Central Bedfordshire Council
**www.centralbedfordshire.gov.uk**

# Dementia:
# Health Needs Assessment

Rebecca Hams

Public Health Registrar

January 2016

## Contents

## Abbreviations

| | |
|---|---|
| A&E | Accident and Emergency |
| AD | Alzheimer’s Disease |
| ACP | Advance Care Planning |
| ADRT | Advance Decision to Refuse Treatment |
| BAME | Black, Asian and minority ethnic |
| BCCG | Bedfordshire Clinical Commissioning Group |
| BP | Blood Pressure |
| BPSD | Behavioural and Psychological Symptoms of Dementia |
| CBC | Central Bedfordshire Council |
| CCG | Clinical Commissioning Group |
| CFASI | Cognitive Function and Ageing Study 1 |
| CFASII | Cognitive Function and Ageing Study 2 |
| CHD | Coronary Heart Disease |
| CHKS | Comparative Health Knowledge Systems |
| CI | Confidence Interval |
| CMDs | Common Mental Disorders |
| CMHT | Community Mental Health Team |
| CQC | Care Quality Commission |
| CQUIN | Commissioning for Quality and Innovation Framework |
| CrISP | Carer Information and Support Programme |
| CV | Cardiovascular |
| DES | Directly Enhanced Service |
| DPC | Dementia Prevalence Calculator |
| ELFT | East London NHS Foundation Trust |
| EuroCoDe | European Collaboration on Dementia |
| EOD | Early Onset Dementia |
| G8 | Government forum of leading advanced economies in the world |
| GCSEs | General Certificate of Secondary Education |
| GP | General Practitioner |
| HNA | Health Needs Assessment |

| | |
|---|---|
| ICD | International Classification of Diseases |
| ICD-10 | International Classification of Diseases – version 10 |
| JSNA | Joint Strategic Needs Assessment |
| LOD | Late Onset Dementia |
| LPA | Lasting Power of Attorney |
| LGBT | Lesbian, Gay, Bisexual and Transgender groups |
| MAS | Memory Assessment Service |
| NHS | National Health Service |
| NICE | Nation Institute for Health and Care Excellence |
| NDNS | National Diet and Nutrition Survey |
| NSC | National Screening Committee |
| ONS | Office for National Statistics |
| PANSI | Projecting Adult Needs and Service Information |
| PAR | Population Attributable Risk |
| PEPS | Partnership for Excellence in Palliative Support |
| POPPI | Projecting Older People Population Information |
| QOF | Quality and Outcomes Framework |
| READ | A coded thesaurus of clinical terms and have been used in the NHS since 1985 |
| REM | Rapid Eye Movement Sleep |
| RCT | Randomised Control Trial |
| SEPT | South Essex Partnership University NHS Foundation Trust |
| START | STrAtegies for RelaTives |
| WHO | World Health Organisation |
| WI | Women’s Institute |

# Executive Summary

This health needs assessment aims to systematically review the needs of people with dementia and their carers in Central Bedfordshire to guide the development of a renewed Dementia Strategy and improve the care and support available.

This report includes the descriptive epidemiology of dementia in Central Bedfordshire, the current evidence base for the prevention of dementia, mapping of existing local services, stakeholder experience, and most importantly qualitative research covering the views of people with dementia, their carers, and people who have previously cared for someone with dementia. The report culminates with key recommendations to address the issues identified. This report has been written with input from commissioners, providers, voluntary organisations, people with dementia, their carers, and people who have previously cared for someone with dementia.

Dementia is associated with a loss of general cognitive ability. There are many subtypes of this illness, with the most common being Alzheimer's Disease. Although the prevalence of dementia increases with increasing age, dementia is not a normal part of aging. Nationally there have been several key policies aimed at increasing the number of people diagnosed with dementia as estimates suggest that nationally just over half the people with dementia have been diagnosed with the condition.

In Central Bedfordshire it is estimated that there are 3010 people with dementia (Dementia Prevalence Calculator, February 2015 dataset). Of these 1663 are predicted to have mild dementia, 980 moderate dementia, and 368 severe dementia. Every three days, two people are diagnosed with dementia via the memory assessment service in Central Bedfordshire. Overall, under the age of 75, dementia mainly affects males, while over the age of 75 females are most affected.

In 2014, the Alzheimer's Society estimated that dementia cost the UK £26 billion a year. Estimating the costs of dementia in Central Bedfordshire poses a number of challenges. Section three explores the costs of unpaid care, social care and health care.

As part of this health needs assessment, an evidence review was conducted for primary, secondary and tertiary prevention. The key message from the primary prevention of dementia was 'What's good for the heart is good for the brain'. For secondary prevention a growing body of evidence to promote a timely diagnosis of dementia and good evidence to support cognitive stimulation and peer support were identified. The review for tertiary prevention focussed on strategies to help people manage the condition such as supporting people to live alone, appropriate use of antipsychotic medication, supporting carers through education and respite provision, and advance planning for long term care.

Overarching these prevention strategies are two key areas, the reduction of stigma and increasing community support. In Central Bedfordshire there are now over 5000 dementia friends and champions helping to make Central Bedfordshire a dementia friendly community.

An analysis of stakeholders views in Central Bedfordshire identified a need for better communication with people with dementia, a lack of out of hours care, and a number of hidden populations (e.g. people with dementia living alone in rural areas). Qualitative research among people with dementia and their carers highlighted several key issues, including providing the right information at the right time and the importance of having consistent care.

The research carried out as part of this health needs assessment has led to the development of recommendations aimed at improving the quality of life for people with dementia and their carers:

1. **Information, support and training is needed throughout the dementia pathway, providing a single point of contact early in the patient journey would be beneficial.**

Rationale: People with dementia and their carers will need different information at different stages of the disease. A single point of contact can greatly support people with dementia and their carers in managing their own dementia journey. Training carers can equip carers with knowledge and techniques to better support the person they are caring for while being mindful of their own health and wellbeing needs. Ultimately this can lead to better health outcomes for the person with dementia and their carer.

*Key sections in HNA and examples:*

- *Support for Carers, including training for carers: Section 7 Page 104.*
- *Single point of contact (e.g. similar to Admiral nurses model): Section 7 Page 106, Section 10 Page 140-1*
- *Out of hours support: Section 10 Page 136.*

2. **Services for people with dementia and their carers should utilise a person centred care approach to ensure the support provided is tailored to the individual's needs.**

Rationale: Each person with dementia will experience their own unique disease characteristics and progression. The experience for carers will also vary and the level of support a carer needs will be unique to their situation. Offering the right support at the right time to the person with dementia and their carer can improve the quality of life for both.

*Key sections in HNA and examples:*

- *Services should recognise the different types of dementia and how the symptoms may manifest in people with different types of dementia: Table 10, page 32.*
- *The needs of younger people with dementia and their families present different challenges and that should be catered for by support services: Section 4 Page 58, 61, 64 and 66.*
- *Support services should cater for people with dementia that do not have a dedicated carer: Section 7 Page 100 and Section 10 Page 138.*
- *Evidence based interventions to support people with dementia and their carers: Section 6 Page 95 and Section 7 Page104.*
- *Support should consider providing the opportunity for carers to share their knowledge either during their experience or after the person they have cared for has passed away: Section 11 Page 153.*

3. **Health and social care providers should look to ensure staff training about dementia is appropriate and helpful to increase the patient and carer experience whether inpatient or outpatient.**

Rationale: Identifying issues early can result in better care for people with dementia and access to support services. This can increase the quality of life for the person with dementia and help them remain in their own homes for longer if the appropriate support is provided.

Key sections in HNA and examples:

- *Correctly recording the status of people with dementia: Section 2 Page 37.*
- *Appropriate training for different staff groups: Section 8 Page 113 and Section 10 Page 141.*
- *Successfully managing patients that do not attend appointments: Section 10 Page 140.*
- *Supporting patients with dementia while inpatient e.g. notifying a dementia nurse specialist on admission for dementia specific actions to be completed conducting a nutritional needs assessment): Section 11 Page 152.*

4. **CBC and BCCG can be a catalyst for dementia friendly communities. This could include:**
    - **Increasing awareness of preventive measures e.g. linking dementia to existing key public health campaigns and services.**
    - **Increasing awareness of dementia across public services and with private organisations.**

Rationale: By raising awareness this should help to decrease stigma associated with Dementia, improving quality of life for people dementia and their carers.
*Key sections in HNA and examples:*

- *Promoting an integrated approach to key public health messages 'What's good for the heart is good for the brain' and understanding the early signs of dementia and where to seek help: Section 5 Page 82 and Section 8 Page 113.*
- *Consider Best practice from other parts of the UK for supporting communities to become dementia friendly: Section 8 Page 112-114, and Section 10 Page 139-141.*
- *It is important to keep people with dementia involved in the community and provide support to encourage this: Section 4 Page 66 and Section 8 Page 112, Section 10 Pages 139-141 and Section 11 Pages 152 and 155.*

The recommendations in this section should be considered with the Local Government Information Unit's recommendations for local authorities Table 39 in Section 8 of the full report and recent publications, including the Alzheimer's Society Dementia 2014: Opportunity for change, and the Department of Health Primer Minister's challenge on dementia 2020. Summaries of the key recommendations in both of these reports can be found in Appendix 12.

# Section 1. Introduction

## What is Dementia?

Dementia is a loss of general cognitive ability; this syndrome is a cluster of different signs and symptoms, often progressive in nature rather than a definitive diagnosis. Symptoms include memory loss, difficulties with thinking or problem solving and difficulties with language. The ICD-10 definition[1] of dementia is:

> *'A syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The impairments of a cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.'*

> ***'If anyone has something different people are afraid of you, but we all have our peculiars, we are all still people and we deserve to have friends.'***
>
> Female with dementia talking about living with dementia
>
> ***'You go in, it's just like having a baby, no handbook or manual, you just leave the hospital and have to learn what works for yourself, but children learn and progress, they don't.'***
>
> Female carer talking about her husband receiving a diagnosis of dementia

There are several types of dementia, these are summarised in **Table 1**.

---

[1] ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO).

**Table 1. Subtypes of dementia, prevalence, characteristics and considerations**

| Type of dementia | Prevalence[2] | Characteristics[3] | Estimated number of people with each subtype in CBC[4] |
|---|---|---|---|
| Alzheimer's' Disease (AD) | 62% | Mainly affects older people, especially women. The key feature is the insidious deterioration in memory and other executive function (reasoning, flexibility, task sequencing etc.). If relatives cannot date when the symptoms started ('probably two or three years ago'), then Alzheimer's Disease is likely. | 1806 |
| Vascular dementia | 17% | There is a step-wise presentation – sometimes noticeable after a 'funny do' an episode of illness, or an operation. Vascular dementia can remain static for long periods, and may progress in little jumps. More common in people with diabetes, high blood pressure, smokers, heart disease or stroke, especially men. | 512 |
| Mixed dementia | 10% | It is not always possible to make a clear distinction between AD and vascular dementia. It is helpful to think of the combination as being a bit like 'two and two makes five' – each illness augmenting the other so that the end result is greater than the sum of the parts.<br>Memory drugs can be tried for the Alzheimer's disease component. | 301 |
| Lewy body dementia | 4% | In Lewy Body dementia, dementia comes first and 'Parkinsonism' often develops later – although often without tremor. Memory may well be preserved at first, but deteriorates later. The key features are difficulties with attention, arousal at night, marked fluctuation in levels of cognition and confusion, vivid and often highly developed, hallucinations, sensitivity to neuroleptics and REM sleep disorder. | 121 |
| Fronto – temporal dementia | 2% | Frontal lobe dementia was previously known as Pick's disease. The development of inflexibility and unreasonableness, blunting of social sensitivity and sometimes aggression may damage important relationships before the diagnosis is suspected.<br>Fronto-temporal dementia usually affects younger patients and may take several years for a diagnosis to be made. | 61 |
| Parkinson's dementia | 2% | In this type of dementia, Parkinson's comes first and one in six patients with Parkinson's go on to develop dementia. | 61 |
| Other | 3% | Includes Huntington's and alcohol related brain impairment. | 91 |

---

[2] Alzheimer's Society, Dementia UK: Second edition (2014)

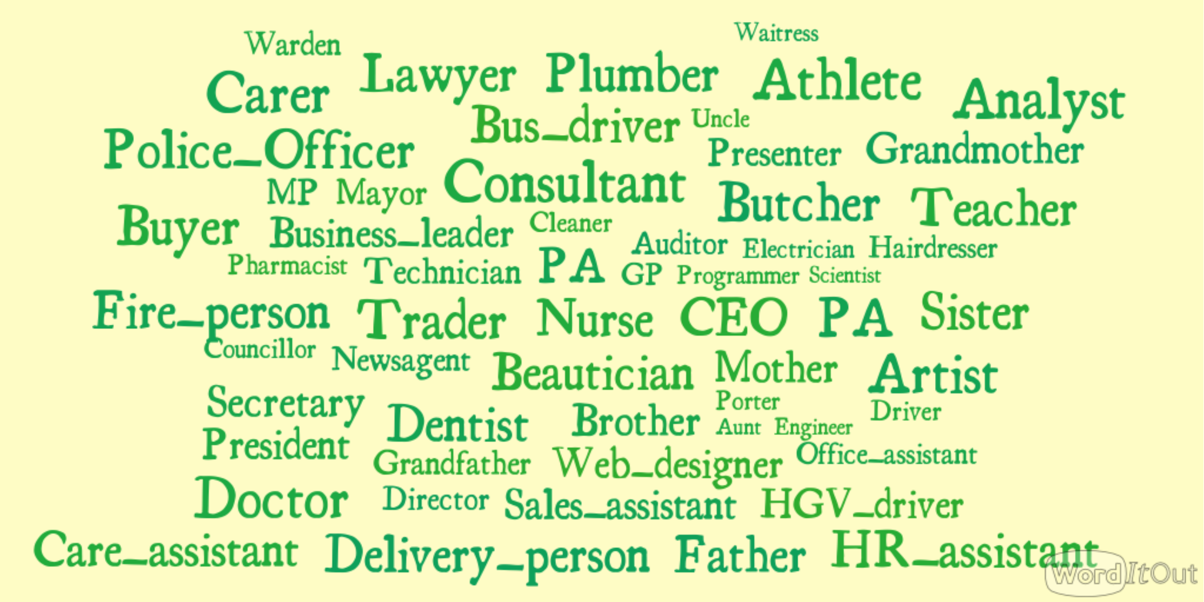
[3] RCGP, Dementia revealed: what primary care needs to know (July 2014)

[4] Calculated using the adjusted number of people estimated to have dementia (3010, February 2015 data) from the Dementia Prevalence Calculator and the prevalence shown in column 2. This number will exceed 100% due to rounding up to demonstrate a whole person.

Dementia is a late onset condition, mainly affecting people aged 65 years and older, this will be the focus age group for the main report; however section 4 provides specific information about young onset dementia, previously known as early onset dementia.

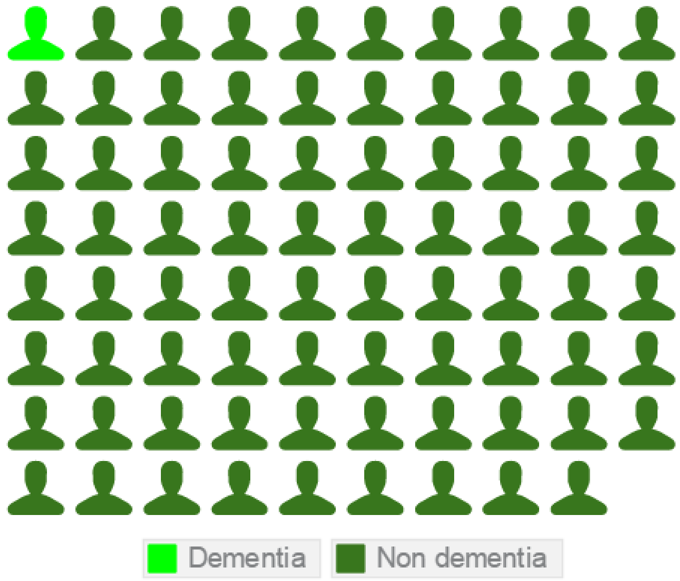
Dementia is a complex illness that has a significant impact on the person with dementia and their support network  as such the wellbeing of the family and carers of the person with dementia will also be included in this needs assessment.

## *Who gets dementia??*



***Anyone can get dementia!***

## 1 person in every 79 in the entire UK population has dementia



> ***'For people over the age of 50 Dementia is the most feared illness of all'.***
>
> **Professor Alistair Burns**
> **NHS England's National Clinical Director for Dementia**

## 1 person in every 14 in the UK population aged 65 or older has dementia

The prevalence of dementia increases with increasing age but is not a normal part of aging. The total age standardised 65+ population prevalence of dementia is 7.1% (based on 2013 data), this means that one person in every 79 people in the entire UK population and 1 in every 14 of the population aged 65 years and over will have dementia. The estimated prevalence of dementia for five year age bands from 60-64 to 95+ is shown in Table 2, these estimates are from the Dementia UK: Second edition[5] and are based on estimates from previous literature reviews and key surveys.

