



CHANGING LIVES



Shaping our dementia journey together



**DEMENTIA PLAN
2020-2025**



"I WAS DIAGNOSED WITH DEMENTIA A COUPLE OF YEARS AGO."

"I have chosen to be open about my diagnosis, or as open as I can be, because not everyone finds a diagnosis easy to accept or deal with. The way we think and talk about dementia needs to change. I want to be open with everyone, without feeling any stigma. I want people to understand that I am still me.

I am pleased to be part of creating this document, along with many other residents. Any dementia plan needs not just to consult with us, but to actively involve us. We are all different, with different needs and different interests, and our voices need to be at the heart of what happens next, too.

Language matters. I am living with dementia. I want that life to be as full and active as possible, driven by my choices, within a community that works together to understand dementia better and removes the stigma. I am pleased that this document reinforces that message and shows how we can work better together to make this a reality."

ALISON

Resident living with dementia



CONTENTS



DID YOU KNOW?

We've involved residents from the start to help us create our 'Dementia Plan'. Over 170 people, made up of those living with dementia and their carers, came along to workshops and one-to-one interviews. We gave a commitment to produce a plan that was both for and by people living with dementia and their carers.



DEMENTIA & CORONAVIRUS

In January 2020 the World Health Organisation (WHO) declared a global health emergency following thousands of new cases of a new virus discovered in Wuhan, China. This led to countries all over the world responding to limit the spread of the novel coronavirus, COVID-19. On 11 March 2020 the WHO declared a global pandemic and measures tightened.

With worldwide figures at more than 270,000 infections and 11,000 deaths the United Kingdom imposed lockdown measures from 23 March requiring people to stay at home and only leave their homes for certain defined purposes. This report was written and agreed before the new virus changed the way people lived their lives in 2020. In order to recognise this and the significant impact COVID-19 has on the lives of people with dementia, we have added some helpful advice throughout. Just look out for the purple coronavirus boxes.

Foreword	02
The Dementia Journey	06
What is Dementia?	08
Prevention and Early Intervention	10
Getting a dementia diagnosis	12
What to expect from a diagnosis	13
Keeping Safe	14
Living with Dementia	16
What's going on in our Boroughs	18
Caring for Someone with Dementia	20
Living at Home with Dementia	21
Home Care	26
Care Homes and Supported Living	30
Planning Ahead	32
Our Dementia Plan	38
What we will do	39
Our Commitments	40
Jargon Buster	42
Thank You	48

DEMENTIA FIRST HAND

Dementia is probably the biggest health care challenge we face today. We want to tackle the issue with commitment and focus making sure that Westminster and Kensington and Chelsea are leading the way as two of the most dementia-friendly boroughs in the country.

To do that, we've called on lots of people who live in our community to tell us what's important to them and how we can help provide them with the support they need.

Working with local residents, we have had the privilege of meeting and supporting many families going through all stages of dementia, from pre-diagnosis to end of life.

We've seen first-hand how frightening a dementia diagnosis can be, and what a significant impact it can have on the person, their friends and family. Each of us have also personally experienced supporting family and friends during their dementia journey.

In our Kensington and Chelsea 'Council Plan' and Westminster 'City for All' manifesto, we commit to improving the lives of people living with dementia and their carers. The quality of care and improving the experiences of those with dementia is also a priority of the NHS' Long-Term Plan. This is in line with the Mayor of London's ambition that London will be a dementia-friendly capital city by 2022.

We've worked with residents and local organisations across both boroughs to explore how we can all act to ensure every aspect of living here in Kensington and Chelsea and Westminster enables people with dementia to live fulfilling and active lives for as long as possible.

We know that the illness does not define a person. Living well with dementia is about much more than just getting the right health and social care - it's about ensuring community, transport, shopping, sports, arts and leisure, housing and more are all dementia-aware and can support people living with the illness to continue to live in our communities.

Last but not least, we want to thank everyone, particularly our residents, who gave up their valuable time and energy to share their stories and shape our plan to become leading dementia-friendly boroughs.

“Living well with dementia is about much more than just getting the right health and social care.”



Dr Neville Pursell
Chair - Central London CCG



Dr Andrew Steeden
Chair - West London CCG



Cllr Sarah Addenbrooke
Lead Member for ASC and Public Health - Kensington and Chelsea Council



Cllr Tim Mitchell
Cabinet Member for Family Services and Public Health - Westminster City Council



BERNIE FLAHERTY
Kensington and Chelsea
and Westminster's Executive
Director of Adult Social
Care and Health

"I'm excited to be involved in this dementia plan in both boroughs."

I was talking to a group of young graduate trainees recently who had joined the councils and I asked them to put their hands up if they knew someone who had dementia. 19 out of 20 did.

We will all know someone who has the condition. Dementia is a real and present concern for us as a society and, as a representative of social care and health, I want to draw on that personal experience to make sure all our work and our plan is totally person-centred and people-focused, drawing on the experiences of our residents to enact policies and commitments that will directly influence and improve their lives.

Our boroughs are making the commitment to be leading 'dementia-friendly' communities and, as Executive Director for Adult Social Care, I want to make sure that the conversations we have with and about our friends and loved ones diagnosed with dementia are open, engaging and honest.

This document is part of enabling these kinds of conversations and demonstrating what we are currently doing to support people living with dementia in the next few years. I am proud to say that this document has been created by, for and with our residents over a number of creative, lively and engaging consultation sessions, and I am delighted that so many residents' voices can be so clearly heard through these pages."



DEMENTIA & CORONAVIRUS

We wrote our Dementia Plan before we knew about the coronavirus pandemic. As we go to publication, there is still a lot to learn about COVID-19 and the long-term effects it will have. The delivery of this plan will accommodate any necessary changes, but our broad values remain the same - to improve the lives of people living with dementia by working in direct partnership with local residents. When we learn more about the virus and its effects, we will add this to the plan.



THE DEMENTIA JOURNEY

We want to support you on your own personal journey with dementia. It may be that you have noticed differences in your mental sharpness that you want to check with your GP, or you may be caring for someone in the later stages of dementia.

No matter which stage you're at, we are working towards making our boroughs a place where you can still live a happy and fulfilled life. We're also on a journey of our own, to develop and implement a whole range of initiatives to truly make Kensington and Chelsea and Westminster 'dementia-friendly'.

This is our plan of what we're going to do to make sure that happens. You'll notice that lots of things have already been implemented, and also spot what's still on our 'to-do' list. One thing you can be assured of, is that we're putting dementia at the top of our agenda.



DID YOU KNOW?

Residents living with dementia and their carers worked on all aspects of the final plan, including the design of this Dementia Journey.



DEMENTIA & CORONAVIRUS

Keeping in touch with family and friends became more difficult during the lockdown and the pandemic. To make things a little easier, technology has played a huge part in helping people stay connected. Tablet computers and mobile phones have been provided in our care homes to allow residents to access online activities and stay in contact with their families. Health and Social Care are working with the voluntary sector to support people living in the community, adapting activities and day opportunities so that they are as safe as possible. We understand the need to balance the risk of infection against the risks of social isolation and loneliness and will continue to find new and creative opportunities to make this happen.

"The GP receptionist rings to remind me about appointments, she checks in on me regularly - about every 5 to 6 weeks."



TECHNOLOGY AND INNOVATION

Smart speakers are like having your own personal assistant. They can tell you the latest weather forecast and news, read you a story and even switch your lights and heating on or off.



To get the most out of our guide, simply find the section below that applies to you and turn to that coloured page:



What is dementia and how to prevent it?

**I'm fit
and well**
PAGE 10



How can I get a diagnosis?

**I've got early
symptoms**
PAGE 12



**I'm living
with dementia**
PAGE 14

Getting the most from dementia
-friendly spaces and support groups



Getting extra help at home

**I'm living with
dementia and
need more help**
PAGE 27



**The later stages
of dementia**
PAGE 30

How to make an
'end of life' care plan

WHAT IS DEMENTIA?

We're all unique and will each experience dementia in our own way. 'Dementia' is an umbrella term that describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

A person with dementia may also find that their mood or behaviour changes. It's a progressive condition which means that changes are often small to start with but will gradually become more obvious over time. How quickly this happens varies greatly from person to person.

If you or a family member has developed dementia, it's always worth asking your GP if they can give you an indication of what might have contributed to it.

There are many diseases that result in dementia. The most common types are:

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy bodies
- Frontotemporal Dementia (including Pick's disease)

There is currently no cure for dementia, although research continues to make strides to improve new treatments and drugs.

"Dementia is changeable, like the weather. When it's a sunny day, I can hold a conversation easily but on a foggy day, finding those words is a real challenge."



DID YOU KNOW?

Over 3,100 people are living with dementia in Kensington & Chelsea and Westminster. By 2030, this figure is expected to rise to over 5,500.

Many people go on to live with dementia for many years after their diagnosis. Early intervention is the key to finding a treatment and medication that can reduce the symptoms and delay development. We also know from research that leading a healthy and active lifestyle can also help to delay the onset of dementia.



