Dementia Strategy 2023-2028



This strategy sets out how we plan to make Milton Keynes a city where people living with dementia and those affected by it can thrive.

Executive Summary

This strategy applies to all adults aged 18 + living in Milton Keynes who have a diagnosis of dementia; are worried they may have symptoms of dementia or are at higher risk of dementia due to their lifestyle or medical condition.

The aim of the strategy is to ensure that significant improvements are made to dementia services across six key areas, from increasing availability in care homes to helping people live well in their own home for longer. It also seeks to ensure that Milton Keynes fulfils its ambition of becoming a dementia friendly city as outlined in the council's Strategy for 2050: New Design $\frac{1}{2}$

"According to the Institute of Public Care there are currently 2,827 people aged 65 + living with a dementia diagnosis in Milton Keynes. This figure is expected to rise to 4,738 by 2040."

"The likelihood of developing dementia increases sharply with age. In the UK around one in thirty (1:30) people have the condition by age 70, which increases to one in five (1:5) by age 80".

What is dementia?



Dementia is a progressive neurological condition which occurs when the brain is damaged by disease (like Alzheimer's) or a series of strokes. Symptoms can include memory loss and difficulties with thinking, problem solving, physical function. lt is language and predominately a disorder of later life, but a small percentage of people under the age of 65 have the condition. Its prevalence rises steeply with age and affects people regardless of gender, social background, or ethnic group. Consequently, the number of people aged 65 and over living with dementia is expected to rise significantly.

1. Introduction

The Council Plan 2022-2026 ² sets out how Milton Keynes City Council will deliver its Strategy for 2050 to ensure everyone in Milton Keynes can lead a happy, healthy life.

It highlights one of the council's main objectives to make Milton Keynes *"a thriving, progressive and sustainable"* place to live that *"promotes independence in older age"* and offers *"support for those with dementia"*.

Priorities 6 and 7 of the Council Plan aim to "*reduce health inequalities*" and "*reduce obesity and levels of smoking*" which are also addressed in *the* Adult Social Care Prevention strategy 2023-2026 $\frac{3}{2}$ which underpins this strategy.

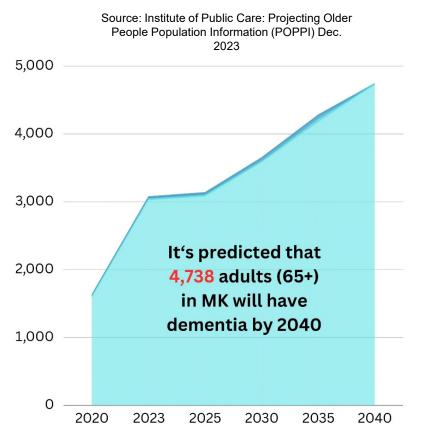
2. Context

The likelihood of developing dementia increases sharply with age. In the UK around one in thirty (1:30) people have the condition by age 70, which increases to one in five (1:5) by age 80 and one in three (1:3) by age 90 $\frac{4}{2}$. According to the Institute of Public Care there are currently 2,827 people aged 65 + living with a dementia diagnosis in Milton Keynes. This figure is expected to rise to 4,738 by 2040.

Dementia is much rarer in younger people (aged 30 to 64) with approximately 69 adults diagnosed with early onset dementia in Milton Keynes in 2023 (<u>Appendix C</u>).

The current cost of dementia care in Milton Keynes is £113 million and that figure is expected to rise to £213 million by 2030. This increase in spending is forecast to reflect the predicted rise in the number of older people living in the city (from the current figure of 42,500 to 50,300 by 2030). Furthermore, it's estimated that Milton Keynes' population (aged 85 +) will double from the current figure of around 5,000 to 10,200 by 2040.

It's therefore crucial that services are put in place to meet the predicted increase in demand.



The graph shows the number of older adults in Milton Keynes aged 65+ predicted to be diagnosed with Dementia; a steep rise can be seen to just under 5,000 people by 2040.

