Dementia Strategy

for Kingston upon Thames

2015-2020
Introduction
Dementia is a set of symptoms that may include memory loss and difficulties with thinking, problems-solving or language. Dementia is caused when the brain is damaged by disease such as Alzheimer’s disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.

This strategy for dementia in Kingston has been drawn up following a review of the trends in dementia in Kingston, a consultation with people with dementia, their families and carers, and in discussion with various organisations and individuals working to support people with dementia and their carers locally.

The purpose of the strategy is to describe the current situation and what will change or develop over the next five years to reflect the views of local people, legislation, policy, the rise in demand from increased numbers of people with dementia, and the resources available.

This strategy build on our vision\(^1\) that

**people with dementia, their carers and family feel Kingston is a place where they can live well in the community, and is one of the best boroughs in the country for dementia care and support.**

People with dementia tell us that they wish to live in the home of their choice\(^2\), near to family and carers, and to receive the best quality care at the right time and in the right place. We have heard that holistic support should be available and that it must be extended to carers, for whom the caring role can be extremely demanding and stressful. We aim to change the culture on Kingston to one that is truly supportive of people with dementia.

The wider mental and physical health needs of people cannot be separated out from a person’s dementia needs and this strategy recognises that any changes to dementia care will need to be aligned to other changes planned for the health and social care of the population of Kingston.

This strategy aims to create a parity of esteem for people with dementia: that is people with dementia can expect the same level of care, support and dignity as someone with a physical illness. This strategy will ensure good quality joined up care for people regardless of age, sex, ethnic group or disability.

Background
The National Dementia Strategy was published in 2009, setting out the vision of transforming dementia services and enabling improved recognition of people with dementia diagnosis earlier in the course of the disease and better quality treatment at all stages of the disease for people with dementia, their family and carers.

The national strategy set out **9 national outcomes** which have become the
benchmark for measuring the success of local strategies across the country, and which we will be adopting. They are:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia
- Those around me and looking after me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life
- I feel part of a community and I am inspired to give something back
- I am confident my end wishes will be respected

This local dementia strategy also links directly to the Kingston Health and Wellbeing Strategy, and takes account of the Prime Ministers Dementia Challenge 2020.

**Local Picture**

In Kingston there are between 1,418 and 1,585 residents over the age of 65 who have dementia. A range is given as there is more than one way to estimate the prevalence of dementia in the population. There are more people registered with Kingston GPs (under the responsibility of Kingston Clinical Commissioning Group) than live in the borough, and for this group the estimated number of people with dementia is between 1,553 and 1,874.

About half of local people with dementia have a formal diagnosis, meaning there are a sizeable number of people believed to be living with dementia who are not known to health and social care services. It is thought that the majority of these people have mild to moderate dementia and are living in the community, usually in their own home.

The numbers of people with dementia is predicted to rise steadily over time.

The prevalence of dementia among older people with learning disabilities is much higher (21.6%) than the general older population.

A small number of younger people in Kingston have early-onset dementia. This group is recognised to have specific differences in their health, care, and social needs.

Most people with dementia have at least one other co-existing illness and 59% of patients with dementia have two or more co-existing illnesses, both physical and mental. The most common mental health problem in people in Kingston is
depression, and depression can occur in people with dementia, although it may often be missed. Falls, mobility problems, urinary tract infections and long term illnesses such as diabetes may also be present. When providing care or treatment for someone with dementia, other conditions or illnesses must be taken into account.

An estimated 12% of people over 65 are from black and minority ethnic groups. Access to services may be challenging due to language barriers, knowledge of services availability, attitudes and practices of service providers and cultural factors.

**Views of local people with Dementia and their Carers**

We have listened to Kingston people who have dementia and their families and carers, to help us understand how Kingston can be a better place to live and how we can deliver better quality services for people with dementia and their carers.