DEMENTIA & CORONAVIRUS

We know that many of our residents have had their routines disrupted during the COVID-19 pandemic. In Kensington and Chelsea and Westminster we have managed to stay in touch using technology and have heard stories of people using technology to contact their family and friends, to enjoy virtual coffee mornings, quizzes, free online classes, and much more!



TECHNOLOGY AND INNOVATION

We're proud to say that when it comes to new technology and innovations that can improve our lives, we are often leading the way. And this will continue to be the case when we look at new products and technology to support people living with dementia and their carers. Examples of Assistive Technology can be found at atdementia.org.uk For more information contact the Adult Social Care team in Kensington and Chelsea or Westminster.



EVERY 3 MINUTES SOMEONE DEVELOPS DEMENTIA IN THE UK

225,000

PEOPLE WILL DEVELOP DEMENTIA THIS YEAR

885,000

PEOPLE ARE LIVING WITH DEMENTIA



THE NUMBER OF PEOPLE OVER 65 LIVING WITH DEMENTIA

2,440

Kensington and Chelsea

3,140

Westminster

DIAGNOSIS RATES FOR DEMENTIA

73.5%

Kensington and Chelsea

70.5%

Westminster

1,045,000

PEOPLE WILL BE LIVING WITH DEMENTIA



1 in 6
PEOPLE OVER THE AGE OF 80 HAVE DEMENTIA

I'M FIT AND WELL

PREVENTING DEMENTIA

EARLY INTERVENTION

We all know the things we need to be doing to stay healthy and happy. The great news is that if we can try and stick to these, our chances of developing dementia reduce and it can help to slow it down too. Here are our top tips.

- ✓ Take part in regular physical exercise - brisk walking, cycling and swimming are all great ways to get your heart pumping.
- ✓ Eat a healthy, balanced diet to maintain a healthy weight.
- ✓ Look after your teeth. Make sure you brush twice daily after meals. Limit sugary or acidic drinks and food and see your dentist regularly for check-ups.
- ✓ Stay mentally active - learn a new skill, read the paper, do the crossword or play Sudoku.
- ✓ Keep a good social life - visit family and friends, volunteer with a local organisation, join a choir or visit a place of worship - whatever you think you'll enjoy.
- ✓ Stop smoking - your local GP will talk you through lots of ways to make it easier.
- ✓ If you drink alcohol, do so in moderation.
- ✓ Don't be on your own - we know this may be easier said than done, but read on to find out some of the initiatives you could be part of.
- ✓ Have your hearing checked regularly. Research shows that using a hearing aid, if you have one, reduces your risk of getting dementia.

Research suggests up to one in three cases of dementia are preventable. Modifiable risk factors include:

- Diabetes
- High blood pressure
- Obesity
- Poor physical health
- Poor oral health
- Hearing impairments

There are also certain factors you can't control that can affect your risk of developing dementia. These include:

AGE

Dementia is not a natural part of ageing. Although it is possible to develop the disease at a younger age, you're more likely to be diagnosed with dementia once you turn 65.

GENETICS

Some genes do not directly cause the illness, but affect your risk of developing it. Other genes do directly cause dementia, but these are rarer than the risk genes. Having a parent or sibling with Alzheimer's disease increases your chances of developing it very slightly, but it does not mean that dementia is inevitable for you.

ETHNICITY

Certain ethnic communities appear to be at higher risk of dementia than others. For example, South Asian, African or African Caribbean people seem to develop dementia more often than white Europeans.

GENDER

More women are affected by dementia than men. Worldwide, women with dementia outnumber men two to one.



DID YOU KNOW?

65% of dementia risk is due to factors you can't change. We can address the other 35% of overall dementia risk factors.

Dementia is now the leading cause of death in the UK, with 1 in 8 people currently dying from the condition. Here in Kensington and Chelsea and Westminster, we've set up a variety of services to help you stay healthier for longer:

- Lower the risk of dementia by taking part in our smoking cessation service, which can protect you from heart disease and poor oral health. Take part in our cardio-vascular disease prevention programme and the alcohol service.
- Our Community Champion projects support physical activity, healthy eating, and wellbeing. To find out more or to become a Community Champion, visit www.communitychampions.uk.org
- If you're feeling lonely, depressed or want to do more physical activity, we may be able to help. Come along to one of our befriending sessions, supper clubs or exercise classes.

“The extra help and support I'm getting has made my future seem much brighter.”

SOCIAL PRESCRIBING

Many factors affect a person's health and wellbeing, from their financial background and social interactions to their education and environment.

In London, 1 in 5 patients go to their GPs about social problems, such as housing or loneliness. Often a patient needs a service which does not come in a bottle or a tube; for example getting rid of mould or joining an art class might work better. Social Prescribing refers patients to relevant support or activities in the community to improve their health and wellbeing.

It can't take away the symptoms of dementia, but it can help to improve general wellbeing. Talk to your GP to find out more.

TECHNOLOGY AND INNOVATION

We've partnered with King's College London and University College London (UCL) to become a 'research ready' borough to improve care, treatment and, ultimately, find a cure for dementia.



GETTING A DIAGNOSIS

We understand that talking about memory loss, or another symptom you're concerned about, can be frightening. However, it is important to get an accurate diagnosis as early as possible.

It's normal to forget things every now and then. But if you, or someone else, have noticed that you're becoming increasingly forgetful or issues with your memory are affecting your everyday life, it's a good idea to visit your GP.

“My partner noticed I was getting more forgetful, not quite myself, and having problems finding the right word.”

Do you know someone who you think may have dementia?

It can be difficult to bring up the issue of memory loss and the possibility of dementia with someone you love. They could be confused, unaware there is a problem, worried, anxious or in denial. We would encourage you to start the conversation, choosing a place that is familiar and non-threatening. Allow plenty of time, so it isn't rushed and you can listen carefully to them.



DEMENTIA & CORONAVIRUS

During the COVID-19 lockdown, it has been particularly difficult for people to get to see their GP or specialist in person. However, the NHS has stressed that people should continue to seek help where necessary. Many appointments have moved online, with telephone and video call appointments available with doctors, nurses and other healthcare professionals. For more information visit: www.nhs.uk/conditions/coronavirus-covid-19/social-distancing/using-the-nhs-and-other-health-services/



DID YOU KNOW?

Only 75% of people living with dementia in our boroughs have a formal diagnosis. That means lots of people might not be receiving the care and support they need.

'I run a business where you have to be on your toes. I noticed things that worried me and I thought, "I must get this checked." My GP was fantastic. He said: "Don't panic!" and he's very supportive. He looks at things very positively. I did feel a bit bereaved, but was very grateful that I had shared it with someone; that made me feel better.

People don't want to know, they look away. I get a huge amount of encouragement from my children but as a society we're not very good with people getting older. There's a stigma around diagnosis. The message should be - "don't be embarrassed, go to your doctor."

You have to live well. Just because you can't remember stuff, it doesn't mean you're boring and uninteresting. It's important to keep your self-esteem. I can do such a lot but I have to allow for things. Even so, many people don't realise I have dementia.'

JACKIE, PATIENT



WHAT TO EXPECT

If you get to the stage where you have decided to visit your GP to get a diagnosis, there are several things they should do:

- Talk about your symptoms and worries.
- Rule out other conditions with similar symptoms (like depression or urinary tract infections).
- Rule out other possible causes of feeling a bit confused (e.g. poor sight or hearing), emotional changes and upsets (e.g. moving to a new house or bereavement), or the side effects of certain drugs.
- Provide you with an explanation for your symptoms, removing uncertainty and allowing you to begin to adjust.
- Allow you to access treatment as well as information, advice and support (emotional, practical, legal and financial).
- Allow you to plan and make arrangements for the future.

Dementia can be difficult to diagnose. Your GP may make a diagnosis or refer you to the Memory Service for a specialist assessment. Your doctor or specialist will explain to you and your family:

- What care and support services are available in your area.
- How to get in touch with your local Dementia Advisor.
- What advocacy services are in your area.
- Where you can get advice about continuing to drive or your employment (if this applies to you).
- Where you can find financial and legal advice.

Don't forget, emotional health is just as important as physical health. If you feel depressed, worried or anxious, talking to your GP can help identify if you need any additional support.

CASE STUDY

FARUKH MALIK

A local GP

"Getting a diagnosis gives you and your family the best chance to prepare and plan for the future. If the diagnosis is dementia, it may come as a shock. You may not know what to think or feel, or what to ask at the time. Make sure you ask to have another conversation once you are a little more settled.

We'll keep in touch and arrange to see you from time-to-time to see how you're getting on. We might prescribe medication that may be helpful in treating some of the symptoms. With treatment and support from healthcare professionals, family and friends, people with dementia can still lead active and fulfilling lives."

USEFUL NUMBERS

Call 999 if you or someone else is in immediate danger, or risk of harm.

