

Lewisham Dementia Strategy –

‘reducing the risk of dementia (or delaying its onset) and enabling people living with dementia and their carers to live well’

2023 – 2026

Contents

What is Dementia?	3
Approach	4
Continuous and meaningful involvement of people with Dementia and their unpaid carers	5
Foreword	6
What our residents want from the Dementia strategy – consultation	7
Executive Summary	8
Introduction	9
Dementia in Lewisham	10
Reducing the risk of dementia	11
Stages of dementia	12
Dementia diagnosis	13
Lewisham Memory Service	14
Person-Centred Care	15
Lewisham Dementia Support Hub	16
Caring (unpaid) for someone with Dementia	17
Carers Lewisham	18
Hospital Care	19
Effective management of behavioural and psychological symptoms of dementia	20
Remaining at home for as long as is possible	21
Feeling part of the community	22
Travelling by public transport	23
Physical environment	24
Dementia friendly Lewisham	25
Last year of life	26
Palliative care team	27
Alzheimer's Journey	28
Measures of success	29



What is Dementia?

'My brain is just... well it's just leaving me and I don't think you can do anything about that'

'Life's completely changed. I'm not very independent. I have to rely on others. Life's going very slowly. Time goes very slowly'

Dementia is not a disease in itself. Dementia is a word used to describe a group of symptoms that occur when brain cells stop working properly.

Dementia affects memory, thinking, behaviour and emotion.

Early symptoms of dementia can include memory loss, difficulty performing familiar tasks, problems with language and changes in personality

There is currently no cure for dementia, but a range of support is available for people with dementia and their carers.

Dementia knows no social, economic, or ethnic boundaries.

Alzheimer's disease is the most common cause of dementia. Other causes include vascular disease, dementia with Lewy bodies and fronto-temporal dementia

'In the UK, Black African and Caribbean people develop dementia more often and at younger ages than their White counterparts. Despite this, Black African and Caribbean people tend to use dementia services much later, often when they are in a crisis or no longer able to cope alone. They are also less likely to receive drug treatments, take part in dementia research and move into a care home.'

Approach

'In developing and implementing our Dementia strategy for Lewisham, we must constantly focus on these three questions:

- Do lifestyle factors reduce your risk of Dementia?*
- If your parents develop Dementia, how would you like them to be treated?*
- If you develop Dementia, how would you like to be treated?'*



Continuous and meaningful involvement of people with Dementia and their unpaid carers

Coproduction

‘With a little bit of support, stimulation and encouragement most people with dementia can do it’

Our strategy has been developed and will be implemented and monitored through ongoing meaningful engagement with people with dementia and their unpaid carers. Only by ensuring that our key outcomes continue to address the needs of people with dementia and their unpaid carers, will we succeed in giving them the sense of respect, dignity, purpose and outcomes they seek and deserve.

Key actions:

- Quarterly updates on impact of the strategy
- Ongoing community consultations and workshops
- An annual survey to seek feedback on the experiences of people living with dementia in their community and changes they would like to see put in place
- Resources (for example, how to communicate with people with dementia and information on dementia) to support the inclusion of the views and voices of people living with dementia in their community

Foreword

In common with the national picture, we're expecting to see a rise in the number of people with dementia in our borough over the years and decades ahead as the size of our older population increases. That's why Lewisham Council is working with local healthcare and social care providers on a new strategy to support people with dementia, and their family and carers.

This strategy will set out our shared ambitions to improve the diagnosis, care and support provided to people with dementia

Our aim is that all people living with dementia and their carers are empowered and know the risk factors for dementia, and where to seek information, advice and help.

It is also our aim that people should have access to the care and support that enables them to live well for as long as possible.

To help us achieve these overall aims, our dementia strategy has identified some key things that we will track to ensure that we are making progress towards our goals. We want to make sure we've got these right – which is why we're encouraging people to share their views on these proposed outcomes. It's important that we hear from people who have direct and indirect experience of dementia so that we can better understand if we're focusing on the outcomes that will really make a difference.

Please take part in our consultation. Responses will help shape the further development of the strategy and we'll share an update on this important work later this year.