In 2014 more than 200 people took part in a consultation process where they told us that there were good aspects of health and social care and that community support from the third sector was particularly valued, but they also highlighted challenges that we need to address. They include:

1. **Improving Well-Being and Awareness** for example by raising public awareness of dementia and other mental health conditions, and providing education and training to family and carers of people with dementia.

2. **Timely Diagnosis and Assessment** by shortening the time between seeing GPs and being assessed by specialists, by involving carers in this process, ensuring people receive a clear diagnosis, with explanations of what to expect next and what support is available.

   ‘Diagnosis in May and assessment not until September. Mother is 87 living alone. Been/still is very stressful and difficult.’

   *(Family member of: 80-94, Dementia & Memory Problems)*

   ‘Nobody explained. I was just given medication and once I was sent to a mindfulness clinic.’

   *(Patient: 65-79, Memory Problems and Depression)*

3. **Increasing Support in the Community** by providing up-to-date, accessible directories of services, improving linkages and information-sharing between services, and addressing isolation and loneliness.

   ‘Most of this you learn as you go along either word of mouth or months down the line, we need to know about these services from the start.’

   *(Carer of: 65-79, Dementia)*
‘There seemed to be no link between support services and the homes she was resident in.’

(Carer for: 80-94, Anxiety, Dementia and Depression)

‘Lonely as only support workers visit. Extra support in April and June needed as anniversaries of family deaths.’

(Patient: 50-64, Depression & Memory Problems)

4. **High Quality Long-Term and Acute Care** by ensuring that staff who are working with patients have the necessary training and understanding to support dementia and other mental health needs, and that staff can take a holistic view (social needs and other aspirations, not just medical needs) and have the time to do so.

‘The services are quick to respond and have proved to be essential for making it possible for my husband to live at home.’

(Family member of: 80-94, Memory Problems & Dementia)

A full report on this consultation in 2014 with patients and carers is available ix.

The views of staff and organisations who deliver dementia care services are critical to ensuring that we have services that are whole system in their design, employing staff that are skilled in delivering high quality dementia care, and working within a dementia-friendly community.

A Stakeholder Event in June 2015 x was an opportunity for a broad range of staff from many organisations to work together with people who have dementia and their families, to review the draft strategy and propose priorities and actions.

We will continue to work with a wide range of people in developing the action plan.

**Co-ordinated Care for people with dementia**

This Dementia Strategy is aligned to Kingston Co-ordinated Care (KCC), which is an extensive programme of transformation in Kingston.

KCC aims to:

- support the development of active and supportive communities in which people are enabled to stay healthy and well, living independently as part of thriving and resilient communities
- develop truly customer-centred care that supports people with complex needs to achieve the best possible quality of life and the goals that matter to them with an increased focus on prevention, proactive care and self-reliance.
People with dementia and their carer’s have some dementia-specific needs, and these are set out and addressed in this dementia strategy. More generic needs that are shared with people who have other complex conditions and illnesses, are primarily covered in the KCC programme, but are referred to here.

This strategy

This joint strategy sets out a direction for the next five years, and recognises the challenges of delivering a seamless service to people with dementia and their carers in an economic climate where demands for services are increasing and public funding is decreasing.

For the person with dementia and their carers, this strategy is about a person-centred, response as depicted in Figure 1.

Figure 1. Support and care for a person with dementia and their carer(s)

This person centred (personalised) approach means maximising the life a person can live, making the most of their abilities, whilst ensuring that support and care is tailored to their individual needs, their family and carers. Within this we recognise there may be particular needs for:
Whole system pathway

This strategy proposes a whole-system care pathway for people with dementia, with four inter-dependent component parts that together describe the journey that individuals and their carers will experience.

Local people tell us that it is a priority for them to have a single framework that encompasses all that is available to people with dementia and their carers. This will make the system easier to understand, promote consistency and reduce confusion.