**Table 2. Estimates for the prevalence of late onset dementia**

| Age in years | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85-89 | 90-94 | 95+ |
|---|---|---|---|---|---|---|---|---|
| Estimates for the prevalence (%) of late onset dementia | 0.9 | 1.7 | 3.0 | 6.0 | 11.1 | 18.3 | 29.9 | 41.1 |

Source: Alzheimer's Society, Dementia UK: Second edition (2014)

---

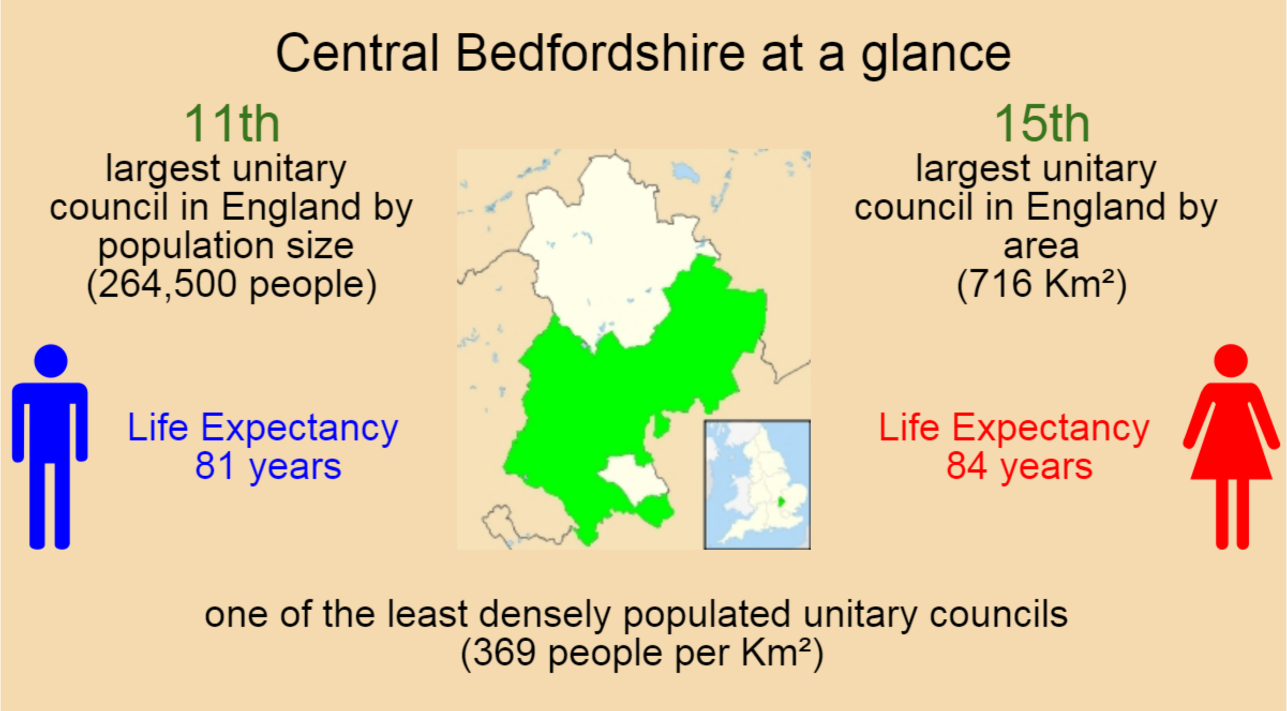
[5] Alzheimer's Society, Dementia UK: Second edition (2014)

## Why is dementia important in Central Bedfordshire?

Central Bedfordshire Council (CBC) covers a population of 285, 856; this population is served by 30 GP practices, grouped into one Clinical Commissioning Group, (Bedfordshire CCG) with five localities (four of which are in CBC).

As the population ages, the number of people living with dementia is expected to increase. The latest population projections[6] for Central Bedfordshire show a 57% increase in the Central Bedfordshire population aged over 65 years by 2030 compared to 2014; this sees an increase from 45,500 to 71,300 people. The largest increase is expected in the 90 years and above age group, this is also the age group with the highest estimated prevalence of Dementia.

**With an aging population, we can expect to see an increase in the number of people with dementia; this will increase the demand for appropriate health and social care resources across Central Bedfordshire.**



Central Bedfordshire at a glance

11th
largest unitary council in England by population size
(264,500 people)

15th
largest unitary council in England by area
(716 Km²)

Life Expectancy
81 years

Life Expectancy
84 years

one of the least densely populated unitary councils
(369 people per Km²)

---

[6] POPPI, Population estimates for Central Bedfordshire. Accessed online 21/10/14 http://www.poppi.org.uk/

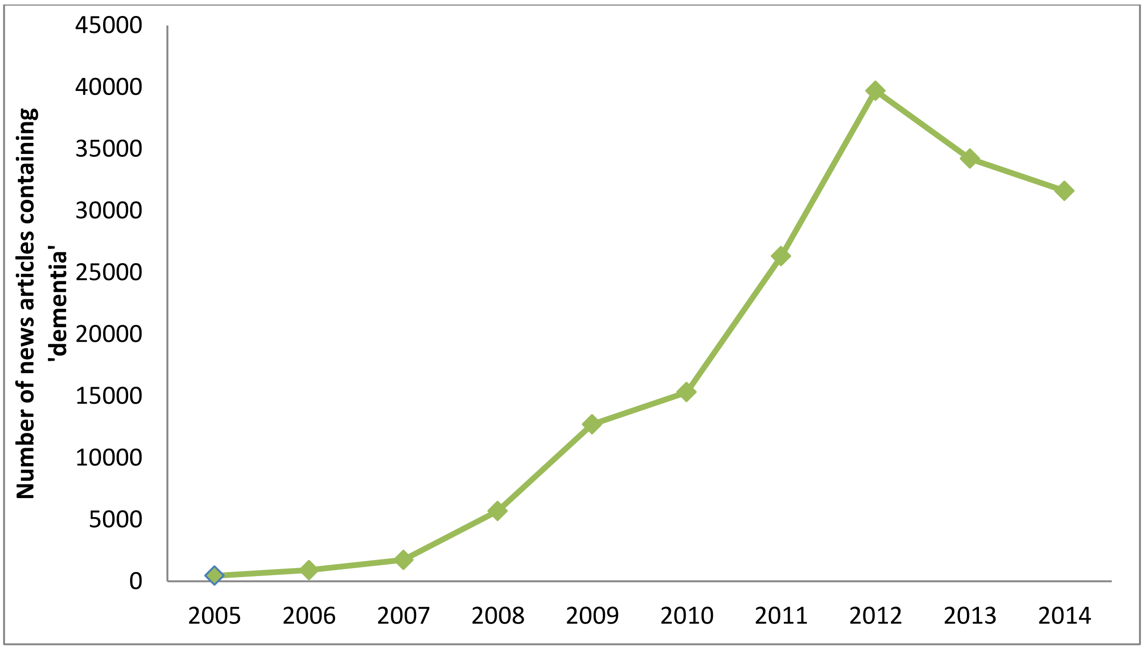
## What is the national context?

Nationally, dementia is a hot topic, in the past two years there have been a number of key publications in the UK including:

- Supporting people with dementia and their carers in health and social care 2006
- Living well with Dementia: A national Dementia Strategy 2009
- Quality outcomes for people with Dementia: building on the work of the National dementia strategy, 2010
- NICE dementia quality standards, 2010
- Common and complex: commissioning effective dementia services in the new world, Alzheimer's Society, 2011
- Prime Minister's challenge on dementia, 2012
- Dementia: A state of the nation report on dementia care and support in England, 2013

Themes from these key documents are summarised in Appendix 1. There has also been international support from organisations including the WHO and Alzheimer's Disease International. In December 2013, the UK held the first G8 Dementia summit. Dementia coverage in national news has increased over the past decade, from featuring in 450 news articles in 2005 to a peak of 39,700 in 2012[7] as shown in Figure 1.

**Figure 1. News articles including 'dementia'**



*Source: Google Analytics, UK All News 'Dementia' 1st January to 31st December*

---

[7] Google Analytics, UK All News 'Dementia' 1st January to 31st December.

## What is the local context?

Locally the Central Bedfordshire Dementia Strategy was launched in 2011 and ended in 2014; this includes recommendations from the 2009 national 'Living well with Dementia' strategy. The corporate commitment to Dementia is strong; a Dementia stakeholder group has been meeting quarterly since its formation in 2009. Outputs from this group are included in Appendix 1.

Central Bedfordshire Council works closely with BCCG both of whom lead Central Bedfordshire Health and Wellbeing Board.

## What will this Health Needs Assessment add?

A health needs assessment is a *"Systematic method for reviewing the health issues facing a population leading to agreed priorities and resource allocation that will improve health and reduce inequalities."*[8]

Needs assessments are:

- A recommended public health tool to provide evidence about a population on which to plan services and address health inequalities.
- Able to provide an opportunity to engage with specific populations and enable them to contribute to targeted service planning and resource allocation.
- Able to provide an opportunity for cross-sectorial partnership working and developing creative and effective interventions.

Potential benefits subsequent to undertaking needs assessment are:

- Strengthened community involvement in decision making
- Improved team and partnership working
- Improved communication with other agencies and the public
- Encourage better use of resources

The challenges of undertaking a needs assessment include:

- Developing a shared language between sectors

---

[8] NICE, Health Needs Assessment: A practical guide, (2005) http://www.nice.org.uk/proxy/?sourceurl=http://www.nice.org.uk/aboutnice/whoweare/aboutthehda/hdapublications/hda_publications.jsp?o=705

- Obtaining commitment from ‘the top’
- Accessing relevant data
- Accessing the target population
- Maintaining team impetus and commitment
- Translating findings into effective action

There are three common approaches to a health needs assessment: epidemiological approach, comparative approach, and corporate approach. Nevertheless, in practice, most health needs assessments use a combined methodology.

- Epidemiological - focuses on the quantitative needs of the population in line with the available evidence base
- Comparative - compares services available locally with those described in the literature and in other areas of the country
- Corporate - gathering the views of interest groups including health organisations, health professionals, social care professionals, voluntary organisations, older people’s groups, users and carers

In this needs assessment covering Central Bedfordshire, a combined methodology will be used. Further details about the methodology used are included in the relevant sections. This approach will complement ongoing work surrounding Dementia in Central Bedfordshire, recommendations will be made with accountable actions. This health needs assessment will be used to inform an update of the Dementia Strategy and updated JSNA chapter.

## Limitations of this Health Needs Assessment

Limitations of this methodology are listed in the relevant sections. For example, in the descriptive epidemiology section, several data sets were not available at the Central Bedfordshire level. In these cases, the most appropriate available data sources were used or estimates calculated to give an idea of the local situation; this is outlined at the relevant point of the needs assessment.

Overall throughout this needs assessment, there is limited local information relating to minority ethnic groups, people with learning disabilities, lesbian, gay, bisexual and transgender (LGBT groups) and prisoners which will need consideration in future planning of dementia care within Central Bedfordshire.

Dementia is an area of health and social care that is currently attracting considerable attention; this results in new publications such as updated evidence, goals and guidelines being produced frequently. While this needs assessment has tried to capture current resources some may have been published after this needs assessment was completed and therefore excluded from this analysis.

# Section 2. Descriptive Epidemiology

- Every three days, two people are diagnosed with dementia via the memory assessment service in Central Bedfordshire
- Dementia diagnosis rate varies from 36% to 101% across GP practices in Central Bedfordshire[9]
- Less than 25% of people diagnosed with dementia in their lifetime will have dementia recorded on their death certificate
- Up to the age of 74 there are more males with dementia in Central Bedfordshire, however in people aged 75 and over, there are more females with dementia.
- Central Bedfordshire generally has a more favourable profile for the risk factors commonly associated with dementia than the England average.

## Incidence

Incidence is a measure of new cases of a disease within a specified population over a specified time period. Local data for the incidence of people living with dementia is not collected; however it can be estimated from the number of people accessing the Memory Assessment Services. In 2013/14 there were 562 referrals to the Memory Assessment Service (MAS) from Central Bedfordshire broken down by age as shown in Appendix 2. Of these cases, 245 were diagnosed with dementia.

Using the distribution of Central Bedfordshire Council's over 75s population (73% of those patients referred in Central Bedfordshire were aged 75 or over) and assuming this is similar for the other age groups, the incidence per locality area can be estimated. This is shown in Appendix 2 and Figure 2.

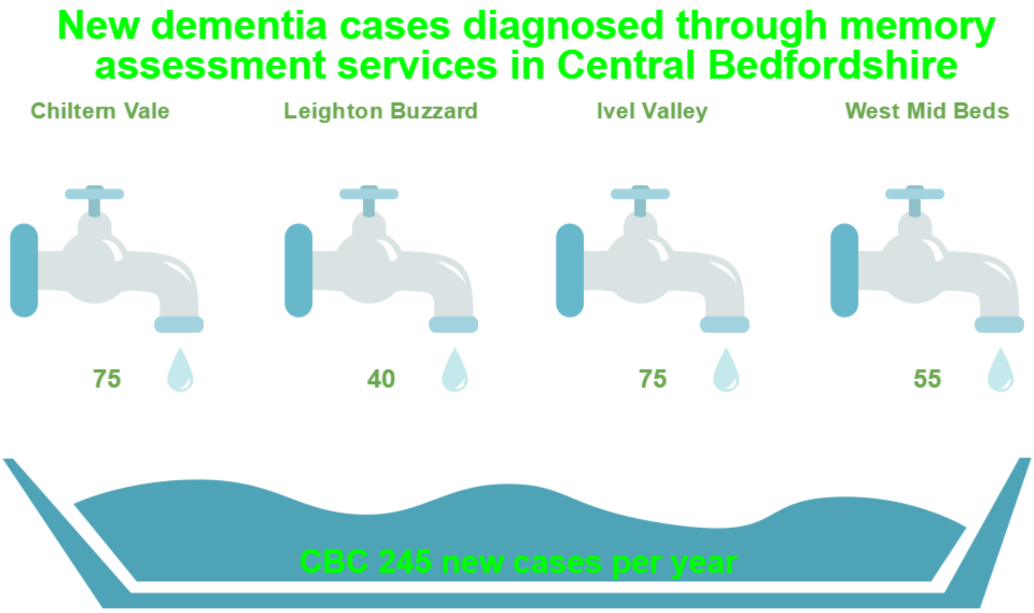
This method only provides a rough measure of the incidence and does not include undiagnosed cases or cases diagnosed outside of the memory assessment clinics –

---

[9] This value is calculated by the number of patients receiving a diagnosis of dementia divided by the estimated expected number of people with dementia in the area. If the number of people receiving a diagnosis is greater than the number of people expected to have dementia this value will exceed 100%.

diagnosis may occur in neurology clinics or GP practices therefore this number is expected to underestimate the true scale of the problem.

**Figure 2. Estimate of incidence of diagnosed cases of dementia in 2013 by memory assessment clinics across Central Bedfordshire.**



## Prevalence

Prevalence is a measure of the proportion of a specified population that has a condition at a specified point in time. One of the challenges of dementia is how to calculate the prevalence of dementia as the true number of people living with dementia includes those diagnosed and those undiagnosed.

In this report, the prevalence of people living with dementia will be illustrated using three tools available that provide estimates of the prevalence of dementia.

### GP Quality Outcomes Framework

Since 2006/07, as part of the quality and outcomes framework (QOF), GPs have maintained registers of patients diagnosed with dementia. This data is available at GP level, in the following tables, the data has been aggregated at Central Bedfordshire Council and Bedfordshire CCG level. Table 3 shows the prevalence as a percentage while Table 4 shows the prevalence as the number of people diagnosed with dementia according to GP QOF registers from 2008/09 to 2013/14.