3. Health inequalities

Some people are at higher risk of developing dementia than others. According to Alzheimer's Society's ⁴ there are several factors which can predispose a person to develop the condition - the key one being age. Lifestyle factors such as underlying health, co-morbidities such as Parkinson's, whether a person smokes or takes exercise can influence risk, as can sustaining a traumatic brain injury (TBI) from a stroke, accident or combat sport such as boxing.

Health inequalities such as gender, ethnicity and socioeconomic factors also play a part in whether or not a person is at risk from developing dementia (<u>page 6</u>). Some health inequalities are fixed such as ethnicity, learning disability and gender and others are caused by social or geographical factors. It's our intention to address all existing health inequalities especially in ethnic minority communities and for those on low income by:

- developing targeted initiatives
- tailoring our messaging to promote dementia risk reduction
- reflecting this in dementia care plans

It's also important to reduce the stigma attached to dementia to help people acknowledge and discuss any problems that they might be having because of their dementia. Other barriers to seeking care, might be due to culturally specific views; that dementia is a normal part of ageing, or that it has a spiritual, psychological or social cause - which has prevented some groups from seeking support ⁵.

WHAT ARE THE MAIN RISK FACTORS ASSOCIATED WITH DEMENTIA?

RISK FACTOR 1 -AGEING

Although dementia is not an inevitable part of ageing, the risk of developing the condition increases as we age. Up until age 65 we have a one in fifty chance of developing dementia but by age 90 that increases to one in three. From age 70 upwards a person's risk of being diagnosed roughly doubles every five years. 4.

RISK FACTOR 2 -ETHNICITY

A few studies have suggested that Black African, Black Caribbean and South Asian ethnic groups are more likely to get dementia than people from White ethnic groups. However more evidence is needed that ethnicity alone is a risk factor for dementia as other socioeconomic factors such as poor access to work opportunities or the effects of living in deprived areas are also cited as factors 4.

RISK FACTOR 3 -GENDER

Dementia is the leading cause of death for women in the UK who make up 65% of positive diagnoses for Alzheimer's disease. Nearly double the number of women (42,000) compared to men (23,000) died of dementia in the UK in 2022 ^Z. According to *Alzheimer's research UK* women may be more affected due to variables such as lowered oestrogen after menopause. Some studies indicate that oestrogen may protect the brain from age related dementia ⁶.

RISK FACTOR 4 – LEARNING DISABILITY

A person with a learning disability, is four times more likely to develop dementia than a person who doesn't have a learning disability. Dementia is much more common in people with Down's syndrome, and onset often begins earlier. If a person with a learning disability develops dementia, they will face different and additional challenges compared to people who don't have a learning disability Z.

RISK FACTOR 5 -SOCIOECONOMIC

There's consistent evidence that risk of dementia is higher in disadvantaged groups and in people who live in deprived areas. This may be because of the lack of opportunities in these areas makes it harder for a person to access further education or jobs that keep them mentally active throughout their life. More deprived areas tend to have higher levels of air pollution and poorer access to health and social services.

RISK FACTOR 6 -LIFESTYLE

There's a lot of evidence that our lifestyle choices can influence whether we get dementia or not. Studies indicate that dementia is lowest in people who have several healthy behaviours mid-life (40–65) including i) regular mental, physical and social activity ii) alcohol in moderation iii) not smoking and iv) keeping a healthy diet 4. Being overweight, smoking and having type 2 diabetes are associated with an increased risk of developing dementia as is traumatic brain injury (TBI) ⁸ and certain inherited genes 4

Alzheimer's Society estimates there are 700,000 unpaid carers looking after adults who are living with dementia in the UK (2021)⁹

4. Strategy aims and objectives

In June 2023 Milton Keynes City Council held an event <u>Talking Dementia</u> which brought together representatives from a wide range of charities and organisations including Alzheimer's Society, Age UK, Carers MK and the Parks Trust, in order to hear first-hand what the residents of Milton Keynes had to say. Over 100 people living with dementia, their carers and family members were invited to share their ideas and tell us what they needed most when it came to meaningful support. Four key themes and six future priorities were identified:



FUTURE PRIORITIES

PRIORITY 1	PRIORITY 2	PRIORITY 3
Increased capacity in care homes for people with dementia, including those with a mental health diagnosis or learning disability.	More tailored support for family carers to help people with dementia stay in their own homes and reduce the need for emergency respite or early care home admissions.	Increase services with high levels of expertise in dementia offering practical advice, and emotional and psychological support to people with dementia and their carers from diagnosis to post bereavement.
PRIORITY 4 Initiatives partnering with Public Health to help reduce the incidence or delay the onset of dementia including smoking cessation, reduced alcohol consumption, exercise, and managing long term conditions linked to dementia for example Type 2 diabetes.	PRIORITY 5 Fulfilling our ambition to make Milton Keynes a dementia friendly city.	PRIORITY 5 Working with Health services and the ICB (Integrated Care Board) as 'one system' to explore joint funding opportunities and collectively plan new service provision.

PRIORITY 1 | INCREASE CAPACITY IN LOCAL CARE HOMES

WHY IS IT IMPORTANT?

When a person can no longer be cared for at home, a care home may be needed. Remaining in the local area is important to maintain contact with familiar services and contact with friends and family.

OUTCOMES |

 People living with dementia in a care home will be cared for in a way that maintains dignity, independence, and choice

WHAT IS CURRENTLY IN PLACE AND WILL CONTINUE?

Currently there is provision in some Milton Keynes care homes for those with dementia, but this is unlikely to meet the increased demand predicted.

WHAT ELSE WILL WE PUT IN PLACE?

 Recommissioning of care homes to ensure a wide range of good quality accommodation and care is available including provision for those with dementia and a learning disability or mental health diagnosis

PRIORITY 2 | HELP PEOPLE TO LIVE WELL AT HOME

WHY IS IT IMPORTANT?

For most people with dementia living in their own home for as long as possible is important. Familiarity with the details of their surroundings; such as floor plan, furniture and bedrooms is known to reduce anxiety and confusion and increase a sense of safety, comfort and awareness in people with the condition. However, for carers to remain in the caring role at home, regular breaks and support are vital to prevent fatigue and entering crisis.

WHAT IS CURRENTLY IN PLACE AND WILL CONTINUE?

- <u>Admiral Nurse Service</u>
- Older Person's Day Care Services
- <u>Carers Support Services (Mobilise,</u> <u>MyTime, CareFree, Carers MK)</u>

OUTCOMES |

- The person living with dementia remains in familiar surroundings with friends and family
- Carers are supported to care for a loved one at home, before crisis point is reached

WHAT ELSE WILL WE PUT IN PLACE?

- Provide a wider range of overnight respite options
- Facilitate more short sessions such as memory walks and activity groups provided by community-based schemes
- Facilitate and support a wider range of activities provided by voluntary and third sector partners
- Ensure information about events is easy to locate, access and understand
- Explore the development of additional day centres for those with moderate to advanced dementia

PRIORITY 3 | INCREASE SERVICES WITH HIGH LEVELS OF EXPERTISE IN DEMENTIA FROM DIAGNOSIS TO POST-BEREAVEMENT

WHY IS IT IMPORTANT?

Ongoing support in the form of practical advice, emotional and psychological support can assist the person with dementia and their carers to feel more able to live a good life with the condition. Support might include help with practical aspects of day-today life, signposting to activities and support groups, or advice around future planning.

WHAT IS CURRENTLY IN PLACE AND WILL CONTINUE?

The commissioned Dementia Information and Support Service (DISS) will continue to support people from initial diagnoses by the Specialist Memory Service (SMS) and throughout their journey with dementia. Additional support from the Admiral Nurse Service will continue.

OUTCOMES |

- The person living with dementia and their carers will know where to go to get support at the different stages of their journey with dementia
- ✓ This will reduce stress and carer breakdown

WHAT ELSE WILL WE PUT IN PLACE?