What our residents want from the Dementia strategy – consultation

How strongly do you agree with the 8 proposed outcomes of the Lewisham Dementia strategy:

- Agree strongly
- Agree, but would like the outcome to go further
- Neutral
- Disagree because the outcome is going in the wrong direction
- Strongly disagree because the strategy should not focus on that outcome

<https://www.rsph.org.uk/static/uploaded/b0d54256-80fa-4a9e-9beb700936daa61a.pdf>

Key outcomes:

1. Increased public awareness of the link between dementia and lifestyle.
2. Increased uptake of healthy lifestyle choices.
3. Increased diagnosis rates
4. Reduced antipsychotic prescribing rates for people with dementia
5. Improved quality of life of people with dementia.
6. Increased proportion of people with dementia who feel encouraged to make decisions about their future care.
7. Increased proportion of people with dementia who are aware they can update their advance care plan at each care review.
8. Increased proportion of people with dementia who participate in activities to promote their wellbeing.

Executive Summary

Preventing Well

There's no certain way to prevent all types of dementia, however, there is good evidence that a healthy lifestyle can help reduce your risk of developing dementia as you get older.

Diagnosing Well

Getting a diagnosis of dementia can give you a better understanding of the condition and what to expect. Timely diagnosis can help you make important decisions about treatment, support and care.

Supporting Well

Recent research has demonstrated that people can live well with dementia if provided with the right support when needed. We will also continue to improve the quality of health and social care with the expectation that improving care and treatment will reduce consumption of antipsychotic medicines amongst people with dementia.

Living Well

People living with dementia also need support from our communities in order to enjoy the best quality of life possible, ensuring that Lewisham is a great place to live for residents with dementia and their relatives.

Dying Well

Enabling person to die in the way that they would have wanted, giving priority to the things that matter most to them. It also supports family and carers during the final stages, as well as after the person has died.

Introduction

Dementia is often associated with older people, but dementia affects adults of all ages. When talking about dementia, the term 'younger' usually covers people below 65 years of age. It is estimated that around xxx Lewisham residents below 65 are diagnosed with dementia.

Dementia is currently the seventh leading cause of death and one of the major causes of disability and dependency among older people globally. 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.

The risk of developing dementia increases exponentially with age. As population ageing continues to accelerate in the UK and worldwide, the number of people living with dementia is set to rise sharply in the decades to come.

Since 2011, successive UK Governments have identified dementia as a national policy and focused on:

- Driving improvements in health and care
- Creating dementia friendly communities
- Promoting better research

Our Lewisham Strategy provides us with an opportunity to:

- Review local progress on implementing the national recommendations
- Collectively agree and monitor the most effective way of reducing the risk of dementia (or delaying its onset) and enabling people living with dementia and their carers to live well'

'I'm a different person to the one my wife married...I can't get through to the part of my brain that wants to ask her how she is, give her a kiss and a cuddle'

Through implementing the Strategy, we will achieve the following 8 outcomes:

1. Increased public awareness of the link between dementia and lifestyle.
2. Increased uptake of healthy lifestyle choices.
3. Increased diagnosis rates
4. Reduced antipsychotic prescribing rates for people with dementia
5. Improved quality of life of people with dementia.
6. Increased proportion of people with dementia who feel encouraged to make decisions about their future care.
7. Increased proportion of people with dementia who are aware they can update their advance care plan at each care review.
8. Increased proportion of people with dementia who participate in activities to promote their wellbeing.