The four component parts of this strategy are shown below and are considered in more detail on the following pages. They are:

1. Improving wellbeing, raising awareness and understanding, reducing dementia risk
2. Timely diagnosis, assessment and intervention
3. Living well - Increasing support in the community for living with dementia
4. High quality care – in times of crisis, care home care and end of life care

Partnership working

The objectives of this strategy cannot be realised without working in partnership with people with dementia, their carers, voluntary organisations, independent organisations in dementia care, health and social care service providers and the wider community. It is our intention to continue to work with our partners to deliver this strategy.

Next Steps

A detailed Action Plan will be developed which will describe how we intend to work together to deliver the objectives set out in this strategy.
Case for change

There is generally a low level of public and non-specialist professional understanding of dementia. The stigma of dementia creates a background where people find it hard to talk about dementia, and avoid addressing the possibility that someone is affected. There tends to be a mis-attribution of symptoms to ‘old age’, an unwillingness to seek or offer help, and a false view that nothing can be done to assist people with dementia and their carers.

Our local consultation found that awareness-raising was important to both reduce stigma and make communities more accepting of dementia and mental illness, as well helping people to recognise symptoms. Local people told us that intergenerational groups, school education were ways that may improve understanding and awareness from an early age\textsuperscript{xii}.

A dementia friendly community is one where its residents have an awareness and understanding of dementia and how they can be helped. Nationally the ‘forget-me-not symbol is a way for communities and organisations to show they are serious about becoming dementia friendly\textsuperscript{xii}.

There are risk factors that can be modified to reduce the risk of developing some types of dementia, particularly vascular dementia. These risk factors include smoking, physical inactivity, high blood pressure and diabetes\textsuperscript{xiv}.

‘The more, as you say, its talked about, about well-known people having it, the better it’s accepted as part of life.’ (Carer, national)

‘More information on what I should have to deal with and what services I could call upon to help’ (Local person with dementia, 2014)

The National Dementia Strategy identified that professional and vocational training are key.

What we want to achieve (our objectives)

1. Improve awareness and understanding of dementia by public and professionals, to reduce stigma and to improve recognition of dementia and the ways to seek help.
2. Reduce risk of developing dementia (particularly vascular dementia) and other mental health problems
3. Enable people to be as resilient as possible by promoting good physical and mental health and wellbeing
4. Empower people with dementia and their carers to have a voice and a role in developing support and services that enable them to ‘live well’
5. Achieve a dementia-friendly Kingston through working with others
Case for change

Only 6 out of 10 people with dementia have a formal diagnosis in Kingston. A diagnosis is often made at a time of crisis, and may come too late for people with dementia to make choices. Memory services offer timely diagnosis and management before a crisis has occurred – this can improve quality of life, delay progression of dementia, allow the person and their family to plan for the future, delay unnecessary admission to care homes (of people who want to stay in their own home) and are cost-effective. Memory services should be available to people of any age and background including those with learning disabilities. Local people have told us that they would like a shorter time between referral, diagnosis and ongoing management and support, including social care support. Meaningful care following a diagnosis of dementia should be co-ordinated and meet national quality standards.

Good quality information helps people and their carers to direct their own care. Local people and carers have told us of their desire to have someone they can approach for help and advice about their individual situation, and to assist them to navigate services and support at any stage in their illness, including at diagnosis. Navigators, such as Dementia Advisors have been shown to be effective in improving the wellbeing and quality of life of people with dementia and their carers.

We have also identified the need for training for a broad range of people who care for and work with people who have dementia, such as primary care staff including GPs, community health, hospital and social care staff, carers, the voluntary sector, home care agencies and care home staff. Training needs range from diagnosis, person-centred treatment, understanding behaviours, and respectful support of people with dementia. Good training should help people with dementia in crisis to remain at home, or return home after a hospital admission.

We know that some people with dementia will need management for other mental health problems, including depression and anxiety. This should be provided by people who understand dementia, and we should ensure people do not fall between services such as Community Mental Health Teams and Kingston Wellbeing Service.