- The Dementia Information Support Service (DISS) will continue to offer information about services, activities and support, making it readily available
- Further support will be developed for people with early onset dementia and those from minority groups

 to better reflect Milton Keynes' diverse population
- The voluntary sector will be developed further to encourage groups to include and cater for people with dementia

WHY IS IT IMPORTANT?

Research shows that having a healthy lifestyle can reduce the risk of developing dementia in later life. The condition is lowest in people who have several healthy behaviours mid-life (40—65) including i) regular mental, physical and social activity ii) alcohol in moderation iii) not smoking and iv) keeping a healthy diet 1. Being overweight, smoking and having type 2 diabetes are associated with an increased risk of developing dementia in later years.

WHAT IS CURRENTLY IN PLACE AND WILL CONTINUE?

Public health provides some public awareness in targeted campaigns.

OUTCOMES |

 Actively raise awareness about which lifestyle choices may increase a person's risk of developing dementia

ONSET OF THE CONDITION

PRIORITY 4 | LIFESTYLE INITIATIVES TO DELAY

 Help people to make lifestyle changes that positively impact their health and reduce the risk of developing dementia in later years

WHAT ELSE WILL WE PUT IN PLACE?

 The Dementia Information and Support Service (DISS) will have a key role in delivering preventive advice to all ages through engagement. They will work alongside public health to reach as many people as possible, both face-to-face and online

WHY IS IT IMPORTANT?

If you have dementia the outside world can seem a hostile, difficult place to be. Urban environments with poor signposting can make something as simple as using public transport or paying for goods or services highly stressful. This can lead to psychological barriers like loss of confidence, being worried about becoming confused or getting lost and not wanting to burden others. By making Milton Keynes dementia friendly, people with dementia will feel more supported and part of their community, giving them the best opportunity to live well.

WHAT IS CURRENTLY IN PLACE?

- *Dementia friends* training is currently offered to companies (e.g. Arriva bus company has completed dementia friends training for all bus drivers in Milton Keynes)
- Housing developers will be given guidelines (supplementary planning documentation) on how to make developments more dementia friendly
- MKCC uses the Herbert Protocol (in conjunction with Thames Valley Police) so people with dementia who go missing can be quickly located

PRIORITY 5 | MAKING MILTON KEYNES A DEMENTIA FRIENDLY CITY

OUTCOMES |

- People with dementia will be able to continue daily activities like shopping and using transport with more confidence
- This will allow people with dementia to continue to live safely and well which will have a positive impact on the whole community

WHAT ELSE WILL WE PUT IN PLACE?

- We'll continue to provide *Dementia friends* training for local businesses and organisations
- We'll encourage the uptake of accessible signage and messaging so people with dementia feel more confident and at ease in public spaces
- We'll build inclusivity into activities so they're easier to access and understand

WHY IS IT IMPORTANT?

Working together to plan new services will allow us to reduce health inequalities and improve population health in MK. Drawing on local expertise and community networks will allow us to share local data and intelligence around dementia and take a targeted approach to designing and delivering services in partnership with Health services. Tapping into the expertise of people who have lived experience will give us a better understanding of people's needs and the services they want.

WHAT IS CURRENTLY IN PLACE?

- We have a dementia specialist nurse in post at Milton Keynes University Hospital to advise staff on inpatient care for those with dementia and to promote staff training
- We have 2.5 full time Admiral Nurses based at MKCC providing a wide range of support to people living with dementia and their families
- The Specialist Memory Service (SMS) provides diagnostic services, initial support and support to care homes
- Commissioners from the Integrated Care Board (ICB) are regularly brought together by BLMK to share best practice and new initiatives

PRIORITY 6 | WORKING TOGETHER TO PLAN NEW SERVICES

OUTCOMES |

- Taking a joint approach to services will increase the range and breadth of specialisms within services to benefit people with dementia
- ✓ For instance, support groups (led by local health practitioners) will be set up to understand the experience people with dementia had when they were in hospital and ways to improve it

WHAT ELSE WILL WE PUT IN PLACE?

