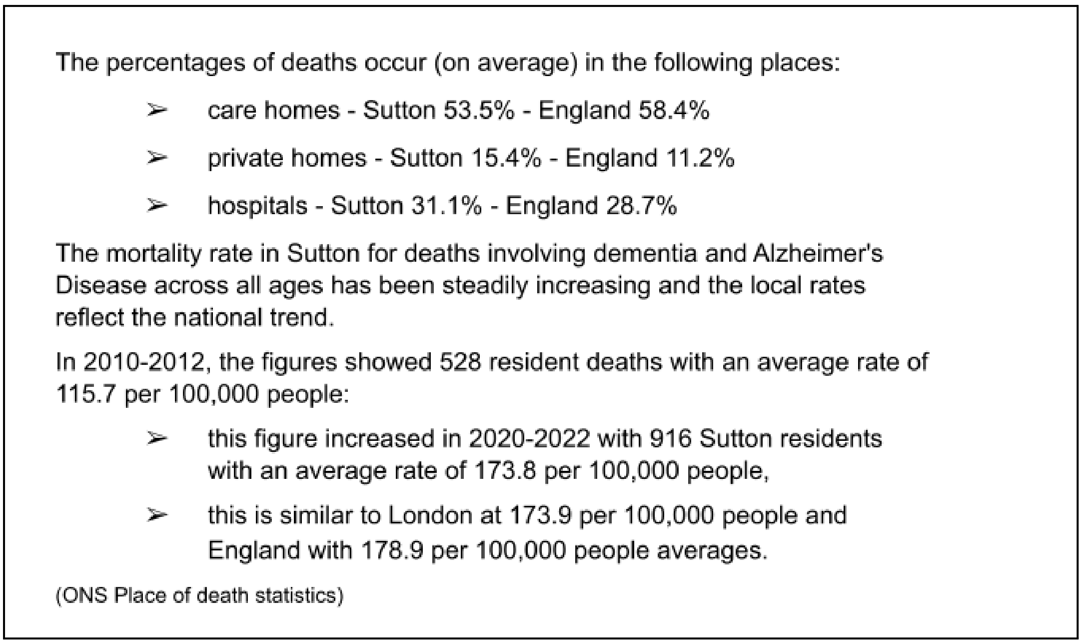
- ➔ Ensure that people with dementia have access to high-quality palliative care.
- ➔ Start conversations about advanced care planning as early as possible (within Dementia Hub, health and social care dementia support pathways). People should have the opportunity to discuss and be supported in making decisions about their future care and support arrangements at all points with their dementia journey.
- ➔ Ensuring that cultural awareness around death and dying is included in training for front line workers put into place in response to this strategy to help ensure that end of life and advanced planning conversations remain compassionate and helpful across local communities.
- ➔ Put signposting and support into place for people living alone with dementia to help them put arrangements into place to inform decision-making around

palliative care and end of life wishes if they are unable to articulate their choices for themselves.

- ➔ Provide signposting to reliable sources for information and advice for people with dementia, their families and carers to help them put legal arrangements in place regarding care and end of life wishes if required. The Sutton Dementia Hub, utilising the expertise of its associated partners, will be skilled in providing this support (currently provided by Age UK Sutton, alongside Hub partners, the Admirals Nurses).
- ➔ Provide peer and one-to-one wellbeing support to help maintain health and wellbeing while preparing for the end of a dementia caring role and losing a loved one.

Dying is a subject that many of us prefer not to talk about, yet we all know is inevitable for all of us. However, death may come earlier for people with dementia often accelerated by associated health conditions they often develop over time. Dying well is important to ensure that individuals with dementia receive compassionate end-of-life care that respects their wishes and provides comfort and dignity.

Place of death statistics for people with dementia consider care homes, home, and hospital settings. They offer valuable information about people’s end-of-life care preferences and the capacity of local health and care services to support them. Monitoring these indicators helps areas to identify opportunities for improvements in providing patient centred care.



The percentages of deaths occur (on average) in the following places:

- ➢ care homes - Sutton 53.5% - England 58.4%
- ➢ private homes - Sutton 15.4% - England 11.2%
- ➢ hospitals - Sutton 31.1% - England 28.7%

The mortality rate in Sutton for deaths involving dementia and Alzheimer's Disease across all ages has been steadily increasing and the local rates reflect the national trend.

In 2010-2012, the figures showed 528 resident deaths with an average rate of 115.7 per 100,000 people:

- ➢ this figure increased in 2020-2022 with 916 Sutton residents with an average rate of 173.8 per 100,000 people,
- ➢ this is similar to London at 173.9 per 100,000 people and England with 178.9 per 100,000 people averages.

(ONS Place of death statistics)

11. Making your voice heard

Throughout this strategy, we confirm our commitment to keeping people with dementia, their families, and carers at the centre of what we do. We will review existing support and develop new services in collaboration with them, underpinned by the latest health evidence. The key principle of this strategy is that people should receive the right support for them, based on their own informed choices and at a time that reflects their personal needs.

To achieve this, we have embedded ongoing opportunities—both on an individual level and across services—for people to receive regular care reviews, co-produce their support plans, and contribute to the design and improvement of support services. This approach ensures that the voices of people with lived experience directly shape the care and support they receive. Examples of this include:

- ➔ Dementia Advisers and Admiral Nurses within the new Dementia Hub supporting people with dementia and their carers to access care reviews—both at their request and as their needs change.
- ➔ Early engagement through the Dementia Hub model, which offers an opportunity to understand and document individual preferences and choices shortly after diagnosis, helping to shape support from the outset of a person's dementia journey.
- ➔ Strengths-based support planning and assessments carried out collaboratively between social workers and the individual receiving care, focusing on what matters most to the person and building on their capabilities.
- ➔ Commissioned services will be required to demonstrate how they involve people with lived experience in care reviews, service delivery, and continuous improvement, including evidence of how feedback directly informs service planning and the development of new community-based programmes.
- ➔ Collaborative co-production between strategy partners, Together for Sutton, and the Dementia Hub to inform the development of the strategy's High-level Delivery Plan, with a focus on working alongside groups at higher risk of developing dementia—such as people with learning disabilities, members of Sutton's Mental Health Partnership, and Integrated Neighbourhood Teams.
- ➔ Adult Social Care's Co-production Group acting as an ongoing forum for co-designing dementia-related resources, awareness materials, and information and signposting tools, ensuring these are accessible and shaped by those with lived experience.

Appendix 1: High-level Delivery Plan

Priority No.	Actions	Outcomes	Lead / responsible	Timescale	Review/ reflect period/ date
1-6	Develop easy read and plain English versions of strategy for residents.	- Summary version using plain English, highlighting service changes and signposting. -Easy-read summary and possible alternate format versions of strategy for accessibility. - Possible development of Fact Sheets for each priority.	Dementia Steering Group LBS Comms ASC Co-production Group	July 2025	Sept 2025
1-5	Dementia Steering Group to review agreed Outcomes Framework with Alzheimer's Society London against approved Strategy.	- Set timelines for interventions and project leads. - Set up various co-production activities' timelines and leads for community-based programming. -Adjust framework where needed and set initial baselines.	Joint Dementia Steering Group (Dementia Strategy partners).	2025	3-6 months
Governance	Set up arrangements for Dementia Strategy Steering Group to continue after	-Confirm membership -Change Terms of Reference -Establish meeting schedule	Current strategy partners with review for changes in 3rd Qtr 2025/26	2025	Quarterly - 6 weekly meetings

	strategy approval to oversee delivery.	-Responsible for reporting to Sutton Place Partnership and Health and Wellbeing Board			
1-5	Set up a working group of strategy partners to develop the educational resources, training and tool kits referenced within the strategy with opportunities for co-production with people with dementia (PWD) and carers.	- Training/workshops for managing symptoms of dementia, advanced planning, putting legal docs in place, etc (with PWD and Carers). - Contingency planning and Safeguarding (for when someone goes missing) tool-kits in collaboration with Carers Strategy/Safeguarding Board work. - Community-based resources and tool-kits (with Community Action Sutton). - Workshops to look at legal and financial issues and practical steps to improve information and support for topics such as LPAs and Deputyships.	Joint Dementia Steering Group (Dementia Strategy partners).	2025 Resources in place by 4th quarter 2025. Carers track commencing Sept 2025 w/Carers Strategy.	3-6 months after resources are put into place to inform further topics/resources.
1	Prevent Well - develop Community Engagement and Comms Plan	People have the information they need to improve their health and wellbeing seeking to reduce dementia incidence within Sutton.	Sutton Council Comms Team Age UK Sutton Community Action Sutton	Initial development 2025 and reviewed	3-6 months

		Identify specific projects for priority cohorts (Learning Disabilities, Women, cultural approaches).		quarterly.	
3	Provision of dementia flats (respite) at Dymond House	Improved respite offer for people with dementia	LBS Commissioning	01/07/2025	6 months
6	Provision of a Dementia Hub	Improved post diagnostic support, consistency of support throughout an individual's dementia journey.	Age UK Sutton Integrated Care Board (ICB) Sutton Council	In place from 01/04/25	3 monthly review led by commissioning team
6	Review reach of 'Hub'	Improve support where diagnosis is given in acute care settings to improve access to 'warm' hand overs.	Commissioners - ICB and LBS		
2-4	Benchmark clinical review timescales	Clarity over timescales with improved consistency	Integrated Care Board (ICB)		
1-3	Mapping and identification of strategy partner collaborations for neighbourhood and community-based interventions	Specific tracks for Prevention and supporting people with dementia, their families/friends and carers. Example - linking the development of a community-based dementia friendly tool kit and prevention activities to the Dementia Cafe activities undertaken by Wallington INT.	Sutton Council Integrated Care Board (ICB) Age UK Sutton Together for Sutton Mental Health Partnership Board (Adults) Community Action Sutton	Development and agreeing initial cohort/ programmes 2025, yearly review Full review 2028	

1-4	Community-based support delivery models	Community groups co-production activities to develop local and community-based support programmes which improved access to support and activities for people with dementia, their friends/family and carers.	Sutton Council Community Action Sutton Together for Sutton	1/7/25	3/6 months
3-5	Contingency planning (with Carers Strategy) What to do when a person with dementia goes missing Collaboration with Sutton Safeguarding Adults Board	Task and Finish group across health and social care partners improves contingency planning for people with dementia and their carers. Topics include: 1. In the event of a carer no longer being able to care or putting treatment wishes or power of attorney into place for people with Dementia. 2. When people go missing and how risks can be judged and mitigated- such as through the use of technology, Herbert Protocol and Alzheimer Society guidance.	Sutton Council Strategy Partners Sutton Safeguarding Adults Board	1/09/25	6 months
1-5	Accessible strategy document development	That the strategy is provided in accessible and summary form to provide improved access for people with dementia and families.	Sutton Council ASC Co-production Group Strategy Partners	01/10/25	

1-4	Community Engagement	Further community engagement opportunities are provided to support the further shaping of the strategy implementation plan	Sutton Council Together for Sutton Strategy Partners	01/06/25	ongoing
3/4/6	Refresh service mapping provided in Appendix 6 ‘The dementia Map in Sutton 2022	-To provide an updated service map for the borough. -Create a resource that people with Dementia, their families and carers can use to find out about and access local activities and support. -Expand on the Carers Offer signposting. - Create a Dementia Friendly category for Sutton Information Hub for residents as well as health and social care frontline workers can use to find out about local support, events and services. All of these actions support improved information to individuals and their families.	Sutton Council Age UK Sutton Integrated Neighbourhood Teams (Link to Carers Offer)	1/11/25	
	Identifying funding opportunities and new funding streams to further extend the reach of dementia support.		Age UK Commissioning Strategy partners	March 2026	

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Appendix 2: Approach to Building a Joint Dementia Strategy

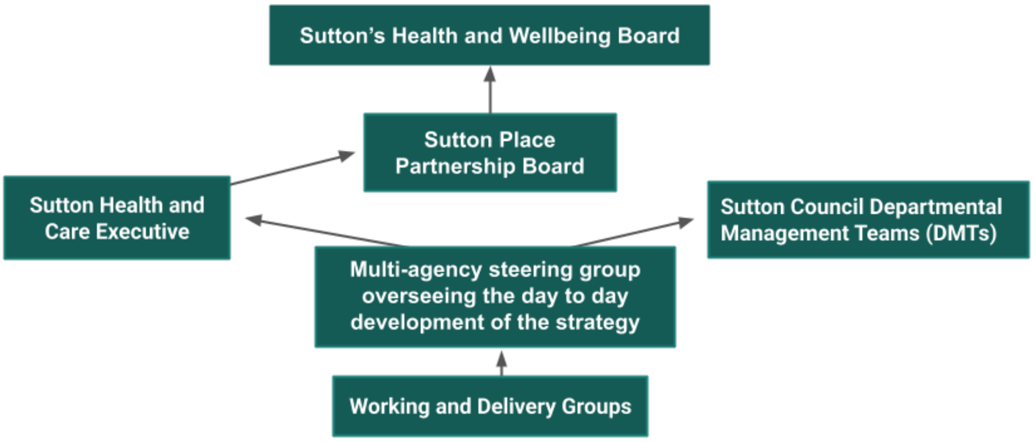
Sutton partners who oversaw the development of the strategy

To develop this strategy, a Multi-Agency Steering Group overseeing four themed task and finish groups was put into place. These groups built the content of this strategy alongside coordinated community engagement and co-production activities.

Additionally, we were able to use points of our collective organisational governance structures (the Sutton Health and Care Executive, the Sutton Place Partnership Board, Public Health Departmental Management Team and Sutton Council's People Departmental Management Team) to share the development of this strategy and with further input from key delivery partners and voluntary sector groups such as Age UK Sutton, Alzheimer's Society London, Sutton Carers Centre. Governance boards and

Once the Joint Dementia Strategy is put into place, the following governance structure will oversee the development and implementation of its Delivery Plan, yearly and third year reviews.

Joint Dementia Strategy Governance Structure



Appendix 3: Community and Stakeholder Engagement

The strategy has been actively informed and shaped by those who are living with or caring for people with Dementia. We have undertaken direct engagement activities within local communities and worked with our partners to conduct interviews, run focus groups and promote surveys to not only gather local intelligence on living with dementia in Sutton but to include as many local voices in shaping the priorities and support put into place through this strategy.

The timing of the development of the Joint Dementia Strategy coincided with community engagement activities informing the Sutton Carers Strategy and also information sessions/focus groups put into place to discuss a change to Sutton's Social Care Charging Policy. All three community engagement campaigns sought input from people accessing care and support services. This included people living with Dementia and the people caring for them. To respect the time taken to participate in community engagement activities, the feedback from the Carers Strategy activities and Charging Policy consultation have been included to further inform various sections of this strategy and identify emerging themes. Most notably, challenges faced in accessing care and support, what people find helpful, where the gaps in provision are, and ideas for improvement. Community Engagement activities have included:

- Interviews with people with Dementia and their Carers conducted by the Alzheimer's Society.
- A Conversation Day held by Age UK Sutton covering a variety of topics and open discussion about living with Dementia.
- A series of focus groups hosted by the Sutton Carers Centre with people who care for people with Dementia.
- A series of focused, themed discussions during Age UK Sutton's weekly Dementia Support Groups.
- Linking community engagement activities with Sutton Council's Social Inclusion team to ensure views and input from across local cultural and heritage-based communities were included in the development of the Dementia Strategy.
- Expanding our reach to local emerging communities with help from Sutton Community Action.

- Working with Health partners to bring community engagement activities to patient experience groups and other service areas.
- Stakeholder engagement focus groups with front line workers.
- A survey aimed at professionals working with people with Dementia.
- Linking focus groups with the Carers Strategy and feedback on the carer experience gained through consultations held throughout 2024.
- Collaborating with colleagues developing the Prevention Strategy to gain resident input into the Preventing Well section.
- Direct engagement with Sutton’s heritage communities, sharing our work on the development of the strategy, identifying key themes and priorities.

Appendix 4: What people told us

Preventing Well

At the start of focus group sessions, even when invited to ask about the Joint Dementia Strategy or the session format, participants often steered the conversation towards dementia prevention and minimising disease risk. This often became a thread within the session when talking about local activities and where people went for information and advice on health and wellbeing topics to inform different sections of this strategy.

Prevention became a live topic in several focus groups, especially those with a high proportion of older people.When presented with the statistic that 45% of dementia cases are preventable, participants often began to discuss healthy lifestyle activities that they themselves take part in – individually and together. These conversations developed into discussions about recognising the symptoms of dementia and brain health.

For example, one group regularly plays Scrabble, has gentle physical activity sessions, and other social events. When discussing how these same activities can help put off Dementia, one member told a story about how regular attendees of these sessions had noticed that one of their friends who also took part wasn't "quite themselves" over a period of time. This led to gentle conversations with the person and their daughter who then arranged for an assessment and was subsequently diagnosed with Dementia.

Different versions of this story and questions about how to both prevent and recognise the signs of Dementia were present in all of the community group-based sessions. Sessions held at the Sutton Carers Centre and Age UK Sutton had different versions of prevention discussions. Mostly from a delay point of view or peer discussions about how to prevent further harm or faster progression of symptoms and how to prepare for cognitive decline and preparing for the need to explore an Appointeeship or Power of Attorney to manage legal and personal affairs and eventual decisions about healthcare when the person with Dementia was unable to do so themselves.

We have linked the Preventing Well section engagement to the development of Sutton's Prevention Strategy. This is to not only share resources for community engagement, but to also bring Dementia prevention messages to the wider population and working age adults.

The role of community and voluntary groups is important to note here. For older people, people who have already received a Dementia diagnosis, and their carers, taking part in activities with people they feel understand them and/or their life experiences is key. The inclusive, welcoming environments these groups provide address a number of health and wellbeing needs from peer support on a number of topics and signposting to trusted services to befriending and preventing loneliness.

Diagnosing Well

Where a person gets their diagnosis and who helps them navigate the process proved to be a pivot point for many people feeding into discussions about their Dementia journey. In any group discussing how a diagnosis was arranged or what kind of resources were given and if there was follow up after a positive result was a mixed bag.

With the launch of the Dementia Hub, there is now a warm handover in place for the Memory Assessment Service. In response to feedback from the final round of carer focus groups, we have added an action to explore ways we can extend this to other places where a dementia diagnosis might be made. For example in hospitals (vascular dementia) where carers told us that they were discharged after diagnosis without signporting or a follow-up.

Living Well

Themes from focus groups and surveys across community engagement campaigns reflected a concern about the availability and quality of Respite Care, the Health and Wellbeing of Carers, difficulties arranging Care and Support with Adults Social Services, and the important role organisations such as Age UK Sutton, Sutton Carers Centre, and online videos on You Tube from national dementia charities and the NHS play in helping people with Dementia and their Carers.

Peer support, one-to-one counselling and activities to both reduce stress and maintain wellbeing were consistently mentioned as important to people with dementia and especially their families and carers. Where to find them and improving signposting was mentioned with suggestions for where better connections between services and promotion could be made.

Community and heritage -based groups both gave feedback about the value of the activities and support available in the borough, but also asked to be partners in establishing more dementia-friendly activities, helping people recognise the signs of dementia and both promote prevention messages as well as help make them more culturally appropriate.

Combined activities organised for people with dementia, their families and carers at Age UK Sutton, those commissioned through Integrated Neighbourhood Teams and by local heritage-based community groups were frequently mentioned as important lifelines. Singing, gentle physical activities, board/card games, arts and crafts, and talking about shared cultural experiences - especially those with a meal - allowed for some time out and enriching activities for the person with early stage or light-symptom dementia. More opportunities for this type of activity and also those which could have care-based support for people with later stage dementia alongside activities and support for families and carers was requested. To support this, a more robust review of available transport should take place.

Caring Well

Themes emerging for Carers primarily came from sessions hosted by the Sutton Carers Centre, the Carers Surveys, Community-based group engagement and Carer outreach asking for input into the Carers Strategy. It is important to note that the Joint Dementia Strategy and the Carers Strategy were developed over the same timeline and both have aims to improve available support and address barriers to accessing health and wellbeing services. The core Carer Offer will be addressed in the Carers Strategy and specific considerations for the Carers of people with Dementia within this strategy.