Call 111 for general health enquiries. This is the number for non-emergency advice.

You can also contact your GP or local pharmacist for advice.

STAYING SAFE AT HOME

It is important to feel safe in your own home and this becomes even more important with a diagnosis of dementia. Dementia does not mean you cannot live at home independently, but there are things you can do to help you stay safe.

FIRE SAFETY

Fitting community alarms linked to smoke alarms and checking home appliances can reduce the risk of fire. London Fire Brigade offers free fire safety checks and they can fit smoke alarms for free. To book a free fire safety visit, simply call **free** on **0800 028 4428** or fill in the form at **www.london-fire.gov.uk**. Alternatively, you can ask a friend or relative to do it for you.

APPLIANCE SAFETY

Have your gas appliances (gas boiler, gas cooker or gas fire) regularly serviced and safety-checked every year by an engineer who is on the Gas Safe Register. Just call Freephone: **0800 408 5500** to find a registered business near you.

Carbon Monoxide alarms cost around £15 and can be purchased from your local DIY store, supermarket or from your energy supplier. Ask your Gas Safe registered engineer if you are not sure which alarm to buy or how to fit it.

PRIVACY

Nobody likes unwanted calls or junk mail, but it can be particularly confusing for someone with dementia.

You can avoid unwanted marketing by:

- Registering for free with the official Telephone Preference Service to stop cold calls. Just call **0845 070 0707**
- Registering with the official Mail Preference Service to be taken off junk mail listings. Just call **0207 291 3310** or go to **www.mpsonline.org**.

Other technologies to help you stay safe include:

- 'Hive' home heating system, which allows family and friends to monitor the property temperature remotely and change it via an app.
- Lifestyle monitoring programmes, such as Alcuris, which help family and friends to understand behaviour patterns when a person is home alone. It can let them know if anything seems unusual.

We also have a dedicated Technology Development Officer, who works closely with technology suppliers to develop products to support people with dementia.

To find out more contact Adult Social Care on:

Kensington & Chelsea - 0207 361 3000

Westminster - 0207 641 2500



TECHNOLOGY AND INNOVATION

We're looking at early intervention technology solutions to help people to manage their lives as the condition progresses. For example, this could involve learning a range of coping strategies.

DRUG TREATMENTS

There are no drug treatments that can cure dementia. However, there are medicines that can help with the symptoms of dementia, or that in some cases may stop them progressing for a while.

A person with mild to moderate Alzheimer's disease or mixed dementia in which Alzheimer's is the main cause may be prescribed one of three different drugs: donepezil, rivastigmine or galantamine. These may give temporary help with memory, motivation, concentration and daily living.

In the moderate or severe stages of Alzheimer's disease someone may be offered a different drug called memantine. This may help with attention and daily living, and possibly ease distress and behaviours that challenge.

Donepezil, rivastigmine and galantamine can also be helpful for someone with dementia with Lewy bodies who has distressing



DID YOU KNOW?

An estimated 1,400 people living with dementia could be living alone in our boroughs – we want to make sure that they are active and independent at home for as long as possible.

hallucinations or delusions, or who has behaviours that challenge (for example, agitation or unusual levels of anger).

For a person with vascular dementia, drugs will be offered to treat the underlying medical conditions that cause dementia. These conditions often include high blood pressure, high cholesterol, diabetes or heart problems. Controlling these may help slow the progression of dementia.

A wide range of other drugs may be prescribed at different times for a person with dementia. These include drugs for depression or anxiety, sleeping tablets or antipsychotics. Please be aware that some of these drugs can have severe side effects and not all are recommended for all types of dementia. Health professionals will generally recommend that a non-drug approach is tried first before prescribing medication, unless a person's symptoms are very severe.



DEMENTIA & CORONAVIRUS

Although good hygiene is more important than ever at the moment, people living with dementia can find excessive handwashing distressing. A couple of tips that may help are:

Prompting – remind people living with dementia to wash their hands, using soap and make sure their hands are fully clean. It may also help to support this with visual and verbal prompts (for example a towel, or a bar of soap) and to positively acknowledge when the task has been completed.

Sensory issues with soap – there are lots of different types of soap products: liquid soap, bars of soap, scented and unscented. It is advisable to work with a person with dementia to understand and be sensitive to their preferences. Some people have also said that using soap inside a fabric pouch or automatic dispenser is easier.

When hand washing is not an option – Sometimes when soap and water is not an option, hand sanitiser may be used instead.



LIVING WITH DEMENTIA

Meet Otto, he desperately wanted a trip down memory lane, to visit his home town of San Remo, Italy.

A trip back to the family home town in Italy doesn't sound like a major achievement. Until you take into account that the gentleman on holiday was 92 year old Otto, a resident in 'extra care' accommodation who has dementia, and that those accompanying him were care staff from Leonora House.

Otto had been talking of going to San Remo to visit his sister for some time. Care assistants Sylvia and Noria worked with his social worker to make it happen for him. From arranging the trip to getting his documents prepared and even taking him on a test train trip to Brighton, the professionalism and attention to detail shown by Sylvia and Noria is a great example of how care staff are dedicated to personalising care for residents.



Otto and Sylvia

“Older residents all have different needs and we try our best to meet them.”

SYLVIA, CARE ASSISTANT

In the early stages of dementia, it is likely that a person will be fairly independent. They should still be able to do most things with a little bit of extra help or by doing it a little differently.

There is no reason why you, or anyone around you, should dramatically change your life or stop enjoying activities you love. In fact, it's quite the opposite. It's important to stay active, keep practising the skills you've learnt in life and get out to see your friends and family as much as possible.



DID YOU KNOW?

In Westminster there is a day centre open 7 days a week to offer support, therapies and activities including gardening, arts & crafts and exercise **(0203 905 6982)**. In Kensington and Chelsea, Chamberlain House are running a weekly surgery where you can pop in for advice, support and guidance **(020 8206 8628)**.

"We're going to pottery together - I've always wanted to do that!"

"I make sure I talk to two to three people a day."

"Seeing the happy faces of people at an event brings me joy, more than the event itself."



GETTING OUT AND ABOUT

There are some great activities in our boroughs that are ideal for people living with dementia and their carers.

- Community hubs and centres offering free and low-cost activities for people over 50.
- Monthly memory cafés, offering a mixture of talks, information, advice, activities and group support for people in the early stages of dementia and their carers. The Rainbow Memory Café hosted by Open Doors is specifically aimed at people living with dementia and their carers from the LGBTQ+ community.
- A number of local organisations offer a variety of arts and culture-based reminiscence, drama or music activities that are accessible to people with dementia and their loved ones.
- Some art galleries run free or low-cost adapted tours and monthly interactive sessions for people in the early stages of dementia. For example, the Wallace Collection and the Victoria & Albert Museum offer dementia-friendly tours.
- There are various choirs across the boroughs that are suitable for people living with dementia.
- Some of our places of worship offer various events and activities for people with dementia that are open to non-members too. Your chosen place of worship might have its own programme of events.
- Reminiscence can stimulate your brain and preserve memories. Lords Cricket Ground run regular arts and sporting reminiscence sessions that are open to everyone.
- Charities, such as Age UK, Octavia Foundation, One Westminster or Neighbourcare offer befriending services to people who might feel lonely.

To find out more about what's going on in your local area, go to

www.peoplefirstinfo.org.uk/events and **www.resonatearts.org/listings**



DEMENTIA & CORONAVIRUS

It has been very difficult for people to get out and about during the current health crisis. Some of our residents have been joining in with some great online activities at home to keep busy; digital concerts, a weekly 'singalong' with care homes forming a Dementia Choir across London, online yoga classes, chair fitness and dance/football sessions. We have also funded dementia bikes and 'magic tables' for digital games in some care homes.

During the pandemic, over 3,000 people in Kensington and Chelsea and Westminster volunteered to support vulnerable people by delivering emergency food and medical supplies, and running social interaction and befriending services.

The councils also supported the Voluntary Sector to deliver personalised activity and crafting boxes in Kensington and Chelsea and to create a pen pal project with young and older people in Westminster, organised by the local Dementia Advisor.



LIBRARIES

If you're living with dementia, or caring for someone who is, the councils' library services have created spaces that are dementia-friendly. All library staff are Dementia Friends. Library archives are housed in a dementia-friendly building, and they offer quiet rooms and a home library service so you can read in peace. They also have a Reading Well prescription service.

Libraries also work closely with the Memory Assessment Service and local arts and wellbeing dementia services. They recently displayed art by people living with dementia and they hosted Resonate Art's artists and poetry sessions.

To find out more about what's going on for people living with dementia, visit your local library, which will display a monthly calendar of activities.

LORD'S CRICKET GROUND, HOME OF MARYLEBONE CRICKET CLUB

Marylebone Cricket Club (MCC) is committed to Lord's becoming a dementia-friendly ground. For the last five years, MCC has enjoyed hosting monthly reminiscence sessions. This is in addition to the annual Memories Match, when Lord's Cricket Ground opens to people living with dementia.