Dementia in Lewisham

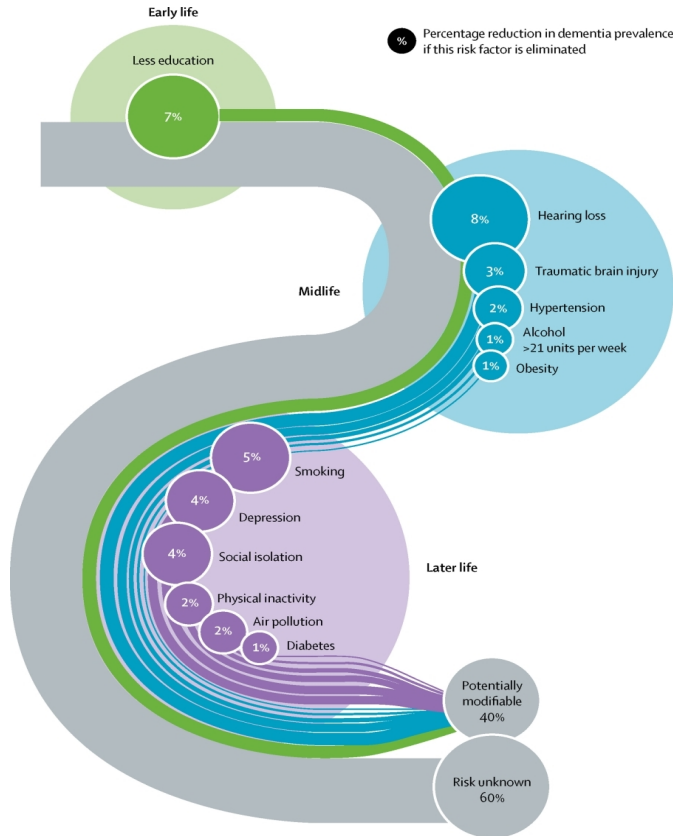
Local context

- There were 59,597,300 people living in England and Wales on 21 March 2021, the day of the latest census. This is over 3.5 million more (6.3%) than in 2011 and is the largest census population ever recorded. In Lewisham, the population size has increased by 9.0%, from around 275,900 in 2011 to 300,600 in 2021. At 9.0%, Lewisham's population increase is higher than the increase for London (7.7%). Lewisham is now ranked 44th for total population out of 309 local authority areas in England, moving up one place in a decade. As of 2021, Lewisham is the 13th most densely populated of London's 33 local authority areas, with around 61 people living on each football pitch-sized area of land.
- The population has continued to age. Across England, more than one in six people (18.4%) were aged 65 years and over on Census Day in 2021. This is a higher percentage than ever before. Within Lewisham there has been an increase of 9.8% in people aged 65 years and over, an increase of 10.8% in people aged 15 to 64 years, and an increase of 1.8% in children aged under 15 years.



Reducing the risk of dementia

Preventing Well



Risk factors

Risk factors in early life (education), midlife (hypertension, obesity, hearing loss, Traumatic Brain Injury, and alcohol misuse) and later life (smoking, depression, physical inactivity, social isolation, diabetes, and air pollution) can contribute to an increased risk of dementia.

By modifying these risk factors through adopting a healthy lifestyle, risk of dementia could be reduced by around a third.

However, just a third (33%) of UK adults think it's possible for people to reduce their risk of dementia. Women are less likely to think it's possible to influence their dementia risk than men (30% compared to 37%). Despite limited understanding of the ability to reduce dementia risk, three quarters (75%) of people believe it's possible for a person to influence their brain health, suggesting that positively reframing dementia risk reduction as 'protecting brain health' represents a major opportunity to increase public engagement.

Stages of dementia

Early stage: the early stage of dementia is often overlooked because the onset is gradual

Common symptoms may include:

- **Forgetfulness**
- **Losing track of the time**
- **Becoming lost in familiar places.**

Middle stage

The signs and symptoms become clearer and may include:

- **Becoming forgetful of recent events and people's names**
- **Becoming confused while at home**
- **Having increasing difficulty with communication**
- **Needing help with personal care**
- **Experiencing behaviour changes, including wandering and repeated questioning**

Late stage: the late stage of dementia is one of near total dependence and inactivity

Physical signs and symptoms become more obvious and may include:

- **Becoming unaware of the time and place**
- **Having difficulty recognising relatives and friends**
- **Having an increasing need for assisted self-care**
- **Experiencing behaviour changes that may escalate and include aggression.**