What we want to achieve (our objectives)

1. Improve identification and provide timely, accurate diagnosis of dementia, using a good quality memory service for people of all ages and backgrounds
2. Ensure people with dementia and their carers are able to navigate and understand the range of support available, by sustainably providing easily accessible, good quality, timely information about the illness, as well as the services available at diagnosis and throughout the course of their care
3. Improve skills and knowledge of health and social care staff, voluntary sector, home care agencies, care homes and carers about the diagnosis, treatment, care, and interaction with, people who have dementia
4. Improve the co-ordination of care for people with dementia and their carers, particularly the links between dementia care and mental health, learning disability services and physical health care
Case for change

Two thirds of people with dementia live in their own homes in the community. Some will be in the early stages of their illness, and others near the end of their lives. It is important to give them choice and control over decisions about their lives, and keep them connected to social networks that they enjoyed prior to the onset of dementia.

Their needs range from access to universal services such as transport, housing, and support maintaining their property and gardens, to help with their physical health including personal care, rehabilitation and reablement and maintaining their peer support networks.

Third sector organisations/the voluntary sector provide a variety of support to people with dementia and their carers. People are often more willing to engage with these organisations, rather than statutory services. This is important for peer support as well as other activities such as home care. Our local consultation found that these services were well-liked. Kingston is developing an Active and Supportive Communities strategy that should reflect the needs of people with dementia.

As dementia progresses, peoples wishes should be at the centre of how support to them and their carers is provided. The support should be provided with dignity, respect and take account of their broader family circumstances, an offer choice, control and flexibility. People should be supported to live in their place of choice, usually at home, for as long as possible.

Family members and carers provide the main support to people with dementia living at home. Good community personal support services are beneficial to people with dementia and their carers. Home care services provided by skilled staff (both main stream services and specialist dementia services) that provide continuity, reliability and flexibility are very important. They can contribute to maintaining a person’s independence, reducing social isolation, preventing admission to care homes and hospital, and supporting carers. Care workers needed to be trained in dementia.

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1 Home care services include personal care such as washing, dressing, house-keeping, cooking, companionship and some health care.
People living alone need an approach that recognises their needs can change abruptly and unexpectedly.

**Specialist dementia homecare and outreach**
providing person-centred care (instead of standard home care) reduces stress and risk of crises for carers and extends the capacity for independent living at home. Commissioning should be outcome rather than task/time based.

**Meaningful day time activity** can come in the form of day care, or other activities that are accessible to people with dementia. Local people have told us that they would like access to a range of activities. The provision of mainstream and specialist day services that keep people connected to local communities and activities such as leisure pursuits is best practice, as set out by the Department of Health and NICE.

Sheltered or extra-care housing that provide opportunities for social interaction, and telecare may help people with dementia remain in their communities. The needs of people with dementia should be considered in the development of housing options.

**Carers’ support** can help maintain a person with dementia in their own home whilst ensuring the needs of the carer are met. Our local consultation found that carers would like a way of meeting for moral support, financial support, practical help at home, information to help decision-making and help with sign-posting to specific help (for example for difficult behaviour) and support navigating services. Support for carers to help them deal with crises, and the changing nature and severity of people’s symptoms, as well as access to psychological therapies are all needed. It is also essential that carer’s can access flexible respite and relief care that best suits their situation or needs, including for people of all ages, ethnic groups and those with physical or learning disabilities. A consistent and co-ordinated approach to carers across all agencies in Kingston is important.

Nationally it is estimated that 40% of people in general hospitals have dementia. People with dementia cost more and many have co-morbid medical conditions and stay longer in hospital. Where ever possible admission to hospital should be avoided. Where this is not possible, people should receive compassionate care by skilled staff, in dementia-friendly environments that minimise the stress and disorientation exacerbated by being in hospital. Kingston Hospital has developed a dementia strategy for the hospital. People showing symptoms of dementia should be referred to the Memory Assessment Service, so that those people, their families and carers receive the same level of support as those whose...
symptoms were first diagnosed when they were at home. It is also important that people with dementia receive good nourishment and adequate assistance to eat when in hospital. A specialist psychiatric liaison service for older people has been running as a pilot at Kingston Hospital, and its role in the dementia pathway should be clarified.