MCC's match day volunteers are Dementia Friends, trained to provide support to people attending major matches at Lord's. Visitors are able to have dementia lanyards, which help staff to identify people living with dementia so that they can provide them with the help they need.



DEMENTIA & CORONAVIRUS

Members of Kensington and Chelsea or Westminster libraries, can borrow and download books, magazines, newspapers, audiobooks and comics for free. All you need is your own device like a mobile phone, iPad or laptop.



TECHNOLOGY AND INNOVATION

In partnership with the Metropolitan police and Buddi we are offering a safer walking service to people who wish to go out but may be at risk of getting lost or confused when out. This is the first service of its kind in London.

To find out more contact Adult Social Care on: **Kensington & Chelsea** - 0207 361 3000
Westminster - 0207 641 2500

CARING FOR SOMEONE

When someone living with dementia can no longer carry out daily tasks for themselves, you may find yourself deciding to become their carer. It is a big commitment, and can be mentally and physically challenging, so make sure you're aware of all the support and financial help available to you.

LOCAL SUPPORT SERVICES

The Carers Hub Service

The Carers Hub Service provide support, information and advice to carers living in our boroughs, including:

- Completing in-depth carers assessments that consider the individual circumstances and specific needs of each carer. It is important you have an assessment so your needs are known and can be supported practically and financially.
- A dedicated information, advice and guidance service for unpaid carers covering carer-related benefits and services.
- Supporting carers to access additional support from a range of sources.
- Support groups and drop-in sessions that allow carers to come together for face-to-face support from their peers or a trained support worker.
- Social, training and information events and activities in the local area. These include IT training, mindfulness workshops and organised trips to local attractions.



DID YOU KNOW?

200 people are confirmed as caring for someone with dementia in our boroughs - but the true figure is likely to be higher.

Open Age 'Time for Me' project

A free weekly support and activities group for carers aged 50 and over living in North Kensington, South Kensington and Chelsea, and Westminster. A diverse programme is organised to provide carers with an opportunity to have some time for themselves, improve their health and well-being, feel less isolated and make new friends.

If you would like to find out more, just get in touch by calling 0208 962 4141.

Admiral Nurse Service

The Admiral Nurse Service provide information, practical advice and emotional support for people living in Westminster or Kensington and Chelsea who care for a relative or friend who has dementia.

Nurses can assist in obtaining professional assessment, support services, welfare benefits and relief care.

What are Admiral Nurses?

Admiral Nurses are specialist dementia nurses who work to support, both practically and emotionally, the family carers of people with dementia.



TECHNOLOGY AND INNOVATION

We're looking at early intervention technology solutions to help people to manage their lives as the condition progresses. For example, this could involve learning a range of coping strategies.

“My partner noticed I was getting more forgetful, not quite myself, and having problems finding the right word.”



How can an Admiral Nurse help me?

- If communication gets hard, an Admiral Nurse is on hand with skills and techniques to help you stay connected to the person you love.
- If someone with dementia is showing signs of fear or distress, an Admiral Nurse will work with you to find the best ways of preventing or managing this.
- If your family is struggling to cope, an Admiral Nurse will be there to help you get the best possible additional care and support.
- If you have questions you can't get answered, an Admiral Nurse will take time to really understand the problem and give you the expert support you need to tackle it.

We know that caring for somebody with dementia can sometimes be a hard and lonely experience.

If you wish to see an Admiral Nurse, please call **020 3317 3667** and request you are referred to the Admiral Nursing Service.

USEFUL CONTACTS

Admiral Nurses: 020 3317 3667

Independent Age: 0800 319 6789

Age UK

Westminster: 0203 004 5610

Kensington & Chelsea: 020 8969 9105

Westway Community Transport: 020 8964 4928

Memory Service: 020 3219 0910

Adult Social Care

Westminster: 0207 641 2500

Kensington & Chelsea: 020 7361 3013



DEMENTIA & CORONAVIRUS

Many carers have told us that since the pandemic it has been particularly challenging for them. Routines have changed, people are working from home and care is not being delivered in the same way it was before. It is more important than ever that carers look after their own mental health and wellbeing. Our websites contain lots of useful information and advice, with links to resources offering support.

ARTS EVENTS CALENDAR

Find out about all the activities open to residents and carers in the borough, at www.peoplefirstinfo.org.uk/events and www.resonatearts.org/listings

SUPPORTING OUR STAFF WHO ARE CARERS

We are establishing a support group for council staff caring for someone with dementia and reviewing our policy on respite care for staff too. If this is of interest to you, just get in touch with your Human Resources team to find out more.

END OF LIFE CARERS SUPPORT

The Carers Network run a specialist project supporting older carers (65 and over) who are caring for a loved one who is approaching the end of their life. They offer one-to-one support to the carer through this difficult time in their life, as well as specialist advice on writing a will, Lasting Power of Attorney and lots more.

FORMER CARERS PROJECT

The Carers Network run a project supporting former carers' who are no longer looking after someone. They can help people understand their identity beyond being a carer, provide practical approaches to manage their physical and mental health and advise on housing and financial changes.

USEFUL CONTACTS

Carers Trust

Helping unpaid carers access the help they need to live their lives.
www.carers.org.uk

Carers Network

T: 020 8960 3033
E: carers@carers-network.org.uk
www.carers-network.org.uk

Open Age - Time for Me

Free or low-cost leisure activities for people over 50 who look after a family member or friend as an unpaid carer.
T: 020 8962 4141
www.openage.org.uk/carers

People First

Supporting independent living and health in your borough.
www.peoplefirstinfo.org.uk/looking-after-someone

Marie Curie Nurses

T: 0800 090 2309
www.mariecurie.org.uk

If things are getting to be too much and you're thinking of moving someone into residential care, it can have a big impact on you too. It's not unusual to feel lonely or experience guilt, so make sure you seek support from your GP.



CARER STORY

WEI ROSE

Wei Rose looks after her elderly parents, in particular her father who has dementia.

"My experience in Westminster of being a carer for someone with dementia is very positive, especially with the range of services and activities provided, which have helped to give both my parents fuller lives. A dementia plan is important as it looks at achieving a long term aim in different areas, from the initial diagnosis of dementia to providing appropriate care, support, transport and dementia awareness in the community. All of which are important for those living with the illness and their carers."



TECHNOLOGY AND INNOVATION

Digital Personal Assistants (PAs), such as Alexa and Google, can help to tackle loneliness and isolation by helping groups of like-minded people interact, especially useful for those diagnosed with dementia who may not be able to get out. Digital PAs also provide entertainment. For example, you can instruct them to read a favourite author or put on a much-loved music track.

YOUNG PEOPLE AND DEMENTIA

Bringing together different generations gives great health benefits for both young and old. It's worthwhile finding ways to involve your child, grandchild, niece, nephew or friend in providing care for the person living with dementia, or just allow them to spend time with the person.

This will help make the situation seem more normal for them, and will prevent them from feeling left out. However, it's important that they continue with their normal lives, so don't give them too much responsibility, or let these tasks take up too much of their time.

- Let the child or young person know that simply being with the person living with dementia and showing them love and affection is the most important thing that they can do.
- Try to ensure that the time they spend with the person is enjoyable. Activities could include going for a walk, playing games, sorting objects, or making a scrapbook.
- Talk about the person's life and interests and show the child or young person photographs and mementos.
- Take photographs of the child or young person together with the person you care for, to remind you all that there can be good times, even during the illness.
- Don't leave a child or young person alone in charge, even briefly, unless you are sure that they are happy about the situation.

- Make sure that the child or young person knows that you appreciate their help, and show them how they are helping the person with dementia.
- Be aware of things that the person with dementia may find upsetting or confusing, and be prepared to provide reassurance if these occur when a child or young person is present.
- Talk to the child or young person afterwards if the person does become upset or confused, to help them understand why this happened.

We have worked with schools to deliver Dementia Friends Awareness sessions for children and young people and we're encouraging young people to volunteer with older people in care homes through the Duke of Edinburgh award scheme.



DEMENTIA & CORONAVIRUS

During the pandemic, we have worked with local schools and children's services under a programme called 'Sunflower Sessions'. Local children created flowers, cards, pictures and letters to bring light and positivity to people living in care homes across both boroughs.



DEMENTIA & CORONAVIRUS

The coronavirus outbreak has placed a strain on everyone, but especially those of us living with dementia. If you, or a friend or family member, currently live with dementia, here are some simple tips specially created to help make things more manageable.

→ STAY SAFE AND WELL

Always stay three steps (two metres / six feet) away from anyone you don't live with and wash your hands regularly. If you develop a cough or a temperature of 38°C or higher, or start to feel breathless, phone 111. Seek and accept help – but only from people you know and trust, or a registered volunteer.

→ STAY CONNECTED

There are lots of ways to stay connected with friends and family, from phone calls and letters to online video calls. You can also feel closer to the important people in your life by thinking about them and looking at photographs.