The importance of peer support and community-based group activities was frequently mentioned as important places to feel connected to society and a sense of “belonging”, find out about services and benefits, and take part in activities supporting overall health and wellbeing. Carers across activities shared stories of losing friends or employment as a result of their caring role. The dementia peer support and group activities are viewed as vital for carers and are often the only time they have to focus on their own feelings and support needs.

Carers of people with dementia expressed a need for more resources in understanding specific symptoms of the disease and how to handle them. Many provide round the clock care and manage symptoms such as seeing people who aren’t there, not recognising loved ones, being scared, etc. Dementia carers asked for ways to help address these complex symptoms compassionately as well as the ongoing stress of living with them. Sharing experiences with carers in similar situations helped them cope to some extent as did resources suggested by the hosting group, but further training was requested for carers, families and also professional carers who may provide cover care when carers need a break.

Being able to take a break was seen as a profound challenge for some Carers - especially for those looking after people approaching or within the advanced stages of Dementia. Ensuring that Carers have strict Adult Safeguarding policies in place as well enhanced background checks was mentioned as was the need for more paid Carers with specific knowledge or experience of helping someone with Dementia. For some communities, the challenge of finding a paid carer from either the same community or one that understands cultural differences in care (in addition to language) was seen as a barrier to provide a break from caring responsibilities. Not being able to find someone the Carer felt confident or safe leaving the cared for person is having a direct impact on the health and wellbeing of Carers.

Later stage dementia carer focus groups had rich conversations about the challenges of applying for and using Lasting Power of Attorney (LTA), Deputyships and arranging for the capacity assessments needed for them. In addition to the widely varying costs solicitors charge, there are mixed experiences using them and in some cases initial advice on which one to apply for needed to be changed after the person with dementia was able to participate in the process. This has resulted in some carers paying for costly residential care with their own money even though they may be recognised as responsible for the legal affairs of the person with dementia, who has the financial resources to pay for their own care. As part of this strategy, we have added an action to its High-level Delivery Plan to include workshops, resources and peer support groups around the use of LTAs, Deputyships and advanced planning alongside those in the pipeline around contingency planning.

What to do when the person with dementia goes missing. Families and carers are appreciative of all of the help the police and local hospitals provide in these situations. However, a better join up between emergency services and helping families and carers put measures into place to safeguard the people with dementia they look after was suggested. This includes wearable tech, understanding the Herbert Protocol and useful resources such as the “This is Me” resource from the Alzheimer’s Society. As a result of this feedback, the partners of this strategy will discuss how to improve the safety-net for people with dementia, dementia training for police and PCSOs, and the promotion of the Herbert Protocol (as well as tools families and carers can use if a loved goes missing) with Sutton’s Adults Safeguarding Board and our current collaboration to improve contingency planning as part of the Carers Strategy.

Sutton Engagement Project

September 2024

Deliverables Lead/commissioned by	David Millen (Commissioning Lead, Sutton Council)
Evaluation Lead	Josh Horne (Senior Health & Social Care Partnerships Officer, Alzheimer's Society)
Date of Report	30.09.2024

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Key Findings/executive summary

Helena, an Alzheimer's Society Dementia Advisor living in Sutton, was able to interview a mix of 10 people in the area: 6 carers and 4 people with a diagnosis of dementia, and took notes of their experience in several areas of their journey, from pre-diagnosis to how they have been supported in living with dementia.

As quantitative data has been collected in other manners by the joint strategy group, we aimed to delve into more personal experiences from people in Sutton.

In most areas, there were mixed experiences depending on certain factors, for example if one particular GP was very involved and linked to other means of support, this would impact the life of the person really positively, as apposed to someone who found they had to be proactive with support and find it themselves.

Experiences of virtual wards were hugely positive, and generally it was found that the Memory Assessment Services were consistent with support. Whilst in other areas such as travel, it was evident that support was either lacking or was not clear to those interviewed. We found that, across people's experiences, there is a need for better information sharing from health and social care professionals, whether it be knowledge/signposting of other services/activities, assistance with finding alternative support such as that online, or help in not only care/future planning but awareness of the right support at the right time.

Introduction

To bolster the development of the Sutton Joint Dementia Strategy, Josh Horne and Amy Bruchez from Alzheimer's Society met with David Millen from Sutton Council, following an introduction from Luke Symons (Local Systems Influencing Officer, Alzheimer's Society – working with David on the strategy), to discuss an opportunity to support in the findings already produced as part of the development of the Sutton Joint Dementia Strategy.

Several key themes have been identified from the strategy's process to date, which have been produced through group meetings and surveys in the area. In addition to quantitative data that has been collected by the strategy group, it was agreed that qualitative data should be collected to further inform the strategy and give more in-depth account of the experience of people living with dementia in Sutton, including those with a diagnosis and their carers.

Context

To gather more detail of people's experience of dementia, it was decided that interviews with a small number of people would provide the opportunity to let conversation naturally open and delve into both the positive and negative aspects of their 'journey'.

Given the progression of the strategy, a timely response was necessary for this project and it was agreed that Alzheimer's Society staff would aim to conduct 6-8 interviews in September, considering that individuals needed to be identified and contacted to arrange interviews, following planning.

Josh met Alzheimer's Society's Regional Manager and Local Service Manager to inform them of the project and ask for local support, and it was agreed that a local Dementia Advisor, Helena Toms, would be able to support in conducting and recording interviews. Having previously supported many individuals in Sutton earlier this year, and living locally, it was agreed that the best approach would be for Helena and Josh to contact people, aiming to arrange interviews in their homes; avoiding any travel barriers for people and ensuring that they are in a comfortable surrounding. It was noted that interviewing in other environments may have led to people not wanting to give a full account of their experiences in certain situations.

Objectives

- To arrange interviews with a range of people in Sutton who have experience of dementia: people with any diagnosis, people with a diagnosis of Young Onset dementia, carers, and where possible those with different backgrounds.
- Produce interview questions and follow up questions that would prompt open answers in relation to these themes, which were produced following conversation with David, emphasised by the emerging strategy document, and recommended by Alzheimer's Society's Evaluation Team as part of the Impact Framework Outcome Themes:
    - Diagnostic Process was well-managed
    - Professionals are able to support my needs
    - Optimal Treatment (I would want to focus on treatment/care plans being reviewed, and being offered interventions to improve day to day life, rather than specifics to medication – let me know if you disagree though)
    - Post-diagnostic Support and Strategies
    - Experience in hospital is Dementia Inclusive
- Record key conversation points from interviews and identify any themes – what was positive and negative about their experience from pre-diagnosis to today.

Evaluation Questions

Can you tell me about your experience of the process to receive a diagnosis?

Follow ups:

- How were you supported along the process of diagnosis?

How has your experience been with health and social care professionals regarding dementia, from pre-diagnosis to post-diagnosis?

Follow ups:

- Did you feel that professionals you've spoken to have had sufficient dementia training?
- Do you feel respected and that you trust professionals to keep your best interests in mind?
- Did you feel there was enough support from health and social care professionals, in relation to non-drug intervention e.g. cognitive stimulation therapy, support groups, art/music groups?

Have you found any barriers in accessing support or activities that you would like to attend?

(Specific to a younger (under 65) diagnosis): Do you feel there is enough support available to younger people with a diagnosis of dementia, considering factors that may be particularly difficult to manage such as employment, or family at home?

- Has your experience of support services been reflective of your age? For example, are settings for services at places that you might usually visit?
- Have you experienced any other barriers to support that are prevalent because of your diagnosis at a younger age?

How have you been supported to manage any changes since you were diagnosed with dementia?

Follow ups:

- Are you provided tools on planning for the future? Were you aware of a care plan?

Have you been in hospital since you were diagnosed with dementia? If so, what would you say made your stay dementia-inclusive, if anything?

Follow ups:

- Do you feel that you were included when discussions around your medical/personal care took place?
- Have you had any experience of virtual wards?
- Did you receive any follow-up support after your stay in hospital?

Questions were kept to the same themes but tailored slightly for carer interviews:

Can you tell me about your experience of the process to receive a diagnosis?

Follow ups:

- Carer: What support were you given as a carer during the process of diagnosis?

How has your experience been with health and social care professionals from a carer's perspective?

Follow ups:

- Did you feel that professionals you've spoken to have had sufficient dementia training?
- Do you feel that professionals are respectful to both you and the person that you care for?

Did you feel there was enough support from health and social care professionals, both for the person you care for and for yourself?

- Have you found any barriers in accessing support or activities that you would like to attend?

How have you been supported to manage any changes since the person that you care for was diagnosed with dementia?

Follow ups:

- Are you comforted with the available options that you have support, for example if the person you care for may show challenging behaviour?

Has the person you care for been in hospital since they were diagnosed with dementia?

If so, what would you say made their stay dementia-inclusive, if anything?

Follow ups:

- Were you offered any dementia-specific support/resources?
- Have you had any experience of virtual wards?
- Was there any follow-up support after their stay in hospital?

Methods

By using the Alzheimer's Society's Dementia Voice Database, we were able to identify a list of people who Helena had previously given support to, who fulfilled our criteria for this project: living locally and either having a diagnosis of dementia or being a carer of someone with dementia. We also aimed to break this list down to people who were more recently supported and were, on last contact, likely to be able to support this work by being interviewed. Potential interviewees were contacted via phone and email initially to check interest and availability. Helena was able to successfully book and conduct interviews with 10 people within the timeframe, including two carers of people diagnosed at a younger age (below 65) and one person with a younger diagnosis. In total Helena conducted interviews with 6 carers and 4 people living with dementia (PLWD):

01 - 1709 PLWD

White British/Christian/80-89/Not living alone

02 - 1709 CARER

White British/Christian/80-89/Living with PLWD

03 - 1809 CARER

East African Asian/Christian/80-89/Living with PLWD/Sheltered accommodation

04 - 1909 CARER

White British/Christian/60-69/PLWD moved in with carer

05 - 1909 CARER

White British/Christian/50-59/Living with PLWD

06 - 2309 PLWD

White British/No religion/60-69/Living alone/Sheltered accommodation

07 - 2409 PLWD

Asian/Sikh/70-79/Living alone

08 - 2509 CARER

White British/Christian/80-89/Living with PLWD

09 - 2709 PLWD

White British/No religion/80-89/Not living alone

10 - 2709 CARER

White British/70-79/No religion/Living with PLWD

Helena explained to each person that Alzheimer's Society does not run the current local support service but offered to make a referral to Age UK.

We aimed to conduct interviews that are roughly an hour in length - this would give ample time to explore certain themes whilst not being overbearing. By asking 5 or 6 overarching questions we could ensure that each theme was given enough time to be discussed and, whilst we had planned follow-up questions, these were not always used as the nature of the response could promote either a different follow-up question or moving on to the next theme. At the end of each interview, Helena asked if there was anything else that the person wanted to add or discuss.

Due to concerns with consent and time management of using audio recording equipment, Helena asked interviewees for consent to write down their responses, and people have been kept anonymous in this report.

From Helena's interviews, we identified themes that were discussed and highlighted particularly positive or negative experiences to be reported.

Findings

In terms of getting a diagnosis, experiences were more negative than positive and this seems very dependent on the GP. Whilst one carer felt the process was straight forward and signposting/referrals to further support was strong, one person with dementia described the process as 'shocking', having not been taken seriously and having to chase the GP and Memory Assessment Service for a referral. Everyone else that Helena spoke to had some level of confusion through the diagnosis:

- Lengthy or delayed diagnosis was noted by the majority, although PLWD 2709 and their carer stated it was 'fairly quick' (2 months from tests to MAS referral) though they needed to be proactive – ***'It wouldn't have happened if it weren't for us'***. One person said that the diagnosis length this was affected by Covid-19. For both of the carers of someone with a younger diagnosis, it was noted that this was caused by ruling out other possibilities for their symptoms due to their age. ***'Early diagnosis is key'.***
- Sub-type of diagnosis caused concern and anxiety. ***'one person says one thing and another says another'***
- A carer of someone with Young Onset dementia highlighted a lack of knowledge from their GP, as they had thought dementia would be unlikely due to a lack of family history of dementia, and there was little to no supporting information or advice when a diagnosis was given. ***'It was a case of 'By the way, you've got Alzheimer's, go and live your life, bye!'***
  They informed Helena there was no follow up appointment/review with the GP for 2 and a half years when they received their 'annual review'. ***'It was like getting hit in the face with a brick. There was no support – just start on these tablets and here's a number if you need it. It was shocking and scary.'***
- Routine appointments didn't feel tailored to dementia.

PLWD 2409 stated that the stigma surrounding dementia caused her to struggle processing the diagnosis and initially didn't want to tell friends about it. ***'If you've got dementia, society seems to say leave it alone.'***

Although some individual experiences with Memory Assessment Clinics were poor, with one diagnosed person stating that their neurologist was always late to appointments and hardly seemed bothered, overall experiences were better when they reached MAS, and one person with dementia said that follow up meetings with the clinic helped with concerns about how their dementia would progress. ***'Things went smoothly once he was under the MAS'***

Generally, there was a positive experience at least of how health and social care professionals talked to people through their diagnosis and beyond, with most people finding them respectful. Two people were very positive of the nurses who visited their homes: ***'very good, kind and thoughtful during home visits'.*** Two carers found that professionals tend to talk to them rather than the person they care for, perhaps due to insufficient training: ***'it's like when someone is on sticks or in a wheelchair – people make assumptions.'***

People stated a lack of signposting to further support: ***'We had to be on the ball. If you are not really certain what to do, you need to do your homework'***

'It's a battle. Even if it was every two months, a phone call for the carer's sake too would help. I'm marooned here really but fortunate with family help. Life has shrunk'.

Interestingly, the younger carers found that online support and resources were good but did, along with others, express concern that other people may not have access to online help, particularly anyone with dementia who lives alone. Another carer told Helena that she'd had multiple issues with technology, particularly in booking appointments online. People mentioned or referred to it being unclear where to access support, with some not knowing where to find out about services, and others simply not aware that other support exists. One younger person with dementia, who used to care in the community for work, said that the support is there but you need to be aware of it: ***'There are lots of leaflets about things but if you don't know where to access them, it's no good.'***

One person didn't have a positive review of NHS professionals, from receiving little support from their GP and not being able to get an appointment, to finding that staff don't ask anything about her dementia. She did state that other organisations have been a lot more helpful, for example Age UK's digital support and activities.

'For me, socialising is very important. Communication is very important.'

A clear need for respite options was emphasised in the interviews, with carers saying that they were either unaware of services, or lacking confidence in a respite service, one example being a mother and daughter who both cared for their husband/father, who is bedbound. The daughter still being in full time employment meant that her mother was the primary carer and whilst she was aware of sitter services, she noted that she wanted to preserve her husband's dignity in terms of personal care so has not engaged with a sitter service. She also found that she had to plan any of her own needs to leave the house, by arranging timings with her daughter.

One carer noted that they had attended a social group for herself, which she found helpful for her own mental health. This carer stated that the person they care for is still mostly independent which has allowed them to attend these groups, but is unaware of other help available such as supportive services around the home and garden.

Whilst carers of someone diagnosed at a younger age reflected positively on the support they have accessed through technology, they also raised concerns and barriers that may be more specific to them:

- Without support, their own career would be impacted and there would be a loss of earnings
- Lack of support in planning for the future, for example pensions
- Day centres perhaps being unsuitable for the person they care for
- Lack of activities for younger people with dementia

What would he do? He can't watch telly all day – he'd stagnate'.

There were some post-diagnostic services accessed by those interviewed, generally these were viewed as really helpful. Two people with dementia told Helena they had benefited from Cognitive Stimulation Therapy, although one felt there should have been a follow-up. ***'It's good for me because it stretches me.'***

Carer 2709 and PLWD 2709 attend a dementia support group, where they enjoy peer support and the organiser signposts and refers to other means of support. It is a well-attended group and therefore they are only able to attend once a month due to availability limitations.

A theme that was highlighted by most people Helena spoke to was travel, whether it be mobility concerns not being met by either private or public transport, costs of transports, or lack of flexibility – carers could not always ensure that the person they care for was ready at the time of transport arriving. One carer who was able to drive complimented a day centre though as they were more accommodating of her not always being able to drop her husband off there at the same time. Another stated that they had been unsuccessful in claiming a Blue Badge, as the application was focused on things like walking distances and not considerate of dementia.

One carer with mobility issues herself found a barrier in that she felt obliged to attend all appointments with the person she cares for and this was sometimes problematic, including transport for hospitals not being accommodating. It was unclear that she didn't have to join her husband at every appointment.

Multiple people mentioned issues with Taxicard:

- Poor service from many drivers
- 'hopeless' and unreliable, on one example arriving 30 minutes late
- Unclaimed by one carer, not confirmed the reason for this

Five of the people Helena interviewed had been admitted to hospital since being diagnosed with dementia or cared for someone who had been. Two people with dementia said their experience was fine; as they were in early stages when admitted it likely didn't impact their visit. They did, however, observe others with dementia whose needs were not being met e.g. being classed as 'no appetite' when they actually needed help with eating. This statement was supported by others interviewed, who said meals and drinks were often left, and two carers said that it the options for food were not clear and that the person they cared for struggled without their help. Another carer told Helena that in addition to food/drinks being left, medication too was simply left and no support offered to take it. Of our interviews, two carers in particular told Helena about particularly negative experiences with hospital:

Carer 1909:

His experience at hospital showed a lack of dementia specific training from staff on a dementia ward and he felt he needed to be with his loved one at all times, including when she spent 'two nights on a trolley in a corridor', although on another occasion he was told he could not stay with his wife. He told Helena about the general lack of support received:

Having attended the hospital as an emergency, [the PLWD] did not have her mobility walker with her to get to the toilet and the corridor afforded no privacy to use a commode. The carer had to attend to, and support, the PLWD at all times including making several requests during their stay for food, drinks and a blanket.

Both Carer 1909 and Carers 2509 stated that their loved one was given incontinence pads (although could use a toilet with assistance) and were left often in wet pads, described as ***'disgraceful and a lack of dignity'***. They also both discussed issues in resources: one being told he should have received a red box to indicate to staff that his wife has dementia and to store items in (after her hearing aid had already been lost), and the other saying that her husband's dentures were list and that he was dressed in someone else's trousers.

> ***It is okay saying be aware of dementia but it's not good if the NHS and local authorities are not backing it up. GPs, hospitals – they've got to start treating dementia and think about it from top to bottom.'***

In contrast to hospital admissions, the same carers (1909 and the two carers interviewed in 2509) outlined 'extremely positive' and 'amazing' experiences of virtual wards, one of whom was referred by a paramedic. The benefits of being at home were clear and communication was consistent and informative. Carers stated that their loved ones were carefully monitored and the nurses who visited were really helpful. ***'I felt it was great. It gave me peace of mind that someone was going to check on her.'*** Carers 2509 were provided an iPad to input data and ask questions, as well as giving them and their loved one the opportunity to have video calls with healthcare professionals. The only concern was that others may not be aware of the service, and this was highlighted by nobody else being aware of virtual wards.

One area not initially explored but came through conversation was that Carer 1809 noted that police in the area have a very good understanding of dementia; giving her advice and talking respectfully to both her and her husband when he was found walking alone.

Limitations/Risks

- Short time frame of project caused concerns over the amount of interviews that could be completed and if we could reach a good range of diverse backgrounds. We would have liked to explore experiences of non-English speakers but were unable to consider translation tools and costs within the time frame.
- We must consider that it's easier to recall particularly negative experiences over positive ones. Often if a service is simply 'good' rather than outstanding, the person using it may not consider discussing it.
- Bias – as Helena conducted the interviews with people she had previously supported, we were concerned that any thoughts on Alzheimer's Society may be overly bias. As so, we have omitted most comments.