Co-ordinated care (as described in the Kingston Co-ordinated Care Programme) for people with dementia can help avoid hospitalisation and support people discharged from hospital. In addition, there is good clinical evidence that people with mild to moderate dementia with deteriorating physical health will do well with physical rehabilitation and reablement from intermediate care teamsxxxii, and health and social care staff should be trained in dementia. People with severe dementia may need a more specialised service.

Primary care teams are a key part of the ongoing co-ordinated care for people with dementia, and GPs play a leading role as part of an existing commitment that from April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.

The opportunity to take part in research into dementia should be made available to all those with dementia who wish to be involved.

What we want to achieve (our objectives)

1. Ensure equitable access for people with dementia to the full range of universal support services, such as handy person services, transport, housing, falls services, reablement and advocacy support.
2. Ensure sustainable local peer support and learning networks for the exchange of practical advice and emotional support for people with dementia and their carers, regardless of age, sex, ethnic group or disability.
3. Listen to carers of people with dementia, and understand their needs, and provide the information, advice, training and support that they identify they need at all stages of dementia in a co-ordinated way across all agencies.
4. Decrease social isolation and loneliness of people with dementia and their carers.
5. Enable people to live at home for as long as they choose, including those who live alone.
6. Ensure there is a choice of good quality community personal support services for people living at home and their carers, including personal home care, day care and respite care.
7. Improve the quality of care in general hospitals for patients who have dementia.
8. Ensure co-ordinated timely discharge from hospital, reducing hospital length of stay for patients with dementia and increasing the proportion of people able to return to their usual place of residence following hospital treatment.
9. Ensure co-ordinated care for those with complex issues, with input from primary care, memory assessment service, integrated health and social care teams and voluntary sector.
Case for change

The aim of good care for people with dementia is to keep people living well, but there will be times when people may deteriorate despite all best efforts, and crises may occur. Some people with advanced illness may need to live in a care home.

Crisis

It is essential that there are robust co-ordinated services that are equipped to provide rapid support to people and their carers in times of crisis, regardless of the cause, be it due to deterioration in their physical health, their mental health, a change to social circumstances or the needs of their carer. Emergency respite may sometimes be required if a family member/carer is unexpectedly unable to look after their loved one. Advanced decisions and contingency/crisis planning will help manage unexpected crises. People with dementia and their carers need to know how to access timely information, families and carers need to know about common changes, what to do to avoid a crisis, who to contact and the care and support options available. Crisis response services for people with dementia will need to be aligned with services for other frail people and people with long-term conditions.

Challenging behaviour and psychotic symptoms

Some people with dementia may develop challenging behaviours such as aggression, damaging property, incontinence, or become withdrawn and difficult to engage. Some people with dementia may have sleeplessness or wandering.

The cause of these behaviours is often distress, but may also be caused by pain or infection. People caring for those with dementia should be made aware of these issues and how to respond to them, either through a scheme for training staff and carers, or through the use of a specialist service for challenging behaviour.

A proportion of people with dementia will have psychotic symptoms, particularly hallucinations. Anti-psychotic medicines should only be prescribed in exceptional circumstances. In 2009 it was estimated that only about one third of people with dementia who are on antipsychotic medication are getting any benefit from them, and they can have bad side effects. Since then the use of antipsychotics nationally has reduced, and we would wish to see this trend maintained in Kingston.

Care Homes

Two thirds of people in care homes have dementia. Dependency is increasing, and nationally it is estimated that over half of people in care homes are not well occupied during waking hours, with behavioural disturbances being common and often treated with antipsychotic medicines.