**Table 3. Prevalence (%) of dementia all ages according to GP QOF registers 2007/08 to 2012/13**

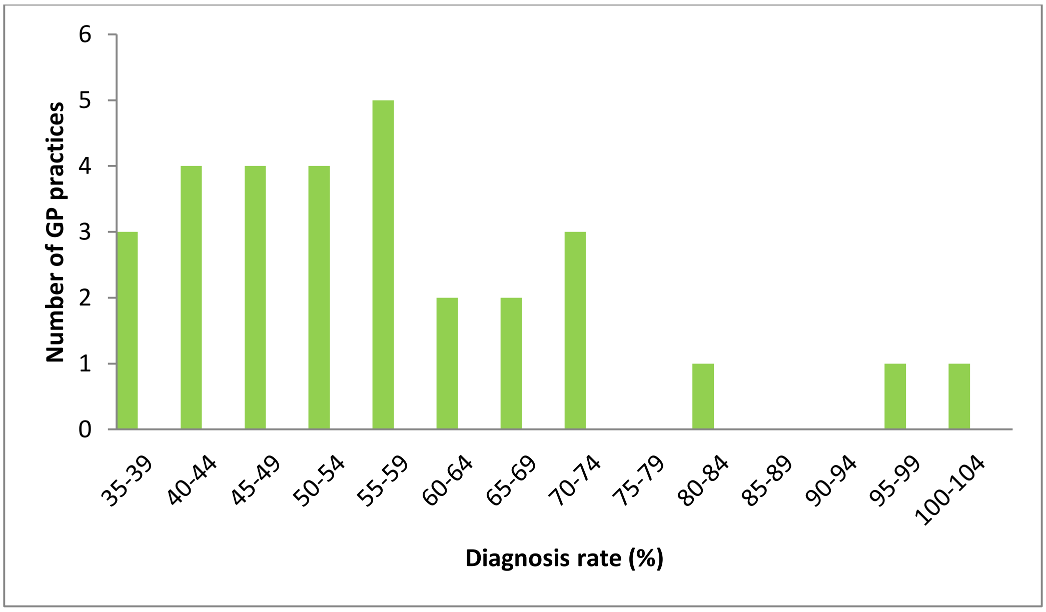
| Area | 2008/09 | 2009/10 | 2010/11 | 2011/12 | 2012/13 | 2013/14 |
|---|---|---|---|---|---|---|
| **BCCG** | 0.37% | 0.41% | 0.43% | 0.47% | 0.51% | 0.57% |
| **CBC** | 0.33% | 0.38% | 0.39% | 0.43% | 0.47% | 0.51% |

**Table 4. Prevalence (numbers) of dementia all ages according to GP QOF registers 2007/08 to 2012/13**

| Area | 2008/09 | 2009/10 | 2010/11 | 2011/12 | 2012/13 | 2013/14 |
|---|---|---|---|---|---|---|
| **BCCG** | 1580 | 1771 | 1878 | 2038 | 2265 | 2568 |
| **CBC** | 888 | 1021 | 1052 | 1168 | 1297 | 1441 |

This data illustrates that the number of patients on the QOF register for dementia is increasing. Although this may be in part due to better diagnosis, there is still wide variation in diagnosis rates between practices as shown in Figure 3. This value is calculated by the number of patients receiving a diagnosis of dementia divided by the estimated expected number of people with dementia in the area. If the number of people receiving a diagnosis is greater than the number of people expected to have dementia this value will exceed 100%.

**Figure 3. Dementia diagnosis rates across CBC GP practices**



*Source: Dementia Prevalence Calculator, February 2015 dataset.*

## Dementia Prevalence Calculator

The Dementia Prevalence Calculator (DPC) enables health and care communities to gain a better understanding of their local estimated prevalence of dementia in the community, and among people living in local care homes. The calculator aims to provide a reliable and up to date estimate of all people living with dementia by using the most recently available QOF registers, the national dementia prevalence rate[10] and care home data from the CQC. The Exeter database provides age-gender specific population data for each GP practice.

The data calculator provides aggregated data at GP, Local authority, CCG, and local area team level. Prevalence is also available at different phases of the disease (mild, moderate, and severe). The data shown in Table 5 is from February 2015.

There are limitations of the DPC data set; these include no adjustment for ethnicity, deprivation or other risk factors for dementia, the DPC data relies on the accuracy of population registers on which some of the data are based.

**Table 5. GP QOF dementia register and estimated number of people with dementia (Dementia Prevalence Calculator)**

| Area | Population | QOF dementia register | Estimated number of people with dementia (adjusted 1.11%) | Dementia gap (number) | Dementia diagnosis rate |
|---|---|---|---|---|---|
| **BCCG** | 457551 | 2760 | 5096 | 2336 | 54.16% |
| **CBC** | 285856 | 1630 | 3010 | 1380 | 54.15% |

## Dementia UK report and POPPI estimates – population projections

Combining the estimates for the prevalence of dementia and the population predictions for Central Bedfordshire gives an estimate of the local situation that we are facing with Dementia looking forwards to 2030. This is illustrated in Figure 4. This estimate was calculated by multiplying the estimated prevalence of dementia by age band shown in Table 2 with population estimates[11] by age band.

This approach assumes that the same rates of dementia will apply in the future and does not take it in to account risk factors and changing prevalence of risk factors over time or by location.

---

[10] Alzheimer's Society, Dementia UK (2007)

[11] POPPI, Population estimates for Central Bedfordshire. Accessed online 21/10/14 http://www.poppi.org.uk/

## Summary of the different methods for estimating the prevalence of dementia

Three methods have been presented that estimate the prevalence of dementia in Central Bedfordshire. The first (GP QOF data) is based on the actual number of people that have received a diagnosis of dementia. The second method (DPC) is based on an estimated number of people that may have dementia; therefore this figure is higher than first method. The final methodology presented combines the estimated prevalence for dementia and the predicted population in Central Bedfordshire to give an estimate of the future scale of the problem.

Through this report, the prevalence calculated using the dementia prevalence calculator will be used as this provides the best estimate of the number of people living with dementia in Central Bedfordshire (diagnosed and undiagnosed).

**Due to an aging population the most dramatic increases in dementia cases by age group will be seen in the older age groups – In 2030 it estimated that 77.7% of people with dementia will be aged 80 or older, these individuals may have other comorbidities and require specialist care to manage their dementia and other health conditions such as diabetes.**

## Changes to the Dementia Prevalence Calculator

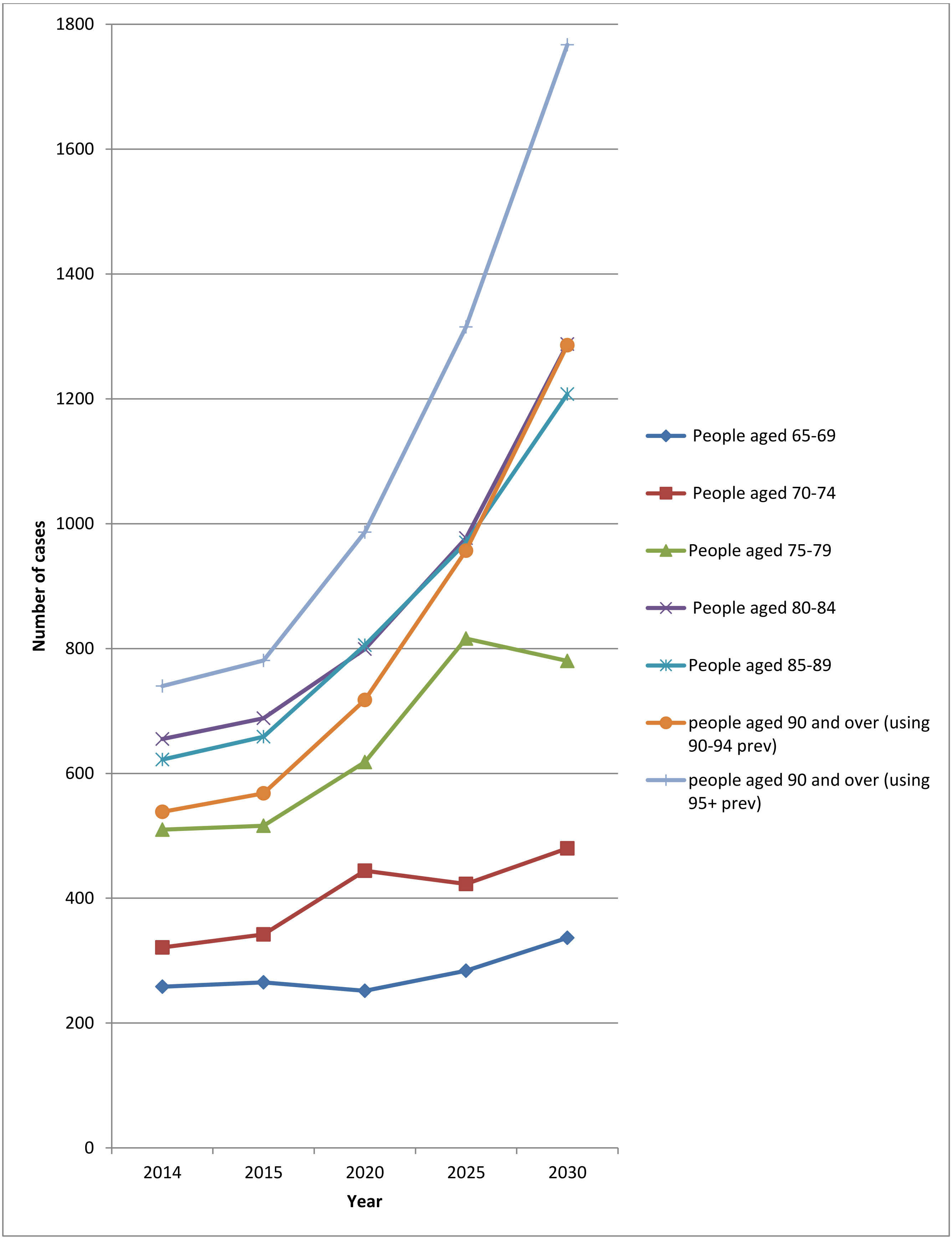
From April 2015, NHS England said it will change the underlying dementia prevalence rates used in the dementia prevalence calculator. Under the current calculation, 7.1% of people aged 65 years and over are estimated to have the disease; this comes from the Delphi consensus expert group in the Dementia UK report from 2007 (which was based partially on the Cognitive Function and Ageing Study I (CFASI) 1991).

The new prevalence rate of 6.5% of people aged 65 and over having dementia is based on a 2013 report by CFASII which found a lower prevalence of dementia – believed to be due to a decrease in the incidence of dementia attributed to improvements in the management of vascular risk factors and higher levels of education.

Once the underlying prevalence rates have been reduced the effect will be an automatic increase on the diagnosis rates nationally. The full 2013 CFASII report can be viewed online via the lancet website:

http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2813%2961570-6/abstract

**Figure 4. Estimates of the scale of Dementia in Central Bedfordshire 2014-2030**



## Mortality

Local mortality data for dementia is scarce. Nationally it has been estimated that less than 25% of people who have had a diagnosis of dementia at some point in their lifetime have dementia recorded on their death certificate[12]. The subjective nature of the doctor stating dementia on the death certificate makes the analysis more challenging with figures often under estimating the role of dementia in mortality.

### Local death certificate analysis

Death certificates were only available for analysis for a subgroup of patients in Bedfordshire; this sample included deaths occurring between 4th June 2013 and 3rd April 2014. Death certificates were available for North and Mid Bedfordshire therefore included Bedford Borough residents and do not include all Central Bedfordshire residents. Of 656 deaths, 91 had a diagnosis of dementia or Alzheimer's recorded as indicated by ICD 10 codes F00-F03. Table 6 and Table 7 show some locally sourced information from death certificates.

**Table 6. Number of occasions when dementia was recorded on death certificates**

| Location of dementia on death certificate | Number of deaths (%) |
|---|---|
| Primary | 19 (21%) |
| Secondary | 12 (13%) |
| Tertiary | 60 (66%) |

**Table 7. Primary cause of death when dementia was indicated as a contributory condition**

| Primary cause of death when dementia is indicated as a contributory condition | Percentage of deaths when dementia is indicated as a contributory condition |
|---|---|
| Frailty in old age / old age | 43% |
| Pneumonia | 30.6% |
| Cancer | 9.7% |
| Other causes (where there are less than five deaths per cause per year combined) | 16.7% |

Unfortunately as the above sample does not include the whole of Central Bedfordshire, the conclusions that can be drawn are limited; however it does show

---

[12] Usefulness of mortality data in determining the geography and time trends of dementia. *Journal of Epidemiology and Community Health*. Martyn CN, Pippard EC. 1988;42(2):134-137.

that nearly 75% of deaths where dementia was recorded as a contributory factor were due to frailty or pneumonia.

## National estimates 2001-2009

Nationally between 2001 and 2009 there were 631,078 deaths where dementia was mentioned on the death certificate, in 39% of cases, dementia was the primary cause of death and in the remaining 61% dementia was listed as a contributory cause of death[13]. The patterns of place of death for people dying from underlying causes of dementia and Alzheimer's disease are broadly similar, the largest percentages of deaths occur in hospital, followed by nursing homes. This may be due to the higher care needs of people with dementia: when they become acutely ill with another condition they are more likely to be admitted to hospital.

## Deaths registered in England and Wales 2013

The Office for National Statistics (ONS) compiles lists of the top ten leading causes of deaths according to death certificates; these are ranked according to WHO lists using ICD-10 codes. The data in Table 8 includes all deaths registered in 2013[14] (This should give a good indication of deaths from dementia during this time period as dementia related deaths are unlikely to be delayed from occurring to being registered).

**Table 8. Top 3 causes of death in England and Wales in 2013**

| **Males** | | | **Females** | | |
|---|---|---|---|---|---|
| **Rank** | **Underlying cause of death** | **Percentage of all male deaths** | **Rank** | **Underlying cause of death** | **Percentage of all female deaths** |
| 1 | Ischaemic heart disease | 15.4% | 1 | Dementia and Alzheimer's disease | 12.2% |
| 2 | Malignant neoplasm of trachea, bronchus and lung | 6.8% | 2 | Ischaemic heart disease | 10.0% |
| 3 | Dementia and Alzheimer's disease | 6.2% | 3 | Cerebrovascular diseases | 7.9% |

---

[13] National end of life care intelligence network: Deaths from Alzheimer's disease, dementia and senility (2010)

[14] ONS statistical bulletin: Deaths registered in England and Wales 2013 (October 2014)

Overall, these sources of data for mortality show that people dying with dementia are likely to have increased care needs and comorbidities. A cohort study in Newcastle[15] found the median number of diseases to be four for men and five for women over the age of 85. The addition of comorbidities to dementia care needs to be carefully considered as people with more advanced dementia may not be able to effectively control other conditions for example by regularly forgetting to take prescribed medication.

## Characteristics of those living with Dementia in Central Bedfordshire

### Age and gender

Nationally the prevalence of dementia in different age bands has been estimated by gender, this information in shown in Figure 5. While it suggests that dementia may affect females more than males in later age, this may be due in part to the longer life expectancy among females. It is hard to capture the true age and sex profile of people with dementia locally due to the diagnosis rate being less than 100%.

In Central Bedfordshire the age and sex profile of those with dementia has been estimated and is shown in
Figure **6**. This graph was generated using the age band prevalence rates shown in Figure 5 with the most recent population figures for Central Bedfordshire (2014 Q3, Exeter figures). Exact numbers are shown in the appendix 2.

---

[15] Health and disease in 85 year olds: baseline findings from the Newcastle 85+ cohort study. *British Medical Journal* (2009) Volume 339 pages b4904.