→ KEEP A SENSE OF PURPOSE

Make a list of jobs and pleasurable activities and create a daily routine that you enjoy. Keep up your usual daily activities such as washing, dressing, eating, cleaning, gardening and watching your favourite TV and radio programmes.

→ STAY ACTIVE

Stay active in ways that you enjoy. Get some daily exercise outdoors if you can, or do some simple indoor exercises – like stretching if you can't.

→ STAY POSITIVE

This is a frustrating time, but try to be patient and thoughtful, and support each other. There will be good days and bad days, but if you're feeling anxious, try using relaxation techniques or call a helpline such as the Alzheimer's Society.

We will get through this, and we will be together again.

ADVICE AND SUPPORT ON STAYING SAFE DURING COVID-19

ROYAL BOROUGH OF KENSINGTON & CHELSEA COVID-19 HUB

T: 0207 361 4326

E: C19Hub@rbkc.gov.uk

www.rbkc.gov.uk/coronavirus-covid-19

WESTMINSTER CONNECTS

T: 0207 641 1222

E: westminsterconnects@westminster.gov.uk

www.westminster.gov.uk/coronavirus

FOR GENERAL UPDATES ON COVID-19 AND NATIONAL GUIDANCE

www.nhs.uk and search for 'coronavirus'

FOR ADVICE ON COVID-19 AND DEMENTIA

www.alzheimers.org.uk and search for 'coronavirus'

BEST PRACTICE: HOW TO HAND WASH

Here is a step-by-step guide from the NHS to washing your hands with soap and water. Make sure you are doing this regularly for at least 20 seconds and remember to dry your hands thoroughly.



PALM TO PALM



**THE BACKS OF
HANDS**



**IN BETWEEN THE
FINGERS**



**THE BACK OF THE
FINGERS**



THE THUMBS



**THE TIPS OF THE
FINGERS**

LIVING AT HOME WITH DEMENTIA

We've created our own dementia-friendly home, looking at changes you can make to each room in the house:

THE LIVING ROOM

- **Make sure there are no trip hazards** – glass furniture can be harder to see; rugs may need an anti-slip mat to ensure they stay in place and get rid of any trailing wires.
- **Don't forget music and the radio** – people tend to find it easier to follow the radio, so don't be afraid to turn the television off. Music can be a great mood and memory booster.
- **Display your photos** – they can help bring back happy memories and have a comforting effect. You may find it helpful to label the location, people and relationships so you can always remind yourself of a special moment.

THE KITCHEN

- **Safety first** – if you have a gas cooker, you can get an automatic shut-off mechanism installed. You can also ask your Gas supplier to fit a gas detector so you'll always be alerted if you ever happen to leave it on.
- **Pin important information to the fridge** – it's somewhere you'll go to often, so stick up useful details you don't want to forget. We've included a pull-out poster with lots of helpful advice that you could use.
- **Use labels to remind you where things are kept** – whether it's your cutlery, food cupboard or pots and pans, having each cupboard labelled will save time and confusion.
- **Avoid clutter** – where possible, try to keep your surface areas clear of too many things, as these can add to confusion.

THE BEDROOM

- **Plug in a night light** – this will help you see where you're going, and you can get motion-sensored lights that only come on when you move around.
- **Install a pressure sensor** – these can either be fitted in to or beside the bed and can detect someone getting out of bed and not returning within a certain time. An alert can then be sent directly to an emergency response or chosen contact, such as your neighbour or carer.
- **Contrasting bed linen** – choose a duvet cover that is bright and bold, so it's easier to see your bed.

THE BATHROOM

- **Talk to us** – it may be that your local council can make some small changes to your bathroom, like installing a bath seat to help you get in and out safely, or a hand rail next to the toilet.
- **Prevent flooding** – you can buy a 'flood prevention plug' that lets water out of the bath when it becomes too full. Some of them will also change colour if the water gets too hot.
- **Contrasting tones** – try and make sure important things in the bathroom like the soap, towel or toilet seat are in a different colour to the floor and walls. This will make them much easier to recognise.
- **Traditional taps** – lots of the new, modern mixer taps can be very confusing to master. It might be worth opting for separate hot and cold taps if you can.
- **Store medicines safely** – keep them stored away in the same place. Check with your local chemist if they can arrange to collect any out-of-date or unwanted medication, so they can dispose of it safely.

MAKING A DEMENTIA-FRIENDLY HOME



We are also exploring how to make our buildings low-stimulus environments, which will benefit not just people living with dementia, but others too, such as autistic people. This involves including dementia-friendly planning policies in Westminster's City Plan and Kensington and Chelsea's Older People's Housing Design Guidance.



DEMENTIA & CORONAVIRUS

During the pandemic we have worked with suppliers locally and across London to deliver personal protective equipment (PPE) to care homes and home care agencies, to support the safety of residents and care workers.



DEMENTIA & CORONAVIRUS

We are working closely with local care homes and supported living facilities, extra care housing schemes and the voluntary sector to share knowledge, guidance and support. This has included working with Public Health England, the London Coronavirus Response Cell and North West London NHS to provide advice and guidance about infection control measures, PPE and best practice.

GETTING EXTRA HELP AT HOME

Home care is an option for people when they need a little extra help at home to manage day to day tasks. It's also called 'domiciliary care' or 'care at home'. Home care support can be as little as a quick check that someone is OK or to make sure they have taken their medication, to 24 hour live-in care.

PATIENT STORY

AISHA'S HOME CARE PROVIDER

There were some very important things in Aisha's life before she had dementia that we continue to help her with. We take her every week to the hairdresser and nail salon. She used to spend a lot of time and effort on her appearance, but when we first started to support her she wasn't doing this anymore. Now she has got this back into her routine and is really enjoying it.

We take her on reminiscence walks in Hyde Park as this is a very special place for her; lots of important events happened in her life there and she regularly remembers these. We support her in reading the Quran in her home. These activities are person centred and structured around her health and wellbeing, rather than purely doing tasks for her.

"We see a high standard of care in the best services and we need to make sure every service achieves the best outcomes for people living with dementia. We are pleased to work closely with the Royal Borough of Kensington and Chelsea and the City of Westminster to drive up standards for everyone who's using the services."

Our Care Quality Commission (CQC) local team



DID YOU KNOW?

85% of people would like to remain in their own homes for as long as possible if diagnosed with dementia. It is estimated that the number of people living with dementia will rise by 40% for Kensington and Westminster between 2017 and 2050.



TECHNOLOGY AND INNOVATION

In partnership with London Fire Brigade, we offer fire safety assessments, smoke alarms, extreme temperature sensors and misting towers. These are active 24 hours a day and send out a message to the fire service if activated.

CARE HOMES AND SUPPORTED LIVING

For lots of people living with dementia, or their carers, there may be a time when further help is required. This can be provided in your own home or within a residential care home.

EXTRA CARE

Extra Care, also known as assisted or supported living, is a type of 'housing with care'. People in extra care housing are able to keep their independence while being assisted with tasks such as washing, dressing, going to the toilet or taking medication. Residents usually have their own self-contained one-bed flat or studio where they are encouraged to live as independently as possible, whilst receiving care tailored to their individual needs. This could include 24-hour care and planned social events in a safe and secure environment.

RESIDENTIAL AND NURSING CARE HOMES

Care homes will have staff 24 hours a day, with a key number of qualified care assistants.

Nursing homes provide all the support that a care home would but registered nurses are also on-site throughout the day and night. Residents usually have a medical condition that needs regular attention from nurses or doctors.

COVERING THE COST OF 'CARE'

The cost of extra care housing will be different depending on the type of care you need. Nursing homes usually cost more than residential homes as they provide nursing care.



DID YOU KNOW?

We're developing a new care home at Beachcroft that will include dementia friendly designs, including a dementia-friendly garden. The home will open in mid-to-late 2020 and is one of a number of dementia friendly settings being planned.

FINANCIAL HELP FROM YOUR COUNCIL

Before deciding how to pay, it's worth asking your local authority for a needs assessment. The council can then help you look at all your options. Just get in touch with Social Services:

Kensington and Chelsea residents go to rbkc.gov.uk or call **020 7361 3000**

Westminster residents go to westminster.gov.uk or call **020 7641 2500**

PAYING FOR YOUR OWN CARE (SELF-FUNDING)

You can choose to pay for care yourself if you're able to afford it or you don't want a financial assessment. Read more about paying for your own care at www.nhs.uk

Need help or advice with finding a care home? Just go to cqc.org.uk/what-we-do/services-we-regulate/find-care-home



TECHNOLOGY AND INNOVATION

Soon we'll be introducing interactive game tables into a number of care settings. These provide cognitive stimulation through fun games that entice children, adults, and older people to get moving and have fun together.



CASE STUDY

LIAM HALLETT, Specialist Older Adult Psychologist and Psychotherapist

Liam has been working with people living with dementia and other mental health difficulties for the last 13 years. He's leading on an exciting and innovative new project.