Recommendations

Based on the conversations that Helena had, the highlighted areas that would benefit people living with dementia, including their carers in Sutton would be:

- Improved knowledge of support available
- Sufficient dementia training & awareness from healthcare professionals
- Suitable travel options
- Services specifically for younger people with dementia

- Wider access to Virtual Wards where possible
- Prompt follow-up support following diagnosis

Recommendation	Examples
Improved knowledge of support available and prompt follow-up from diagnosis	• Improved accessibility to online resources • Consolidated information packs, with information on the activities and services available (ideally updated regularly) • Services encouraged to promote to one another • Promote referrals to other experts e.g. Citizen's Advice for benefits • Carer's support services to be promoted alongside support for the person with a diagnosis. • Clear planning from diagnosis - when follow up appointments will happen and who to contact if anything changes • Consider who in the system can help with care/future planning
Sufficient dementia training & awareness from healthcare professionals	• Review training for healthcare professionals both broadly and role specific e.g. in a hospital setting • Care planning support & similar useful resources e.g. 'This is Me' • Signposting/referrals to other support more frequently
Suitable travel options	• Encouragement/advice on claiming benefits to support travel • Services more understanding of timing difficulties – people arriving at different times • Review Taxicard suitability for people with dementia
Services specifically for younger people with dementia	• Co-produce services/activities • Consider training for current services aimed towards younger people • Review support available for benefits access and planning

Wider access to Virtual Wards where possible	• Assess how virtual wards are being offered • Consider broader use of virtual wards • Collaborate with other organisations as the use of virtual wards increases across the UK.

Conclusions

There are helpful services in Sutton being used both by people with a diagnosis and their carers, and Memory Assessment Services are thought of fondly in general. Throughout these interviews we have heard of mixed experiences of most areas discussed, highlighting a lack of consistency and a need for more personalised support in the journey of someone with a diagnosis and their carer. There is a need for more awareness: of other available support, and from some professionals in regard to signposting and dementia training. There is a clear opportunity to further develop in some areas as stated in the Recommendations section.

As the Sutton Joint Dementia Strategy continues to be developed, we hope that this report can provide additional evidence, of both areas that could be improved, and those that could share best practice.

Age UK Sutton In Conversations: Dementia – Joint Dementia Strategy consultation

Highlight Report

Age UK Sutton currently deliver Sutton borough's Dementia Support Service which includes 121 advice and support for those living with Dementia and those who care for someone with Dementia. Age UK Sutton (AUKS) also provides Dementia Peer Support opportunities through the delivery and facilitation of peer groups at four locations across the borough.

People known to Age UK Sutton through this work were invited to attend an opportunity to feed into the Dementia Strategy consultation phase, and these opportunities were also promoted by Age UK Sutton through the website and social media.

26 people responded to the invitation to attend the sessions, with some people requesting an alternative opportunity due to not being able to attend the in-person event on the date.

In Conversations:

Age UK Sutton have established a model of quality and reliable consultation through a method we call "In Conversation" in the past this model has allowed Age UK Sutton to feed into the Sutton Plan – with actions taken to "make Sutton an Age Friendly place" (World Health Organisation), we have been able to join older people with younger people through an intergenerational exploration of what makes them feel safe or unsafe living in Sutton.

In this instance for the Dementia Strategy, Age UK Sutton have been best placed to facilitate good quality discussions (conversations) about the elements included in the Dementia Strategy, whilst giving the person living with Dementia a real voice that can be amplified through this work.

Creating a comfortable space, with refreshments, trusted people to speak with and lead the facilitation, we have been able to ensure the people have an accessible opportunity to use their voice and share their experiences.

Dementia In Conversation – Wednesday 18th September

The day was broken into three sessions, 10-11am 12-1pm 2:30-3:30pm, to ensure we would have small enough groups to make sure the environment for safe open discussion was possible.

Each group was facilitated by 2x Dementia Service staff with overview and leadership of the day carried out by the Service Manager, Michelle Blagrove.

By the end of the sessions we had spoken to 8x people living with Dementia and 10x carer's of people with Dementia. There were at least 3x people living with Dementia that attended without a carer. The groups were mixed experience and demographic backgrounds.

Profiles of Contributors:

Session 1:

Client A – Raymond – is 85 years old and has been living with Dementia for 10 years, he lives with his wife who cares for him, but as he tells us they care for each other really.

Client B – Mim – is 85 years old and cares for Raymond, she has become forgetful and her husband thinks she may have Dementia also. She has family who try to help but really only manage to pop in at weekends.

Client C – Peter – is 78 years old and has been living with Dementia diagnosis for 2 years, he lives with his wife Ann who cares for him, he has a daughter who is not involved in supporting him on a regular basis.

Client D – Ann – is 62 years old and cares for her husband Alan, she has recently been unwell herself but was very motivated to attend this opportunity to have their thoughts and feelings included.

Client E – Susan is 60 years old she cares for her Mum in her 90's who has dementia – they do not live together so Susan visits at least twice a day and manages her family/home duties alongside work and caring her mum.

Session 2:

Client F: Sally is 75 years old she has been living with Dementia symptoms for a number of years, she lives alone and is supported by her Grandson, she does not have other care at this stage and is extremely unhappy with her living arrangements that have a negative impact on her life throughout every aspect.

Client G: Mary – is 79 years old and has been caring for her husband who lives with Dementia – he is advanced to such a level that he was unable to attend and struggles with communication and wanders which risks his safety.

Client H: Jan – is a carer for her Mum who has lived with Dementia for 5 years – Jan works and also takes care of her Mum who lives alone and has carers that visit throughout the day. Jan's big concern is her mum's hoarding and reluctance to have help.

Client I: Robert, 81 – is a carer for his wife Valerie who has lived with Dementia for 2 years but has seen a quick progression over the last year.

Client J: Valerie is 79 years old and lives with Dementia – she was an active member in her church community but is now limited to tasks she can participate in. She is becoming less able to communicate independently but was supported throughout the session.

Client K: Jolly is 55 years old she is a carer for her husband Dewan who has been diagnosed with Dementia in the last year – his health has created a huge impact on both their lives and they are coming to terms with life and the expectation of the future

Client L: Dewan is the husband of Jolly, he was an engineering professional throughout his career which has been cut short due to Dementia, he is just 63 years old.

Session 3:

Client M: Debbie – Debbie was diagnosed with Dementia in March 2024, the news is still a shock and upsetting to her and her daughters, Debbie is 74 years old and is still very active in her life learning piano and going with friends to Cambridge

Client N: Liz – is Debbie's daughter they are in early stages of working out what Dementia means to them and what support they will need – they are newly accessing support for Age UK Sutton.

Client O: Ruth is 57 years old she is a fulltime carer for her husband who is 67 years old and lives with Dementia and mobility issues, they are reliant of family being with him for her to leave the home as she felt he would not manage at todays session.

Client P: Chris – is in his 60's years old living with Dementia

Client Q: Helen is 82 years old and cares for her husband Tony who has Dementia, he is 86 and was diagnosed with mixed Dementia in 2023

Client R: Lynne is daughter and carer of Helen, she has a sister Sandra and they both support their parents

Client S: Carole is 69years and lives with Dementia, she was diagnosed with early stage Alzheimer's in 2023

Client T: Phil is 80 years old and lives with Vascular Dementia

Client U: Jean is 77 years old and is the wife and carer of Phil, she has been using Dementia Services in Sutton for over 5 years.

After Michelle made an introduction to the group about the purpose of the session and the timeline of the Dementia Strategy work the facilitators started the discussions.

The discussions covered 5 areas:

Discussion 1:

If we think about the key elements of the strategy:

"Preventing Well" "Diagnosing Well", "Living Well" and "Dying Well"

What do you think would **most impact** any of these areas and how do you think it would make a difference in any of those specific key areas.

For example: The Memory Clinic appointments – very important to "Diagnosing well" and without this service this element would be negatively impacted.

Discussion 2:

Thinking about getting the **right information at the right time**, can you tell us if you knew how and where to get information from? Can you share where you got information?

Further Question: What would have made it easier for you to get what you needed?

Discussion 3: (Ask one at a time)

a. Thinking about services you have been in contact with specifically regarding Dementia, can you tell us if you **felt involved in key decisions**, if so how was this done, if not what could have been better?

b. If you had any **worries of concerns** did the **service take you seriously**? If not what could have been better?

c. Did you feel the **staff communicated with you** in the **way you needed**? If not what could have been better?

d. Did you feel supported by the service, was there anything you experienced that you'd like others to have a similar experience of? (examples of good practice?)

e. Thinking about services you have been in contact with specifically regarding Dementia, do you feel generally satisfied with the services available? If not why not?

Discussion 4:

What do you think the barriers are for people experiencing Dementia to access good information and support?

Discussion 5: The council are developing a joint strategy between Social Care and Health – what do you want them to really think about and make sure is included as a priority?

The group were also informed there is an online survey they can complete that the council have compiled if they wish to do that also.

Discussion and Feedback:

The quality of discussions that happened throughout the day was quite incredible – we have tried to record as much of what was said so this report can reflect the exact words and voices of the people who shared with us.

Throughout the discussions key themes discussed:

- The importance of early detection
- Supportive conversations with GP's
- Importance of feeling heard about presenting symptoms
- Importance of the role of family being heard when sharing concerns
- There is little known about "Preventing Well"
- A general acceptance from those diagnosed that it was accepted as a part of getting older
- Challenges can be in getting seen by the right practitioner
- Cheam Resource centre are a critical part of Diagnosis but many felt that 2 sessions was not enough and that they want to be kept "under review" of a specialist rather than a GP
- Little understanding about medication options – some people shared that no options available for them due to low blood pressure
- Diagnosis is a scary time for many but straight talking and having time to absorb the news in a comfortable space is important
- Having the option to seek further support, information and advice is essential to the next stages with many people sharing how they didn't know who to turn to
- Many carer's said the used "Google" but found it overwhelming and they wanted to talk to someone who understood
- Face to face contact is important at the stage of diagnosis and accepting the next stages, wanting to find out what is available
- Many people said they had not and would not have been able to find information digitally online or wouldn't be able to manage email contacts
- Living well looks different to everyone we spoke to – for some people they were resigned that they are not well and will not be able to "live well" compared with others who very indignantly shared how they were doing all they can to "live well" by staying active, getting healthier through diet and exercise, making their health a priority in order to "fight the oncoming decline" - "I'm not letting it beat me"

- Some people shared that they want people to know they have Dementia so they can be better supported in public but don't know how to do this when they struggle to communicate.
- Some people do not want to be labelled as "someone with Dementia" as they still feel very much themselves and the condition does not define them
- Some people found sharing their diagnosis with others hard because they were not able to find the right words and felt guilty sharing the news as it makes loved ones so upset
- Almost everyone agreed that they found it upsetting and offensive that there is a belief held that someone with Dementia "dies twice" or loved ones experience anticipatory grief when there is a diagnosis – as portrayed in a TV Advert from the Alzheimer's Society
- Living well includes getting access to good quality social interaction, exercise and healthy living – but it also looks like being able to manage practical tasks such as finance and income, managing their home and being safe
- Dying well was a subject that many of the groups found harder to talk about, either expressing that they don't like to think about it or talk about it with others, or the response that they have a will or LPA in place – some people shared they have funeral plans while others shared they have not thought about sharing their wishes with loved ones
- Most people didn't know or think there would be options for end-of-life planning – hospices are considered a place that people who have cancer go to die

- When asked about getting information at the right time – almost all participants said how helpful it was to be referred from diagnosis to an advise service
- Many of the people attending have been supported practically by Age UK Sutton, from getting advice about benefits, transport, blue badges, housing options, referrals to Care Needs Assessments
- Some people shared that getting too much information at the diagnosis stage would have been overwhelming but once supported by Age UK Sutton they found it easy to ask for what information they needed when it was needed
- Sutton Carer's and Admiral Nurses were also noted as sources of information and support that was welcomed, there was some confusion around when and why the Admiral Nurses could help
- Most participants found it harder to think about barriers to getting good information; online/digital was considered a significant barrier, not being able to access face to face support, preference for home visits as getting to community locations can be difficult due to barriers with public transport and driving

- When accessing services for Dementia many people said they felt heard, with some exceptions where they had felt disregarded as "Just aging" mostly through contact with GP surgeries
- They felt heard in the diagnosis process but wanted more opportunity to be in contact with specialist rather than reliant on GP to make re-referrals
- Mostly people felt that people communicated to them in the way they want, it was expressed that most people with Dementia are not directly spoken to when in hospital with the professional directing things to the carer – they find this frustrating but also

understandable as they assume the professional is very busy and they don't want to waste their time

- People want the strategy to make sure that people with Dementia have a voice and that services they access are available to them on a consistent basis – they like knowing they can rely on help and support throughout their journey
- They want to make sure its as simple as possible to get support and advice about Living Well with Dementia from one place
- They want to increase what is available for people with Dementia to access such as social activities
- They want transport and travel to be taken into account when planning services and activities for older people as this is often a barrier for people to access things that are available
- Many people felt they could not have applied for benefits or blue badges without support
- Blue Badges are hit and miss as to whether someone with Dementia can get one "hidden disability" not taken into account and claims rejected which is frustrating for carers who need to use disability parking at appointments etc

In addition to this report there will be an Appendix of quotes from the attendees that will allow you to hear the voices of people with Dementia and the Carer's who participated in this "In Conversations" event.

Example:

"the doctor we knew for over 40 years knew us well, she didn't say anything other than that she told us that she had seen it coming on, I hadn't, but I suppose that's because I live with it perhaps" Carer

"it was a long time ago so I don't remember much in that respect thinking about it I don't think I would have known anyway, mostly I do know what's going on, right from when I was diagnosed" PWD

"we wouldn't have known (if she hadn't picked it up) but the early you can catch it (be diagnosed) the better so you can do something about it" carer

"nothing about preventing was available" "how to recognise it, we are 85 now so we are bound to be losing our memory surely"

Dying well most people hadn't thought about it much or knew what would really have a positive impact

"what else is there to do, yes we can have cleaners, and family want to buy a house with an annex"

"everybody in our family helps"

"it starts with the GP, I said I was forgetful, oh its your age, I was so upset, but for 2 years, probably more but she just left me, I was pretty cross I wanted to say I've paid all my National

Appendix 5: Additional information about the Dementia Hub implementation

For Implementation in 2025/2026

- Enable the further testing of pathways and key interfaces, providing an opportunity for further development across this new financial year i.e. 2025/26.
- Establish the impact of resourcing within the hub and in associated teams.
- Test the impact of earlier and post diagnostic intervention and support on service demand.

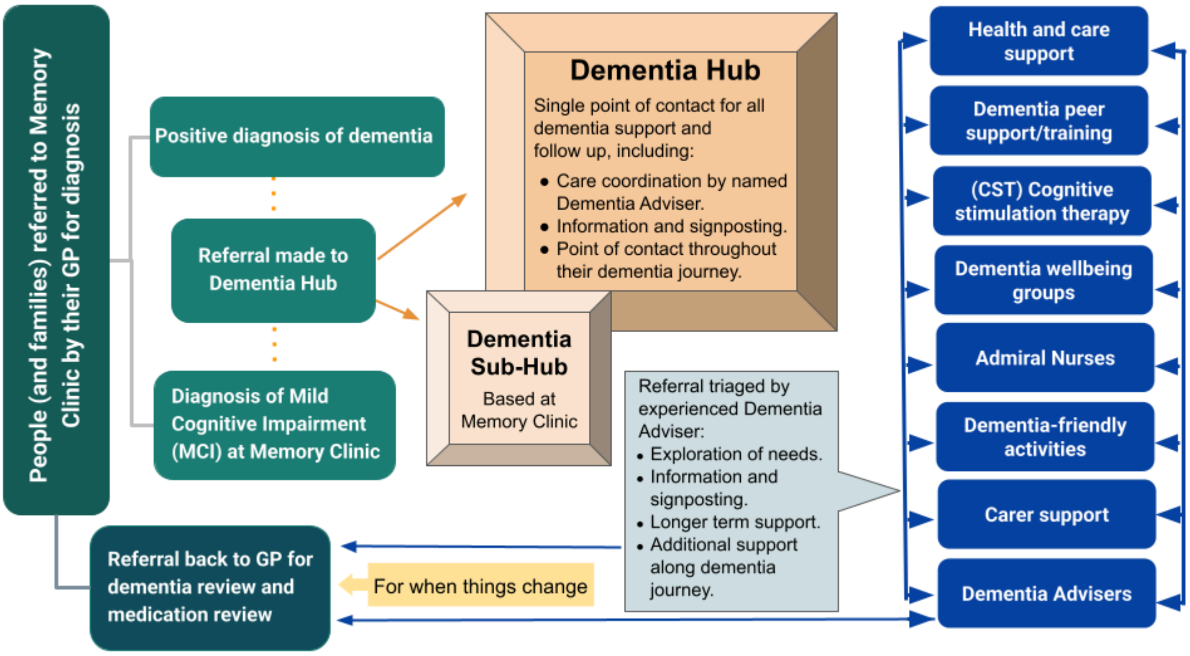
Staffing implications

Staffing is our key resource. With this principle the strategy partners agree that the strategy carries some specific staffing implications which include:

- Development and upskilling of the Role of Dementia Advisers within the proposed new Dementia Hub.
- Testing a more seamless process between diagnosis, understanding need (triage) and supportive step up and step down support whilst managing caseloads between agencies.
- Person Centered Practice and ensuring that the person and those caring for them are central in care support and future planning. Staff understand the value of prevention and the impact of social inclusion and participation.
- Need for core dementia awareness training to be available for all practitioners and frontline staff with additional modules, reflecting roles and experience etc.
- Staff are able to facilitate difficult and sensitive conversations, that might raise awareness, support advanced care planning etc.
- Health checks continue to be prioritised as a wide target but need to ensure that for people over 50/60 years, memory issues and dementia awareness are included as a part of each check.
- Key teams have dementia ‘champions’ or ‘ambassadors’ to support and guide other staff, supporting decision making and risk assessment.
- Staff are able to work collaboratively understanding their and others roles and responsibilities.

- ➢ Staff are supported to understand and where possible, prioritise reviews of people with dementia.

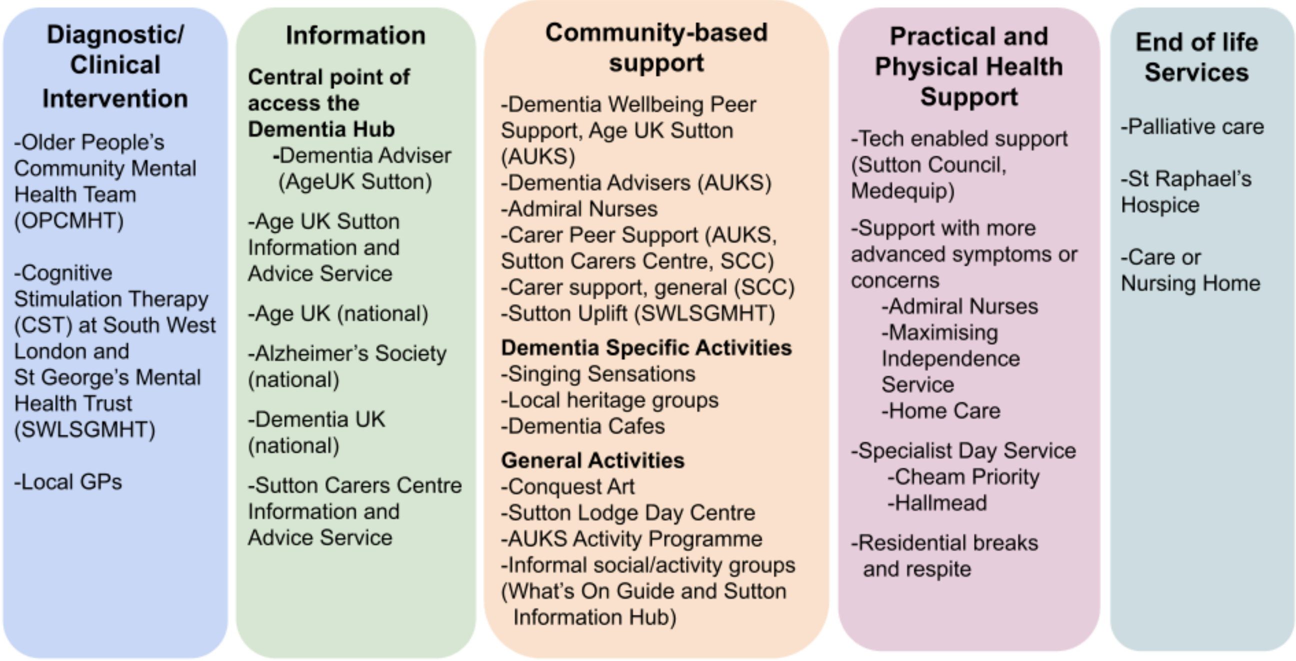
Dementia Hub delivery model



Additional information about the development of the hub is included in Sutton Dementia Hub -Developing a Joint dementia strategy.