Dementia diagnosis

Diagnosing Well

You can help reduce stigma

You are in a better position to speak out

You can make empowering choices

Your family will be better able to support you

You can focus on what's important

You get an accurate diagnosis so you will know what to expect

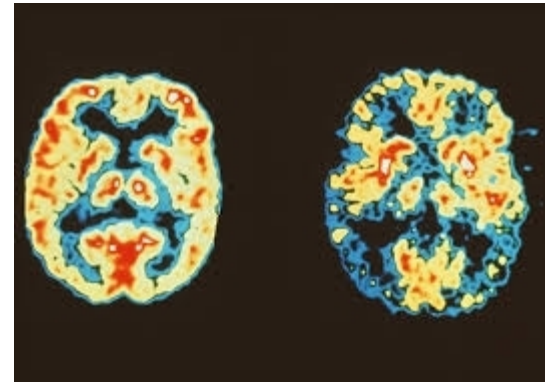
You can make empowering choices

You can become more actively involved in your personal decisions, including health and social care

You can lift heavy cloud from your face

Dementia affects each person in a different way, depending upon the underlying causes, other health conditions and the person's cognitive functioning before becoming ill.

Although there is no cure for dementia at the moment, an early diagnosis means its progress can be slowed down in some cases, so the person may be able to maintain their mental function for longer. A diagnosis helps people with dementia get the right treatment and support. It can also help them, and the people close to them, to prepare for the future. With treatment and support, many people are able to lead active, fulfilled lives with dementia.



Lewisham Memory Service

Comprehensive assessment, treatment and support options

The Lewisham Memory Service offers comprehensive assessment, treatment and support options to anyone over the age of 18 with memory problems likely to indicate dementia. The aim of the service is to assess dementia early and provide a timely diagnosis, so people with dementia and their carers can understand the condition, learn of treatment options and opportunities to participate in research, and connect with appropriate support resources to facilitate living well.

Our multidisciplinary team works in collaboration with the memory clinics at University Hospital Lewisham to provide high quality specialist care. The service is unable to directly support those with serious behavioural and psychological symptoms of dementia but can refer on to other community mental health teams for such support.

Following assessment, staff will coordinate individualised care planning. This may include prescribing medication if appropriate, post diagnostic support and sign-posting, problem solving strategies and referrals to relevant support services such as the Lewisham Dementia Support Hub.

Phone: 0203 228 0939

Email: memoryservicelewisham@slam.nhs.uk

Website: <https://slam.nhs.uk/service-detail/service/memory-service-lewisham-148/>

Person Centred Care

Supporting Well

It has made me feel isolated in a way, because I haven't got anything to talk about. And the other thing is, because I do try and act normal, but I don't feel that I am.

In the beginning – maybe I shouldn't have, but: 'Well, I'm sorry, I can't do that because I've got dementia'. And they're like: 'Uh, uh...' So I panicked. I thought people would understand in this day and age.

We went into the consultation husband and wife and came out person suffering from dementia and carer

Support should be sensitive to the person as an individual. This is called person-centred care.

One of the foundations of the Strategy is the expectation that all services and businesses will embed the principles of person-centred care into all aspects of service delivery. The principles promote:

- The human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers
- The individuality of people living with dementia, and how their personality and life experiences influence their response to dementia
- The importance of the person's perspective
- The importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

The principles also emphasise the importance of taking account of the needs of carers and supporting and enhancing their input.

Lewisham Dementia Support Hub

Single point of access

Currently being worked up as service will be provided by the Alzheimer's Society from 01 April 2023

Caring (unpaid) for someone with Dementia

Caring Well - the capacity to care is the thing which gives life its deepest significance

'The care of dementia is actually the care of two people: the person with the illness and the person taking care of them'

'Although your loved one may not remember you or might do things that frustrate you, this is the time when he or she needs you the most'

'No matter who you are, what you've accomplished, what your financial situation is – when you're dealing with a parent with dementia, you yourself feel helpless. The parent can't work, can't live alone, and is totally dependent, like a toddler. As the disease unfolds, you don't know what to expect'

It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.

We know from carers locally that peer to peer support is vital and often the information they gain from other carers is more valuable and relevant than information provided by health and social care professionals.