**Figure 5. The national prevalence of dementia by age and gender**

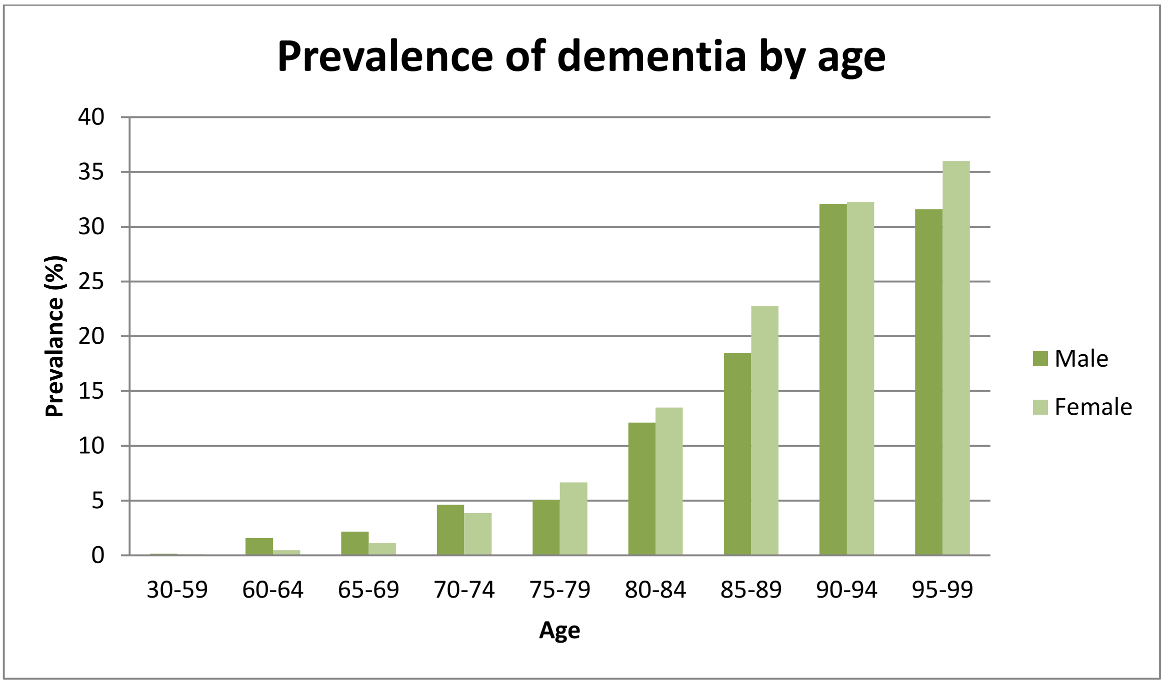
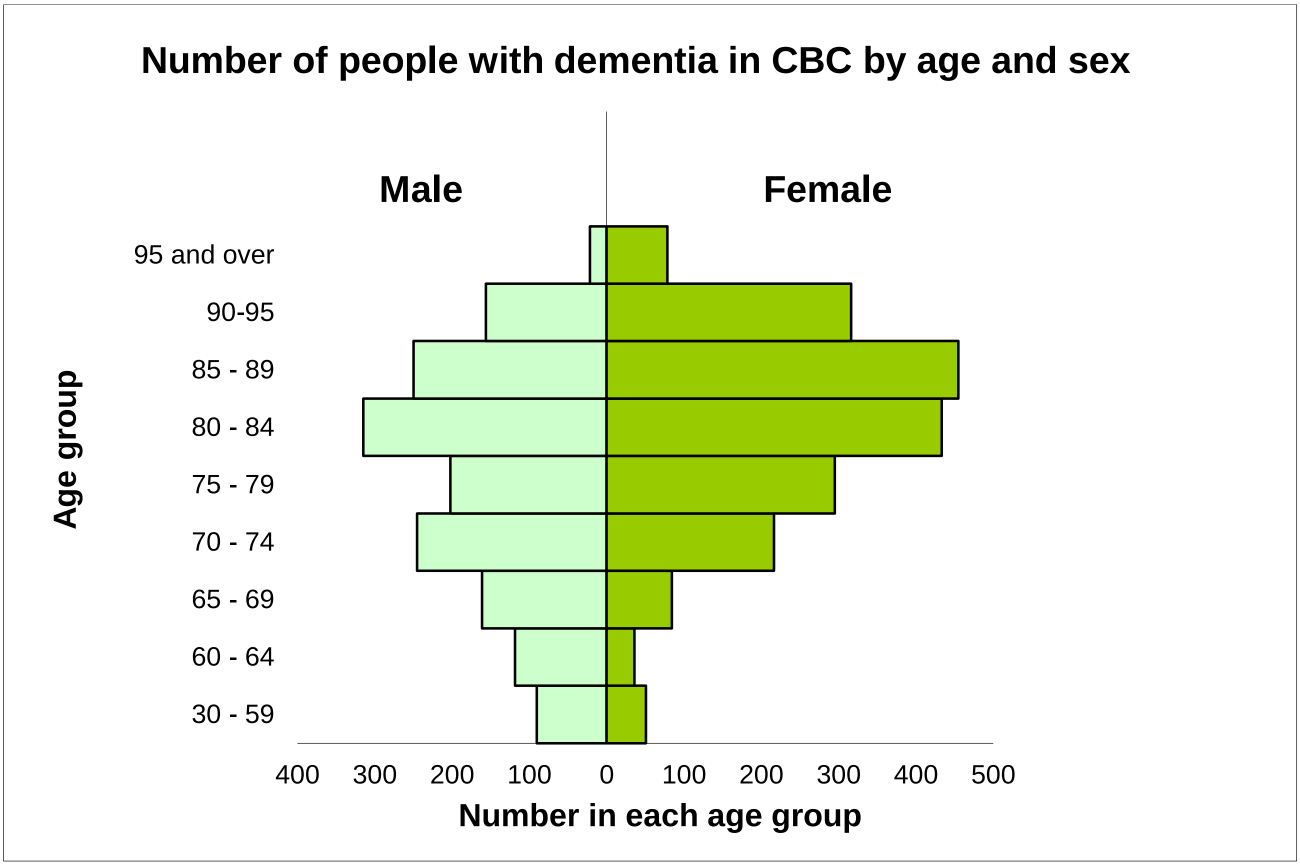


**Figure 6. Number of people with dementia in CBC by age and sex**



## Ethnicity

Unfortunately it is not possible to report on the ethnicity of people with dementia in Central Bedfordshire, additionally, nationally there is very little information available.

> ‘Given that the evidence is still sparse, the assumption has been that the prevalence of dementia is the same among all ethnic groups in the UK. This may not be correct, at least for some black ethnicities. The likely effect would have been to underestimate numbers of people with dementia.’

*Source: Dementia UK, Second edition, 2014*

Thinking about the risk of developing dementia, certain ethnic groups have higher levels of underlying risk factors, especially for vascular dementia. Central Bedfordshire is less diverse than England as a whole, and has a greater proportion of people who are White British (89.7%), Table 9 shows the ethnic origin of CBC residents.[16]

**Table 9. Ethnic origin of CBC residents**

| Ethnic origin | Percentage of CBC residents |
|---|---|
| White British | 89.7% |
| White Other (Not white British, white Irish or Gypsy or Irish Traveller) | 2.8% |
| Indian | 1.0% |
| Other | 5.3% |

As the population ages and the number of older people from different ethnic groups’ increases there will be increasing need to ensure that culturally sensitive and relevant services are in place to support people with dementia. In particular people who learnt English as a second language may forget their English language skills or even that they migrated to England, this could result in individuals becoming socially isolated and not seeking medical help for dementia and other conditions.

## Dementia subtype

The estimated number of people with each subtype of dementia in Central Bedfordshire is shown in Table 10. This has been calculated using the adjusted number of people estimated to have dementia (February 2015 data) from the Dementia Prevalence Calculator and the prevalence shown in column 2 Table 1.

---

[16] Office for National Statistics, 2011 Census

These estimates should be used with caution but may be helpful in planning future service provision as the number of people with dementia requiring specialist services increases and the type of specialist needs does differ according to sub type of dementia.  More information about the different subtypes is shown in Table 1.

> ***'Not everyone with dementia has the same needs, the type of dementia is important, I'm lucky my husband isn't aggressive, he is still a big strong man, I worry I wouldn't be able to cope'***
>
> Female, Carer

**Table 10. Estimated number of people in CBC with each subtype of dementia**

| Type of dementia | Estimated number of people with each subtype in CBC[17] |
|---|---|
| Alzheimer's' | 1806 |
| Vascular dementia | 512 |
| Mixed dementia | 301 |
| Lewy body dementia | 121 |
| Fronto – temporal dementia | 61 |
| Parkinson's dementia | 61 |
| Other | 91 |

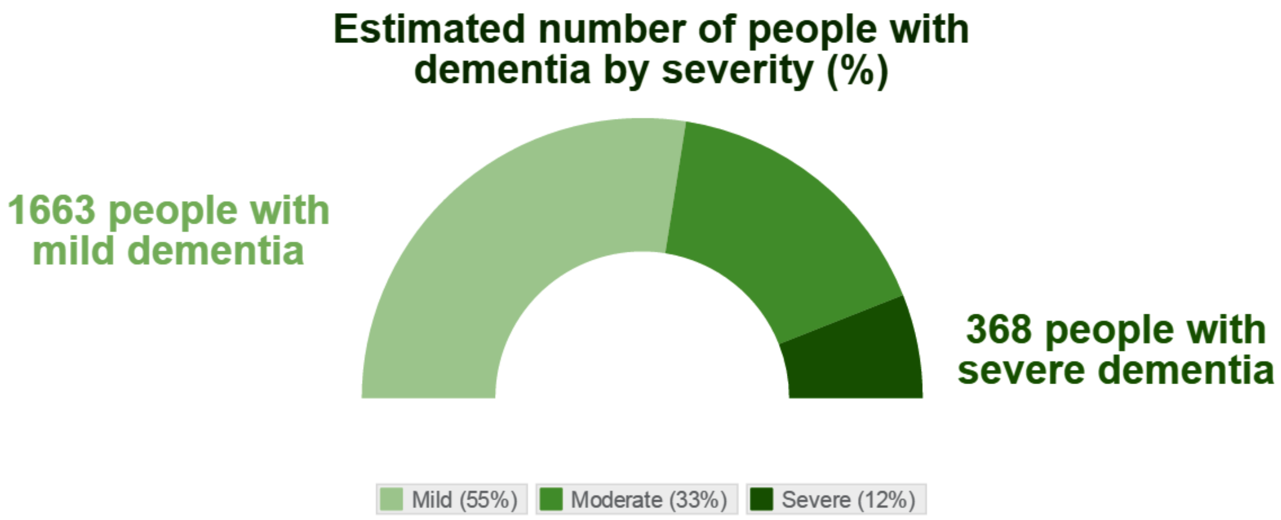
## Severity of dementia

The severity of dementia cases in Central Bedfordshire is illustrated in Figure 7; exact numbers are available in the appendix. These estimates are from the dementia prevalence calculator. Currently the majority of cases are mild dementia, however as these cases deteriorate and become more severe there will be increased pressure on local services.

---

[17] Summarised from table 1

**Figure 7. Estimated number of people with dementia by severity**



### Severity of dementia

Dementia is categorised as mild, moderate or severe:

Mild dementia includes impaired attention and memory, short term memory loss, occasional confusion, coping with daily activities and living independently but with assistance.

Moderate dementia includes recent amnesia, disorientation in time and place, poor reasoning and understanding of events, requiring some help with personal care and daily routine.

Severe dementia includes incoherent speech, inability to recognise close relatives, incontinence and dependence on personal care services.

Not every person with dementia will experience the later symptoms such as aggression and disorientation.

## Learning disabilities

The information available locally about people with learning difficulties is limited and does not include the number of patients with dementia and specific learning disabilities. QOF indicator LD001 (*The contractor establishes and maintains a register of patients aged 18 or over with learning disabilities*) has 880 people on the register for Central Bedfordshire in 2014.

Those with learning disabilities have a higher risk of developing dementia and are more likely to develop dementia at a younger age – in particular the specific association between Down's syndrome and Alzheimer's Disease has been well documented. The link between Alzheimer's and Down's syndrome is not fully understood but it has been postulated this is due to a protein that causes brain cell damage in Alzheimer's being located on chromosome 21 (people with Down's syndrome have an extra copy of this chromosome), which could explain their increased risk of developing Alzheimer's disease.

The link between dementia and other learning disabilities is less established. However studies have indicated that the risk is three to four times higher than the general population, with the risk increasing from 1 in 10 of those aged 50 to 65 to nearly three quarters of those aged 85 or over[18]. A challenge for people with a learning disability and dementia, particularly for those with a more severe learning disability, will be to identify the early stages of dementia and receive a diagnosis.

Although dementia generally affects people with a learning disability in similar ways to people without a learning difficulty, there are some important differences; these are shown in the box below:[16]

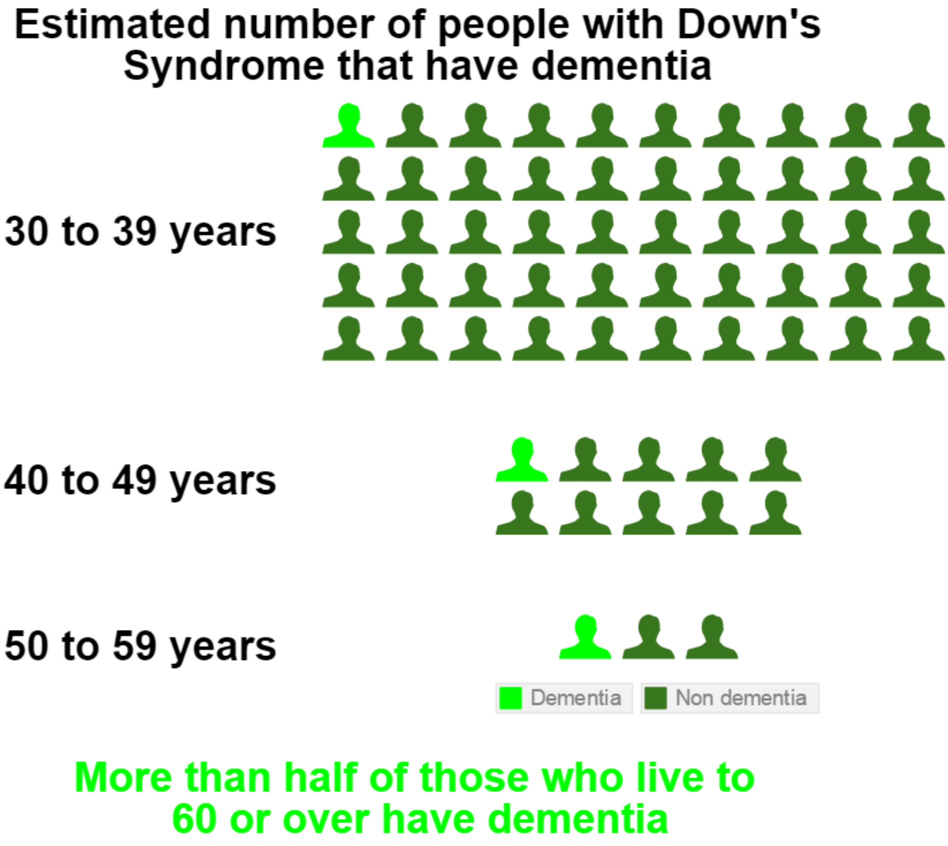
**People with a learning disability:**

- are at greater risk of developing dementia at a younger age – particularly those with Down's syndrome
- often show different symptoms in the early stages of dementia
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia
- may already be in a supported living environment, where they are given help to allow them to live independently
- may have already learned different ways to communicate (e.g. more non-verbal communication if their disability affects speech)
- will require specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

---

[18] Alzheimer's Society, Learning disabilities and dementia http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

**Figure 8. Estimated number of people with Down's Syndrome that have dementia**

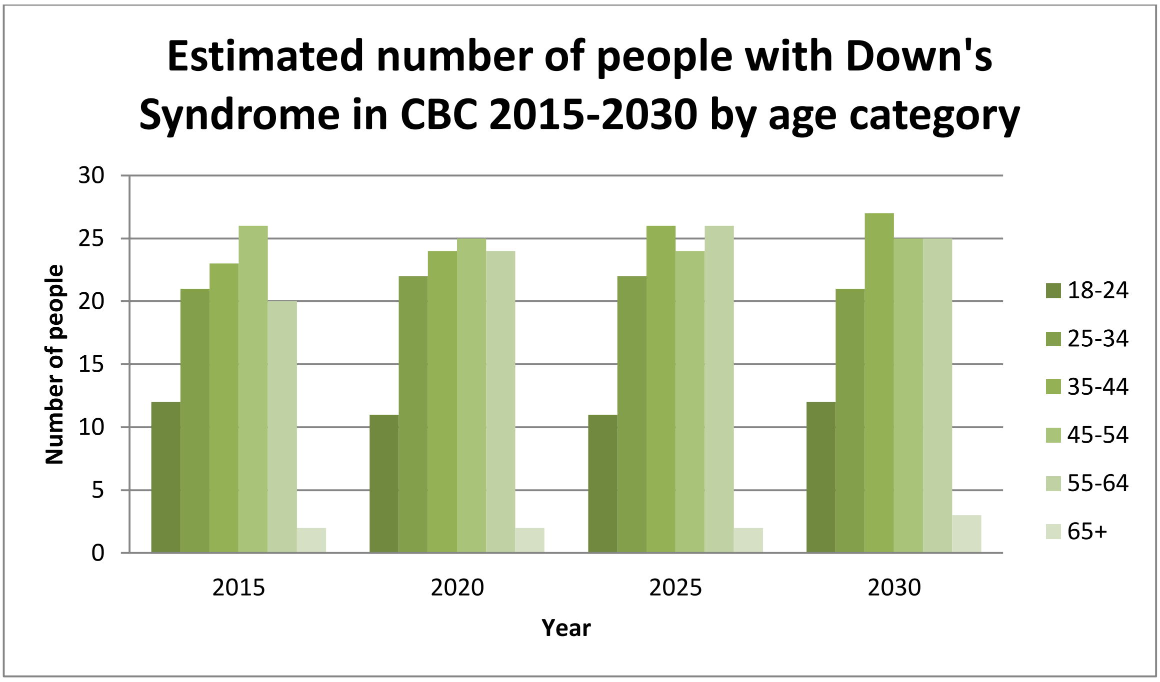


Down’s syndrome is the most common diagnosed learning disability. Figure 8 illustrates how the proportion of people with dementia varies in those with Down’s syndrome at different ages. Using the Projecting Adult Needs and Service Information (PANSI) system local estimates for the number of people with Down’s syndrome is shown in Figure 9: these estimates should be used with caution, especially for the older age groups as the average life expectancy for people with Down's syndrome is approximately 59 years[19]. Combining these sources allows an estimate of the number of people with Down’s syndrome and dementia to be calculated; for Central Bedfordshire there are estimated to be 19 people living with Down’s syndrome and dementia. The age breakdown is shown in Table 11.

---

[19] The changing survival profile of people with Down's syndrome: Implications for genetic counselling. *Clinical Genetics.* Glasson EJ, Sullivan SG, Hussain R, Petterson BA, Montgomery PD, Bittles AH. (2002) 62:390–393

**Figure 9. Estimated number of people with Down's Syndrome in CBC 2015-2030 by age category**



Currently in Central Bedfordshire, there are no specific services for people with dementia and an underlying learning disability. Although the numbers of people with dementia and a learning disability are small, their needs are specific. A literature review in 2011 showed that people with Down's syndrome require multiple services including social care services[20].