Appendix 6: Current Cross-Sector Dementia Support Offer in Sutton

Dementia Map in Sutton 2025



Diagnostic/ Clinical Intervention

-Older People's Community Mental Health Team (OPCMHT)

-Cognitive Stimulation Therapy (CST) at South West London and St George's Mental Health Trust (SWLSGMHT)

-Local GPs

Information

Central point of access the Dementia Hub
-Dementia Adviser (AgeUK Sutton)

-Age UK Sutton Information and Advice Service

-Age UK (national)

-Alzheimer's Society (national)

-Dementia UK (national)

-Sutton Carers Centre Information and Advice Service

Community-based support

-Dementia Wellbeing Peer Support, Age UK Sutton (AUKS)
-Dementia Advisers (AUKS)
-Admiral Nurses
-Carer Peer Support (AUKS, Sutton Carers Centre, SCC)
-Carer support, general (SCC)
-Sutton Uplift (SWLSGMHT)

Dementia Specific Activities
-Singing Sensations
-Local heritage groups
-Dementia Cafes

General Activities
-Conquest Art
-Sutton Lodge Day Centre
-AUKS Activity Programme
-Informal social/activity groups (What's On Guide and Sutton Information Hub)

Practical and Physical Health Support

-Tech enabled support (Sutton Council, Medequip)

-Support with more advanced symptoms or concerns
-Admiral Nurses
-Maximising Independence Service
-Home Care

-Specialist Day Service
-Cheam Priority
-Hallmead

-Residential breaks and respite

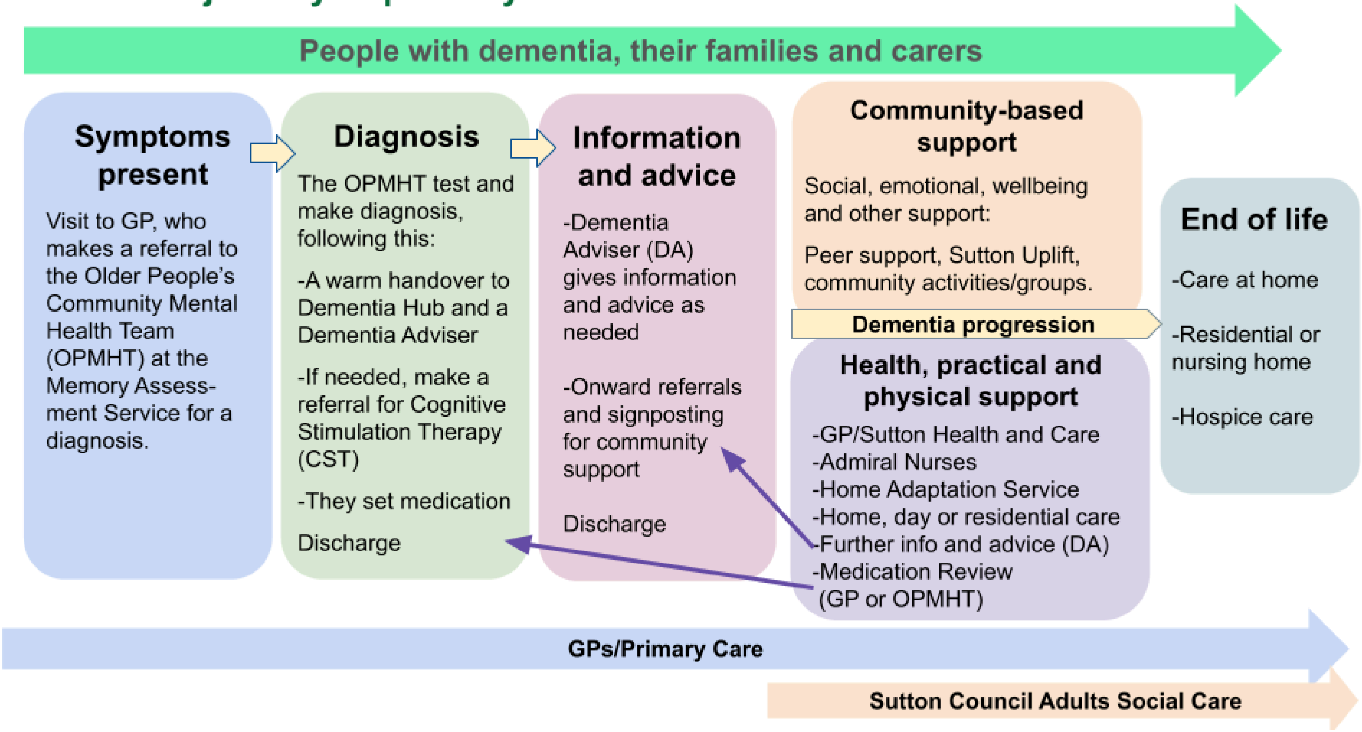
End of life Services

-Palliative care

-St Raphael's Hospice

-Care or Nursing Home

Dementia journey or pathway in Sutton 2024



People with dementia, their families and carers

Symptoms present

Visit to GP, who makes a referral to the Older People's Community Mental Health Team (OPMHT) at the Memory Assessment Service for a diagnosis.

Diagnosis

The OPMHT test and make diagnosis, following this:

-A warm handover to Dementia Hub and a Dementia Adviser

-If needed, make a referral for Cognitive Stimulation Therapy (CST)

-They set medication

Discharge

Information and advice

-Dementia Adviser (DA) gives information and advice as needed

-Onward referrals and signposting for community support

Discharge

Community-based support

Social, emotional, wellbeing and other support:

Peer support, Sutton Uplift, community activities/groups.

Dementia progression

Health, practical and physical support

-GP/Sutton Health and Care
-Admiral Nurses
-Home Adaptation Service
-Home, day or residential care
-Further info and advice (DA)
-Medication Review (GP or OPMHT)

End of life

-Care at home

-Residential or nursing home

-Hospice care

GPs/Primary Care

Sutton Council Adults Social Care

From this ‘as is’ mapping and analysis there were identified specific areas of improvement these were as follows:

- a current need for development and strengthening of our post diagnostic support for individuals and their families.
- Closer working between those providing support for example Admiral Nurses (who provide special support to people with dementia and carers) with Dementia Advises, ensuing opportunities for shared and collaborative working along with improved ‘ caseload management’.
- Review of functions where capacity was particularly challenging.
- Information and advice being more accessible.
- Improved representation and MAT through the provision of a proposed ‘sub hub’ ensuring that both staffing connections and initial contact with individuals and their families can be established early in the individual's dementia journey at the pace that’s right for them.
- A need to strengthen, along with the specific steps within the new borough wide carers strategy, support to unpaid carers.
- Need to redo the mapping once the strategy has started implementation to ensure all services and providers are captured

A need to strengthen our approach to supporting Sutton's wider communities, including those who have more recently moved to the UK, or are from ethnic, religious or belief minority backgrounds and, who are currently less visible in services

Appendix 7: Dementia in Sutton

In Sutton it's estimated that 2,107 people aged 65+ have dementia but only 1,559 (74%) have a recorded dementia diagnosis. In 2022/23, Sutton's QOF dementia prevalence (all ages) was 0.7% which was in line with the England average (0.7%) but higher than the SWL average (0.6%).

At a more local level, across the four Sutton PCNs there is variation in QOF dementia prevalence, reflecting differences in the age structure of these populations. Wallington PCN and Cheam and South Sutton PCN, have a higher proportion of individuals aged 65 and over, and the highest QOF dementia prevalence at 0.8% and 1.0%, respectively. In contrast, Carshalton PCN, which has a lower proportion of older residents, has the lowest rate at 0.5%. Central Sutton PCN's rate is similar to the Sutton average at 0.7%.

A further 59 people in Sutton have a recorded diagnosis of early onset dementia, when symptoms develop before the age of 65, usually between 30 to 65 years of age, a crude rate of 3.32 per 10,000, similar to the England average (3.05 per 10,000) and significantly higher than London (2.19 per 10,000).[1]

Research indicates that among individuals diagnosed with dementia in England, 14.36% of cases are mild, 27.83% are moderate, and 57.80% are severe. Applied to Sutton's population this would suggest that of the 1,618 diagnosed cases of dementia (all age), approximately 232 are mild cases, 451 moderate cases, and 935 severe cases.[2]

Diagnosis

The proportion of diagnosed dementia cases in Sutton (76%) is significantly higher than the averages for London (65.6%) and England (63%). However, estimates suggest that 548 people in the borough (24%) are living with dementia but have not been diagnosed.

Currently, there is no cure for dementia, and the range of available treatments is limited. Existing treatments primarily focus on managing symptoms and improving quality of life. Medications such as acetylcholinesterase inhibitors and memantine can provide temporary relief from cognitive symptoms, while non-pharmacological interventions, including cognitive stimulation therapy, cognitive rehabilitation and

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[1] Dementia Profile - Data - OHID (accessed 15/7/2024)

[2] Prevalence | Background information | Dementia | CKS | NICE.

lifestyle modifications, aim to enhance wellbeing.[3] The limited scope of treatments highlights the importance of early diagnosis and comprehensive care planning to maximise the benefit of the available options. Early diagnosis can also provide timely access to social support, help for carers and carers assessments and training to promote independence and wellbeing.

Research suggests that certain groups may be less likely to receive a timely dementia diagnosis, delaying opportunities to plan their care.[4][5][6] [7]

- Stigma, language barriers, and cultural perceptions of health and caring may affect how people from minority ethnic groups seek support for dementia. Delays in diagnosis can also be exacerbated by a lack of culturally appropriate services, access to interpreters, or culturally appropriate diagnostic tools.
- People with learning disabilities may also experience delays in diagnosis. Symptoms of dementia can overlap with other health issues or be mistaken for aspects of the learning disability itself. Additionally, a lack of awareness about dementia can prevent people from seeking help for memory problems.
- Those living in areas of higher deprivation.
- As dementia is often thought of as a condition of old age, the early symptoms of early onset dementia are not always recognised and may be attributed to other causes including depression, stress, menopause, physical health problems and relationship issues. This can lead to a delay in getting an accurate diagnosis.

To ensure an accurate diagnosis, NICE recommends that anyone with suspected dementia is referred to a specialist dementia diagnostic service.[8] Data to identify trends in the number of local GP assessments for dementia, GP initial memory assessments and referrals to a memory clinic from GP practices are not available for analysis.

Dementia projections

Nationally and locally, the prevalence of dementia is expected to rise significantly due to the ageing population, leading to increased demand for healthcare services, social care support (community and residential), support for carers and suitable housing options. This has profound implications for service costs and the wider

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[3] What are the treatments for dementia? NHS website
[4] Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland
[5] Ethnic minority communities: Increasing access to a dementia diagnosis (Alzheimer's Society) 2021
[6] Dementia and people with learning disabilities: making reasonable adjustments - guidance - GOV.UK
[7] What is young onset dementia? Dementia UK
[8] Referral, diagnosis and care planning | NICEimpact dementia | Reviewing the impact of our guidance.

community, and will require strategic planning and resource allocation to manage the growing burden effectively.

Projecting Adult Needs and Service Information (PANSI) data predicts that there will be a gradual increase in early onset dementia cases in Sutton from 2023 to 2040. Overall, the total number of cases is projected to increase from 55 in 2023 to 60 in 2040, reflecting a 9.09% rise. The most significant increases are expected in the 50-59 and 60-64 age groups, with younger age groups remaining relatively stable.

The Projecting Older People Population Information (POPPI) suggests that in Sutton the number of individuals aged 65+ living with dementia will increase by 39.8% between 2023 and 2040 rising from 2,421 to 3,389 in that time. The 90+ age groups will experience the most significant increases (83.7% in males and 41.6% in females).

Moreover, POPPI estimated that in Sutton in 2023, 64.1% of dementia cases in those aged 65 and older were female, while 35.9% were male. By 2040, dementia cases are predicted to increase more significantly in men (50.3%) compared to women (33.9%). Consequently, the overall proportion of male cases is projected to rise to 38.6%, while female cases will decrease to 61.4%, slightly narrowing the gender gap.

As Sutton's population changes and becomes more ethnically diverse, the borough will need to adapt and tailor its approaches to dementia prevention. For example, research suggests that risk factors such as high blood pressure may have a greater impact on dementia risk for South Asian and Black individuals compared to those of White ethnicity, highlighting the importance of culturally competent prevention strategies.

Supporting and treating people with with dementia

Supporting people with dementia involves a holistic approach to develop tailored interventions integrating medical treatments to manage symptoms and comorbidities, alongside social, emotional, practical, and financial support.[9] NICE guidance covers the assessment, management and support for people with dementia and their carers.

A dementia personalised care and support plan outlines what matters to an individual, the care and support they receive, and contingency plans for the future. These plans are developed in primary care and reviewed at least once every 12 months.

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[9] Dementia rarely travels alone: Living with dementia and other conditions APPG 2016

In 2022/23, 74.2% of dementia care plans in Sutton had been reviewed within the past 12 months. This was lower than the South West London (SWL) average (78.9%) but statistically similar to the national average (73.6%). The pandemic significantly disrupted the review process, causing a dramatic drop in reviewed care plans, but these numbers have since recovered.

Dementia often coexists with other long-term conditions, which complicates care. Research indicates that 77% of individuals with dementia also suffer from conditions such as heart disease, stroke, and diabetes. These individuals are nearly twice as likely to have three or more other specific health conditions and four times more likely to have five or more compared to the general patient population. As dementia severity increases, diagnosing comorbidities becomes more challenging, potentially leading to underdiagnosis.[10]

Data from the SWL Health Insights dashboard indicate that in Sutton, 57.3% of patients with dementia have hypertension, 26.2% have diabetes, and 20.8% have depression. These are higher compared to the Alzheimer's Research study's findings, which reported 44% with hypertension, 20% with diabetes, and 17% with depression. However, these comparisons should be regarded with caution as the SWL dataset appears to under-report dementia cases compared to other datasets.

The progression of dementia complicates the management of other health conditions. For example, someone with dementia may struggle with day to day activities including oral health or managing LTCs such as diabetes, causing conditions to deteriorate and potentially resulting in an emergency hospital admission.

Hospital admission can trigger distress, confusion and delirium for someone with dementia. This can contribute to a decline in functioning and a reduced ability to return home to independent living.[11] From 2022 to 2024, in Sutton, individuals with dementia spent a total of 129,180 days in the hospital. Data from the SWL Health Insights team showed that the three primary diagnoses contributing to the greatest total length of stay were a tendency to fall, urinary tract infection (UTI), and fractured neck of femur.

Information about direct standardised rates of emergency admissions and short-stay hospital admissions for those aged 65 and over is published on Fingertips. Data up to 2020 indicated that Sutton's performance for both indicators was significantly above the national average. This higher rate of emergency and short-stay admissions could indicate that additional support in the community could help to

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[10] https://www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing

[11] Hospital care | NICEimpact dementia | Reviewing the impact of our guidance.

prevent people from reaching a crisis and needing hospitalisation. Therefore, more recent information is needed to understand if this trend has continued since 2020.

Social care and coding

The following CQC datasets, are not considered in the analysis, but offer context for commissioners:

- The percentage of residential care homes and nursing homes rated by the Care Quality Commission as suitable for persons with dementia (aged 65+).
- Dementia: Quality rating of residential care and nursing home beds (aged 65+).
- Dementia: Residential care and nursing home bed capacity (aged 65+).

Appendix 8: Data Sources

Throughout this strategy, we have included footnotes referencing specific health evidence, advice and data. A report made to the Dementia Strategy Steering group's prevention task and finish group in 2024 features Sutton specific data and projections and NHS England recommendations for dementia prevention. (Appendix 10). Additionally, the following data sources were used to develop this strategy:

1. Dementia Statistics Hub, Alzheimer's Research UK.
2. **Dementia prevention, intervention, and care: 2024 report of the *Lancet* standing Commission,** Livingston, Gill et al. The Lancet, Volume 404, Issue 10452, 572 - 628
3. NHS "Living with dementia" webpages.
4. 2024 Dementia Carers Count survey.
5. Alzheimer's Disease International, 2024
6. Lancet Commission on Prevention, Intervention and Care (Alzheimer's Research UK, 2022).
7. Black and South Asian people are more likely to be diagnosed at an earlier age and die earlier from dementia as white people. (Mukadam et al, 2022).
8. An estimated 50% of people with Down's Syndrome will develop dementia due to Alzheimer's as they age. (National Institute on Aging, NIH, 2020).
9. Dementia Profile - Data - OHID (accessed 15/7/2024)
10. Prevalence | Background information | Dementia | CKS | NICE.
11. What are the treatments for dementia? NHS website
12. Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland
13. Ethnic minority communities: Increasing access to a dementia diagnosis (Alzheimer's Society) 2021
14. Dementia and people with learning disabilities: making reasonable adjustments - guidance - GOV.UK
15. What is young onset dementia? Dementia UK
16. Referral, diagnosis and care planning | NICEimpact dementia | Reviewing the impact of our guidance.
17. Dementia rarely travels alone: Living with dementia and other conditions APPG 2016
18. https://www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing
19. Hospital care | NICEimpact dementia | Reviewing the impact of our guidance.

Appendix 9: Key national legislation and local policy

Dementia is considered against a number of areas of legislation which include the following:

Mental Capacity Act 2005

People with dementia may lose capacity and become unable to make some decisions. The MCA covers important decision making about a person's property, financial affairs and health and social care. It also covers everyday decision making, such as decisions about what a person wears, what they eat and their personal care. The Act sets out the concept of Mental Capacity - it means are they able to make a specific decision. This might be due to an injury so they might have a learning disability, a mental illness or a condition that affects their brain- such as dementia

To have Mental capacity a person must be able to:

- Understand the information that is relevant to the decision they want to make
- Keep the information long enough in their mind to make the decision
- Weigh up the information that is available to make the decision
- Communicate their decision

Naturally, some decisions are more complex than others and require consideration..

Options for looking ahead might include- setting up a Lasting Power of Attorney LPA, creating an Advanced Decision eg types of treatment they want to receive - these are legally binding

Care Act 2014

The Care Act introduced new functions for local authorities. This is to make sure that people are able to:

- Access services that prevent their care needs from becoming more serious to delay the impact of their needs

- Get the information and advice they need to make a good decision about care and support

- Receive a range of provision of high quality, appropriate services to choose from.

In relation to dementia the Care Act focuses upon the wellbeing of individuals needing care and support, emphasising needing care and support, emphasising dignity and the importance of safeguarding vulnerable adults.

As well as establishing eligibility for social care the Act also places an emphasis upon prevention, avoiding and delay.

The Human Rights Act 1998

This Act seeks to protect fundamental flights ensuing that individuals with dementia are treated with respect and care fee from inhumane treatment, reinforcing the legal protection in care environments

Appendix 10: Glossary

Admiral Nurse
Admiral Nurses are trained mental health nurses who can offer specialist help, support and advice for people with dementia and their carers. Admiral nurses are available via telephone support or there may be face to face services in your area. Admiral Nurses are provided by Dementia UK, sometimes in partnership with other organisations such as the NHS.