'The Care Home In-Reach project is a year-long pilot in four care homes in the two boroughs focused on working with residents as individuals and their specific needs. It's very person-centred. We look at each resident's life story, experience and personal journey and work with a range of professionals to tailor support around that individual person's needs.

We want to promote improved quality of life, wellbeing and safety of care home residents, and improve the skills and capabilities of the staff who care for them. It's about passing on knowledge and good practice and being collaborative. We collaborate across several big organisations and focus on every single individual's experience. Every person's journey matters.'

CASE STUDY

MOTITECH BIKES

We were some of the first boroughs to pilot the innovative Motitech Dementia Bikes in four care homes. Residents can explore over 350 locations, all from an exercise bike that hooks up to a televisual experience; so you might be riding through the mountains in Tuscany or going off-road in New Zealand.

"This was my seventh time. Mostly I've been doing routes along the North African coast, I have really enjoyed it."



DID YOU KNOW?

We've created a new team called Quality Assurance (QA) to act as an 'independent eye' on the standards of our local services.

PLANNING AHEAD, END OF LIFE CARE

When someone is living with dementia, it's important to make sure that certain financial and legal decisions are put in place. Here are our recommendations of what you should do.

LEGAL AND FINANCIAL

- ➔ Set up a Lasting Power of Attorney (LPA) - in the event you are not able to make decisions, you will have enabled a family member or trusted acquaintance to do so.
- ➔ Make a will - it ensures that when you die, your money, property and possessions go to the people you choose. If you die without making a will, the state decides who to apportion your assets to. A person with dementia can still make or change a will, provided you can show that you understand its effect. Your will must be signed and formally witnessed. It should also be kept in a safe place where others can find it, either at home or with a solicitor. It's always a good idea to consult a solicitor who specialises in writing wills. The cost of a solicitor will vary - ask what the fee will be and what this includes before going ahead. Some charities offer a free will writing service, so it's worth checking with them.

MEDICAL

- ➔ In the event that you are hospitalised, you may want to consider what your wishes are about treatment. This is only invoked where the medical situation is critical. A person living with dementia may express their wishes using:
 - 'Advance decision to refuse treatment', which is a legally binding document or
 - 'Advance statement of wishes', which is not legally binding, but will be taken into account.

- ➔ Sometimes doctors make a medical decision that if a person's breathing or heart stops, there should be no attempt to resuscitate them. This is known as a DNR (do not resuscitate) or DNAR (do not attempt resuscitation) order. It is a good idea to talk about these situations with your loved ones or a trusted friend or someone like a solicitor when you are well, so that your wishes are known if this situation arises and you know the full implications. This often gives people peace of mind.

"We wanted to carry on with life as long as we could, knowing that it would change over time, but also knowing that it was important for my husband to have his independence. We have made Powers of Attorney both medical and financial in favour of our daughter".

CARERS

It's never an easy conversation to have but understanding the wishes of someone living with dementia means they can get the care they want in the later stages of dementia.

If they're not ready to talk about the specifics, trying to get to know their values, wishes and beliefs more generally can help in the future when decisions need to be made on their behalf.

It's also worth considering making plans for care in case you're not able to continue your role, for example If you (the carer) are admitted to hospital.

You can get advice on how to find the right care home at [cqc.org.uk/what-we-do/services-we-regulate/find-care-home](https://www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home)



CASE STUDY

MANDY ANDREWS AND TEREZIE WICKENDEN,

Our Dementia Advisors,
explain their roles.

“As Dementia Advisors we support people who have received a diagnosis of dementia. In our role we usually visit service users at home, and also provide telephone and email support. We are a continuous point of contact for as long as they need us.

Our work involves providing information, advice and support to help people feel informed and able to access appropriate help when needed.

We can help people understand and manage their symptoms, provide tips on living well and strategies on how to maintain a quality of life. We provide information and signposting to support people to stay living independently at home, accessing suitable social activities and care options if necessary.

We support people living with dementia in a person-centred way to feel in control and plan their future using tools such as the **Lasting Power of Attorney** and **Advance Statements**.

“We run regular Memory Cafés that offer support, information and stimulating activities.”



END OF LIFE CARE

When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them.

PALLIATIVE CARE

Palliative care is for anyone diagnosed with a life-limiting illness, including dementia. It focuses on maintaining a person's quality of life by relieving discomfort or distress (whatever the cause). Any palliative care in place continues alongside end of life care.

Palliative care professionals at a local hospice or hospital may give specialist input if this is needed. This team of professionals should keep you updated on any changes in the person's condition and involve you in any decisions.

The person should always have an up-to-date care plan that includes end of life plans and is shared with those involved in the person's care.

END OF LIFE CARE

End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care.

It's for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days.

CARERS

Everyone reacts and copes with bereavement in their own personal way.

How you feel following a bereavement may be affected by different things, such as your relationship with them and your situation and personality. Sometimes, you may find that you can't grieve and it can take a long time for your feelings to come out.

Some carers may feel a sense of emptiness after bereavement. This can be for different reasons, including struggling to come to terms with the loss of the person, missing their defined role as a carer, feeling like they have too much free time - especially if they've lost past interests and hobbies and they've not been in touch with other people while caring. All of this can add to feelings of loneliness and isolation.

Some people find it hard to adjust to living without the person. It can help to talk through these feelings with someone you trust or a professional.

PLANNING FOR A FUNERAL

It has become more common to plan and even pay for a funeral in advance. The advantages of doing this include being able to plan the funeral that you would like. It can also make it easier for your family and friends to arrange the details. Undertakers or funeral service companies should be able to provide you with more information about funeral planning.



TECHNOLOGY AND INNOVATION

Pressure mats linked to pagers

These can help support family or a carer who is living with someone who is at risk when getting in or out of bed or a chair. The mat is pressure-activated and an alert is sent to a family member's pager. This allows them to be in another part of the house or garden, giving everyone the space they may need.

USEFUL CONTACTS

Marie Curie

Care and support through terminal illness www.mariecurie.org.uk/help or call 0800 090 2309

Macmillian Nurses

Care and support for cancer www.macmillan.org.uk or call 0808 808 0000

Cruse Bereavement Care

National Helpline 0808 808 1677
Local 020 8964 3455

“Death and dying should be a natural matter to discuss. Palliative care for me, should start, the minute that you get a diagnosis. People tend to regard dying as something unnatural, but it isn’t.”



DEMENTIA & CORONAVIRUS

Our plan was written before the pandemic, but we know that the impact on people living with dementia will be felt for many years to come. We will be working on specific actions to support people living with dementia and their carers affected by the COVID-19 crisis and lockdown measures.

MAKING OUR BOROUGHS DEMENTIA-FRIENDLY



CASE STUDY

ANDREW CARPENTER,
Dementia lead, Kensington
and Chelsea and Westminster
councils

"I've enjoyed getting to know so many lovely people and working with them to make our boroughs leading dementia-friendly communities. It's been amazing to see how keen people are to help make things better and do their part.

To raise awareness of dementia, I worked closely with the local Dementia Action Alliance to put scarves on famous statues around our boroughs. We did this during Dementia Action Week and followed it up with a social media campaign.

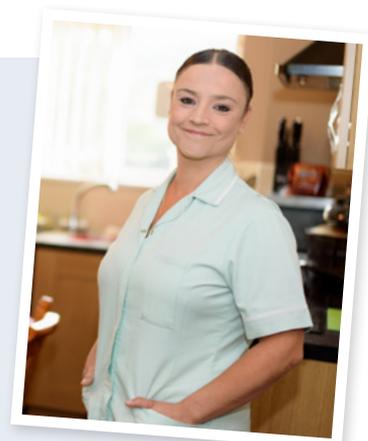
With my colleagues, I've also set up the Dementia Partnership Group alongside Bernie Flaherty, our Kensington and Chelsea and Westminster Executive Director of Adult Social Care and Health, as a way of involving local people in the long-term. Made up of residents living with dementia, and their carers, the group gives us direct feedback on our services, from adult social care to housing, leisure and transport. It's vitally important that residents really do inform how we do things in Kensington and Chelsea and Westminster".



COMMUNITY NHS SERVICES

There's a great range of local NHS services in Kensington and Chelsea and Westminster.

This includes Admiral Nurses (specialist dementia care nurses), the Memory Assessment Service, which assesses and diagnoses dementia and provides other dementia support services, through to talking therapies for all patients and carers with low-levels of cognitive impairment or with caring responsibilities. Speak to your local GP to find out more.



INTEGRATED CARE

Both the West London CCG and the Central London CCG work with the councils and local health, care and community organisations. They provide services to meet the needs of older people with multiple physical, mental health and care needs, including people with dementia.

Though not yet available in the whole of Westminster, the Integrated Care Teams work to create a single care plan that is monitored by a range of professionals, benefits patients and staff and means you only need to tell your story once. Talk to your local GP to see how you can be part of these services.