**Table 11. The estimated number of people living with Down's syndrome and dementia in Central Bedfordshire**

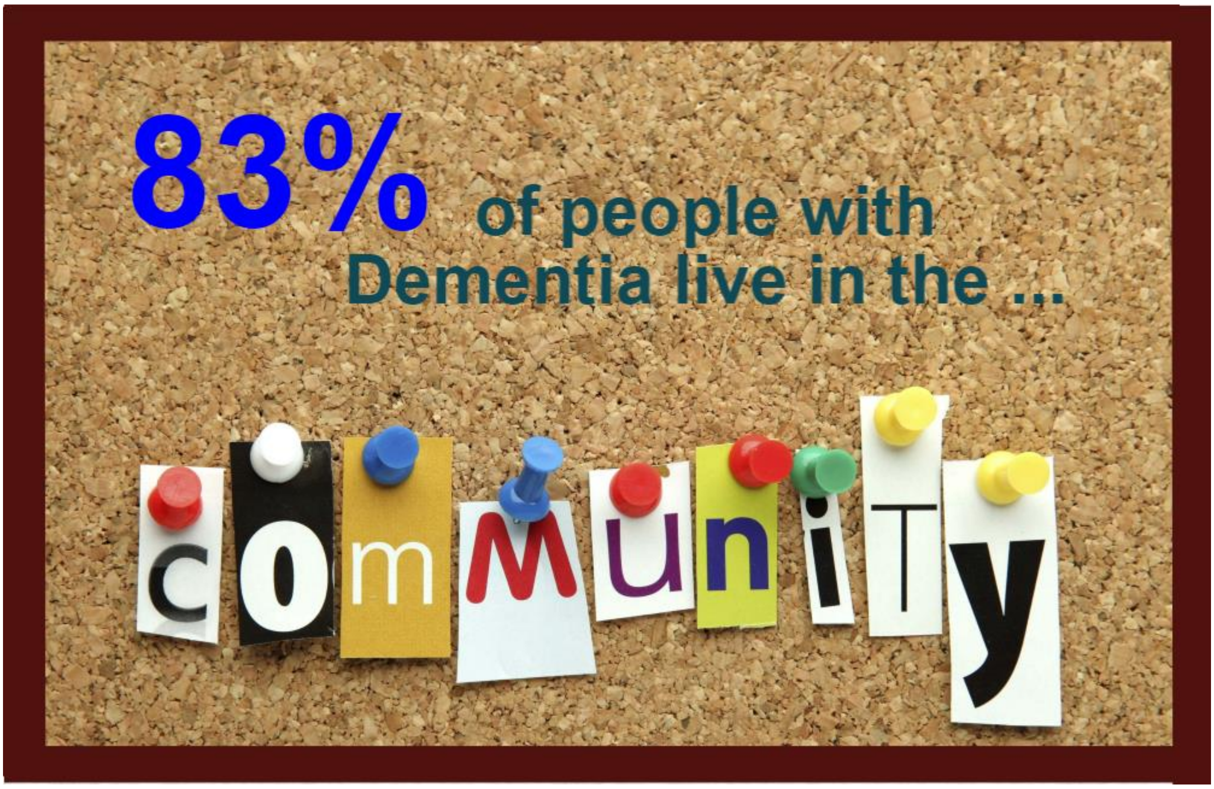
| Age band | Estimated number of people with Down's Syndrome (CBC) | Estimated number of people with Down's Syndrome with dementia |
|---|---|---|
| **18-24** | 12 | 0-1 |
| **25-34** | 21 | 0-1 |
| **35-44** | 23 | 2 |
| **45-54** | 26 | 6 |
| **55-64** | 20 | 9 |
| **65+** | 2 | 1 |
| **Combined ages 18+** | 104 | 19 |

---

[20] The needs of people with learning disabilities who develop dementia: A literature review. *Dementia.* Penny Llewellyn. (May 2011) vol. 10 no. 2 235-247.

## Accommodation status of people living with Dementia

The accommodation status of people living with dementia in Central Bedfordshire is available from the dementia prevalence calculator. Actual numbers can be found in the Appendix 2.



The England average for the percentage of people with dementia living in the community is 67%. Having a higher percentage of people with dementia living in the community can be seen as a favourable outcome, however nationally one third of people with dementia living in the community live alone, this equates to 824[21] people across Central Bedfordshire. Special attention is required to ensure that those living alone do not suffer from social isolation and their care needs are met.

The dementia prevalence calculations are based on underlying assumptions and the accuracy of GP practice records of the place of residence of its patients.

---

[21] Using the February 2015 data from the dementia prevalence calculator there are estimated to be 2494 people living in the community, one third of this figure is 824 people.

## Other relevant groups

A limitation of this needs assessment is the lack of information available for specific groups including BAME, LGBT and Prisoners. These groups may not access health services in a timely manner which could delay diagnosis and support. For prisoners the early signs of dementia may be confused for challenging behaviour. Although Bedfordshire’s only prison is within Bedford Borough, it houses offenders from across Bedfordshire. Currently there are less than five prisoners over the age of 65 and none with a diagnosis of dementia.

## Prevalence of key risk factors

The prevalence of several key risk factors for dementia will be considered. While it is not possible to report the prevalence of these risk factors in people with dementia the prevalence of these risk factors in the wider community is important to understand when considering preventative approaches to dementia. How these risk factors relate to dementia will be explored in
Section 5. Evidence base for primary prevention of dementia.

Clustering of risk factors for dementia is an important consideration when investigating the local prevalence of risk factors.

What does clustering mean?

Clustering is when a person may have several interconnected risk factors for a disease thus the overall effect of these risk factors may not be the sum of all of the risk factors combined.

A recent paper in the Lancet, *'Potential for primary prevention of Alzheimer's disease: an analysis of population-based data'*[22] modelled the potential for primary prevention of Alzheimer's disease using seven potentially modifiable risk factors that have consistent evidence of an association with the disease (diabetes, midlife hypertension, midlife obesity, physical inactivity, depression, smoking, and low educational attainment). The study found that:

*'Assuming independence, the combined worldwide Population Attributable Risk (PAR) for the seven risk factors was 49·4% (95% CI 25·7–68·4), which equates to 16·8 million attributable cases (95% CI 8·7–23·2 million) of 33·9 million cases. However, after adjustment for the association between the risk factors, the estimate reduced to 28·2% (95% CI 14·2–41·5) which equates to 9·6 million attributable cases (95% CI 4·8–14·1 million) of 33·9 million cases.'*

Locally if we apply the adjusted rate of 28·2% (95% CI 14·2–41·5) to our local estimated population of 3010[23] people with dementia we have the potential to prevent 849 (428 – 1,250) cases of dementia by modifying the seven key risk factors.

---

[22] Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology* (2014) 13: 788–94

[23] Dementia Prevalence Calculator, February 2015 data

## Behavioural risk factors

Behavioural risk factors have been shown to increase the individuals' risk of developing dementia, sometimes through the development of intermediate risk factors; section 5 provides the latest evidence about how these risk factors are linked to developing dementia. The prevalence rates are included here to show the local potential for reducing the population risk of developing dementia.

## Alcohol

There is one adult alcohol related indicators on the Public Health Outcome Framework for Central Bedfordshire as shown in Table 12.

**Table 12. Alcohol related indicators in CBC**

| Indicator | Year of data collection | Indicator value | How CBC compares regionally and nationally |
|---|---|---|---|
| The number of admissions involving an alcohol-related primary diagnosis or an alcohol related external cause, directly age standardised rate per 100,000 population | 2011/12 | 479 | Significantly better than the England average, comparable with region |
|  | 2012/13 | 518 |  |

> ***'I can't really leave my husband as he will leave the house to buy alcohol, he was a previous alcoholic, it's hard for me to handle him when he's drunk, the only option is to let him sleep it off.'***
>
> Female carer

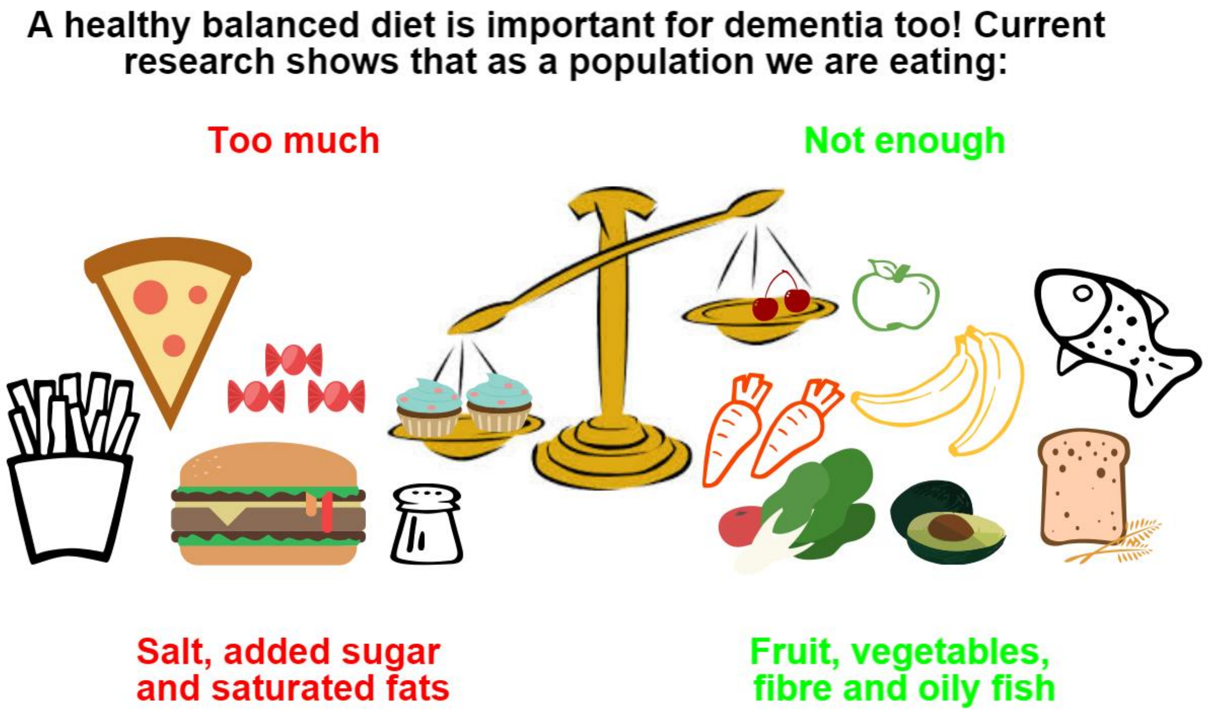
## Diet

Dietary information is not readily available at the local level, this is in part due to the complexity of accurately recording a subjective measure of what people eat and the quantities involved. Nationally the latest National Diet and Nutrition Survey (NDNS) data released on the 14th May 2014[24] shows that overall the population is still consuming too much saturated fat, added sugars and salt and not enough fruit, vegetables, oily fish and fibre.

One source of information about diet at a local level is the Public Health Outcomes Framework, indicators 2.11i – 2.11iii. These indicators related to 2014 data from the Sport England Active People Survey as shown in Table 13. This supports the national research that people are not eating enough fruit and vegetables.

**Table 13. Public health outcome framework diet indicators (2014 data)**

| Indicator | Central Bedfordshire value |
|---|---|
| 2.11i. The percentage of people consuming at least five a day | 55.6, this is lower than the England average but not significantly different |
| 2.11ii The average number of fruit eaten (per day) | 2.61 this is lower than the England average but not significantly different. |
| 2.11iii The average number of vegetables eaten (per day) | 2.47 this is higher than the England average but not significantly different. |



---

[24] https://www.gov.uk/government/news/new-national-diet-and-nutrition-survey-shows-uk-population-is-eating-too-much-sugar-saturated-fat-and-salt

## Smoking

The prevalence of adult smokers in Central Bedfordshire is recorded on the Public Health Outcome Framework as shown in Table 14.

**Table 14. Smoking prevalence in CBC residents**

| Indicator | Year of data collection | Indicator value | How CBC compares regionally and nationally |
|---|---|---|---|
| % Adults aged 18 and over smoking | 2012 | 18.3% | Significantly better than the England average, comparable with region |
| | 2013 | 15.0% | |

> ***'My husband has challenging behaviour, he likes his own way, he smokes and drinks, he will forget lots of places but has never forgotten the corner shop for alcohol and cigarettes.'***
>
> Female carer

## Physical inactivity

Physical inactivity in Central Bedfordshire is recorded on the Public Health Outcome Framework as shown in Table 15. The indicator is the number of respondents aged 16 and over, with valid responses to questions on physical activity, doing less than 30 "equivalent" minutes of at least moderate intensity physical activity per week in bouts of 10 minutes or more in the previous 28 days expressed as a percentage of the total number of respondents aged 16 and over.
Active People Survey, Sport England

**Table 15. Physical inactivity among CBC residents**

| Year of data collection | Indicator value | How CBC compares regionally and nationally |
|---|---|---|
| 2013 | 29.6%<br>(25.6 – 33.5) | Higher but not significantly different to the England average |

## Intermediate risk factors

Intermediate risk factors have been shown to increase the individuals' risk of developing dementia; section 5 provides the latest evidence about how these risk factors are linked to developing dementia. The prevalence rates are included here to show the local potential for reducing the population risk of developing dementia. Some of these risk factors are attributable to behaviours, however in the evidence based review that follows in section 5 they will be discussed as intermediate risk factor so are included in this section here for consistency.

### Blood Pressure

Hypertension is recorded as a QOF indicator, in March 2014 there were 39,029 patients on the hypertension QOF register; this is 13.86% of the Central Bedfordshire population. There are also several QOF management indicators; including the percentage of patients with hypertension in whom the last blood pressure reading (measured in the preceding 9 months) is 150/90 mmHg or less, for Central Bedfordshire this figure is 85.15%. This can be interpreted as of all the people with high blood pressure in Central Bedfordshire, only 15% are not currently well managed.

### Diabetes

Diabetes is recorded as a QOF indicator, in March 2014 there were 13,177 patients (aged 17 and over) on the diabetes QOF register; this is 5.87% (Confidence range 5.78% to 5.97%) of the Central Bedfordshire population.

There are also several QOF management indicators; including the percentage of patients newly diagnosed with diabetes, on the register, in the preceding 1 April to 31 March who have a record of being referred to a structured education programme within 9 months after entry on to the diabetes register, for Central Bedfordshire this figure is 95.81%.

### Obesity

Obesity is recorded as a QOF indicator, in March 2014 there were 23,495 patients on the obesity QOF register (a register of patients aged 16 or over with a BMI ≥30 in the preceding 12 months); this is 10.32% of the Central Bedfordshire population.

### Serum Cholesterol

Serum cholesterol is an important risk factor for dementia; local data is not available however local CHD data is available as a QOF indicator. In March 2014 there were 8,434 patients on the CHD QOF register; this is 3.05% of the Central Bedfordshire population.

## Depression

Estimates of depression are included under ‘Common mental disorders (CMDs)’:

> *‘mental conditions that cause marked emotional distress and interfere with daily function, but do not usually affect insight or cognition. They comprise different types of depression and anxiety, and include obsessive compulsive disorder.’*

Using the Projecting Adult Needs and Service Information (PANSI) system local estimates for the number of people with a common mental disorder are shown in Table 16. This is based on a prevalence rate of 19.7% for women and 12.5% for men applied to ONS population projections for the 18-64 population to give estimated numbers predicted to have a mental health problem, projected to 2030. Depression is recorded as a QOF indicator; there are two management indicators as shown in Table 17.

**Table 16. Estimated number of CBC residents with a common mental disorder**

| | 2015 | 2020 | 2025 | 2030 |
|---|---|---|---|---|
| People aged 18-64 predicted to have a common mental disorder | 26,420 | 27,322 | 28,141 | 28,492 |

**Table 17. QOF Depression indicators**

| QOF indicator | CBC value |
|---|---|
| The percentage of patients aged 18 or over with a new diagnosis of depression in the preceding 1 April to 31 March, who have had a bio-psychosocial assessment by the point of diagnosis. | 90.66% |
| The percentage of patients aged 18 or over with a new diagnosis of depression in the preceding 1 April to 31 March, who have been reviewed not earlier than 10 days after and not later than 35 days after the date of diagnosis | 78.66% |

## Educational Attainment

Low educational attainment has been linked to increased risk of dementia. In 2014, in Central Bedfordshire a higher proportion of pupils achieved 5+ GCSEs A*-C including English and Math’s compared to the England average: 57.1% locally compared to 53.4% for England average.

Although having a higher level of educational attainment is beneficial for reducing the risk of dementia, dementia can still occur in highly educated individuals. Diagnosing patients with a high level of educational attainment can be difficult as they may find it easier to ‘pass’ the test.

## Summary of the local prevalence of key risk factors for dementia

Table 18 illustrates how the prevalence of the key risk factors for dementia discussed above compare to the England average. While this is a useful comparator, it is worth noting that the England average is not the most desirable outcome and that even if the local prevalence rate is significantly better than the England average there is more than can be done to achieve a more favorable prevalence locally to lower the local population risk of dementia.