Adults with Incapacity (Scotland) Act 2000
Adults with Incapacity (Scotland) Act 2000 is the legal framework for safeguarding the welfare, finances and property of adults who lack capacity to make some or all decisions for themselves. It is underpinned by five key principles. These must be applied when decisions are being made on behalf of the person or the Act is being applied.

Advance Care Plan (ACP)
An advance care plan (ACP) is a document you can use to specify a person's preferences for future health care or medical interventions. Advance care plans come into effect when a person is unable to communicate their preferences or make decisions e.g. becomes seriously ill, injured or their dementia had progressed.

Advance Decisions to Refuse Treatment (ADRT)
Sometimes called a 'living will'. This is a decision you can make now to refuse specific treatments in the future. It lets healthcare professionals know your wishes if you are not able to communicate them. All treatments you are refusing must be named. ADRT is legally binding if it meets the legal requirements of the Mental Capacity Act 2005.

Advance Statements
This is a written statement which includes your preferences, wishes, beliefs and values about the care you want in the future. This might be instructions for how you would like to be cared for (such as your daily care, religious practices) or where you would like to be cared for (such as at home, in a hospice). An advance statement can be legally binding.

Age UK
Age UK is a leading UK charity with the aim of supporting all older people. They provide information, a free national advice helpline, advice, and local services, including a range of literature around many aspects of dementia.

Age UK Sutton
Age UK Sutton is the local charity supporting older people, who are committed to enabling older people in Sutton to Age Well by providing vital information, advice, and support that enable informed decisions about finances, health, and care. Age UK Sutton currently are the lead providers of the Dementia Hub.

Alzheimer's Society
The Alzheimer's Society is a leading dementia charity in the UK. They provide support for people with dementia and carers through their website and Dementia Connect. They have a free national helpline, an online forum, and a wealth of information about many aspects of dementia and support. In some areas of the UK, they provide direct one to one support and dementia support groups through Dementia Advisers.

Anxiety
Anxiety is a feeling of tension and stress, often along with worried thoughts. Anxious feelings may cause physical changes like increased heart rate or blood pressure. Anxiety is normal in stressful situations, such as when having your memory tested or visiting a doctor. When anxiety persists or is very strong and interferes with daily life, you should talk to a doctor or psychologist, as there are treatments that can help.

Assistive technology
Assistive technology describes a wide range of objects or software which may assist in making everyday tasks easier or safer. Examples may be bathroom handrails or ramps, or smart phone apps and electronic falls detectors.

Care Certificate
The Care Certificate is an agreed set of standards that define the knowledge, skills and behaviours expected of specific job roles in the health and social care sectors.

Care Act 2014
The Care Act 2014 is an Act of the Parliament of the United Kingdom that sets out local authorities' duties in relation to assessing people's needs and their eligibility for publicly funded care and support.

Care Co-ordinator
Part of personalised care, Care co-ordinators help people with dementia to co-ordinate and navigate care across the health and care system, helping them make the right connections, with the right teams at the right time.

Care Needs Assessment
Care Needs Assessments are carried out through your local authority (council). Assessments are carried out telephone or face to face assessment, to work out what help you can receive from the local authority. This support may be to help with your daily activities or your living environment.

Care Plan
A care plan is a written document which captures decisions made between the health care team, the individual, carers and family members. The care plan may include details of the clinical diagnosis, personal preferences, care goals, treatment and management, and risk assessments.

Care Quality Commission (CQC)
The Care Quality Commission is part of the Department of Health and Social Care of the United Kingdom. Established in 2009, it regulates and inspects health and social care providers in England

Care worker
A paid worker who supports a person at home or in residential care. They might help with a variety of tasks including showers and personal care, housework, shopping, and social activities.

Carer
A carer (might also be referred to as a family carer, care partner, or supporter) is any person who supports a person who might need help. The primary carer is the main supporter. Support may be practical (for example, transport, cooking, making appointments) and emotional. Carers are usually family members or friends and are not paid.

Carer’s assessment
Carer’s Assessments are carried out through your local authority (council). Assessments are carried out either by telephone or a face to face assessment, to work out what support you can receive as a carer from the local authority. This may be financial help, practical help, or access to equipment.

Carer’s UK
Carer’s UK are a leading national charity who provide expert advice, information and support for specifically for issues which affect carers. This includes all conditions

and ages. Carer's UK have an online forum, a national helpline and a range of fact sheets providing practical information.

Chronic Disease

Chronic diseases (also known as Long Term Conditions) affect people long-term and can greatly impact on quality of life. Examples include dementia, arthritis, mental health conditions, cancer diabetes, chronic pulmonary obstructive disease (COPD), Asthma and back pain.

Cognition

Cognition describes how the brain works. This includes: understanding information, memory, the senses (sight, hearing, touch, smell, or taste) and being able to use this information appropriately. It also involves brain function which helps us to get things done (executive function), such as solving problems, attention, social awareness, and decision making. Dementia can affect cognition in many ways.

Cognitive Rehabilitation

Therapies which improve *cognitive* function by relearning skills, such as reasoning, perception and thought.

Cognitive stimulation therapy

A programme of structured activities, often within a small group, over several sessions led by a trained nurse, an occupational therapist, or a carer. Sessions are designed to improve mental abilities including attention, memory, and language.

Comorbidity

Experiencing two or more diseases or medical conditions at the same time is called comorbidity. This may impact treatment and health planning.

Community Mental Health Team

A team of healthcare specialists including: psychiatrists, psychologists, community psychiatric nurses, social workers, and occupational therapists, who work together to offer mental health support for people with dementia and other conditions.

CPD

CPD stands for Continuing Professional Development. It refers to the process of tracking and documenting the skills, knowledge and experience that professionals gain both formally and informally as they work, beyond any initial training.

Day Centre
A Day Centre is a service which is provided by Local Authorities, the NHS, or voluntary/private organisations. It is a place where the person living with dementia can go during the day to socialise with others and take part in activities.

Dementia
Dementia is a group of conditions that may be caused by a range of diseases that affect the brain. This may result in changes to brain function, thinking, behaviour, and the ability to carry out everyday tasks. It may be described as progressing over a range of stages: early/mild, moderate, and severe/advanced. The most common type of dementia is Alzheimer's disease. Other common types include vascular dementia, frontotemporal dementia, or dementia associated with Parkinson's disease.

Dementia UK
Dementia UK are a leading dementia charity who support people with dementia and their carers. They provide Admiral Nurse Services (in some areas), a telephone hotline, a website and virtual clinics.

Dementia Advisers
Dementia Advisers are trained, non-medical professionals provide support face to face and over the telephone. They can help people with dementia and their carers with support around all aspects of living with dementia from diagnosis to end of life care. Contact Age UK Sutton to talk to a Dementia Adviser.

The Dementia Training Standards Framework
The Dementia Training Standards Framework, commissioned and funded by the Department of Health, details the essential skills and knowledge necessary across the health and social care spectrum.

Depression
Depression is a constant feeling of sadness and loss of interest, which may stop someone doing their normal daily activities. It may affect their eating, personal care, change their behaviour, or lead to the person withdrawing from those around them. Symptoms can range from mild to severe. It may not be easily recognised in someone with dementia if their behaviour has changed as their condition develops. Carers are also at risk of depression.

Dietician
Dieticians provide advice on eating and nutrition and the impact this may have on overall health. Your GP can refer you to nutrition and dietics services.

Disability
Disability refers to impairment caused by a broad range of health conditions. The impairment may have developed over time, occurred due to an accident or trauma or may have been present from birth. Under the Equality Act 2010 you are classed as having a disability if you have a physical and/or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities. Dementia is classed as a disability. This may help protect your rights and access to financial support and services.

DVLA
The Driver and Vehicle Licensing Agency (DVLA) is a government agency which regulates driving in the UK. A dementia diagnosis must be reported to the DVLA if the person wishes to continue driving. The DVLA will then make an assessment of the person’s suitability to drive.

Emotional resilience
Our emotional resilience describes how we respond to challenging and stressful situations and events. These might be big life changes or everyday challenges. Building emotional resilience can help you to adapt to stressful situations, and cope better with life’s ups and downs. Emotional resilience can change over time. Having good support is key to emotional resilience.

Enablement
A way of supporting individuals to carry on completing everyday living tasks when this may be challenging.

Environment
Our world around us which influences our lives and quality of life. This may be where we live, work, our social environment (our relationships and connections with others, cultural and spiritual values) and economic and political situations. All these combined can impact our choices and quality of life.

Functional ability
Functional ability is a medical way of describing a person’s ability to carry out everyday tasks and activities.

Geriatrician
A doctor who specialises in diagnosing and providing medical treatment and care of older people, usually 65 years and above.

General Practitioner (GP)
GP or doctor is the healthcare professional based in your local surgery, practice, or health centre. They are part of the primary care team. They are likely to be the first person you visit if you are concerned about your health. They can assess your health, do tests, refer you to specialist services, prescribe medications, give you advice and offer other healthcare support.

Health and Safety Executive
The Health and Safety Executive is a UK government agency responsible for the encouragement, regulation and enforcement of workplace health, safety and welfare, and for research into occupational risks in Great Britain

Home Care
Home care is when trained care staff travel to the homes of people who require some extra assistance and support. This is usually arranged through local councils or private agencies. Home care is ideal for anybody who wishes to keep living in their own home, but could do with some extra help.

Integrated Neighbourhood Teams, INTs
The Integrated Neighbourhood Teams programme aims to improve care and support for people who use health and care support, their carers and families by putting a greater emphasis on joining up and coordinating services to provide proactive and preventative care through a joint approach within Sutton’s neighbourhoods.

IAPT
Improving Access to Psychological Therapies (IAPT), now NHS Talking Therapies is a programme developed to improve the delivery of, and access to, evidence-based, NICE recommended, psychological therapies for depression and anxiety disorders within the NHS.

IMCA
Independent Mental Capacity Advocate (IMCA) is a professional person who can help to protect the rights of a person who lacks mental capacity to make important decisions about their health, wellbeing, and finances. An IMCA can become involved in decisions if the person does not have a relative or friend who can act on their behalf.

Lasting Power of Attorney (LPA)
A lasting power of attorney is a legal document that lets you appoint one or more people to help you make decisions or to make decisions on your behalf if you no longer have mental capacity to make important, specific decisions. There are two types of Lasting Power of Attorney available: health and welfare, and property and financial affairs with separate costs for each. This is Power of Attorney in Scotland and Enduring Power of Attorney in Northern Ireland. Documents are available via government websites.

Liberty Protection Safeguards (LPS)
The Liberty Protection Safeguards provide protection for people aged 16 and above who are or who need to be deprived of their liberty in order to enable their care or treatment and lack the mental capacity to consent to their arrangements. LPS is applicable in England and Wales.

Local Authority
Your local authority is the local government or 'council' responsible for the area you live in. They control access to funds and resources for social care. They conduct assessments for Care Needs Assessments and Carer's assessments.

Memory
Memory is a brain function which allows us to translate, store, retain and recall information and past experiences.

Mental capacity
Legal definition and test of someone's ability to make a decision. A healthcare professional might assess decision-making using a test which is set out in the Mental Capacity Act (2005).

Mental Capacity Act (2005)
Law to protect people with impairment of brain or mind and make sure they are included in important decisions about their life. Applicable in England and Wales only. (See AWI for Scotland and Mental Capacity Act 2016 NI for Northern Ireland).

Mental Capacity Act (NI) 2016
Law to protect people with impairment of brain or mind and make sure they are included in important decisions about their life. Applicable in Northern Ireland only.

Mental Capacity Act (2005) Code of Practice
The Mental Capacity Act (2005) Code of Practice provides guidance to anyone who is working with and/ or caring for adults who may lack capacity to make particular decisions. It describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves.

Mild Cognitive Impairment (MCI)
MCI may see the early beginnings of Cognitive impairment which might include early issues with memory or in sequencing actions or events. Such impairment may not lead to dementia nor indeed progress any further. However, this can impact upon daily living and provides us with an opportunity to improve recognition and where appropriate, support further investigation along with opportunities to look at coping mechanisms. The preventative focus - prevent, reduce and delay is equally valid in seeking to keep healthy and well through activity, maintaining social contacts and maintaining a balanced diet.

National Health Service (NHS)
The National Health Service (NHS) is publicly funded and provided by the government. It provides medical and health care services for everyone living in the UK. Most services are ‘free at the point of delivery’ meaning you do not have to pay for a GP visit, tests, or a stay in hospital. Payment is made through public taxes. Some services are only part funded and unless you have an exemption you may have to pay for part of the cost of treatment. Examples include prescriptions, dentist, and opticians.

Neurology
Neurology is a specialist medical service which focuses on the diagnosis and treatment of disease of the brain and nervous system. Your GP may refer you to neurology services.

NICE Guidelines
The National Institute for Health and Care Excellence (NICE) guidelines are evidence-based recommendations for health and care in England. They set out the care and services suitable for most people with a specific condition or need.

Nursing Home
Accommodation where 24-hour support from qualified nurses is provided to people with a higher level of care needs than care homes, including medical needs. Like residential homes, nursing homes also offer opportunities for activities and socialising.

Occupational therapy
Occupational therapy is a specialist service which can support you to improve your ability to do everyday tasks. For example, looking after yourself, your home, getting out and about, and communicating with others. Your GP may refer you to an occupational therapist if you need support with everyday tasks or equipment, or home adaptations.

Old Age Psychiatry
Old Age Psychiatry services specialise in the prevention, diagnosis, and treatment of mental, emotional, and behavioural issues in older people, usually over 65 years of age. Your GP may refer you to an Old Age Psychiatry service.

Perception
Perception is a brain function which enables us to recognise something through our senses (such as sight, hearing, taste, smell, and touch. It may also describe an individual's view of a situation, object, or a situation.

Physiotherapy
Physiotherapy is a service which specialises in movement, exercise, and manual therapy, education with people affected by injury, illness, or disability. Physiotherapists aim to maintain health for people of all ages, helping patients to manage pain and prevent disease. Your GP may refer you to physiotherapy services.

Practice Nurse
A practice nurse works in primary care (usually a General Practitioner's surgery) and provides education, advice, and support for a range of health issues, including dementia. They perform clinical procedures within their scope of practice. They are part of the primary care team.

Primary care
Healthcare which is based in the community, not in a hospital setting. Such as GP practice, dentist, pharmacy, and optician.

Psychology
Psychology is a service which specialises in assessments, support, and interventions to manage mental health needs for people with dementia, carers, and other conditions. They can help with issues such as mood and challenging behaviours.

Reablement
Describes services which support people with their independence through helping the person to regain or maintain skills to carry out everyday tasks. Reablement services may be put in place after a period of illness or hospital admission.

Rehabilitation
Rehabilitation is a process of supporting people to regain their health. Rehabilitation services may be put in place following a hospital admission or in cases of injury, illness, or surgery.

Reminiscence therapy
Group sessions or individual activities which focuses on encouraging the person to think and talk about their past. Photos, books, films, or topics of interest can be helpful prompts.

Respite Care
Respite care means taking a break from caring, while the person living with dementia is looked after by someone else. It ranges from getting a volunteer to sit with the person living with dementia for a few hours, to the person going to a day care centre, to a short stay in a care home.

Residential Care
Accommodation where people receive 24-hour support to meet their daily needs such as personal care and taking medication. They also have daily activities and opportunities for socialising.

Sheltered Housing
Sheltered housing, sometimes referred to as retirement housing, is a type of housing "with support" that suit people who want to live independently but need a bit more support or those who want to live in a smaller home that is easier to manage.

Social Care
Social care services can provide help with day-to-day living because of illness or disability. Social care services are provided by the local authority, charities and voluntary organisations, and private companies. They also provide support for carers.

SCIE
The Social Care Institute for Excellence (SCIE) is a UK charity and improvement agency. SCIE shares knowledge about what works in practice across social care,

social work and beyond, covering adults', families' and children's care and support services.

Social prescribing
Referral to local, non-medical services to support your wellbeing by a primary care health care professional such as a GP or practice nurse. Examples of services might include a local walking group or a befriending service.

Speech and Language Therapy (SALT)
Speech and language therapy services offer support with conditions which affect speech, language, and swallowing abilities. Your GP may also refer you to a SALT team for support with communication.

Stereotypes
Stereotypes fixed ideas of a particular person or thing, which is applied to all in that group, which may not be founded on evidence or fact.

Supported Living
Supported living offers more support than sheltered housing, and means that individuals have their own home, but staff are usually available 24-hours a day to help with tasks such as personal care and taking medications.

Sutton Place Partnership
Sutton Place Partnership Board is the local 'place based partnership' which leads the design and delivery of integrated health and social care services in Sutton. The Board includes representatives from the Council, the NHS, and the local voluntary and community sector.

Third-party Mandate
In banking, a third party mandate is a written instruction from a person authorising another person 'third party' to carry out any day-to-day transactions on their account(s).

Wellbeing
This concerns your general health and includes your physical, mental, emotional, spiritual, social, and occupational (sense of purpose) health.

Will
This is a written document which states what will happen to a person's assets (money, property, valuables) after they die. Your will must be formally witnessed and signed to make it legally valid.

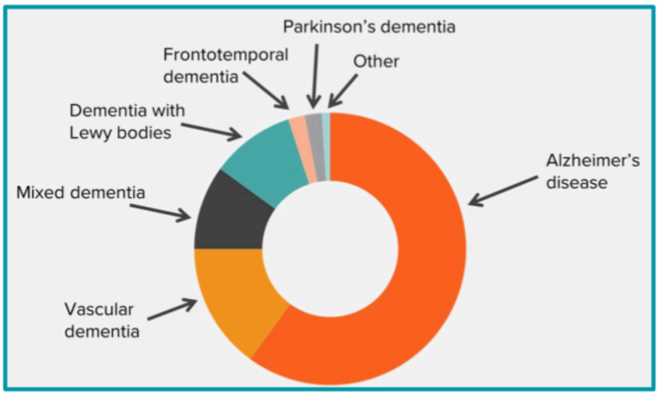
Young onset dementia
This refers to a diagnosis of dementia received before the age of 65 years.

https://www.forwardwithdementia.org/en/dementia-glossary/

Appendix 11: Report from prevention task and finish group, dementia strategy steering group

Background

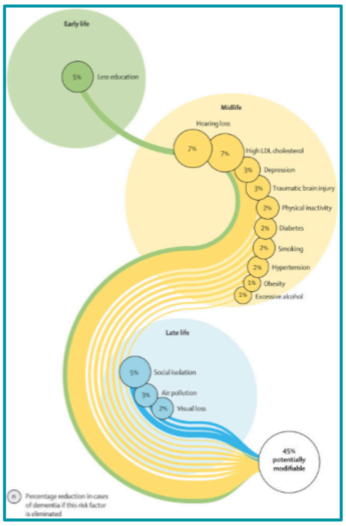
Dementia



Although dementia mostly affects older adults, it is not a part of normal aging.

Dementia is not a specific disease but a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities. Dementia is progressive, which means the symptoms will gradually get worse.

Alzheimer's disease is the most common type of dementia. One well-known gene that influences Alzheimer's risk is apolipoprotein E (APOE).



Findings Dementia prevention, intervention, and care: 2024 report of the Lancet Commission

Since the 2020 Lancet Commission report, new evidence has identified **vision loss** and **high cholesterol** as modifiable risk factors for dementia. This increases the number of recognised risk factors from 12 which were included in the 2020 report to 14 in 2024.

Modifying these 14 risk factors could prevent or delay nearly half (45%) of dementia cases.

The Lancet Commission stress the importance of being ambitious about prevention - at national and international governmental levels as well as individually tailored interventions.