People respond well to the opportunity to share positive and negative experiences with those who understand. The Dementia Hub within Lewisham ... (to add)

Carers Lewisham

Supporting unpaid carers who care for a friend or family member who couldn't manage without them

If you are an unpaid carer, Carers Lewisham provide a range of services that you can access:

- Advice and Information,
- Emotional support
- Short breaks
- Opportunities to meet other carers
- Relaxation days and well-being sessions
- Specialist support for carers of people with dementia, carers of people with mental health problems, older carers and carers who are caring for someone nearing the end of their life.

Phone: 020 8699 8686

Email: info@carerslewisham.org.uk

Website: <https://www.carerslewisham.org.uk/about-us/>

Hospital care

Supporting Well

Ensuring all people with dementia admitted to hospital have a comprehensive assessment of cognition, delirium, pain, continence and nutritional needs

Ensuring all people with dementia with social care needs who are in hospital have a named discharge coordinator to ensure a safe and planned discharge from hospital

Ensuring all health and social care hospital staff encourage and enable people (living with dementia) to give their own views and opinions about their care

Ensuring all people with severe dementia have an assessment prior to admission that balances the person's current medical needs with the additional harms they may face in hospital, such as a longer length of stay and increased mortality.

- At any one time 1 in 4 hospital beds are occupied by people living with dementia.
- 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.
- Before admitting a person living with dementia to hospital, the value of keeping them in a familiar environment as well as any advance care and support plans should be taken into account.



Effective management of behavioural and psychological symptoms of dementia

Supporting Well

Antipsychotic drugs are a group of medications that are usually used to treat people with Severe Mental Illness (SMI) such as schizophrenia. In some people antipsychotics can eliminate or reduce the intensity of certain symptoms. However, they also have serious side effects for people living with dementia.

An independent review of the use of antipsychotic medication for people with dementia (The Banerjee Report, Time for Action, 2008) concluded that:

- Antipsychotic use was too high in patients with dementia, and that the associated risks outweighed the benefits in most of these patients because these drugs seemed to have only a limited positive effect in managing dementia symptoms.
- Antipsychotics seemed to be used too often as a first-line response to difficult behaviour in dementia (most often agitation), rather than as a considered second-line treatment when other non-pharmacological

NICE advice states that a person living with dementia should only try an antipsychotic if they are at risk of harming themselves or others, or if they are severely distressed. The antipsychotic should be tried alongside other activities to try to help their distress. Risperidone is the only licensed anti-psychotic of choice for short-term use which is licensed for 6 weeks use, after which a review should follow.

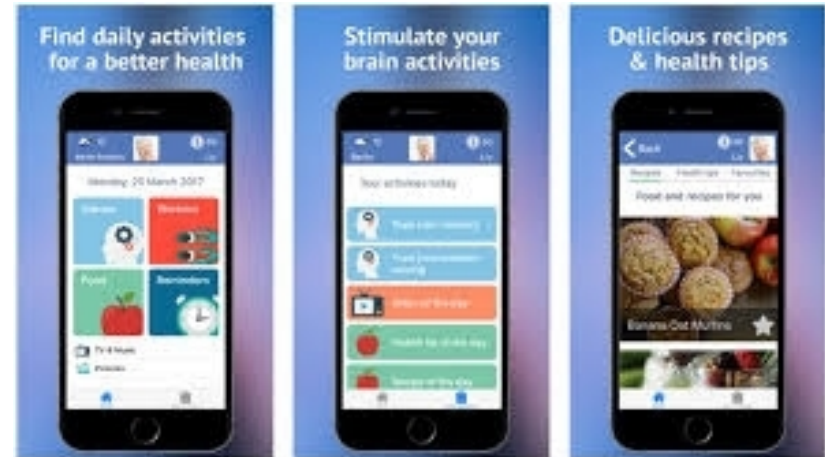


Remaining at home for as long as is possible

Living Well

Most people with dementia live at home (Alzheimer's Disease International, 2018) and want to remain at home for as long as possible as the home environment provides a sense of familiarity and safety. Remaining at home also enables people with dementia to engage in typical everyday activities e.g. shopping, talking with neighbours etc.