WORKING TOGETHER

Our ambition to become a leading dementia-friendly borough is shared with other public, private and third sector organisations.

Both directly, and through the Dementia Action Alliance, we work closely to ensure our services work effectively for people living with dementia, our environments are dementia-friendly and our staff are Dementia Friends. We also share best practice and resources.

For example, we're working with the Met Police, London Fire Brigade and many other

public sector partners to deliver the Mayor's ambition to make London the first dementia-friendly capital in the world.



CASE STUDY

SUPT. MARK LAWRENCE,
Lead for Mental Health

"Every year MPS Officers complete over 10,000 'Merlin' reports about adults who may be vulnerable through dementia. That's an average of over 27 reports completed every day across London.

Responding to dementia in all of its guises, whether it's looking for missing people or investigating crimes that take advantage of vulnerability, represents a significant safeguarding issue for the police, its partners and the community it serves. And of course, most officers and staff will have friends or relatives touched by dementia. This is why the MPS is committed to supporting the Mayor in his ambition to make London the first dementia-friendly capital city in the World by 2020.

As part of this commitment, the MPS is encouraging as many of its staff as possible to be Dementia Friends, and is actively engaged in Dementia Action Alliances across London, working in partnership with initiatives like the Herbert Protocol*. We applaud the work being conducted in Kensington and Chelsea and Westminster and we look forward to working with partners across both boroughs to help people live well with dementia and improve the service we provide to both those experiencing dementia and the carers and relatives that support them".

"The MPS is committed to supporting the Mayor in his ambition to make London the First Dementia Friendly Capital City in the World by 2020."

DEMENTIA FRIENDS

Small changes make a big difference, and we will lead the way by introducing many new ideas and initiatives across our councils, helping others to become dementia-friendly. We will support shops, galleries and leisure centres to train their staff as Dementia Friends, so you know

there's always a welcome anywhere you go. All council staff will become Dementia Friends by 2020, with 70% by Christmas 2019. We are pledging real changes to the way we work to become more dementia-friendly. For example, we already ensure any building we build is designed, constructed and finished in a dementia-friendly way.

*The Herbert Protocol is a national scheme introduced by the police. Working with other organisations, it encourages carers to fill out a form of useful information that could be used if a vulnerable person goes missing.

OUR DEMENTIA PLAN

People are living longer, and the number of those developing dementia is increasing. This means the cost of care is increasing and putting pressure on our services.

We want to enable people to live life to the full by creating dementia-friendly communities. We also know people with dementia want to live at home for as long as they can, so we want to help provide the extra care they need.

We know that there's great work going on already to transform our boroughs into leading dementia-friendly communities, but there's a lot more we plan to do.

- Raising awareness of dementia and ways to help prevent it.
- Providing personalised, timely and high-quality services.
- Creating a community that is dementia-friendly.
- Giving unpaid carers good support.

We'll know we've been successful if:

- Through The Dementia Action Alliance, we achieve Dementia Friendly Community accreditation by 2020.
- 6,000 Dementia Friends are created from public, private and third sector organisations across both boroughs by December 2020.
- The percentage of short-term dementia acute care admissions is reduced to below the national average by 2025. Short-term dementia acute care admissions currently represent 32% of all hospital admissions of people living with dementia in Kensington and Chelsea and 33% in Westminster. This will show community care and support is working.
- Our new, targeted survey of dementia carers shows an increase in carer satisfaction with council services by 2025.

“You know a place is dementia friendly when, as soon as you walk in the door, there's a welcome.”



TECHNOLOGY AND INNOVATION

The Memrabel 2 is a clock that displays the day, time and date. It also has 20 alarms which can be set up with pictures, written prompts and recorded videos to help remind people to do things. This could be when to eat a meal, exercise or a prompt about a GP appointment.

WHAT WE'LL DO

There's already some great stuff taking place across our boroughs. We will continue to ensure we're leading the way to create dementia-friendly communities by:

PRIORITY 1

Raising awareness of dementia and ways to prevent it

-  Launching an awareness-raising dementia campaign in 2020.
-  Making all our staff Dementia Friends with 70% already trained - and helping others to do the same.
-  Having an easy-to-find dementia area on our website.

PRIORITY 3

Creating a community that is dementia-friendly

-  Providing a toolkit for businesses and other local organisations to help them become dementia-friendly.
-  Working with the Salvation Army's Central London venue to pilot a quiet space and community hub.

“Out in the street they don't know I have dementia; everyone is a spectator and no one helps. People are detached.”

PRIORITY 2

Providing personalised, timely and high-quality services

-  Piloting a holistic single plan to ensure that people living with dementia can properly plan for the future they want from diagnosis onwards.
-  Incorporating more specialist adjustments for people with learning disabilities into our home support services.
-  Arranging bespoke training for health and social care staff to best support people living with dementia and their carers with partners.

PRIORITY 4

Giving unpaid carers good support

-  Establishing a support group for council staff caring for someone with dementia.
-  Reviewing respite care to ensure it is fit-for-purpose and takes into account people's individual needs.

“We need more information on dementia for the general public to overcome fears and stigma.”

OUR COMMITMENT TO YOU

PRIORITY 1

Raising awareness of dementia and ways to reduce the risk

WE COMMIT TO:

-  Encouraging residents to take action to reduce the risk of dementia and to seek a timely diagnosis.
-  Promoting understanding, acceptance and support within the community for people living with dementia.
-  Raising awareness of dementia and the needs of people living with dementia amongst public and private sector partners.
-  Increasing awareness of dementia and the needs of people living with dementia amongst council and NHS staff.

“I have learnt that we can adjust to changes in our relationship. We do have very happy times.”

PRIORITY 2

Providing personalised, timely and high-quality services

WE COMMIT TO:

-  Ensuring that services are easy to use and support is joined up (including for multiple health needs), recognising that people are more than their diagnosis.
-  Creating services that are personalised and relevant, because we acknowledge that everyone is different.
-  Providing residents with the right information and advice, in the right place and at the right time.
-  Continuing to innovate and provide high-quality services, exploring new technology to give people living with dementia the best care.
-  Making sure good quality staff receive the necessary training to best support you.

“Although I’m glad to be there for him, it was so hard to give up my life to care for my Dad.”



OUR COMMITMENT TO YOU

PRIORITY 3

Creating a community that is dementia-friendly

WE COMMIT TO:

-  Embedding dementia design across all council services.
-  Working with local public, private and third sector organisations to create a holistic, dementia-friendly community.
-  Ensuring that communities are aware of and make the most of the services and activities available to them.
-  Using technology and digital solutions to support people to live independently in their communities for as long as possible.
-  Making available the latest memory devices and technology.
-  Doing everything we can to support you to stay where you are.
-  Ensuring the suppliers we work with to deliver our dementia strategy are aligned with our Corporate Social Responsibility strategy.

PRIORITY 4

Giving unpaid carers good support

WE COMMIT TO:

-  Giving carers personalised support, including respite care.
-  Ensuring carers are well informed about dementia and the needs of people living with it.
-  Providing carers with information about services, networks and activities for carers, as well as those for people living with dementia.
-  Supporting carers of people with dementia in the workplace and encouraging others to do the same.

“My wife makes me feel safe. She writes down for me where I am going because as soon as I go out of the door, I have no memory of where I am going or why.”



JARGON BUSTER

We understand that dementia can open up a whole new vocabulary of medical and legal words that you might not know. So, we've tried to list them below with their meaning. We hope it helps.

WORD OR PHRASE	EXPLANATION
Acute Care	Short-term health care that you receive in hospital following an injury, operation or illness. It is different to any care you may receive for an ongoing health condition from your GP, community nurse or other professionals in the community where you live.
Advocacy	Help to enable you to get the care and support you need that is independent of your local council. An advocate can help you express your needs and wishes, and weigh up and take decisions about the options available to you. They can help you find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.
Intergenerational	People of many different ages and generations coming together.
Lasting Power of Attorney (LPA)	A legal agreement where you allow someone to make decisions on your behalf about your property and finances or health and welfare, if the time comes when you are unable to make these decisions for yourself.
Dementia Action Alliance (DAA)	The DAA is a local network of people and organisations, working together to improve the lives of people living with dementia
Clinical Commissioning Group (CCG)	CCGs are responsible for planning, designing and commissioning (paying for) health services in their local area.