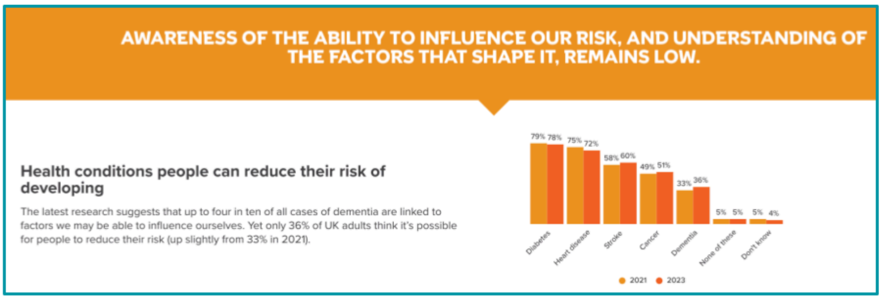
- Actions to decrease dementia risk should begin early and continue throughout life.
- Risk is clustered in individuals; therefore, interventions should often be multicomponent.
- Risk is modifiable irrespective of APOE genetic status. Multicomponent interventions addressing several risk factors potentially benefit individuals with either high or low genetic dementia risk.

Learning disability

Analysis of the data from a range of studies suggested

- age-related dementia of all types is more common at earlier ages in people with learning disabilities than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population)
- across all over-60 age groups the prevalence was estimated at 2 to 3 times greater in people with learning disabilities
- people with Down's syndrome are at particular risk of early onset Alzheimer's disease
- data from GPs show that the number of people with learning disabilities diagnosed with dementia is 5.1 times the number expected, "if general population age and sex specific rates had applied"

But…



AWARENESS OF THE ABILITY TO INFLUENCE OUR RISK, AND UNDERSTANDING OF THE FACTORS THAT SHAPE IT, REMAINS LOW.

Health conditions people can reduce their risk of developing

The latest research suggests that up to four in ten of all cases of dementia are linked to factors we may be able to influence ourselves. Yet only 36% of UK adults think it's possible for people to reduce their risk (up slightly from 33% in 2021).

Local situation

About Sutton's population

210,053 people live in Sutton

Age

- **49,482 (23.6%)** people are aged < 18 years
- **128,387 (61.1%)** people are aged 18-64 years
- **32,184 (15.3%)** people are aged 65+

Source: ONS Mid- 2022 Population Estimates, 2023

Male and female

- **108,311 people (51.6%)** are female
- **101,742 (48.4%)** are male

Source: ONS Mid- 2022 Population Estimates, 2023

Ethnicity

The population is increasingly diverse

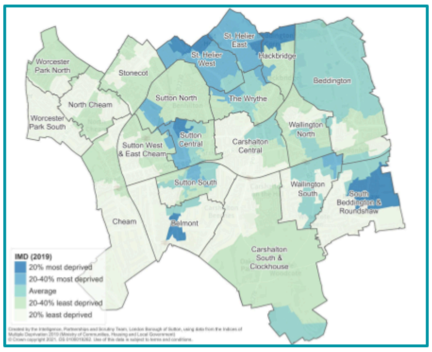
- **119,425 (57%)** people are white British
- **90,092 (43%)** people are from other ethnic groups

Deprivation

- **6% of small areas (7 out of 121)** in Sutton are in the 20% most deprived areas in the country.
- **35% of small areas (42 out of 121)** are in the 20% least deprived areas in England.

Source: Sutton Strategic Needs Assessment [5]

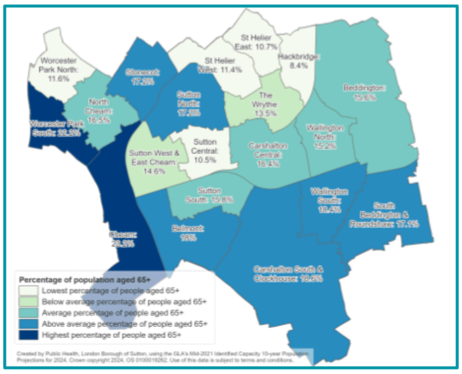
Deprivation by neighbourhood in Sutton (IMD 2019)



Source: DCLG, 2019[9]

About Sutton's population aged 65+

Map to show the percentage of ward population aged 65+ in Sutton



Created by Public Health, London Borough of Sutton, using the GLA's Mid-2021 Identified Capacity 10-year Population Projections for 2024. Crown copyright 2024. OS 0100019262. Use of this data is subject to terms and conditions.

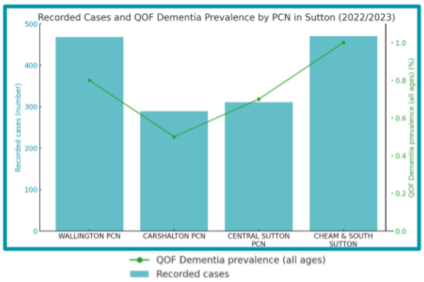
Source: GLA, 2023

Higher proportion of older residents in the South and West:
The wards in the western part of the borough, Cheam (23.2%) and Worcester Park South (22.2%), have the highest proportion of residents aged 65 and over. The southern wards Belmont (18.0%), Carshalton South and Clockhouse (18.6%), Wallington South (18.4%) and South Beddington and Roundshaw (17.1%) along with Stonecot (17.2%) and Sutton North (17.3%) also have a relatively high proportion of older residents.

Lower proportion of older residents in the North:
The northern wards such as Hackbridge (8.4%) and St Helier East (10.7%) have the lowest percentages of residents aged 65 and over. St Helier West (11.4%) and Worcester Park North (11.6%) have a lower proportion of older residents compared to the southern and western wards.

Central areas:
Wards located more centrally, such as Sutton South (15.8%), Carshalton Central (16.4%), Wallington North (15.2%) and Beddington (15.6%) have an average percentage of elderly residents, compared to other Sutton wards.

Dementia QOF prevalence (all ages)



In Sutton in 2022/2023 the dementia QOF prevalence (all ages) was 0.7% which was in line with the England average (0.7%) but higher than the SWL average (0.6%). Locally, there is variation in dementia prevalence by PCN, reflecting differences in the age structure of these populations.

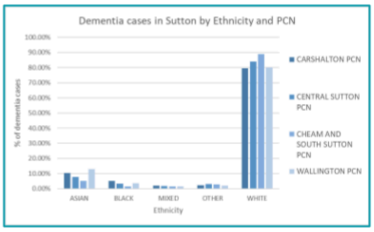
The graph on the left plots the number of recorded dementia cases by PCN and the QOF prevalence (all ages) for each PCN. However within Sutton it is estimated that about 24% of dementia cases remain undiagnosed (see diagnosing well).

(Definition: The recorded dementia prevalence is the number of people with dementia recorded on GP practice registers as a proportion of the people (all ages) registered at each GP practice).

Dementia QOF Prevalence all ages 2022/23

PCN	Recorded cases of dementia	PCN population (registered)	QOF Dementia prevalence (all ages)
Wallington PCN	468	56,587	0.8
Carshalton PCN	289	54,705	0.5
Central Sutton PCN	311	46,885	0.7
Cheam and South Sutton PCN	470	48,196	1.0
Sutton	1,538	206,373	0.7

SWL QOF Dementia (Demographics)



Data note: The SWL Health Insights data has a smaller cohort of people with a QOF dementia recorded diagnosis (n=1,300) than OHID and NHSE. However, the SWL data enables us to look at our population in more granular detail.

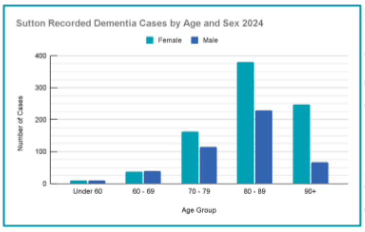
In Sutton, the majority of people with a recorded diagnosis of dementia are White (British and non-British) across the 4 PCN areas. This is inline with Sutton's population where 57% of Sutton's residents are White British, with a further 11.1% who are White, from non-British backgrounds.

There are 9.08% of dementia cases in patients from Asian backgrounds. Research has shown that there has been a continued increase in the prevalence of dementia in this ethnic group. Individuals of Asian ethnicity are at greater risk of cardiovascular disease, hypertension and diabetes, which increase the risk of dementia and contribute to increased prevalence.

Dementia typically affects older adults with most cases diagnosed in those aged 65+. it can be seen from the figure to the right that a substantial portion of dementia cases in Sutton fall within the age category 80-89 years old.

In Sutton, there is a higher prevalence of dementia cases in females aged 70 and over. This is likely to be a consequence of the fact that women live longer than men and age is the biggest known risk factor for the condition.

	Under 60	60-69	70-79	80-89	90+
Female	10	38	162	380	248
Male	10	40	115	229	68
Total	20	78	277	609	316



* From SWL Health Insights Data Extract 7th May 2024

Dementia and Comorbidities

Dementia often coexists with other long-term conditions, which complicates care. Research indicates that 77% of individuals with dementia also suffer from conditions such as heart disease, stroke, and diabetes. These individuals are nearly twice as likely to have three or more additional specific health conditions and four times more likely to have five or more compared to the general patient population. As dementia severity increases, diagnosing comorbidities becomes more challenging, potentially leading to underdiagnosis.

In Sutton, 1 in 3 patients registered with a GP** have a long-term condition. Amongst patients with dementia:

- 11% (143) have one long-term condition
- 89% (1,157) have complex comorbidities

Patients diagnosed with dementia often suffer from other long term conditions.

In Sutton*:

- 57.3% (745) have hypertension (QOF)
- 26.2% (340) have diabetes (QOF)
- 20.8% (270) have depression

---

*The HIN research is the latest available research on Dementia comorbidities.

** From SWL Health Insights Data Extract 7th May 2024

Date note: The SWL Health Insights data has a smaller cohort of people with a QOF dementia recorded diagnosis (n=1,300) than OHID and NHSE. However, the SWL data enables us to look at our population in more granular detail.

Future trends

Early Onset Dementia Predictions for Sutton

Group	2023	2025	2030	2035	2040
Males 30 - 39	<5	<5	<5	<5	<5
Males 40 - 49	<5	<5	<5	<5	<5
Males 50 - 59	17	17	17	18	18
Males 60 - 64	11	12	12	12	12
Total Males 30 - 64	32	33	33	34	35
Females 30 - 39	<5	<5	<5	<5	<5
Females 40 - 49	<5	<5	<5	<5	<5
Females 50 - 59	11	11	11	12	12
Females 60 - 64	7	7	7	7	7
Total Females 30 - 64	23	23	24	24	25
Persons 30 - 39	<10	<10	<10	<10	<10
Persons 40 - 49	<10	<10	<10	<10	<10
Persons 50 - 59	28	28	28	30	30
Persons 60 - 64	18	19	19	19	19
Total Persons 30 - 64	55	56	57	58	60

Source: PANSI: Projecting Adult Needs and Service Information

Projecting Adult Needs and Service Information (PANSI) data predicts that there will be a gradual increase in early onset dementia cases in Sutton from 2023 to 2040. For males aged 30-64, the cases are expected to rise from 32 to 35, a 9.38% increase. For females in the same age group, the cases are predicted to grow from 23 to 25, an 8.70% increase. Overall, the total number of cases for both genders combined is projected to increase from 55 in 2023 to 60 in 2040, reflecting a 9.09% rise. The most significant increases are seen in the 50-59 and 60-64 age groups, with younger age groups remaining relatively stable.

The prevalence of early onset dementia is likely to be systematically underestimated as identification early in the disease course is reliant on interactions with services and not all those experiencing symptoms will seek help.

Projected Dementia Cases in Sutton (2023 and 2040)

Based on population estimates, in Sutton the total number of people living with dementia aged 65 and over is expected to increase from 2,421 in 2023 to 3,384 in 2040, a 39.8% increase. In both male and females the 90+ age group is expected to show the largest percentage increase for both males and females, with 83.7% and 41.6% respectively.

POPPI data suggests that in 2023, 64.1% of dementia cases in those aged 65 and older were female, while 35.9% were male, likely due to women's longer life expectancy and age being a key risk factor. By 2040, dementia cases in this age group will rise more in men (50.3%) compared to women (33.9%). Consequently, the overall proportion of male cases is projected to increase to 38.6%, while female cases will decrease to 61.4%, indicating a slight narrowing of the gender gap.

Sex/Age	65-69	70-74	75-79	80-84	85-89	90+	Total
2023 (Male)	68	112	170	196	181	141	868
2040 (Male)	84	158	223	309	272	259	1305
% Increase (Male)	23.5	41.1	31.2	57.7	50.3	83.7	50.3
2023 (Female)	83	120	257	304	364	425	1553
2040 (Female)	103	162	317	410	485	602	2079
% Increase (Female)	24.1	35.0	23.3	34.9	33.2	41.6	33.9
2023 (All)	151	232	427	500	545	566	2421
2040 (All)	187	320	540	719	757	861	3384
% Increase (All)	23.8	37.9	26.5	43.8	38.9	52.1	39.8

Source: POPPI

About Sutton’s population - INT Population by Age and Ethnicity

Carshalton INT	65-69	70-74	75-79	80-84	85-89	90+	Total
Asian/ Asian British	118	105	63	52	30	6	373
Black/ Black British, Caribbean or African	84	34	33	22	16	2	190
Mixed or Multiple ethnic groups	28	17	14	5	1	1	66
Other ethnic group	34	20	8	11	4	2	78
White/ White British	1220	1090	724	611	389	204	4237
Total	1484	1265	840	700	439	215	4942

Central Sutton INT	65-69	70-74	75-79	80-84	85-89	90+	Total
Asian/ Asian British	221	195	110	94	46	20	685
Black/ Black British, Caribbean or African	67	47	31	29	18	4	195
Mixed or Multiple ethnic groups	24	32	14	19	8	3	99
Other ethnic group	72	65	25	18	13	8	200
White/ White British	1650	1577	1184	876	642	423	6351
Total	2033	1914	1364	1035	727	458	7528

Data Note: INT resident population by age and ethnicity. This has been apportioned to reflect the PCN registered patients resident in each ward. Belmont’s population is split 50/50 between CASS and Central Sutton, and Carshalton Central’s population is split 50/50 between Carshalton and Wallington to reflect that approximately half of people in both wards attend a GP practice in two PCNs.

Source: 2021 Census (ONS, 2023)

About Sutton’s population - INT Population by Age and Ethnicity

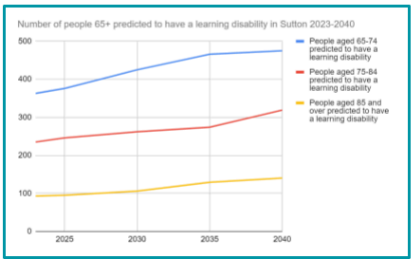
Cheam & South Sutton INT	65-69	70-74	75-79	80-84	85-89	90+	Total
Asian/ Asian British	350	259	160	109	44	19	940
Black/ Black British, Caribbean or African	43	23	20	23	7	3	118
Mixed or Multiple ethnic groups	34	13	19	18	6	3	92
Other ethnic group	79	64	35	21	4	7	209
White/ White British	1864	2110	1544	1103	777	477	7874
Total	2369	2467	1778	1273	838	509	9231

Wallington INT	65-69	70-74	75-79	80-84	85-89	90+	Total
Asian/ Asian British	305	260	165	140	70	22	961
Black/ Black British, Caribbean or African	123	74	57	44	19	8	324
Mixed or Multiple ethnic groups	27	30	15	12	4	2	90
Other ethnic group	50	37	30	15	10	5	146
White/ White British	2212	2314	1652	1079	764	483	8503
Total	2717	2714	1917	1289	866	520	10022

Data Note: INT resident population by age and ethnicity. This has been apportioned to reflect the PCN registered patients resident in each ward. Belmont’s population is split 50/50 between CASS and Central Sutton, and Carshalton Central’s population is split 50/50 between Carshalton and Wallington to reflect that approximately half of people in both wards attend a GP practice in two PCNs.

Source: 2021 Census (ONS, 2023)

Learning disabilities



Learning Disabilities - baseline estimates Sutton

	2023	2025	2030	2035	2040
People aged 65-74	363	376	425	466	475
People aged 75-84	235	246	262	274	319
People aged 85 and over	93	95	106	129	140
Total population predicted to have a learning disability	691	717	793	869	934

POPPI data projections suggest a significant increase in the number of individuals aged 65 and over with learning disabilities (LD) in Sutton, rising from 691 in 2023 to 934 by 2040, with notable increases in the 75-84 and 85+ age groups. This growth is likely to require additional health and care services, carer support, and infrastructure. Prevention strategies, such as LD annual health checks, will be important for promoting healthy lifestyles and enabling early detection and management of health issues.

POPPI data also suggests that there are 3,778 people with a learning disability aged 18+ living in Sutton, yet only 1,031 of these individuals have a recorded learning disability in GP records. While these estimates might overstate the number of individuals needing support, they highlight the importance of ongoing work to ensure that residents receive appropriate prevention advice to reduce their risk of dementia.

Population change

Age Group (Years)	2023	2028		2033	
	Number	Number	% Change from 2023	Number	% Change from 2023
0-4	11,914	11,324	-5.20%	11,439	-4.20%
5 to 10	16,637	14,542	-14.40%	13,681	-21.60%
11 to 17	20,453	20,429	-0.10%	18,063	-13.20%
18-24	14,433	15,441	6.50%	15,858	9.00%
25-64	117,073	117,577	0.40%	117,339	0.20%
65-84	28,463	31,721	10.30%	34,754	18.10%
85+	4,606	4,849	5.00%	6,044	23.80%
TOTAL	**213,580**	**215,882**	**1.10%**	**217,178**	**1.70%**

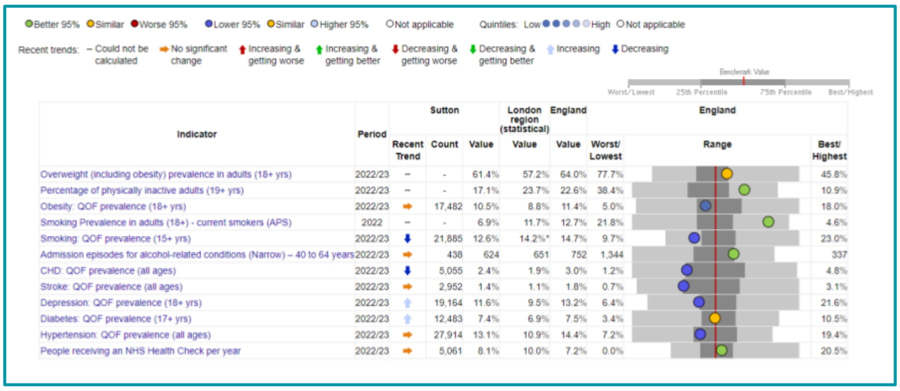
Between 2023 and 2033 the number of older people living in Sutton is predicted to increase significantly.

- The number of people aged 65-84 years is expected to increase by 18%
- The number of people aged 85+ is expected to increase by 24%.

As the number of older people increases so do the predicted number of cases of dementia (see next slide).