However, findings from an Alzheimer's Society survey of over 350 people living in the community with dementia reported that over half experience loneliness (58%) and isolation (56%), and are losing touch with people since being diagnosed (56%). Around a third said they felt unable to spend time with friends now they have dementia (29%) and around a quarter (27%) feel they are not part of their community and have disclosed that they feel people avoid them (23%).



Feeling part of the community

Living Well

People with dementia face challenges with memory, thinking, concentration and language. This can make it difficult for them to do everyday tasks we might take for granted, such as taking the bus.

Less than half (47%) of people with dementia say they feel part of their community.

There is a need to tackle the stigma and social isolation associated with dementia through strategies to engage and include people with dementia in community activities. The availability of accessible community activities that are appropriate to the needs of people living with dementia, along with suitable transport options, are important for a community to become dementia friendly. The engagement of people living with dementia in existing community activities rather than only specialised activities is also important. Providing people with dementia the opportunity to remain in their homes and within their communities should be a guiding principle.

Key actions:

- Working with schools to raise awareness in younger people about dementia
- Showcasing the stories of people with dementia volunteering within the community
- Programmes to support people with dementia to remain in employment
- Collaborations with local community organisations to provide education on dementia in order to support continued involvement of people with dementia in community activities



Travelling by public transport

Living Well

Being able to travel by public transport can be a key factor in helping people with dementia retain their independence and live well.

What public transport operators can do:

- Become Dementia Friends
 - Make spaces dementia friendly - Be aware of how the physical environment in travel hubs can affect people living with dementia. making it easier for someone to board the bus
 - Be patient while they find their travel pass
 - Waiting for them to sit down before moving
 - Improve accessibility when creating new stock
-
- 'In a dementia friendly Lewisham'...get quote



Physical environment

Living Well

The physical environment, from streetscape to individual shops, plays a key role in determining the extent to which people with dementia find their community dementia friendly. People with dementia have said that a physical environment in which they can find their way around, know where they are, and that makes them feel safe, is a huge advantage and an ideal gateway to their communities.

Key actions:

- An assessment of the local environment to identify key spaces and ways to improve them for people with dementia
- Identification of opportunities for collaboration with other initiatives

- 'In a dementia friendly Lewisham.... Get quote

Dementia friendly Lewisham

Living Well

A dementia friendly Lewisham is defined as a place or culture in which our residents with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential.

Key outcomes include:

1. Increased awareness and understanding of dementia
2. Increased social and cultural engagement for the person with dementia
3. Legal and other measures in place to empower people with dementia to protect their rights
4. Increased capability of health and care services to develop services that respond to the needs of people with dementia
5. Actions to improve the physical environment whether in the home, residential care, hospitals or public places

- 'In a dementia friendly Lewisham, ... need to define

Last year of life

Dying Well

‘Our worst fear isn’t the end of life but the end of memories’

‘End of life decisions should not be made at the end of life ’

‘The end of life deserves as much beauty, care and respect as the beginning’

It can be difficult to recognise when someone with dementia is nearing the end of their life, in part because the disease progression is so unpredictable. You can support the person by communicating with them and helping them with any symptoms they have.

While it may be upsetting to think about, having important conversations with the person with dementia, and planning ahead, can mean they have a better experience at the end of their life. This includes whether they should be resuscitated if they have a heart attack, and any religious practices they want observed.

As dementia progresses, carers may find it difficult to provide emotional or spiritual comfort to a person who has severe memory loss. However, even in advanced stages of dementia, a person may benefit from such connections.

Palliative or hospice care teams may be helpful in suggesting ways for people with dementia and their families to connect at the end of life. They also may be able to help identify when someone with dementia is in the last days or weeks of life.

Palliative care team

Dying Well

To be added

Alzheimer's Journey

By Ruth Murphy

There are no more happy birthdays or happy anniversaries
They are in the past now, just fading memories.
This journey changes everything, nothing is the same
The person you shared your life with no longer knows your name.

Some friends who have known you no longer do you see
What is the point, they say, he doesn't remember me.
Don't ask him to remember, just reminisce stories of the past
He will enjoy your company while that moment lasts.