**Table 18. Summary of the local prevalence of key risk factors for dementia**

| Risk factor | CBC comparison to England average | |
|---|---|---|
| Alcohol- admissions to hospital due to alcohol specified conditions | Lower than the England average and comparable with the region | 🟢 |
| Diet | Similar to the England average | 🟡 |
| Smoking prevalence among adults | Significantly lower than the England average | 🟢 |
| Physically inactive adults | Higher but not significantly different to the England average | 🟡 |
| Blood Pressure | Higher than the England average | *significance level unavailable |
| Diabetes | Significantly lower than the England average | 🟢 |
| Obesity | Slightly higher than England average but not significantly different | 🟡 |
| Serum Cholesterol | England average is unavailable for comparison | *significance level unavailable |
| Depression | Local estimates are based on national prevalence rates | NA |
| Educational attainment | Higher than the England average for GCSE level | 🟢 |

**Key:**

🟢 **Significantly better than the England average**

🟡 **Not significantly different to the England average**

🔴 **Significantly worse that the England average**

# Section 3. The cost of dementia in Central Bedfordshire

## Summary of the cost of dementia

**Please read the full section to appreciate the assumptions made in these calculations**

- Using the current dementia diagnosis rate of 54.15%, we could expect the current estimated cost of dementia to be in the region of £53-57 million per annum.
- There are an estimated 2559 unpaid carers in Central Bedfordshire supporting people with dementia.
- The estimated total opportunity cost of unpaid care in Central Bedfordshire is £26,149,248 per annum.

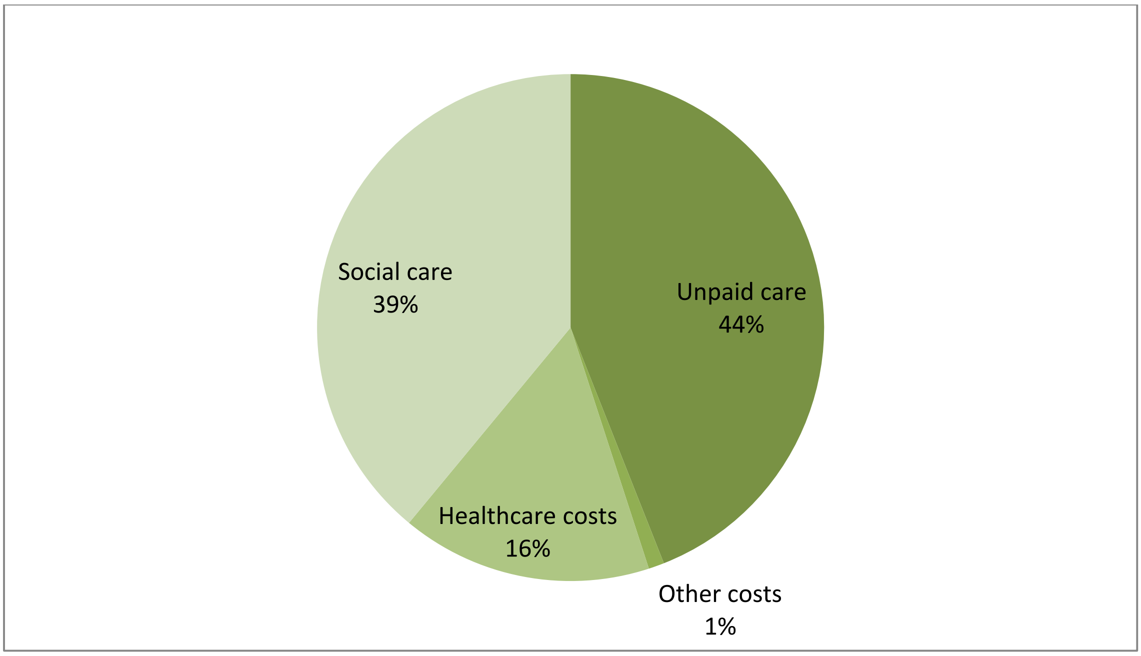
This chapter of the health needs assessment contains information about the estimated cost of dementia starting with national estimates and a breakdown of the three key components of dementia costs. These three components, unpaid care, social care and health care will subsequently be explored in more detail. Local estimates will be calculated where possible but these should be interpreted with caution due to the accompanying assumptions used in their estimation.

## National estimates of the cost of dementia care

While the cost of dementia has been estimated at the national level, information is not readily available at a local level. In 2014, the Alzheimer's Society[25] estimated that:

- Dementia cost the UK £26 billion a year
- This includes over £4 billion in health care costs and over £10 billion in social care costs
- Unpaid carers save the UK economy £11 billion per year
- Dementia costs £1.6 billion to UK businesses per year

**Figure 10. The percentage split between key areas of dementia care by cost**



*Source: Alzheimer's Society 2014 report*

The overall costs outlined above are expected to be underestimates of the true cost of dementia. There is a clear need to reduce costs and this can be achieved by improving the quality and cost effectiveness of services and by focussing on prevention activities. Examples of possible cost-reduction activities are shown in Table 19.

---

[25] Alzheimer's Society, Dementia 2014: Opportunity to change

**Table 19. Areas where potential cost savings can be made in dementia care**

| Cost component | Potential savings |
|---|---|
| Healthcare costs | • Earlier diagnosis via memory assessment services, leading to a reduction in the need for residential care<br>• Reducing length of hospital stay by providing psychiatrist led multidisciplinary assessment or intermediate care<br>• Reducing hospital admissions by using the hospital at home scheme<br>• Regularly reviewing medication usage and reducing the use of antipsychotic medication in people with dementia |
| Social care costs | • Reducing the need for residential care by coordinated health and social care management<br>• Reduce the costs of residential care by supporting carers to maintain their own health (including mental health conditions) to allow them to care for loved ones at home in a safe effective manner for as long as is practical |
| Costs to the patient, family and other informal carers | • Better training for informal carers, for example from occupational therapists |

*Source: The Health Foundation 'Spotlight on dementia care' 2011.*

## Social care

Although dementia is a medical condition, a large proportion of the associated costs are for activities of normal everyday living such as help getting dressed, help with personal care and eating. These non-medical costs are deemed social costs and set dementia aside from other medical conditions as these costs will not be covered by the NHS. Therefore the financial impact on families and adult social care is greater than other conditions where the necessary care is seen as part of the medical aspect of the illness.

As the severity of dementia increases, the need for social care increases resulting in higher costs. The total annual cost per person with dementia in different settings is estimated as follows:

**Table 20. The estimated cost of dementia care in different settings**

| Setting | Cost per year |
|---|---|
| People in the community with mild dementia | £25,723 |
| People in the community with moderate dementia | £42,841 |
| People in the community with severe dementia | £55,197 |
| People in care homes with dementia | £36,738 |

Source: Alzheimer's Society, Dementia 2014: Opportunity for change

On average the costs for caring for a person with dementia in a care home are lower than a person with severe dementia in the community because of the hours of care required. For example someone with severe dementia may require round the clock care which is cheaper to provide in a care setting than in a private residence where care is more likely to be a on a one to one basis.

## Local estimates of the cost of dementia care

The complex nature of how services for people with dementia are delivered and funded, make estimations of the local cost of dementia extremely challenging. For example, a person may be diagnosed via their GP, Memory Assessment Service or other hospital department (e.g. Neurology). The person with dementia may be under the care of generic older people's teams or community mental health teams. The person may be a self-funder or use council provided social care packages. A large proportion of these services are commissioned in block contracts making the cost breakdown difficult.

In an attempt to quantify how much is spent locally on dementia care the figures shown above in Table 20have been applied to the local population using a series of assumptions. Using data from the dementia prevalence calculator (February 2015 data) we have an estimate of the number of people expected to have dementia by severity and residential status. Two models were created using different assumptions and then three diagnosis rates were applied to each model.

Dementia diagnosis rates applied to each model:

a) Local dementia diagnosis rate (From Dementia Prevalence Calculator February 2015 dataset), this is 54.15% for Central Bedfordshire
b) National ambition of 67% dementia diagnosis rate
c) 100% dementia diagnosis rate

Model 1 assumes that:

- All people living with dementia live in the community

**Table 21. Model one - local estimates of the cost of dementia**

| Setting | Cost per year | Estimated number of eligible people CBC | Total cost (£) |
|---|---|---|---|
| People in the community with mild dementia | £25,723 | 1663 | 42,777,349 |
| People in the community with moderate dementia | £42,841 | 980 | 41,384,180 |
| People in the community with severe dementia | £55,197 | 368 | 20,312,496 |
| Model 1a costs applying current diagnosis rate of 54.15% | | 1630 | 56,572,684 |
| Model 1b costs applying national ambition of diagnosis rate of 67% | | 2017 | 69,997,596 |
| Model 1c costs applying 100% diagnosis rate | | 3011 | 104,474,025 |

Model 2 Assumes that:

- All people living with mild dementia are living in the community,
- People living with moderate dementia are split between community and care settings*
- People living with severe dementia are living in care settings

*The split has been estimated by subtracting the number of people with severe cases of dementia from the number of residents in care settings registered with dementia to give a remainder for care setting. The number of people with moderate dementia in the community setting is then the number of people with moderate dementia minus those already assigned to care setting.

**Table 22. Model two - local estimates of the cost of dementia**

| Setting | Cost per year | Estimated number of eligible people CBC | Total cost (£) |
|---|---|---|---|
| People in the community with mild dementia | £25,723 | 1663 | 42,777,349 |
| People in the community with moderate dementia | £42,841 | 832 | 35,643,712 |
| People in care homes with dementia | £36,738 | 516 | 18,956,808 |
| Model 2a costs applying current diagnosis rate of 54.15% | | 1630 | 52,730,116 |
| Model 2b costs applying national ambition of diagnosis rate of 67% | | 2017 | 65,243,173 |
| Model 2c costs applying 100% diagnosis rate | | 3011 | 97,377,869 |

The true estimate of the costs of dementia is likely to lie somewhere between the two models as not everyone with dementia is living in the community and not all people with severe dementia are living in care settings.

If we were to apply the current dementia diagnosis rate of 54.15% to the models above, we could expect the current estimated cost of dementia to be in the region of £53-57 million per annum or £65-70 million per annum if the national target of 67% of people with dementia were diagnosed. A diagnosis rate of 100% would result in an estimated cost of dementia in the region of £97-105 million per annum for Central Bedfordshire.

## Unpaid care

The largest costs of dementia care are informal care costs; these are met by unpaid carers. This is likely to be in the form of care from a spouse or another close family member. The impact of unpaid care on society and the carer is Table 23.

**Table 23. Possible implications of informal care on society and carers**

| Impact on society | Impact on the carer |
|---|---|
| • Taking people out of the workforce<br>• Informal carers may only seek help once the person they care for has reached a crisis point where they are unable to cope any longer<br>• If they are caring informally they may not be paying taxes (no income) | • Higher prevalence of mental health conditions<br>• Social isolation for the carer<br>• Immediate and long term financial implications – e.g. Reduced earning potential and not paying in to a pension fund |

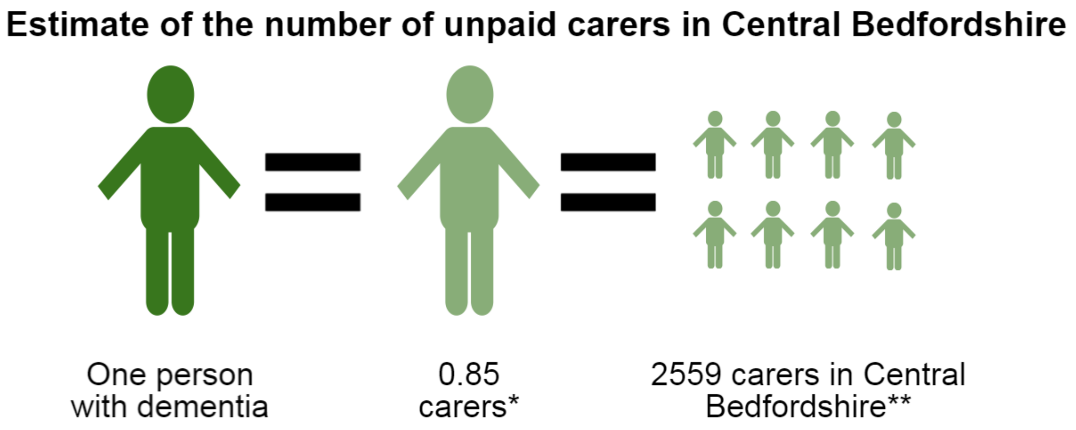
Currently unpaid carers are mostly female family members – changes in society with smaller families, higher divorce rates, and changing expectations coupled with an aging population will is likely to more pressure on social services for paid carers.

The number of hours of unpaid care required has been estimated by dementia severity in a US study[26]. The current UK minimum wage for adults over 21 (£6.50 per hour) was used to calculate the annual cost of unpaid care provided 52 weeks of the year. This gives a snapshot of the opportunity costs to unpaid carers, however this figure should be interpreted with caution as the informal care hours are only an estimate and this was based on a US study over ten years ago. An unpaid carer may also be capable of earning more than the minimum wage.  Using the number of people estimated to have each severity of dementia (Dementia Prevalence Calculator, February 2015 dataset) the total opportunity costs of unpaid care in Central Bedfordshire can be estimated. This information is summarised in Table 24.

**Table 24. Opportunity cost of unpaid carer time**

| | Hours of informal care per week | Annual cost at minimum wage (£6.50) per person with dementia | Number of people in CBC with severity of dementia | Estimated annual opportunity cost of unpaid care in CBC |
|---|---|---|---|---|
| Mild dementia | 13.1 | £4428 | 1663 | £7,363,432 |
| Moderate dementia | 39.4 | £13,318 | 980 | £13,051,640 |
| Severe dementia | 46.1 | £15,582 | 368 | £5,734,176 |
| Total opportunity cost of unpaid care in CBC | | | | £26,149, 248 |

**Figure 11. Estimate of the number of unpaid carers in Central Bedfordshire**



*There are estimated to be 0.85 carers per person with dementia[27] **based on an estimated 3010 people with dementia.*

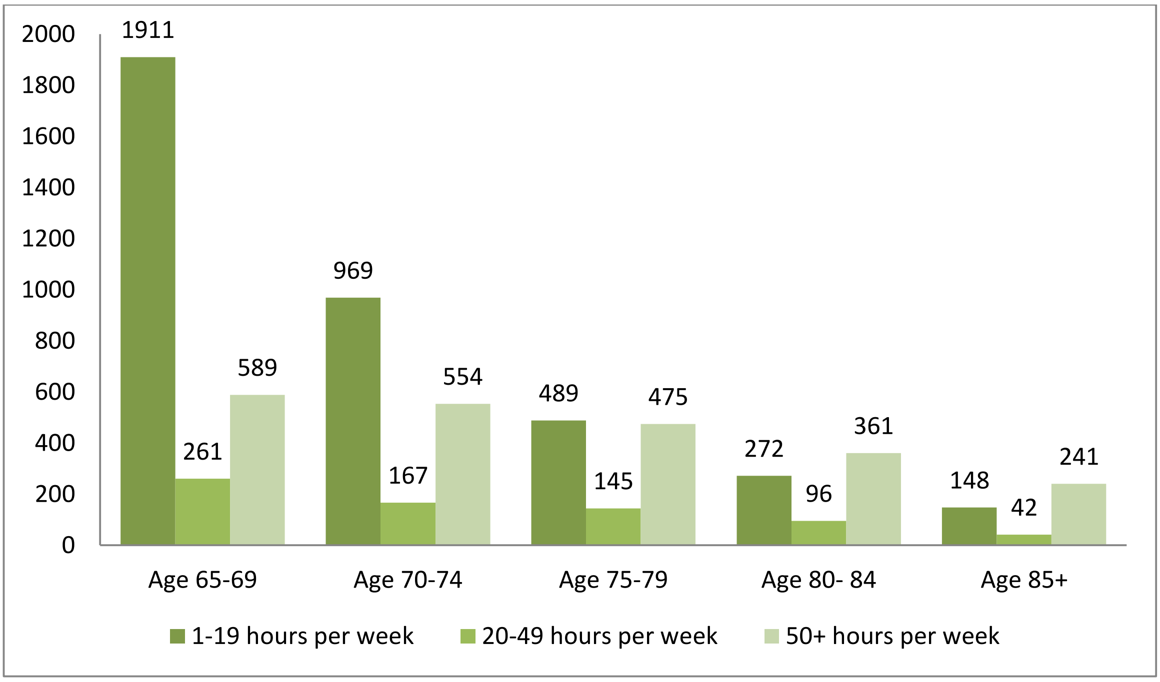
---

[26] National Estimates of the Quantity and Cost of Informal Caregiving for the Elderly with Dementia. *Journal of General Internal Medicine* (2001). 16 770-778.
[27] NICE guidance CG42 (2006) http://www.nice.org.uk/guidance/cg42/evidence

Although we can estimate how many unpaid carers we would expect for the number of people with dementia in our area, unfortunately specific demographic information about these carers is not available.