Preventing well

Dementia: preventing well profile for Sutton



🟢 Better 95% 🟡 Similar 🔴 Worse 95% 🔵 Lower 95% 🟡 Similar ○ Higher 95% ○ Not applicable Quintiles: Low ● ● ● ● ○ High ○ Not applicable

Recent trends: – Could not be calculated ➡ No significant change ⬆ Increasing & getting worse ⬆ Increasing & getting better ⬇ Decreasing & getting worse ⬇ Decreasing & getting better ⇧ Increasing ⬇ Decreasing

Indicator	Period	Sutton			London region (statistical)	England	England		
		Recent Trend	Count	Value	Value	Value	Worst/ Lowest	Range	Best/ Highest
Overweight (including obesity) prevalence in adults (18+ yrs)	2022/23	–	-	61.4%	57.2%	64.0%	77.7%	🟡	45.8%
Percentage of physically inactive adults (19+ yrs)	2022/23	–	-	17.1%	23.7%	22.6%	38.4%	🟢	10.9%
Obesity: QOF prevalence (18+ yrs)	2022/23	➡	17,482	10.5%	8.8%	11.4%	5.0%	🔵	18.0%
Smoking Prevalence in adults (18+) - current smokers (APS)	2022	–	-	6.9%	11.7%	12.7%	21.8%	🟢	4.6%
Smoking: QOF prevalence (15+ yrs)	2022/23	⬇	21,885	12.6%	14.2%*	14.7%	9.7%	🔵	23.0%
Admission episodes for alcohol-related conditions (Narrow) – 40 to 64 years	2022/23	➡	438	624	651	752	1,344	🟢	337
CHD: QOF prevalence (all ages)	2022/23	⬇	5,055	2.4%	1.9%	3.0%	1.2%	🔵	4.8%
Stroke: QOF prevalence (all ages)	2022/23	➡	2,952	1.4%	1.1%	1.8%	0.7%	🔵	3.1%
Depression: QOF prevalence (18+ yrs)	2022/23	⇧	19,164	11.6%	9.5%	13.2%	6.4%	🔵	21.6%
Diabetes: QOF prevalence (17+ yrs)	2022/23	⇧	12,483	7.4%	6.9%	7.5%	3.4%	🟡	10.5%
Hypertension: QOF prevalence (all ages)	2022/23	➡	27,914	13.1%	10.9%	14.4%	7.2%	🔵	19.4%
People receiving an NHS Health Check per year	2022/23	➡	5,061	8.1%	10.0%	7.2%	0.0%	🟢	20.5%

Summary statistics for sport and physical activity in Sutton (Adults)

73.3% of adults in Sutton are **active** = **116,000** people (aged 19+)

Significant higher than England (67.1%)... …and London (66.3%) on average

17.1% of adults in Sutton are **inactive** = **27,000** people (aged 19+)

lower than England (22.6%)... …and London (23.7%)

21.4% of adults in Sutton aged 18+ **are obese** similar to England (25.9%) but worse than London (19.7%)

1 in 3 people registered with a Sutton GP **have 1 or more long term conditions,** compared to 1 in 4 people in England

18.2% of people in Sutton **walk for travel** at least 3 days a week compared to 15.1% in England

1.7% of people in Sutton **cycle for travel** at least 3 days a week compared to 2.3% in England

1 in 6 deaths in the UK are associated with **physical inactivity**

1 in 6 people will experience a mental health problem this year **26,393 Sutton residents**

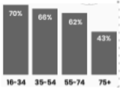
Every year, nearly **1,000** Sutton residents aged 65 and over have an emergency hospital admission because of a fall

1,559 People, aged 65 years and over, registered with a Sutton GP, are estimated to have diagnosis of dementia

INEQUALITIES IN PARTICIPATION (Data for England, Active Lives Adult Survey 2022/23)

Age and gender

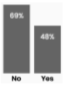
Men (66%) are generally more active than women (61%) and those who describe their gender in another way (61%). For all groups, activity levels decrease with age.



Disability and LTCs

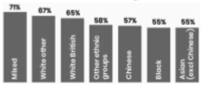
Activity levels amongst disabled people or those with a long-term health condition are lower (48%) than those without (69%). Unpaid carers are also less likely to be active.

Carers UK (2021)



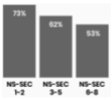
Ethnicity

There are differences in activity levels based on ethnic background.



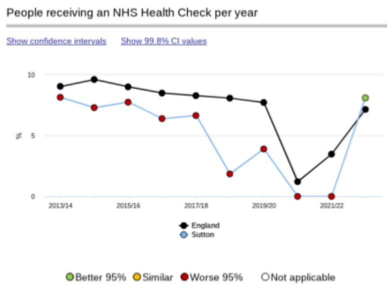
Socio-economic groups

Those in routine jobs, who are Long-term unemployed or have never worked are the least likely to be active (53%).



Preventing Well: NHS Health Checks

NHS Health Checks 2013/14 - 2022/23



A research study found that 77% of people living with dementia also live with other health conditions. These include conditions which are linked to an increased risk of dementia as well as others which have a known association with dementia, including heart disease, stroke/TIA, and diabetes.

The NHS Health Check programme can detect early signs of these conditions and can help to reduce the risk of these conditions developing for those aged 40 to 74 years of age.

All those who have a NHS health check are made aware that the risk factors for cardiovascular disease are the same as those for dementia. While those aged 65 - 74 years are also told about signs and symptoms of dementia and are signposted to memory services if appropriate.

In 2022/23 5,061 (8.1%) residents had an NHS Health Check in Sutton, significantly higher than the national average (7.2%) but lower than London (10.0%). Locally a new contact with Sutton PCNs has seen a dramatic improvement in the performance of the NHS Health Check programme in the borough.

Learning Disability Annual Health Checks 2023

The learning disabilities health check scheme is designed to encourage practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check, which includes producing a health action plan. Data in the table below is for individuals aged 18+ for England, SWL ICB, Sutton and the four PCNs.

Learning Disability Annual Health Checks 2023

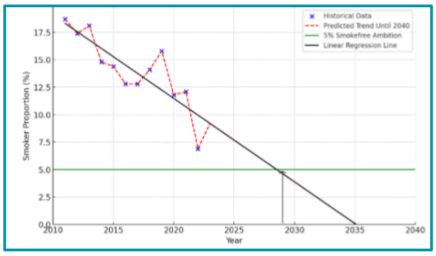
Area Name	Total LD Register (age 18+)	Completed health checks (age 18+)	Health Checks Declined	% Completed health checks
England	286,721	226,701	14,245	79.07%
NHS SWL ICB	6,353	5,502	239	86.60%
Sutton	1,031	900	31	87.29%
Central Sutton PCN	168	148	4	88.10%
Wallington PCN	410	363	7	88.54%
Carshalton PCN	216	180	12	83.33%
Cheam and South Sutton PCN	237	209	8	88.19%

In 2023, of the 1,031 adults on the LD register in Sutton, 900 completed their health checks, achieving a completion rate of 87.29%, higher compared to the national average of 79.07%. Within Sutton, the four Primary Care Networks (PCNs) performed well, with completion rates between 83.33% and 88.54%. Wallington PCN had the highest rate at 88.54%, followed by Cheam and South Sutton PCN at 88.19%, Central Sutton PCN at 88.10%, and Carshalton PCN at 83.33%. A total of 31 individuals declined health checks. While Sutton's LD health check completion rate exceeds the NHS South West London Integrated Care Board (ICB) average of 86.60%, the absence of confidence intervals means that it's not possible to say if this is statistically significant.

Preventing Well: Smoking

Smoking is one of the most significant risk factors for dementia. It doubles the risk of dementia by increasing the risk of cardiovascular disease, diabetes and stroke. Narrowing the blood vessels in the heart and brain and causing oxidase stress which damages the brain.

The Government has committed to achieving a Smokefree Generation and on 4 October 2023, the government published Stopping the start: our new plan to create a smokefree generation. Add about prevalence and link to doc



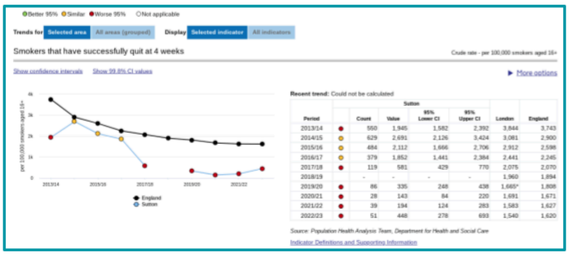
The graph on the left shows the predicted trend in smoking prevalence in Sutton. Based on most recent APS data (2022), it will take seven years for smoking prevalence in adults (18+) to reach 5%. Meaning that Sutton will be 'Smokefree' by 2029.

Assuming a linear decrease in smoking rates this is equivalent to a total of 3,052 quits or 436 smokers quitting each year in Sutton, (based on an adult population of 160,571). Although smoking prevalence in Sutton is considerably lower than the national average, fewer adults successfully quit smoking after four weeks than the national and regional averages.

Preventing Well: Smoking Cessation

Smokefree Generation

As part of the Government's commitment to Stopping the start: our new plan to create a smokefree generation £70 million of additional funding has been allocated per year nationally to support local stop smoking services. Sutton's allocation is £195,000. This funding will be used to improve uptake of local stop smoking services by contributing to a communication campaign, funding new outreach workers to deliver smoking cessation services in the community and providing training for frontline staff. There are opportunities to improve the quit rate in Sutton which has been significantly below the national and regional average since 2017/18.



Smokers that have successfully quit at 4 weeks

Crude rate - per 100,000 smokers aged 16+

Recent trend: Could not be calculated

Period	Sutton					London	England
		Count	Value	95% Lower CI	95% Upper CI		
2013/14	●	550	1,945	1,582	2,392	3,844	3,743
2014/15	●	629	2,691	2,126	3,424	3,081	2,900
2015/16	●	484	2,112	1,666	2,706	2,912	2,598
2016/17	●	379	1,852	1,441	2,384	2,441	2,245
2017/18	●	119	581	429	770	2,075	2,070
2018/19		-	-	-	-	1,960	1,894
2019/20	●	86	335	248	438	1,665*	1,808
2020/21	●	28	143	84	220	1,691	1,671
2021/22	●	39	194	124	283	1,583	1,627
2022/23	●	51	448	278	693	1,540	1,620

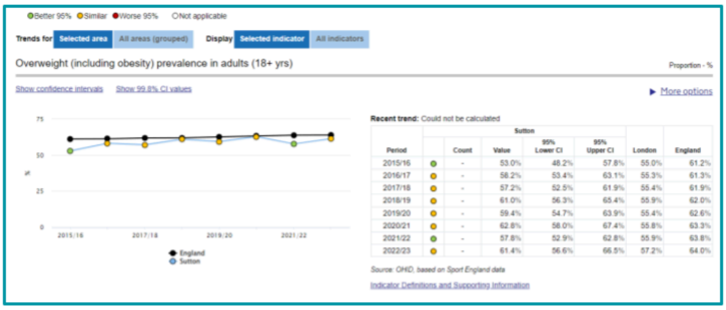
Source: Population Health Analysis Team, Department for Health and Social Care

Indicator Definitions and Supporting Information

In 2022/23 169 smokers in Sutton set a quit date, a rate of 1,475 per 100,000 which was significantly lower than the London (2,890 per 100,000) and England (2,998 per 100,000) averages.

The same year, 51 people in Sutton successfully quit smoking at four weeks, a rate of 448 per 100,000 which was significantly below the London (1,540 per 100,000) and England (1,620 per 100,000) averages.

Obesity



Overweight (including obesity) prevalence in adults (18+ yrs)

Proportion - %

Recent trend: Could not be calculated

Period	Sutton					London	England
		Count	Value	95% Lower CI	95% Upper CI		
2015/16	●	-	53.0%	48.2%	57.8%	55.0%	61.2%
2016/17	●	-	58.2%	53.4%	63.1%	55.3%	61.3%
2017/18	●	-	57.2%	52.5%	61.9%	55.4%	61.9%
2018/19	●	-	61.0%	56.3%	65.4%	55.9%	62.0%
2019/20	●	-	59.4%	54.7%	63.9%	55.4%	62.6%
2020/21	●	-	62.8%	58.0%	67.4%	55.8%	63.3%
2021/22	●	-	57.8%	52.9%	62.8%	55.9%	63.8%
2022/23	●	-	61.4%	56.6%	66.5%	57.2%	64.0%

Source: OHID, based on Sport England data

Indicator Definitions and Supporting Information

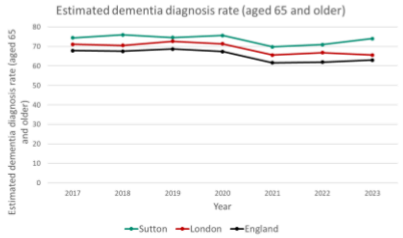
The graph and accompanying data show the prevalence of overweight (including obesity) in adults aged 18 and over in Sutton compared to London and England from 2015/16 to 2022/23. Sutton's prevalence has remained relatively stable, generally following the national trend and regional trend, with values ranging from 53.0% in 2015/16 to 61.4% in 2022/23.

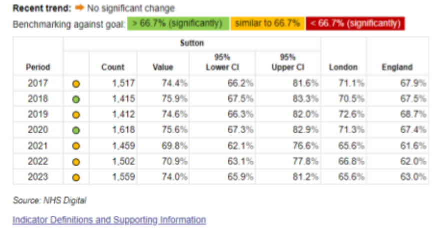
In 2022/23, approximately 21.1% of adults in Sutton were obese, which is comparable to London (21.9%) but significantly lower than the national average (26.2%). Increasing the proportion of residents who maintain a healthy weight could help to reduce the risk of dementia.

Diagnosing Well

Dementia: diagnosing well

A timely diagnosis enables people living with dementia, their carers and healthcare staff to plan accordingly and work together to improve health and care outcomes. However, not every person living with dementia has a formal diagnosis which will enable them to access services


Estimated dementia diagnosis rate (aged 65 and older)


Recent trend: ➡ No significant change

Benchmarking against goal: > 66.7% (significantly) similar to 66.7% < 66.7% (significantly)

Period	Sutton					London	England
		Count	Value	95% Lower CI	95% Upper CI		
2017	🟡	1,517	74.4%	66.2%	81.6%	71.1%	67.9%
2018	🟢	1,415	75.9%	67.5%	83.3%	70.5%	67.5%
2019	🟡	1,412	74.6%	66.3%	82.0%	72.6%	68.7%
2020	🟢	1,618	75.6%	67.3%	82.9%	71.3%	67.4%
2021	🟡	1,459	69.8%	62.1%	76.6%	65.6%	61.6%
2022	🟡	1,502	70.9%	63.1%	77.8%	66.8%	62.0%
2023	🟡	1,559	74.0%	65.9%	81.2%	65.6%	63.0%

Source: NHS Digital

Indicator Definitions and Supporting Information

From the 2023 national figures, of the 2,107 people aged 65 and older who are estimated to be living with dementia, only 1,559 people have been diagnosed with dementia in Sutton. This is about ¾ of the population, leaving **26% of residents (548) undiagnosed.**

Other factors that can delay diagnosis

Research suggests that certain groups may be less likely to receive a timely dementia diagnosis, delaying opportunities to plan their care.

People from minority ethnic groups can be hesitant to seek support due to stigma, language barriers, and cultural perceptions of health and caring. Delays in diagnosis can also be exacerbated by a lack of culturally appropriate services, access to interpreters, or culturally appropriate diagnostic tools.

Those living in areas of higher deprivation.

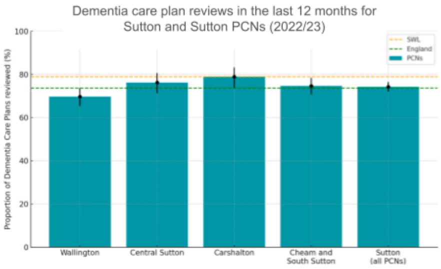
Younger people: as dementia is often thought of as a condition of old age, the early symptoms of early onset dementia are not always recognised and may be attributed to other causes including depression, stress, menopause, physical health problems and relationship issues. This can lead to a delay in getting an accurate diagnosis.

It's important to recognise dementia in individuals with learning disabilities as early as possible. However, this can be difficult to do because symptoms of dementia may overlap with other health issues the person has or be confused with the learning disability itself. Additionally, individuals might not seek help for memory problems because of a lack of awareness about dementia.

For those with Down's syndrome, the onset of epilepsy later in life can be a significant indicator of dementia. Therefore, it's essential for professionals and carers to be aware of changes in health and behaviour and seek medical advice when necessary.

Regular health checks, that include an assessment of physical and mental health, vision, hearing, and a medication review, are important. Any health issues should be addressed promptly. Those showing dementia symptoms should undergo investigations to identify treatable causes of cognitive decline. Additionally, individuals with Down's syndrome should receive a baseline dementia assessment at age 30 to monitor any changes over time.

Supporting Well



Dementia care plan reviews in the last 12 months for Sutton and Sutton PCNs (2022/23)

Dementia care plan reviews in GP practice

A dementia personalised care and support plan outlines what matters to an individual, the care and support they receive, and contingency plans for the future.

In 2022/23 in Sutton approximately 74.2% of dementia care plans were reviewed in the last 12 months. This was lower than the SWL average (78.9%) but statistically similar England (73.6%). However there was local variation, and in Wallington PCN just 69.7% of dementia reviews were completed, significantly lower than the Sutton and England averages.

Unsurprisingly, the proportion of care plans reviewed fell dramatically during the pandemic but has been increasing since.

PCN	Number of dementia Care Plans reviewed (2022/23)	Proportion of Dementia Care Plans reviewed % (2022/23)	CI lower	CI upper
Wallington	326	69.7%	65.3%	73.6%
Central Sutton	237	76.2%	71.2%	80.6%
Carshalton	228	78.9%	73.8%	83.2%
Cheam and South Sutton	351	74.7%	70.6%	78.4%
Sutton (all PCNs)	1,142	74.2%	72.1%	76.5%
SWL	8,010	78.9%	78.1%	79.7%
England	339,023	73.6%	73.5%	73.8%

Social care support for people with Dementia (years ending June 2022 - June 2024)

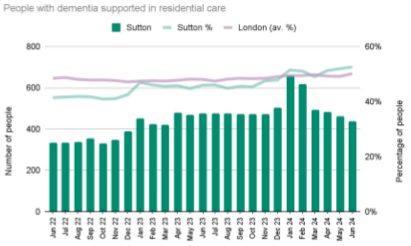
- As of the year ending June 2024, 439 people with dementia were supported in residential care, and a further 374 in the community.
- The number of people with dementia being supported by social care appears to have increased dramatically over the past year.

Residential

- Over the past three years, the percentage of people with dementia supported in residential care has increased from 41% to 53%.
  - Although the percentage of people supported in residential care has increased (from 48% to 50%) across London over the same time period, the increase seen in Sutton has been more rapid, and has taken Sutton from below the regional average, to above.
- There was a large increase in the number of people with dementia supported in residential care in January and February 2024.

Community

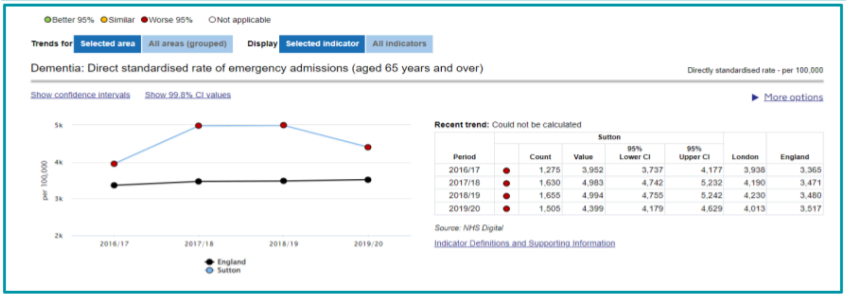
- Between July 2023 and October 2023, there was large growth in the number of people with dementia being supported in the community (from 287 people to 559 people).
  - Between the years ending June 2022 and 2024, the percentage of people supported in the community across London declined from 22% to 20%. This is in contrast to an increase seen in Sutton from 17% to 24% (driven by the increase, as above, over the past year.



People with dementia supported in residential care

People with dementia supported in the community

Dementia: Direct standardised rate of emergency admissions (aged 65 years and over)



Dementia: Direct standardised rate of emergency admissions (aged 65 years and over)

Directly standardised rate - per 100,000

Recent trend: Could not be calculated

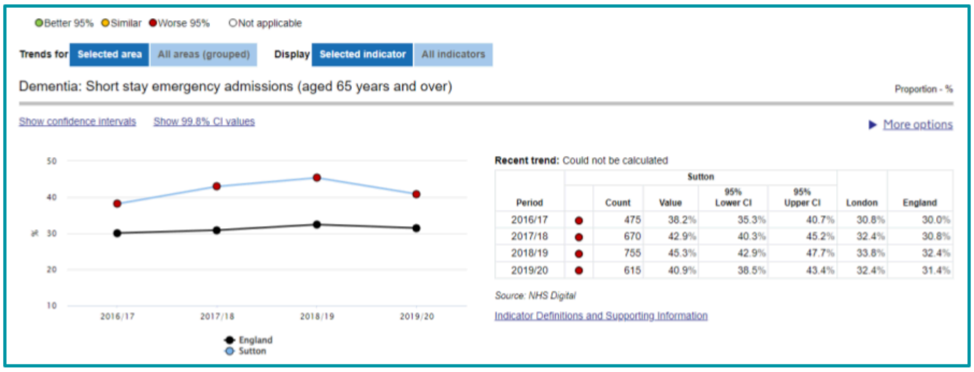
	Sutton						
Period		Count	Value	95% Lower CI	95% Upper CI	London	England
2016/17	●	1,275	3,952	3,737	4,177	3,938	3,365
2017/18	●	1,630	4,983	4,742	5,232	4,190	3,471
2018/19	●	1,655	4,994	4,755	5,242	4,230	3,480
2019/20	●	1,505	4,399	4,179	4,629	4,013	3,517

Source: NHS Digital

Indicator Definitions and Supporting Information

Analysis of Emergency Admissions to Hospital with Dementia data for 2018-19 to 2021-22 identified the ten most common primary diagnosis reasons (with a secondary diagnosis of dementia) to be urinary tract infection, tendency to fall, lobar pneumonia, sepsis, pneumonia, fracture of neck of femur, lower respiratory infection, pneumonitis due to food and vomit, COVID-19 and acute renal failure.