He sits alone in his room with no one else around

I wonder what is on his mind, what memory has he found?
He stands at the mirror conversing with a friend.
He doesn't know the reflection speaking back is him.

He whiles away the hours standing or sitting there
Does he ever wonder why he is left alone right here?
There are strangers who approach him wanting him to go
He is reluctant, they're people he doesn't know.

They want him to shave & shower. He doesn't understand.
Give him patience & comfort, try to hold his hand.
Speak slowly & speak clearly, do not try to hurry
Rushing this process will only cause him worry.

Assure him he can do it himself, if he needs your help
you're here.

Let him have his dignity. It will alleviate his fear.
Warm the water, close the curtain. Give him privacy
Pass him soap & shampoo. He'll do a good job, you'll see.

He spent his life with people, likes to interact pleasantly.
When he's left alone in his room, there's no one there to see.
His eyes light up with joy when little children come around
He doesn't have to know them. It's happiness he's found.

Come out to visit him, while away an hour.
To provide company & happiness: it is your power.
He is robbed of the future, can't remember the past
Give him pleasure in the moment, is that too much to ask?

Don't stay away & avoid this person you once knew.
Reach out, still be a friend, you know, this could be you.

Measures of success

Preventing Well

Structure	Process	Outcome
<ul style="list-style-type: none">• Evidence that service specifications for behaviour change interventions and programmes include actions to raise awareness of lifestyle changes that could reduce the risk of developing dementia.• Evidence that training for practitioners delivering behaviour change interventions and programmes includes how to advise and support people to reduce the risk of developing dementia.• Evidence that information about the link between unhealthy behaviours and the risk of developing dementia is included in local health promotion materials	<ul style="list-style-type: none">• Proportion of people attending behaviour change interventions and programmes in mid-life who are advised that the risk of developing dementia can be reduced by making lifestyle changes.	<ul style="list-style-type: none">• Increased public awareness of the link between dementia and lifestyle.• Increased uptake of healthy lifestyle choices.

Measures of success

Diagnosing Well

Structure	Process	Outcome
<ul style="list-style-type: none">Evidence of local referral criteria and pathways to ensure that people with suspected dementia are referred to a specialist dementia diagnostic service.	<ul style="list-style-type: none">Proportion of people with dementia who have a record of attending a specialist dementia diagnostic service up to 12 months before entering on to the GP practice register.	<ul style="list-style-type: none">Self-reported or carer-reported quality of life of people with dementia.

Measures of success

Supporting Well

Structure	Process	Outcome
<ul style="list-style-type: none">• Evidence of local arrangements to ensure that people with dementia and people involved in their care have early and ongoing opportunities to discuss advance care planning.	<ul style="list-style-type: none">• Proportion of people with dementia who are given information about advance care planning at diagnosis.• Proportion of people with dementia having a health or social care review who have a documented discussion about advance care planning.	<ul style="list-style-type: none">• Proportion of people with dementia who feel encouraged to make decisions about their future care.• Proportion of people with dementia who are aware they can update their advance care plan at each care review.
<ul style="list-style-type: none">• Evidence of local arrangements to ensure that people with dementia have a single named health or social care practitioner to coordinate their care.• Evidence of local agreement of the role and functions of the named practitioner.	<ul style="list-style-type: none">• Proportion of people with dementia who have a named practitioner responsible for coordinating their care.• Proportion of people with dementia who have a care and support plan.	<ul style="list-style-type: none">• Self-reported or carer-reported quality of life of people with dementia.• Carer-reported quality of life of carers of people with dementia.

Measures of success

Living Well – promoting wellbeing

Structure	Process	Outcome
<ul style="list-style-type: none">• Evidence of local arrangements to ensure that a range of activities are available that promote wellbeing for people with dementia.• Evidence of local arrangements to ensure that people offering activities to promote wellbeing to people with dementia discuss the person's preferences with them and tailor the activities to these.• Evidence of local arrangements to support access to a range of activities that promote wellbeing for people with dementia, such as transport options.	<ul style="list-style-type: none">• Proportion of people with dementia who discuss activities to promote wellbeing at a review of their care plan.• Proportion of people with dementia who take part in activities to promote wellbeing that are tailored to their preferences.	<ul style="list-style-type: none">• Self-reported or carer-reported level of satisfaction with activities to promote wellbeing.• Self-reported or carer-reported quality of life of people with dementia• Level of independence of people with dementia.