WORD OR PHRASE	EXPLANATION
Co-ordinate My Care (CMC)	CMC keeps an online 'urgent care plan'. These plans are personalised to the patient and can be accessed by different emergency care services, so the information is easy to find and all in one place.
Court of Protection (COP)	The COP makes decisions on financial or welfare matters for people who can't make decisions at the time they need to be made (they 'lack mental capacity').
Dementia Partnership Group (DPG)	A group of residents living with dementia and their carers in Kensington and Chelsea and Westminster, who advise and inform council services.
Co-production	Where residents and users of services act as equal partners with professionals in designing care and support services you receive. Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.
Health and Welfare Deputy	A Health and Welfare Deputy is appointed by the Court of Protection. They can make certain decisions on behalf of a person who doesn't have the mental capacity to do so themselves.
Whole-systems (or Holistic) Approach	Looking at every aspect of how a system works – such as the health, social care and housing system – and understanding what each part does, where the connections are and how it all fits together. Looking at the system in this way should help show how things can be done differently and better, working with the whole community together.
Psychiatrist	A medical doctor specialising in the diagnosis and treatment of mental illness, including dementia.
Statutory Services	Organisations that have a legal responsibility to do something, and whose role and powers are defined by law. They are different to voluntary organisations, which may provide some of the same services but which are not set up by law. Your local council is an example of a statutory organisation, as is the NHS.

MEET MICK

Living with dementia has its challenges – not everyone understands it or how it affects people living with it, like me, or people caring for someone living with dementia, like my partner Kathie.

It's also not just about being understood. Because of my dementia, my partner and I have different needs – my sight could be affected, so I might avoid black mats at entrances. I have confused them before for a big black hole!

This plan highlights some of the great initiatives that are already in place across Kensington & Chelsea and Westminster. I'm thrilled that it's not just focused on health and social care but thinks about a person's whole life.

“I want to be able to continue to live at home for as long as possible in a community that continues to understand and support me.”

I'm really glad to have been involved in developing this plan with other people, like me and Kathie. However, there's more to do. Now that people living with dementia have outlined what they need to live well, we are calling on everyone – neighbours, businesses, doctors – to do their bit to put this into action.

So I am pleased to be able to close this document as the first step towards transforming my home boroughs into leading dementia-friendly communities. Join me in starting this journey together.

Mick, lives with dementia and is cared for by his partner, Kathie.



HELP BEAT DEMENTIA

Vital studies into early diagnosis, prevention and new treatments for dementia are taking place in the UK – but more volunteers are needed. Anyone over 18, with or without dementia, can register their interest as a volunteer. To sign up, or find out more, just go to www.joindementiaresearch.nihr.ac.uk

We are also working together with local research groups and will keep you posted about any study opportunities you can take part in.

Join
dementia
research

USEFUL CONTACTS

GENERAL ADVICE AND INFORMATION ON DEMENTIA

Age UK

T: 0800 678 1602 or go to www.ageuk.org.uk

Alzheimer's Society

Advice for people affected by dementia.

T: 0300 222 1122 or go to www.alzheimers.org.uk

Dementia UK

Provides specialist dementia advice and support for families through its Admiral Nurse service. T: 0800 888 6678

or go to www.dementiauk.org

Admiral Nurses

Information, practical advice and support for people who care for a relative or friend who has dementia. T: 020 3317 3667

Young Dementia UK

Support, information and guidance for those who are affected by young onset dementia.

www.youngdementiauk.org

HEALTH AND CARE SERVICES

Age UK

Advice on dementia care, funding care provisions and entitlements to benefits.

Kensington and Chelsea - T: 020 8969 9105.
www.ageuk.org.uk/kensingtonandchelsea

Westminster - T: 020 3004 5610.
www.ageuk.org.uk/westminster

BME Health Forum

Health advice for members of the black, Asian and minority ethnic communities.

T: 07958 479217
www.bmehf.org.uk

Marie Curie

Care and support through terminal illness.

T: 0800 090 2309
www.mariecurie.org.uk

Macmillan Nurses

Care and support for cancer.

T: 0808 808 0000
www.macmillan.org.uk

People First

Supporting independent living and health.

www.peoplefirstinfo.org.uk/looking-after-someone

Dementia Advisors

Practical support, advice and guidance on services and local activities.

Kensington and Chelsea - T: 020 3181 0002
Westminster - T: 020 3905 6981

Adult Social Care Services

Local social care, information, advice and support.

www.rbkc.gov.uk
www.westminster.gov.uk

ADVICE FOR CARERS

Carers Network

Advice and support on Carer's Assessment, Benefits, Legal Rights and Wellbeing.

T: 020 8960 3033

E: carers@carers-network.org.uk
www.carers-network.org.uk

Carers Trust

Helping unpaid carers access the help they need to live their lives.

www.carers.org.uk

Carers UK

Advice and support to anyone looking after a family member or friend with dementia.

T: 0808 808 7777
www.carersuk.org

Open Age - Time for Me

Free or low-cost leisure activities for people over 50 who look after a family member or friend as an unpaid carer.

T: 020 8962 4141
www.openage.org.uk/carers

Revitalise

Respite holidays for carers.

T: 0303 303 0145
www.revitalise.org.uk

Westway Community Transport

A local charity providing transport for those who find it difficult to get around.

T: 020 8964 4928
www.westwayct.org.uk

THINGS TO DO IN YOUR AREA**Rainbow Memory Café**

For members of the LGBTQ+ community living with dementia.

T: 020 7239 0400

www.openingdoorslondon.org.uk/rainbow-memory-caf

Arts4Dementia

Empower and inspire people with early-stage dementia with artistic stimulation.

T: 020 7239 4954

www.arts4dementia.org.uk

Creating with Dementia

Nationwide listings of arts events for people with dementia.

T: 07775 784520

E: creatingwithdementia@gmail.com

Resonate Arts

Find out what activities are on in your area.

T: 020 7321 2702

www.resonatearts.org

STAYING SAFE**The Metropolitan Police**

In an emergency call **999**. If you want to report a crime call **101**

The London Fire Brigade

For information on fire prevention & safety advice, or to get a free fire alarm fitted.

T: 020 8555 1200 or www.london-fire.gov.uk

NHS

For urgent medical attention call **111** or **999** in an emergency. For general medical information and advice, go to www.nhs.uk

STAYING SAFE DURING COVID-19**Kensington & Chelsea COVID-19 Hub**

T: 0207 361 4326

E: C19Hub@rbkc.gov.uk

www.rbkc.gov.uk/coronavirus-covid-19

Westminster Connects

T: 0207 641 1222

E: westminsterconnects@westminster.gov.uk

www.westminster.gov.uk/coronavirus

National Covid-19 guidance

www.nhs.uk and search for 'coronavirus'

Covid-19 and dementia

www.alzheimers.org.uk and search for 'coronavirus'

This plan was written with the support and advice of over 170 residents. Thank you for giving up your time to inform and shape our thinking.

We want to thank the Abbey Centre, the Advocacy Project, Age UK RBKC, Opening Doors, Resonate Arts and Musawa for facilitating workshops and one-to-one interviews with residents. Without your help, it would not have been possible to reach out to so many residents, ensuring that the plan is genuinely co-produced with residents who reflect our boroughs' diversity.

We also want to thank everyone from a wide variety of organisations who have inputted into our strategy, including representatives from health and social care professions as well as the worlds of design, architecture, business, culture, sport and more. Your advice and support during the development of the plan has been invaluable and we look forward to working with you again to implement it.



OTHER LANGUAGES

Information from this document can be made available in alternative formats and in different languages. If you require further assistance please use the contact details below.

Arabic

يمكن توفير المعلومات التي وردت في هذا المستند بصيغ بديلة ولغات أخرى. إذا كنت في حاجة إلى مزيد من المساعدة، الرجاء استخدام بيانات الاتصال الواردة أدناه.

Farsi

اطلاعات حاوی در این مدارک به صورتهای دیگر و به زبانهای مختلف در دسترس می باشد. در صورت نیاز به کمک بیشتر لطفا از جزئیات تماس ذکر شده در ذیل استفاده کنید.

French

Les informations présentées dans ce document peuvent vous être fournies dans d'autres formats et d'autres langues. Si vous avez besoin d'une aide complémentaire, veuillez utiliser les coordonnées ci-dessous.

Portuguese

A informação presente neste documento pode ser disponibilizada em formatos alternativos e em línguas diferentes. Se desejar mais assistência, use por favor os contactos fornecidos abaixo.

Somali

Macluumaadka dokumentigan waxaa lagu heli karaa qaabab kale iyo luuqado kala duwan. Haddii aad u baahan tahay caawinaad intaas dhaafsiisan fadlan isticmaal xiriirka faahfaahinta hoose.

Spanish

La información en este documento puede facilitarse en formatos alternativos y en diferentes idiomas. Si necesita más ayuda por favor utilice la siguiente información de contacto.

FOR FURTHER ASSISTANCE CONTACT

The Royal Borough of Kensington & Chelsea
Tel: (020) 7361 3000
Email: SocialServiceLine@rbkc.gov.uk
www.rbkc.gov.uk

The City of Westminster
Tel: (020) 7641 6000
Email: adultsocialcare@westminster.gov.uk
www.westminster.gov.uk



A GREAT BIG THANK YOU!



THE ROYAL BOROUGH OF
KENSINGTON
AND CHELSEA



The City of Westminster



The Royal Borough of Kensington & Chelsea

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www.nhs.uk

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