However through the POPPI database we can estimate the number of people aged 65 and over providing care to a partner, family member or other person. These estimates were based on data from the 2011 census and applied to population projections. They do not include caring activities that form part of employment. Unfortunately it is not possible to break down these figures by condition therefore the numbers in Figure 12 below are higher than would be expected if data were available specifically for people caring for someone with dementia. However they do provide an insight into the age profile of older carers, this is important as these older carers may be at risk of developing dementia themselves and could also be looking after someone with dementia. There are estimated to be 6720 carers over the age of 65, including 431 over the age of 85 in Central Bedfordshire.

**Figure 12. Provision of unpaid care (all conditions) in Central Bedfordshire**



## Healthcare costs

Healthcare costs associated with dementia have been estimated for both primary and secondary care. The results of an economic analysis by the University of Oxford for the Alzheimer's Research Trust in 2010[28] are shown in Figure 13 below.

**Figure 13. Healthcare costs associated with dementia**

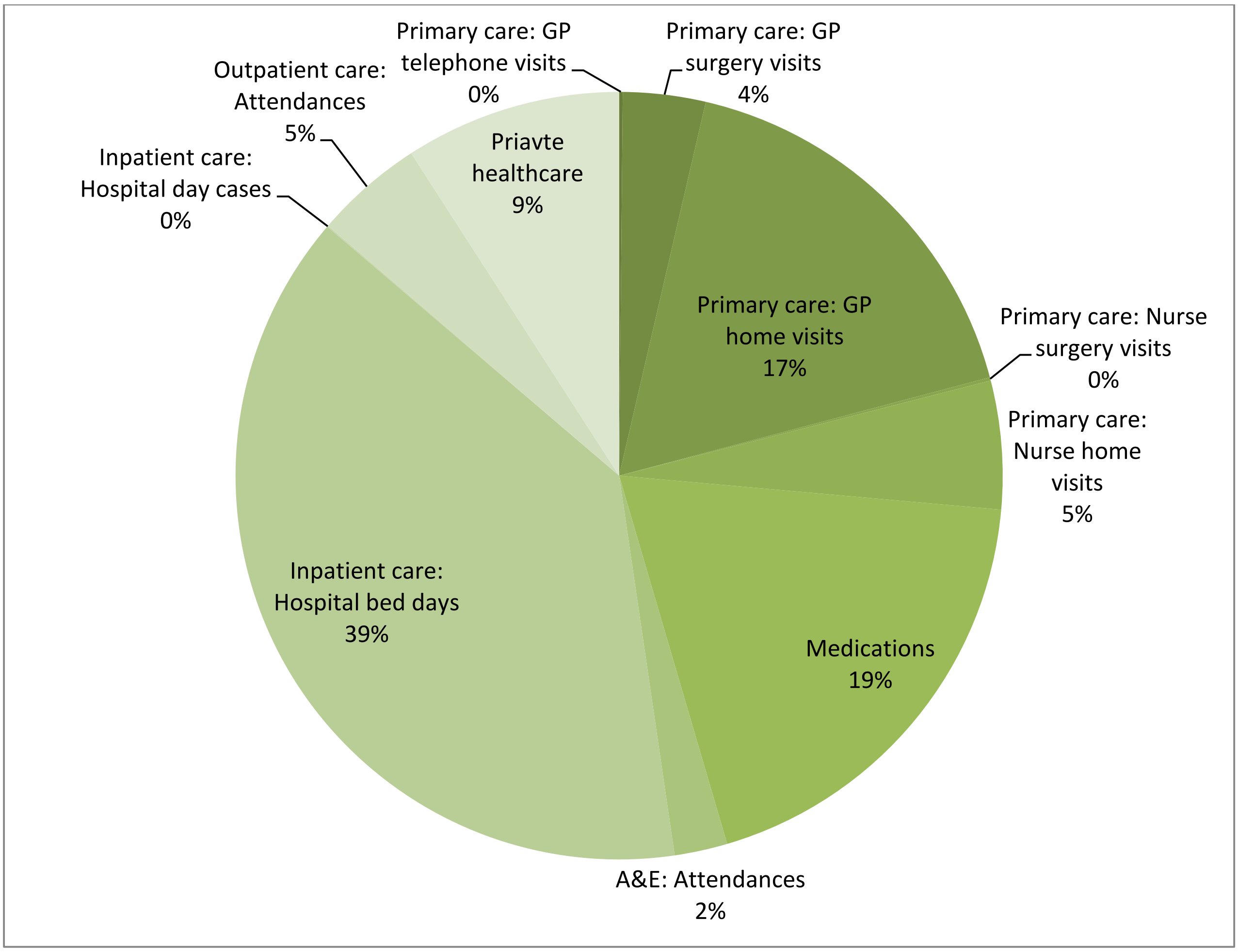


Figure 13 shows that the majority of healthcare costs (39%) are spent on inpatient hospital care. The Alzheimer's Society estimate that up to a quarter of hospital beds are occupied by people with dementia at any one time.[29] Additionally there is evidence to suggest that people with dementia have longer than average durations

---

[28] Alzheimer's Research Trust. The economic burden of dementia and associated research funding in the United Kingdom (2010). http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/Dementia2010Full.pdf

[29] Alzheimer's Society, Dementia 2014: Opportunity to change

of hospital stays, are more likely to be readmitted, and have a higher rate of in hospital mortality.

While in hospital a person with dementia is more likely to have a fall, become confused and less able to take care of themselves – this can result in the person being unable to return to their previous place of residence as a step up in their care package may be required.

The most common reasons for admitting a person with dementia to hospital are shown in Table 25. Most common reasons for a person with dementia. Where evidence is available, the differences in average length of stay between a person with and without dementia are shown.

**Table 25. Most common reasons for a person with dementia being admitted to hospital**

| Reason for hospital admission | Percentage of admissions among people with dementia | Average length of stay all patients | Average length of stay patients with dementia |
|---|---|---|---|
| Fall | 14% | | |
| Fracture | 12% | Hip fracture = 26 days[1]<br>Neck of femur = 20 days[2] | Hip fracture = 43 days[1]<br>Neck of femur = 23.1 days[2] |
| Urinary tract infection | 9% | 10.8 days[2] | 14.4 days[2] |
| Chest infection | 7% | 9.3 days[2] | 11.7 days[2] |
| Transient Ischaemic attack | 7% | Acute cerebrovascular disease = 18.2 days[2] | Acute cerebrovascular disease = 21 days[2] |

*Sources:*

[1] *The Health Foundation 'Spotlight on dementia care' (2011) Chapter four.* *http://www.health.org.uk/public/cms/75/76/4181/2703/Spotlight_Dementia%20Care.pdf?realName=1pWJno.pdf*

[2] *CHKS (Comparative Health Knowledge Systems) Insight Report: An economic analysis of the excess costs for acute care for patients with dementia (2013)* *www.chks.co.uk/userfiles/files/Dementia_an_economic_analysis.pdf*

## National investment in dementia research

While the costs of dementia are enormous, the amount invested in research focusing on dementia is disproportionate to the average cost per patient. This is shown in the next two infographics. Source: Alzheimer's Research Trust, Dementia 2010: The economic burden of dementia and associated research funding in the UK.

**Figure 14. Proportion of UK healthcare average costs per patient between dementia, cancer, stroke and heart disease**

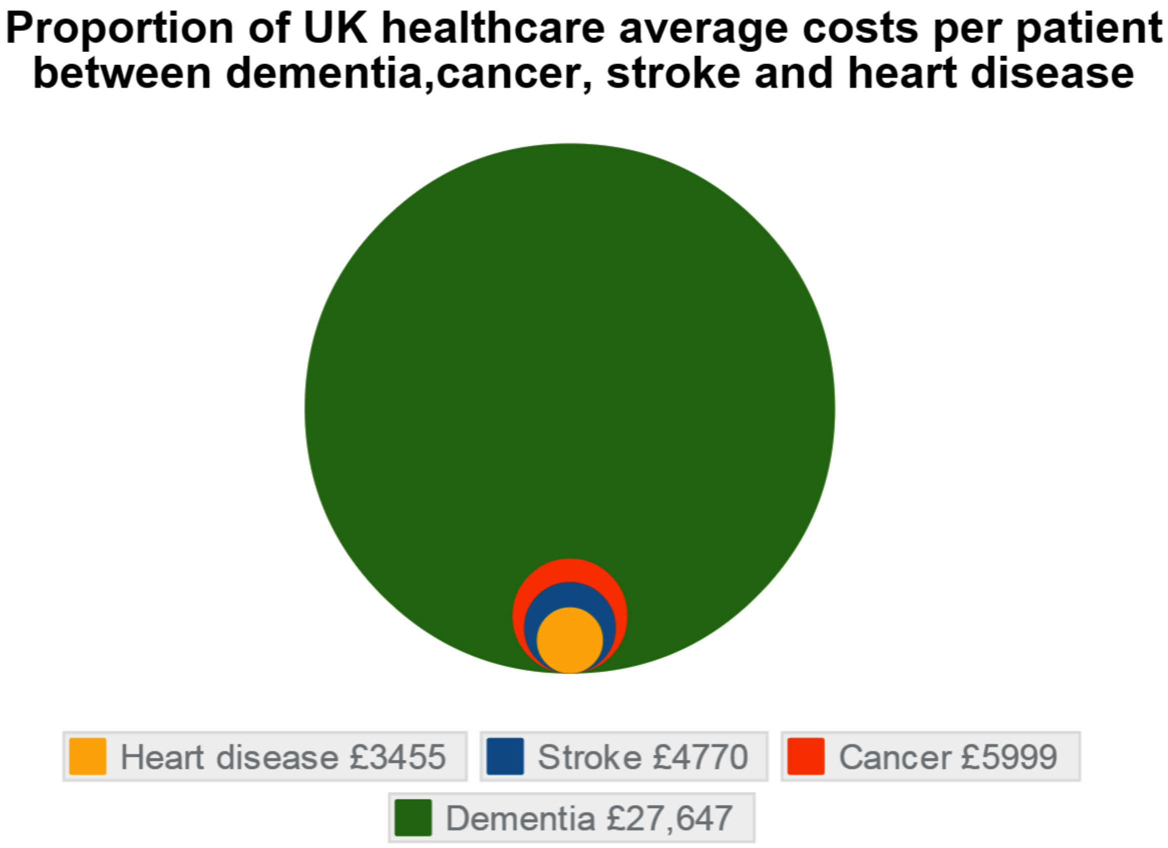
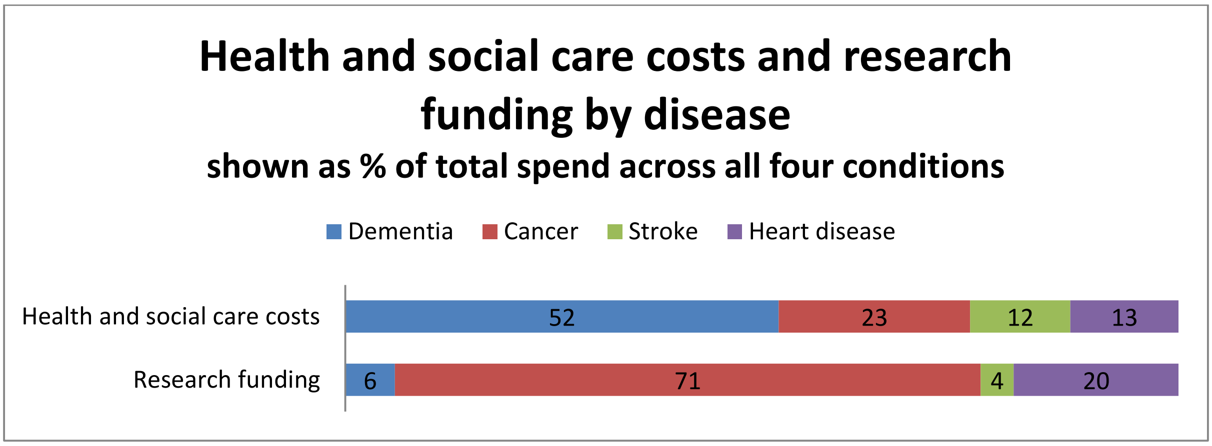


**Figure 15, Health and social care costs and research funding by disease**



# Section 4. Younger people with dementia

## Summary of younger people with dementia

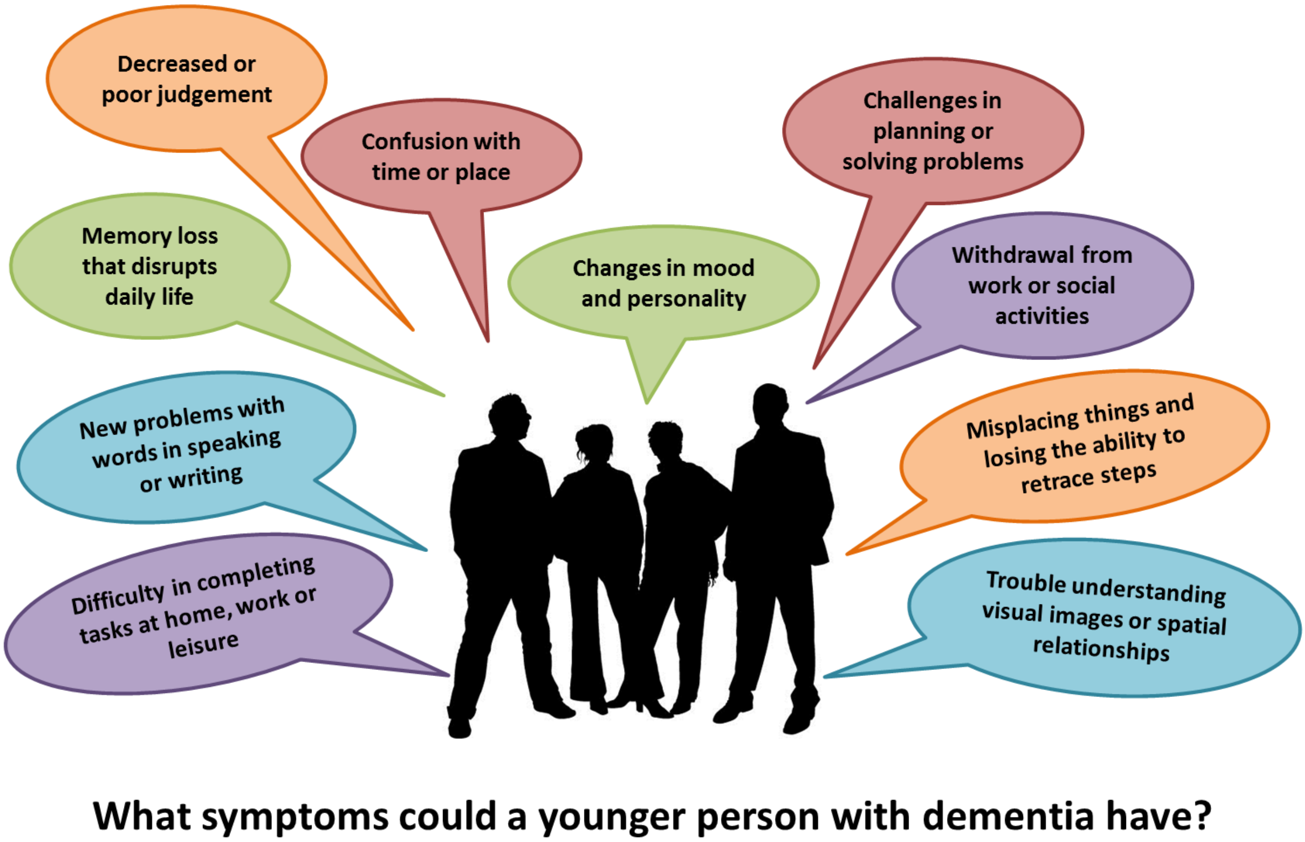
- Younger people with dementia have specific needs that need to be addressed.
- It is estimated that there are 297 people in Central Bedfordshire under the age of 65 with dementia.
- This group is more likely than older people with dementia to be male and from a wider range of ethnic backgrounds.
- Younger people with dementia are more likely to have a delay in getting a diagnosis, be diagnosed away from a Memory Assessment Service, and not access mainstream services for people with dementia that are typically tailored to people over the age of 65.

The term 'younger people with dementia' has previously been known by several names 'early onset dementia', 'presenile dementia' and 'young onset dementia'. In this report the term 'young onset dementia' will be used as this is currently the most favourable term as it avoids confusion with early diagnosis of dementia.

Young onset dementia is generally defined as when the patient is aged under 65 at the time of onset. Young onset dementia has its own set of challenges, which can include: difficulties reaching a diagnosis, the physical fitness of younger patients and the social impact of a diagnosis including the effect on family members such as children.

Information about people with learning disabilities and dementia, including estimates of the number of people with a learning disability and dementia, are shown in section 2. Generally people who have a learning disability and dementia will be younger, for example one in three people aged 50-59 with Down's syndrome are estimated to have dementia.

Figure 16. Symptoms a younger person with dementia may experience



Source: Adapted from Young Dementia UK [30]

## Estimating the number of younger people with dementia

The number of people affected by young onset dementia is hard to estimate. A recent systematic review by the European Collaboration on Dementia (EuroCoDe)[31] concluded that the prevalence of younger people with dementia differed depending on the subtype but generally the prevalence increased as age approached 65, this is in line with the prevalence of dementia in people aged over 65: as age increases the prevalence also increases.