Measures of success

Living Well – managing distress

Structure	Process	Outcome
<ul style="list-style-type: none">Evidence of local arrangements to ensure that people with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.	<ul style="list-style-type: none">Proportion of people with dementia who have started non-pharmacological or pharmacological treatment for distress who had a structured assessment before starting treatment.	<ul style="list-style-type: none">Antipsychotic prescribing rates for people with dementia.Self-reported or carer-reported quality of life of people with dementia.

Measures of success

Living Well – supporting carers

Structure	Process	Outcome
<ul style="list-style-type: none">• Evidence that education and skills training are available for carers of people with dementia.• Evidence that education and skills training are tailored to the needs and preferences of carers of people with dementia.• Evidence that support is available for carers to be able to attend training knowing that the person they care for will be safe and cared for.	<ul style="list-style-type: none">• Proportion of carers of people with dementia who have a discussion about education and skills training.• Proportion of carers of people with dementia who take part in education and skills training.	<ul style="list-style-type: none">• Carer-reported quality of life of carers of people with dementia.• Carer-reported level of satisfaction with the tailoring of the support to their needs and preferences.• Self-reported or carer-reported quality of life of people with dementia.

Measures of success

Dying Well

Structure	Process	Outcome
<ul style="list-style-type: none">• Evidence that education and skills training are available for carers of people with dementia.• Evidence that education and skills training are tailored to the needs and preferences of carers of people with dementia.• Evidence that support is available for carers to be able to attend training knowing that the person they care for will be safe and cared for.	<ul style="list-style-type: none">• Proportion of carers of people with dementia who have a discussion about education and skills training.• Proportion of carers of people with dementia who take part in education and skills training.	<ul style="list-style-type: none">• Carer-reported quality of life of carers of people with dementia.• Carer-reported level of satisfaction with the tailoring of the support to their needs and preferences.• Self-reported or carer-reported quality of life of people with dementia.

Measures of success

Annual survey

We will undertake an annual survey of people with dementia asking them to rate on a scale of 1 - 5 whether they agree or disagree with the following statements

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have the knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future.

In relation to carers – an annual survey will be undertaken within the Maximising Wellbeing of Carers service

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾, BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾, Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽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⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

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.

Dementia diagnosis

Referral route

Lewisham Memory Service is a memory assessment and diagnosis service. Many other agencies in Lewisham also provide services for people with dementia, depending on the presenting difficulties. This guide aims to help you identify the most appropriate service. To discuss any aspect of a potential referral, please phone our Duty Clinician on **020 3228 0939**. Referrals should be emailed to memoryservicelewisham@slam.nhs.uk

Has the memory problem been present for at least 6 months? If onset is acute, please rule out delirium, vascular events or head injury

YES

Have you ruled out reversible physical causes for memory difficulties? E.g. hypothyroidism, anemia, poor diabetes or blood pressure control, sleep apnoea

YES

Are there co-morbid mental health problems? Please screen for depression and optimise mood. Consider referral to IAPT (0203 049 2000) or Mind CSS (020 3228 0760). There is little value in memory assessment until mood has been stabilised. If the patient is currently under another SLAM team, please make them aware of the memory problem.

NO

Is the patient drinking alcohol to excess? Consider referral to alcohol cessation services (New Direction Lewisham - 020 8314 5566). Memory difficulties are common in intoxication and alcohol withdrawal. There is little value in memory assessment until the person abstains from alcohol or reduces their intake to recommended limits.

NO

If you have ruled out the above, refer to the Memory Service for assessment. Please include a history of the memory difficulties, medical history, medication, screening blood tests, details of anyone who will need to support the patient to attend an appointment and whether an interpreter is required.