Kingston borough has a large number of registered residential and care homes, and sheltered housing. The Council supports eligible people to live in these places (6.8 people...
What we want to achieve (our objectives)

1. Improve services and the system response for individuals and their carers experiencing or at risk of a crisis, meeting their needs and keeping them connected to their local community.
2. Improve the quality of long term care (care homes) for people with dementia and mental health issues, including reducing avoidable admissions to hospital.
3. Ensure appropriate care of people with challenging behaviour, wherever they live.
4. Raise the standards of care for people with dementia reaching the end of life, and ensure that every person with dementia, their family and carers are given the opportunity and support to plan ahead.
5. Improve the availability of and access to create alternative accommodation to prevent early entry into residents/nursing care.
6. Ensure the appropriate use, and prevent over-use, of anti-psychotics in dementia.

‘There seems to be no link between the support services and the [care] home she was resident in’

per 1000 in residential homes and 5.6 per 1000 in nursing homes), although many people pay privately. Many of these people have dementia, but they may not have a formal diagnosis. Often these care home residents have high needs and may develop challenging behaviour, have co-existing physical problems, are at risk of falls, and deterioration resulting in hospital admission. Some of these admissions are avoidable. Some people in receipt of ‘continuing care’ will have dementia.

Dementia care homes do not have to provide evidence to CQC of the ability to care for people dementia when they register. In Kingston it is important that every care home provides high quality care, meeting agreed criteria xxxvi, which is joined up with other dementia services.

End of life care

Early conversations with people with dementia are important so that people can plan ahead for their future care, including palliative and end of life care. This reduces the likelihood that difficult and emotional decisions have to be made in crisis, when the wishes of the person with dementia cannot be taken into account. An event in July 2015 reiterated the importance of such contingency planning xxxvii.
### Summary of what we want to achieve across the whole system

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Dementia in Kingston - pathway

Improving Wellbeing, Raising Awareness, Reducing risk

Timely Diagnosis, Assessment and intervention

Living well with dementia – increasing Support in the Community

High Needs: High quality crisis care and end of life care

Memory Assessment Service

Co-ordinated, informed, person-centred review and support

End of life care

Stay at home
Residential/Nursing Home
Extra care housing

- Reducing dementia risk
- Recognising there is a memory problem
- Day time activities
- Social, befriending groups
- Community and Voluntary sector
- Flexible respite

- Information (accessible)
- GPs (physical and mental health needs)
- Dementia Navigators (advisors)
- Carer support
- Specialist needs including hospital, mental health

Dementia-friendly Kingston
References


ii YouGov Poll (2014) for the Alzheimer’s Society found that 86% of people want to stay at home for as long as possible if diagnosed with dementia rather than go into a care home.


iv Calculation based on CFAS II published in 2014, which estimates 6.5% of over 65 year olds will have dementia. To date NHS England has been monitoring dementia diagnosis rates using Alzheimer’s Society 2007 prevalence rates, but from Spring/Summer 2015 will move to using CFASII. ONS 2013 midyear estimates for Kingston Borough

v Calculation based on Alzheimer’s Society Research 2007 which estimates 0.0095% of total population has dementia, ONS 2013 midyear estimates for Kingston Borough

vi Calculation based on target number for Kingston CCG from NHS England, and based on CFASII.

vii Calculation based on Alzheimer’s Society Research 2007 which estimates 0.0095% of total population has dementia

viii National Audit Office (2007) Improving Services and support for people with dementia


xi Dementia Strategy for Kingston – A stakeholder event, June 2015

xii Dementia Strategy for Kingston – A stakeholder event, June 2015

xiii Department of Health and Rt Hon Norman Lamb (2013) Improving care for people with dementia, policy

xiv Public Health England (Fact Sheet 15) The National Cardiovascular Intelligence Network: cardiovascular disease key facts


xviii NAO (2007) Improving services and support for people with dementia: London TSO

xix NICE National Quality Standards for Dementia


xxi Dementia Strategy for Kingston – A stakeholder event, June 2015
National Dementia Strategy


Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy


Department of Health () Everybody’s Business. Integrated mental health services for older adults: a service development guide.

NICE (2006) Dementia: supporting people with dementia and their carers in health and social care. NICE CG 42


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Department of Health (2009) National Dementia Strategy

Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

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Dementia Strategy for Kingston – A stakeholder event, June 2015