- Work with the voluntary sector to increase activities and support for those living with dementia and their carers – to help reduce social isolation
- Work with health colleagues to promote preventative measures and the benefits of early diagnosis

HOW WILL WE MEASURE SUCCESS?





We'll measure success using qualitative measures such as surveys, observation and interview and quantitative measures such as statistical analysis.

For example:

- We'll collate feedback from people who use our services and their carers by hosting more in-person, face-to-face events like *Talking Dementia* (July 23), co-production workshops and online surveys. Feedback gathered will then be used to shape new services
- We'll identify and celebrate the achievements of services and the people who use them, illustrating when and how people are living well with dementia in Milton Keynes
- We'll campaign to raise awareness about dementia, so that more people can get diagnosed earlier. We'll then measure any increase in diagnosis rates achieved
- We'll continue to monitor the number of people using commissioned services, their demographic and experience

5. Conclusion

This strategy forms part of the council's overarching strategy to make Milton Keynes a *Dementia friendly* city, so people who are either living with dementia or affected by it can truly thrive.

In the short term we want to help people become less fearful of dementia; to know that it's possible to live well with the condition and that there's support to do this.

We also want people to be aware that by taking preventative measures in mid-life and by adopting a healthier lifestyle, dementia can be delayed or even prevented. We'll do this by actively raising awareness and supporting people to make changes if they want to.

We also know that an early diagnosis opens the door to future care and treatment, which helps people planahead while they are still able to make important decisions on their care and support needs. Expanding services, like the Dementia Information Support Service (DISS) and Specialist Memory Service (SMS) and with the help of our Health partners and voluntary sector organisations, we can offer people living with dementia, and especially their carers more tailored support at each stage of their journey.

6. Key documents and references

- Council plan 2022-2026.pdf (milton-keynes.gov.uk)¹
- Strategy For 2050 New Design FOR EMAIL.pdf (milton-keynes.gov.uk)²
- ASC Prevention strategy 2023-2026 ³
- Risk factors for dementia (2021) Alzheimer's society 4
- Health Matters: Health Inequality and dementia UK Health Security Agency (2016) 5
- Hormones and dementia | Alzheimer's Society (alzheimers.org.uk) ⁶
- Deaths due to dementia Dementia Statistics Hub ⁷
- Traumatic Brain Injury | Symptoms & Treatments | alz.org ⁸
- Carers UK's 'State of Caring 2021' report Alzheimer's Society responds | Alzheimer's Society (Nov. 2021) 9
- MKCC Market Position Statement 10

7. Action Plan

Increased capacity in care homes for people with dementia, including those with a mental health diagnosis or learning disability



- Work with providers to develop the number of care home beds that cater for those with dementia and a learning disability or mental health diagnosis.
- Improved training of staff to upskill to have the skills to support people with Dementia

Information shared with care homes about the support available from the Challenging Behaviour team and Care Home Liaison Practitioner.

Increased and more tailored support for family carers to help people with dementia stay in their own homes and reduce the need for emergency respite or early care home admissions



- Increase the variety of respite options, including making use of the VCSE sector and the wide range of opportunities for leisure that can provide a break for the carer and person living with dementia.
- Improved sharing of information on the range of opportunities available to both professionals and the public.

Increase in services with high levels of expertise in dementia offering practical advice, and emotional and psychological support to people with dementia and their carers from diagnosis to post bereavement



- Easily accessible information on the range of support, services and activities available, kept up to date by the Dementia Information and Support Service.
 - Support, services and activities that are inclusive and reflect the diverse community of Milton Keynes.

Encourage and develop the voluntary sector to provide opportunities for those with dementia, this could be a new opportunity or adaption of an existing one. ear 2/3

Year

Initiatives which, in partnership with Public Health, can help reduce the incidence or delay the onset of dementia including smoking cessation, reduced alcohol consumption, exercise, and managing long term conditions linked to dementia for example Type 2 diabetes.