Dementia: Short stay emergency admissions (aged 65 years and over)



Dementia: Short stay emergency admissions (aged 65 years and over)

Proportion - %

Recent trend: Could not be calculated

	Sutton						
Period		Count	Value	95% Lower CI	95% Upper CI	London	England
2016/17	●	475	38.2%	35.3%	40.7%	30.8%	30.0%
2017/18	●	670	42.9%	40.3%	45.2%	32.4%	30.8%
2018/19	●	755	45.3%	42.9%	47.7%	33.8%	32.4%
2019/20	●	615	40.9%	38.5%	43.4%	32.4%	31.4%

Source: NHS Digital

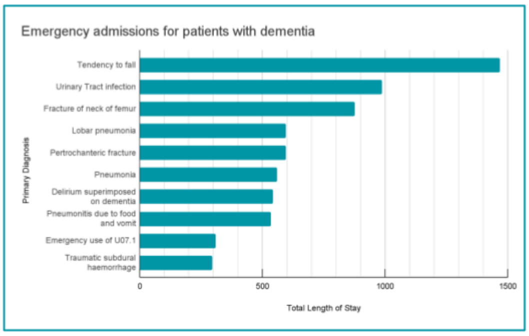
Indicator Definitions and Supporting Information

Dementia: Emergency Admissions

Across 2022-24, **patients with dementia spent a total of 129,180 days in hospital**. The ten primary diagnosis reasons which generated the greatest total length of stay in hospital for patients with dementia is shown in the figure to the right.

People with cognitive impairment such as dementia are at greater risk of falling and sustaining a serious injury which is consistent with the numbers of primary diagnosis relating to tendency to fall, fracture of neck of femur (hip fracture) and pertrochanteric fracture (hip fracture) in the highest total length of stay. Falls may indicate overall physical frailty which is consistent with the ageing process, but those with young onset dementia may also become frail.

People with dementia are at risk of developing a urinary tract infection (UTI) due to weakened immune systems, difficulties in maintaining personal hygiene and catheter use. UTIs may cause delirium in older people and people with dementia. The infection may also speed up the progression of dementia.


Emergency admissions for patients with dementia

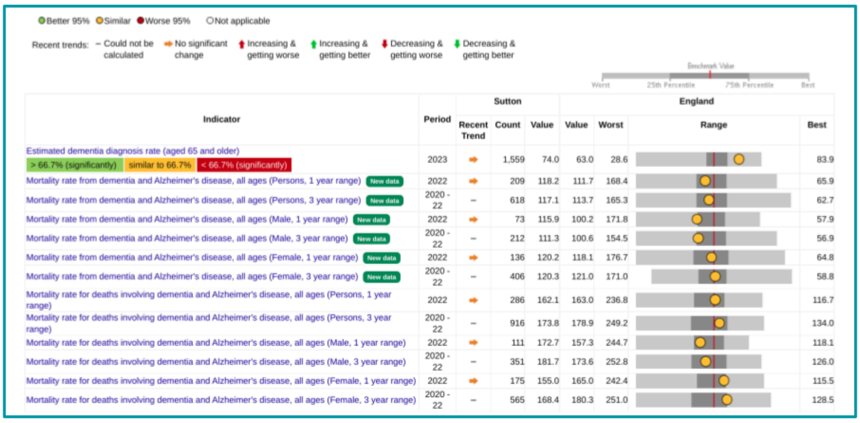
Date note: Primary diagnosis - Emergency use of U07.1. This code is for Covid-19, virus identified. *

The SWL Health Insights data has a smaller cohort of people with a QOF dementia recorded diagnosis (n=1,300) than OHID and NHSE. However, the SWL data enables us to look at our population in more granular detail.

* From SWL Health Insights Data Extract 14th May 2024

Dying Well

Dementia: mortality profile for Sutton

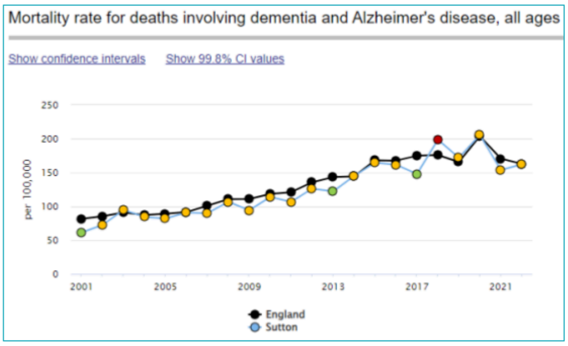


● Better 95% ● Similar ● Worse 95% ○ Not applicable

Recent trends: – Could not be calculated → No significant change ↑ Increasing & getting worse ↑ Increasing & getting better ↓ Decreasing & getting worse ↓ Decreasing & getting better

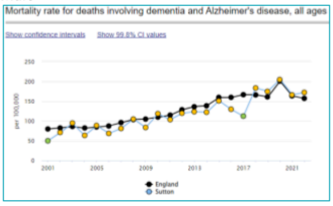
Indicator	Period	Sutton			England			
		Recent Trend	Count	Value	Value	Worst	Range	Best
Estimated dementia diagnosis rate (aged 65 and older) 🟩 > 66.7% (significantly) 🟨 similar to 66.7% 🟥 < 66.7% (significantly)	2023	→	1,559	74.0	63.0	28.6		83.9
Mortality rate from dementia and Alzheimer's disease, all ages (Persons, 1 year range) New data	2022	→	209	118.2	111.7	168.4		65.9
Mortality rate from dementia and Alzheimer's disease, all ages (Persons, 3 year range) New data	2020 - 22	–	618	117.1	113.7	165.3		62.7
Mortality rate from dementia and Alzheimer's disease, all ages (Male, 1 year range) New data	2022	→	73	115.9	100.2	171.8		57.9
Mortality rate from dementia and Alzheimer's disease, all ages (Male, 3 year range) New data	2020 - 22	–	212	111.3	100.6	154.5		56.9
Mortality rate from dementia and Alzheimer's disease, all ages (Female, 1 year range) New data	2022	→	136	120.2	118.1	176.7		64.8
Mortality rate from dementia and Alzheimer's disease, all ages (Female, 3 year range) New data	2020 - 22	–	406	120.3	121.0	171.0		58.8
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Persons, 1 year range)	2022	→	286	162.1	163.0	236.8		116.7
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Persons, 3 year range)	2020 - 22	–	916	173.8	178.9	249.2		134.0
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Male, 1 year range)	2022	→	111	172.7	157.3	244.7		118.1
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Male, 3 year range)	2020 - 22	–	351	181.7	173.6	252.8		126.0
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Female, 1 year range)	2022	→	175	155.0	165.0	242.4		115.5
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages (Female, 3 year range)	2020 - 22	–	565	168.4	180.3	251.0		128.5

Dementia & Alzheimer's Disease



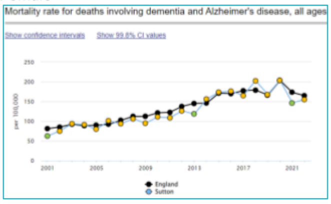
Mortality rate for deaths involving dementia and Alzheimer's disease, all ages

Male



Mortality rate for deaths involving dementia and Alzheimer's disease, all ages

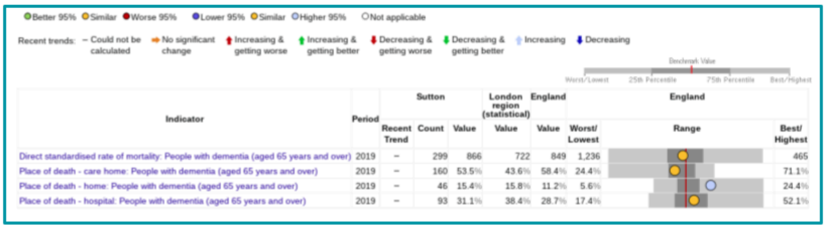
Female



Mortality rate for deaths involving dementia and Alzheimer's disease, all ages

In 2022, Sutton's all age mortality rate for deaths involving dementia and Alzheimer's disease (118.2 per 100,000) is higher than London (101.2 per 100,000) and England (111.7 per 100,000).

Dying Well

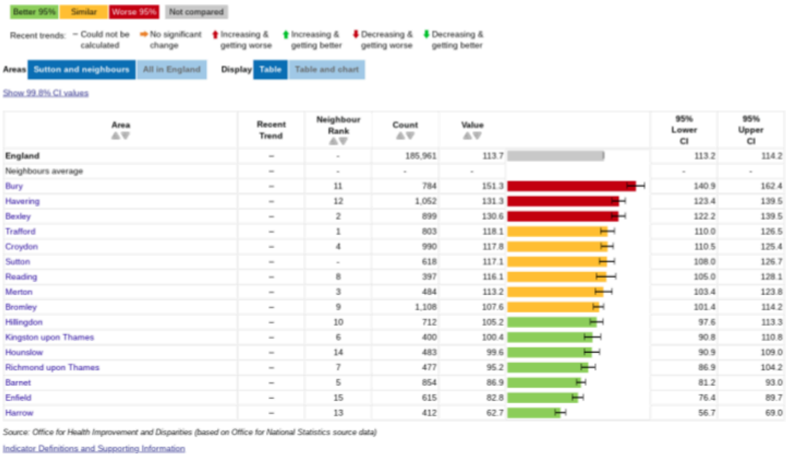


Indicator	Period	Sutton			London region (statistical)	England	England		
		Recent Trend	Count	Value	Value	Value	Worst/ Lowest	Range	Best/ Highest
Direct standardised rate of mortality: People with dementia (aged 65 years and over)	2019	–	299	866	722	849	1,236		465
Place of death - care home: People with dementia (aged 65 years and over)	2019	–	160	53.5%	43.6%	58.4%	24.4%		71.1%
Place of death - home: People with dementia (aged 65 years and over)	2019	–	46	15.4%	15.8%	11.2%	5.6%		24.4%
Place of death - hospital: People with dementia (aged 65 years and over)	2019	–	93	31.1%	38.4%	28.7%	17.4%		52.1%

Source: Fingertips (accessed 27/07/2024)

Place of death statistics for people with dementia consider care homes, home, and hospital settings. They offer valuable information about people's end-of-life care preferences and the capacity of local health and care services to support them. Monitoring these indicators helps areas to identify opportunities for improvements in providing patient centred care.

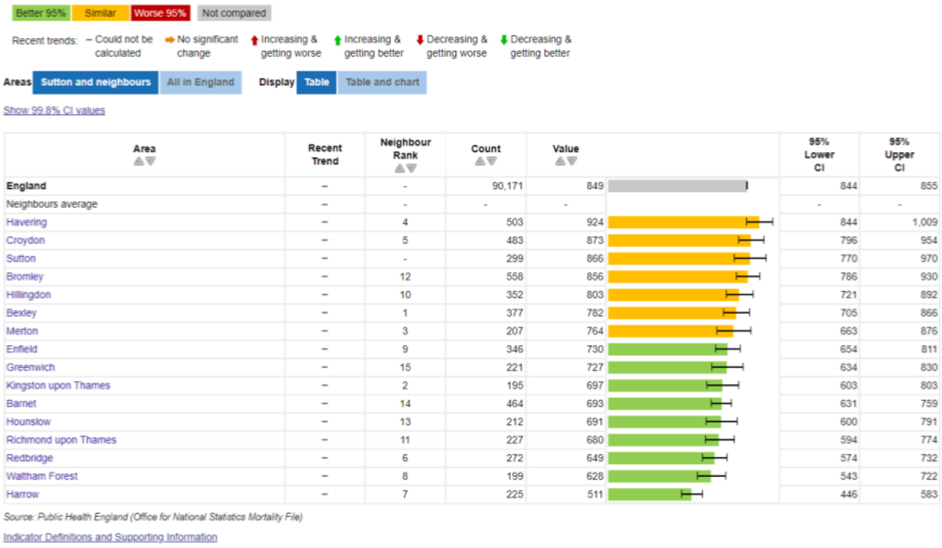
The place of death statistics above show that the percentages of deaths in care homes (53.5%), homes (15.4%), and hospitals (31.1%) in Sutton were all similar to the England averages of 58.4%, 11.2%, and 28.7%, respectively in 2019.



Area	Recent Trend	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	–	-	185,961	113.7	113.2	114.2
Neighbours average	–	-	-	-	-	-
Bury	–	11	784	151.3	140.9	162.4
Havering	–	12	1,052	131.3	123.4	139.5
Bexley	–	2	899	130.6	122.2	139.5
Trafford	–	1	803	118.1	110.0	126.5
Croydon	–	4	990	117.8	110.5	125.4
Sutton	–	-	618	117.1	108.0	126.7
Reading	–	8	397	116.1	105.0	128.1
Merton	–	3	484	113.2	103.4	123.8
Bromley	–	9	1,108	107.6	101.4	114.2
Hillingdon	–	10	712	105.2	97.6	113.3
Kingston upon Thames	–	6	400	100.4	90.8	110.8
Hounslow	–	14	483	99.6	90.9	109.0
Richmond upon Thames	–	7	477	95.2	86.9	104.2
Barnet	–	5	854	86.9	81.2	93.0
Enfield	–	15	615	82.8	76.4	89.7
Harrow	–	13	412	62.7	56.7	69.0

Source: Office for Health Improvement and Disparities (based on Office for National Statistics source data)

Indicator Definitions and Supporting Information



Area	Recent Trend	Neighbour Rank	Count	Value	95% Lower CI	95% Upper CI
England	–	-	90,171	849	844	855
Neighbours average	–	-	-	-	-	-
Havering	–	4	503	924	844	1,009
Croydon	–	5	483	873	796	954
Sutton	–	-	299	866	770	970
Bromley	–	12	558	856	786	930
Hillingdon	–	10	352	803	721	892
Bexley	–	1	377	782	705	866
Merton	–	3	207	764	663	876
Enfield	–	9	346	730	654	811
Greenwich	–	15	221	727	634	830
Kingston upon Thames	–	2	195	697	603	803
Barnet	–	14	464	693	631	759
Hounslow	–	13	212	691	600	791
Richmond upon Thames	–	11	227	680	594	774
Redbridge	–	6	272	649	574	732
Waltham Forest	–	8	199	628	543	722
Harrow	–	7	225	511	446	583

Source: Public Health England (Office for National Statistics Mortality File)

Indicator Definitions and Supporting Information

Policy

Policy

NHS Long Term Plan (2019)

Major Conditions Strategy: Case for Change (2023)

Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset | Guidance | NICE (2015)

assessment, management and support for people living with dementia and their carers | Guidance | NICE (2018)

Together six groups of major health conditions drive over 60% of mortality and morbidity in England, and it is increasingly common for patients to experience two or more of these conditions at the same time.

Our strategic framework focuses on:

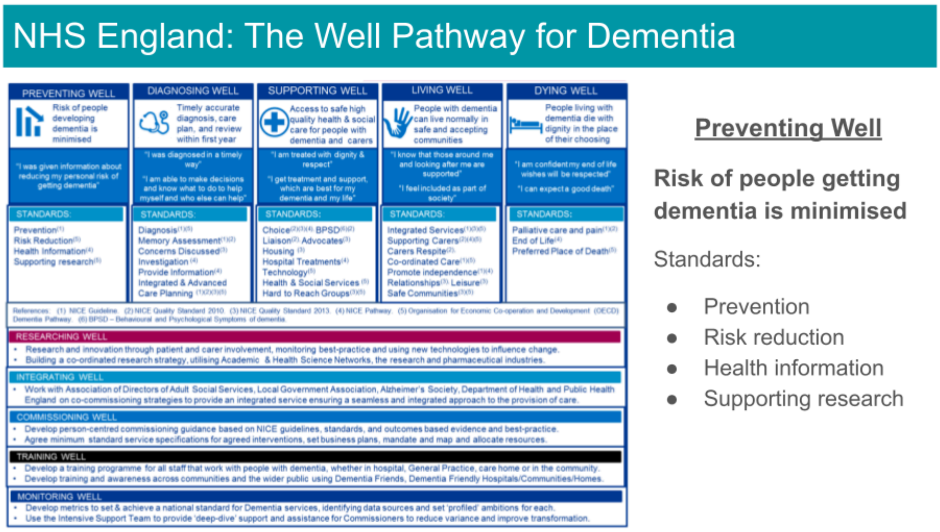
Primary prevention: acting across the population to reduce risk of disease

Secondary prevention: halting progression of conditions or risk factors for an individual

Early diagnosis: so we can identify health conditions early, to make treatment quicker and easier

Prompt and urgent care: treating conditions before they become crises

Long-term care and treatment: in both NHS and social care settings



NHS England: The Well Pathway for Dementia

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
Risk of people developing dementia is minimised	Timely accurate diagnosis, care plan, and review within first year	Access to safe high quality health & social care for people with dementia and carers	People with dementia can live normally in safe and accepting communities	People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS:	STANDARDS:	STANDARDS:	STANDARDS:	STANDARDS:
Prevention(1) Risk Reduction(5) Health Information(4) Supporting research(5)	Diagnosis(1)(5) Memory Assessment(1)(2) Concerns Discussed(3) Investigation (4) Provide Information(4) Integrated & Advanced Care Planning (1)(2)(3)(5)	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)	Integrated Services(1)(3)(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)	Palliative care and pain(1)(2) End of Life(4) Preferred Place of Death(5)

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.

RESEARCHING WELL
- 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.

INTEGRATING WELL
- 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.

COMMISSIONING WELL
- 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.

TRAINING WELL
- 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.

MONITORING WELL
- 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.

Preventing Well

Risk of people getting dementia is minimised

Standards:

- Prevention
- Risk reduction
- Health information
- Supporting research

Ignore - holding content for possible placement

We need as in part a balance to what is strongly a community strategy a section about bed / accommodation based services. eg Where people with dementia are placed in care homes of ECH because their dementia has progressed to a stage where they are no longer able to live safely in their normal place of residence and / or caring roles have broken down. Recommissioning to provide a dementia respite care flat at Dymond House as a redesign of the re-ablement flats. Where the Council commissions - meeting the needs of people with dementia is a key requirement - 5.29 the provider shall be expected to manage the needs of the person with dementia. The provider is expected to ensure:

a) all care and support is provided within the legal requirements of the Mental capacity Act (2005) and Mental Health Act (1983 and 2007, incl. Deprivation of Liberty and safeguards, b) all care and support provided for service users with dementia is provided in line with NICE guidelines and (where available) local and national dementia initiatives, c) all staff have a knowledge and understanding of the signs and symptoms of long standing/ chronic/severe dementia supported by relevant training such as dementia training and how to communicate effectively with people with dementia, d) the premises (including fixtures and fittings are consistent with best practice on creating a 'dementia friendly environment (which may include the use of specialised technology, e) all staff are responsive to the service users individual needs and support service users choice and ability to make decisions (where ever possible), f) the service care plan includes activities of daily living tha\t maximise *independence and enhance function, adapt and minimise the need for support (wherever possible), g) to ensure any services users experiencing behavioural and psychological symptoms of dementia is referred to a GP to consider specialist assessment.*

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