- The dementia information and advice service will deliver
 information to inform the public of actions that prevent
 dementia, the early symptoms and the benefit of early diagnosis.
 Public health will work with other services to deliver preventive advice.
- Use of public engagement events to include information on prevention and include attendance by groups that encourage health and wellbeing.

Making Milton Keynes a dementia friendly city Priority 5

- Awareness raising and promoting the benefits of the Herbert Protocol
- Encouraging individuals and business to access Dementia Friends training

Embedding a dementia friendly approach in areas such as transport, planning, retail

Work together as a system, Health services and the ICB to explore joint funding opportunities and collectively plan new service provision.



- MKCC representation continues at the BLMK Dementia Steering Group.
- Development of voluntary sector to encourage hard to reach groups inclusion and access to services.

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Appendix A – Current provision

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Specialist Memory Service Diagnose dementia following GP referral (MSNAP accredited)

Post diagnostic support is also provided: Cognitive stimulation courses for people diagnosed with dementia and psychosocial 14-week courses for carers

The service also has a Challenging Behaviour Team and Care Home Liaison Practitioner who diagnoses in Care Homes and provides support for Care Home staff. Referral route

Referral

route

G.P for dementia diagnosis. Care homes can contact direct for support.

Dementia Information and Support Service (DISS) The service provides information and support for people living with dementia and their carers by phone, email, post or where needed personal visits. It is run by trained dementia support workers. Carers support and information groups and activities including Singing for the Brain are also provided.

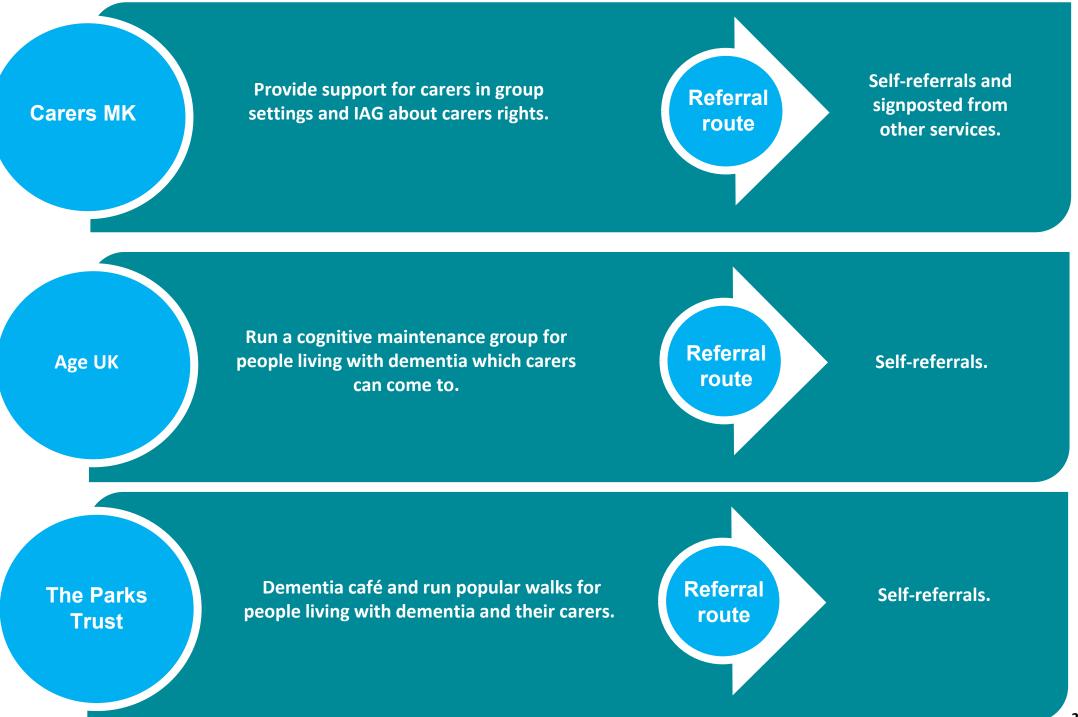
Direct from SMS or from Primary Care, Adult Social care and selfreferrals.

Admiral Nurse Service Admiral Nurses are employed by MKCC to provide support to carers and families who are struggling to care for people in complex cases. Support is provided at home and in the community. Consultancy and training are also available from this service

Referral route

Primary Care, Adult Social care and selfreferrals.

Appendix A – Current provision



Appendix A – Current provision

MKCC Flowers MKCC Sheltered Housing with care, Referral House & provide specialist extra care facilities route **Courteney's** for people with dementia. Lodge Day Care services are run at Simpson and the **MKCC Simpson** Referral Kitchener Centre, transport is provided. These are and Kitchener route for people living with dementia, not carers. **Day Centres**

MKCC Housing Allocations, Social Worker referral.

> MKCC Social Worker.

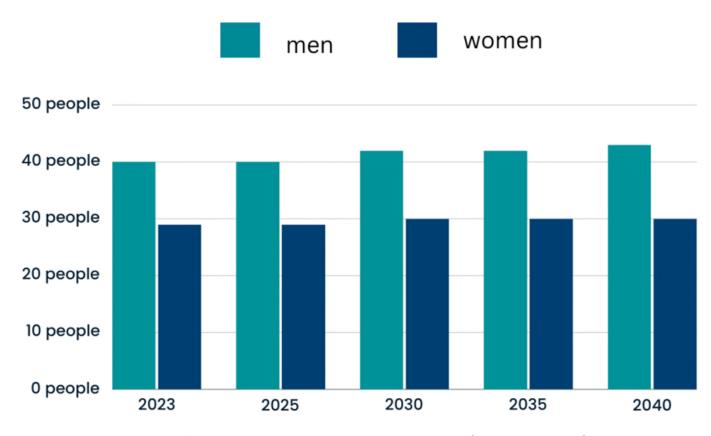
Appendix B

Key national legislative and policy

- The Care Act (2014)
- NHS Long Term Plan (2019)
- Health and Social Care Integration: Joining up care for people, places, and populations (2022)
- National Institute for Health and Care Excellence Guidance
- (NICE) (2018) Dementia: assessment, management and support for people living with dementia and their carers
- People at the Heart of Social Care: adult social care reform

Appendix C

Number of people living in Milton Keynes aged 30-64 predicted to have early onset dementia, by age and gender, projected to 2040

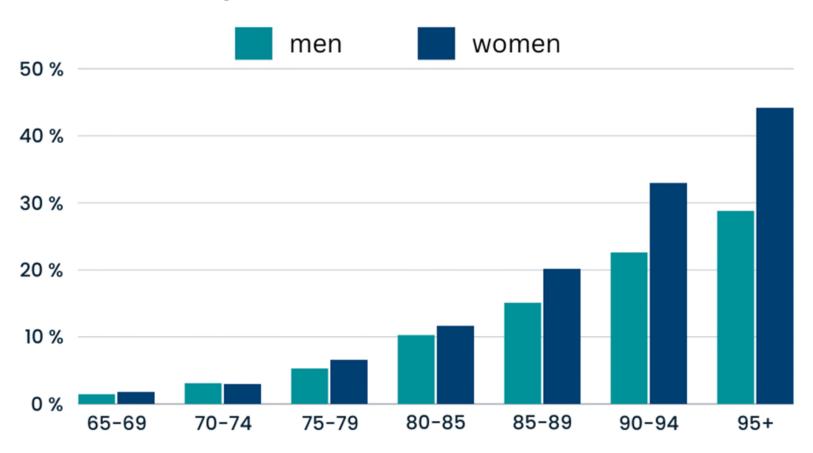


source: Institute of Public Care www.pansi.org.uk (December 2023)

Appendix D

% Rates of dementia for men and women by age

Figures are taken from Dementia UK (2014)





Thank you for reading this document.

If you have any comments or feedback, please contact the MKCC Commissioning Team at:

CCTeam@milton-keynes.gov.uk