---

[30] http://www.youngdementiauk.org/signs-symptoms

[31] Estimating the burden of early onset dementia; systematic review of disease prevalence. *European Journal of Neurology.* Lambert MA et al. April 2014. 21(4):563-9.

The review highlighted a range of methodological challenges linked to estimating the prevalence of younger people with dementia, including:

- Often studies and reviews are not specific to the subtype of dementia, the results reported may include several subtypes which may not be a representative case mix of the wider population.
- There are a relatively small number of cases of younger people with dementia and even smaller numbers being involved in research – this may affect the generalisability of results.
- Some studies rely on registers which would only capture those accessing services due to their dementia, registry data also rely on being correctly coded.
- The prevalence rates appear to increase with age yet some studies did not breakdown the age bands between 30 and 64, depending on the age mix of participants in the study this could lead to an over or under estimation of the number of people with dementia.

> **'The younger the onset of dementia, the more likely it is that the patient has a genetic or metabolic disease'** [32]

## Estimating the incidence of dementia in younger people

Locally, the incidence of younger people diagnosed with dementia via Memory Assessment Services is known. However, this method does not include younger people diagnosed with dementia via other services, and therefore this will be an underestimate of the true incidence.

Between April 2014 and March 2015 there were nine people in Central Bedfordshire diagnosed with dementia under the age of 65, this included diagnoses for Dementia in Alzheimer's with early onset, Frontotemporal dementia and lewy Body Dementia.

---

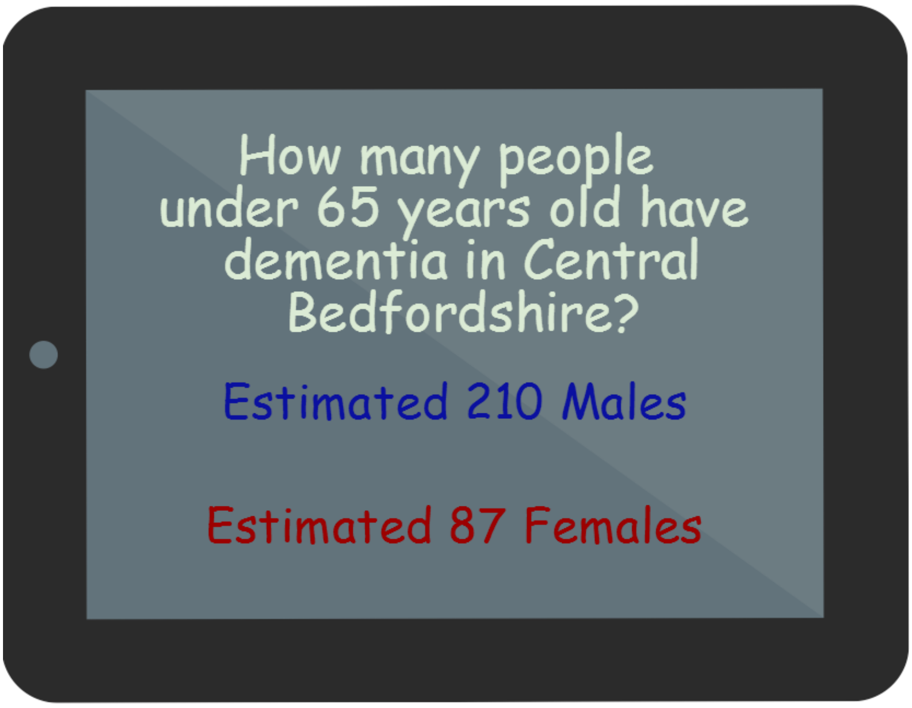
[32] The diagnosis of young-onset dementia. *Lancet Neurology.* Rossor MN et al. 2010;9(8):793-806.

## Estimating the prevalence of dementia in younger people

In the Alzheimer's Society 'Dementia Update' 2014 report, the authors acknowledge that in their original 2007 report, they probably underestimated the number of younger people with dementia. Overall they state the prevalence of dementia in people aged younger than 65 years at the point of diagnosis rose from 2.2% (in 2007) to 5.2% (in 2014) of all the people with dementia.

In Central Bedfordshire, using the new prevalence rates results in a rise in the estimated number of younger people with dementia from 72 (using 2007 methodology) to 297 people (using the 2014 methodology). Both methodologies are included in appendix 4 for reference to give context to the substantial increase in estimated numbers of younger people with dementia. For the purpose of service planning, the estimates using the 2014 prevalence rates should be used.

**Figure 17. Estimated number of younger people with dementia in Central Bedfordshire**



## Subtypes of dementia commonly observed in younger people with dementia

The case mix of younger people with dementia is different to dementia in over 65s. This is illustrated in Figure 18 and Figure 19. Half of all cases of dementia in the under 65s are attributable to Lewy Body dementia, Fronto-temporal dementia, alcohol related brain impairment, and rarer forms of dementia; the same subtypes account for only 11% of dementia cases in those aged 65 and older. This adds to the challenge of managing patients with young onset dementia as some side effects such as aggression in Lewy body dementia are more common in these sub types. A list of rarer forms of dementia can be found in Appendix 4.

**Particular issues faced by younger people with dementia**

**In general, younger people with dementia are more likely to:**

- be **in work** at the time of diagnosis
- have a partner who still works
- have **dependent children**
- have **ageing parents** who they need to care for
- be more **physically fit** and active
- have heavy **financial commitments**, such as a mortgage
- have a **rarer form** of dementia.

*Source: Alzheimer's Society, Younger people with dementia*

Figure 18 Prevalence of different sub types of dementia in those under 65 years

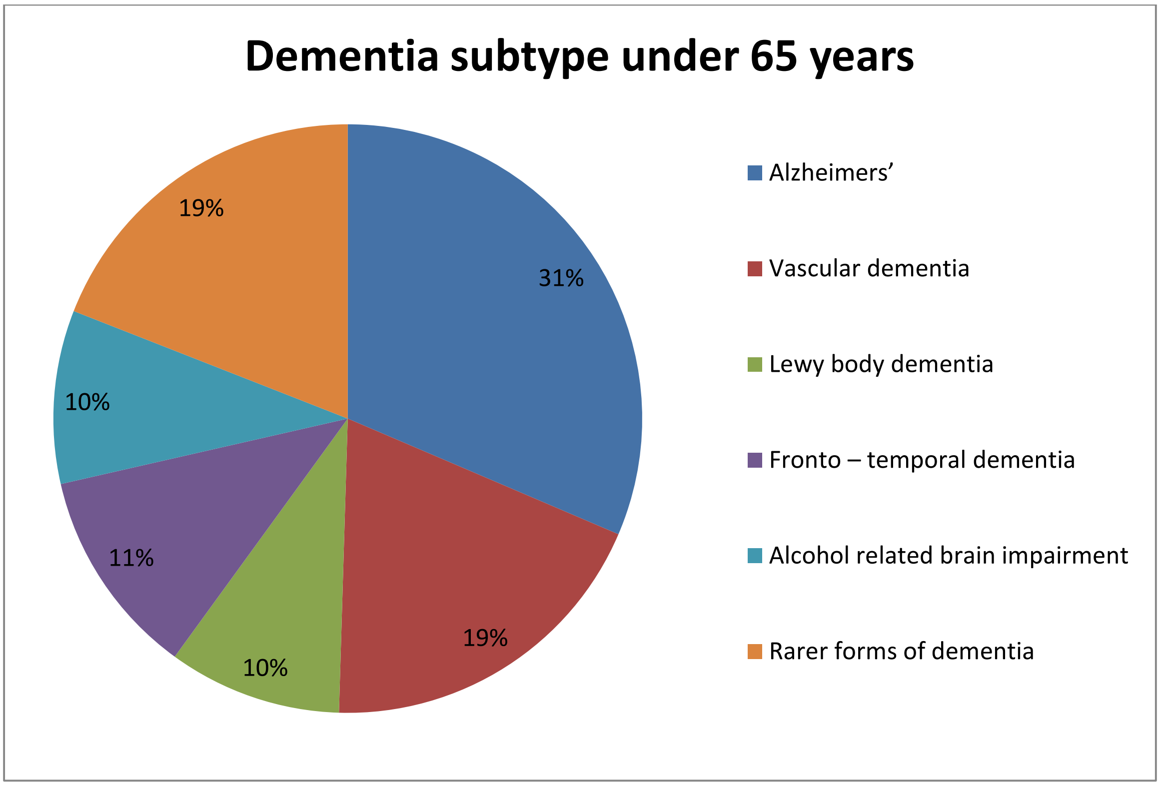
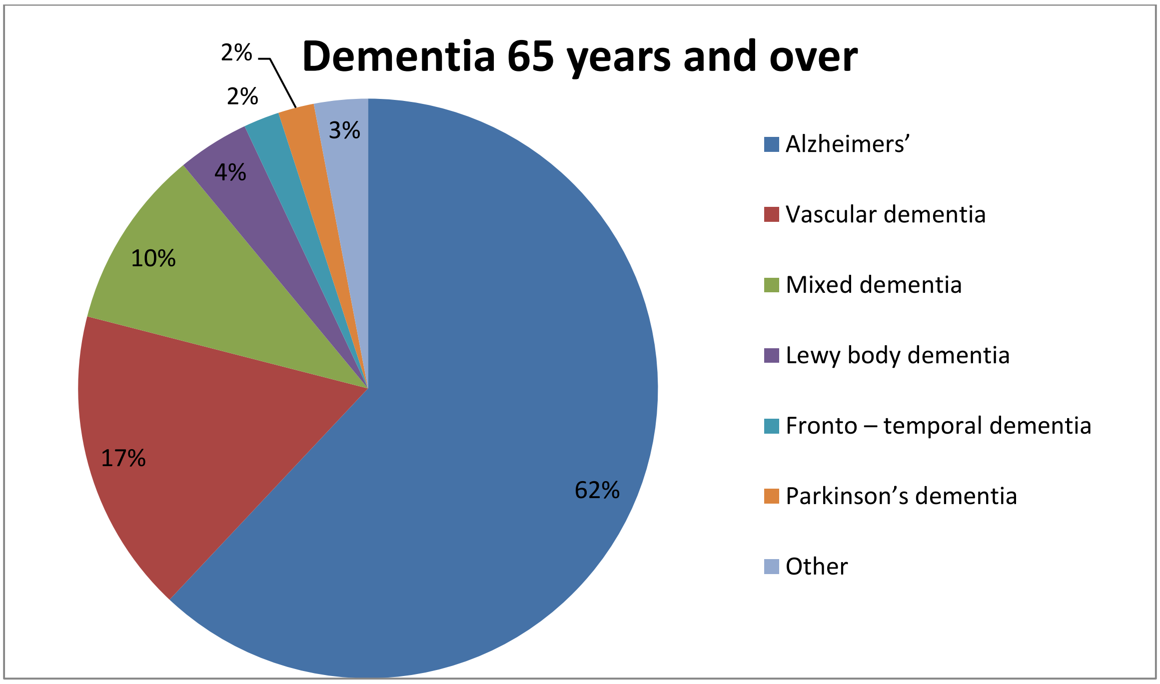


Figure 19 Prevalence of different sub types of dementia in those aged 65 or above



## Risk factors for young onset dementia

People with Down's syndrome and other learning disabilities are prone to developing dementia at a younger age; usually people with Down's syndrome develop Alzheimer's disease (See section 2).

Apart from alcohol related brain impairment, a number of the subtypes of dementia seen in younger patients have a high genetic component. For example in Fronto-temporal dementia which most commonly occurs between the ages of 45 and 65, 40 per cent of cases will have a family history of the disease.

Alcohol related brain impairment is also known as Korsakoff's syndrome, strictly speaking it is not a type of dementia, rather a condition resulting in loss of short term memory. Korsakoff's syndrome is caused by lack of thiamine (vitamin B1). A number of theories have been presented that explain why people who drink excessively are often thiamine deficient[33].

The ethnicity of younger people with dementia is more mixed than older onset dementia: 6% of all people with dementia among black and minority ethnic groups are young onset, compared to only 2% for the UK population as a whole.[34]

*"I was told: 'it's only stress', 'this is depression', 'it's a symptom of menopause', 'everyone slows down a little' etc."* (person diagnosed with vascular dementia at age 52, five years after first seeking medical attention for her symptoms)[35]

*"By the time I was given a diagnosis, I had had several years of failing my job, been forced to retire, become penniless. Had I had a diagnosis (my employer) would have been legally bound to give me a lesser job. What a waste!"* (person was diagnosed with vascular dementia at age 52)

*"We were self employed and had to close down our business because my husband was the only one skilled to operate the machinery. Due to the fast progression of the disease, it was not possible to sub-out the work or deal with a business and still take care of my husband"* (carer of a person diagnosed with Alzheimer's disease age 50)

*Source: Early onset dementia: a national challenge, a future crisis, Alzheimer's association, 2006*

---

[33] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=98
[34] http://www.youngdementiauk.org/young-onset-dementia-facts-figures
[35] Alzheimer's Association: Early onset dementia: a national challenge, a future crisis (2006)

### Services specifically for patients with young onset dementia

Nationally, while awareness of dementia in those aged 65 or older is growing, there is still a lack of specialist support for younger people with dementia. This can make it very difficult for younger people to receive a diagnosis or access adequate support.

This review has not identified any services that specifically target young onset dementia in Central Bedfordshire. Patients can be seen as part of the memory assessment service or neurology teams but there may be barriers to prevent younger patients accessing other services such as support groups.

Attending a support group for dementia can be a daunting experience for someone newly diagnosed, particularly if the group is predominantly comprised of much older people with different needs and interests.

Cambridgeshire and Peterborough Foundation Trust[36] do have a specific service for younger people with dementia; these services are operated as two different zones: north - based in Doddington and south - based in Cambridge.

Nationally there is an active charity 'Young Dementia UK'[37] which have free resources available online including information and support. This group were contacted as part of this needs assessment, they posted information on their social media inviting younger people in Central Bedfordshire to contact the author to discuss their experiences of living with dementia. At the time of writing no responses had been received. Any future responses will be directed to the strategy leads.

## Results of a literature review

As there was a gap in the knowledge base locally, a literature review was conducted. Information was collated into three areas:

1. Issued faced by younger people with dementia
2. The impact on carers of younger people with dementia
3. Recommended solutions for younger people with dementia and their carers.

References for the sources of information discussed below are shown in Appendix 4.

---

[36] http://www.cpft.nhs.uk/help/young-onset-dementia_2.htm

[37] http://www.youngdementiauk.org/

### Issues faced by younger people with dementia – collated results from a literature review

- Difficulty and delays in getting a diagnosis – not something doctors are looking for in younger patients
- Loss of employment and job related benefits and income
- Less time paying into a pension and penalty fees for withdrawing pension early
- One partner may use up all the family savings
- Lack of appropriate medical care, residential care and community services
- Partner that may not have worked previously – this raises a challenge should they go out to work or care for partner. There may be specific implications for those with children.
- Lack of suitable respite and residential care
- Concerns about genetic transmission
- Changing relationships with ones spouse, young children and parents
- Concerns about who will care for older relatives

### Impact on carers of younger people with dementia

A review article was found, which was based on 17 articles published up to October 2008[38], the key points were:

- Caregivers of EOD patients experience high levels of burden and depression, and encounter a variety of psychological problems
- These problems are partly related to their phase in life
- As yet, it is not clear if EOD caregivers experience higher levels of burden than LOD caregivers, because the current studies are methodologically limited

### Recommended improvements for younger people with dementia and their carers.

From the articles reviewed the following tables were created to organise views according to the source of the recommendation.

---

[38] Impact of early onset dementia on caregivers: a review. *International Journal of Geriatric Psychiatry.* Deliane van Vliet et al. 2010 November; 25(11): 1091–1100

**Table 26. Recommended improvements for younger people with dementia - views from people with dementia and their carers**

| Younger people with dementia views | Family members and carers views |
|---|---|
| Provide services that reflect the needs of people with early onset dementia based on their perceptions of their needs | Provide information about early onset dementia and available services |
| Provide support groups specifically for people with early onset dementia | Provide support groups that are specifically intended and convenient for families of people with early onset dementia |
| Provide opportunities for social interaction | Provide in home respite care and supervision |
| Provide help for the peoples family, especially young children and teenagers | Provide transportation |
| Do not assume that the person with dementia is doomed or incapable | |

**Table 27. Recommended improvements for younger people with dementia – views shared across people with dementia and their families**

| Views shared across younger people with dementia and their family members and carers |
|---|
| Increase knowledge about early onset dementia and sensitivity to the feelings of people with the condition among doctors and other health professionals |
| Increase knowledge about early onset dementia among employers including practical ways employers can help younger people with dementia |
| Provide opportunities to work on a volunteer or part time basis |
| Provide adult day programmes that meet the needs of people with early onset dementia |
| Promote information on what financial help is available |

# Section 5. Evidence base for primary prevention of dementia

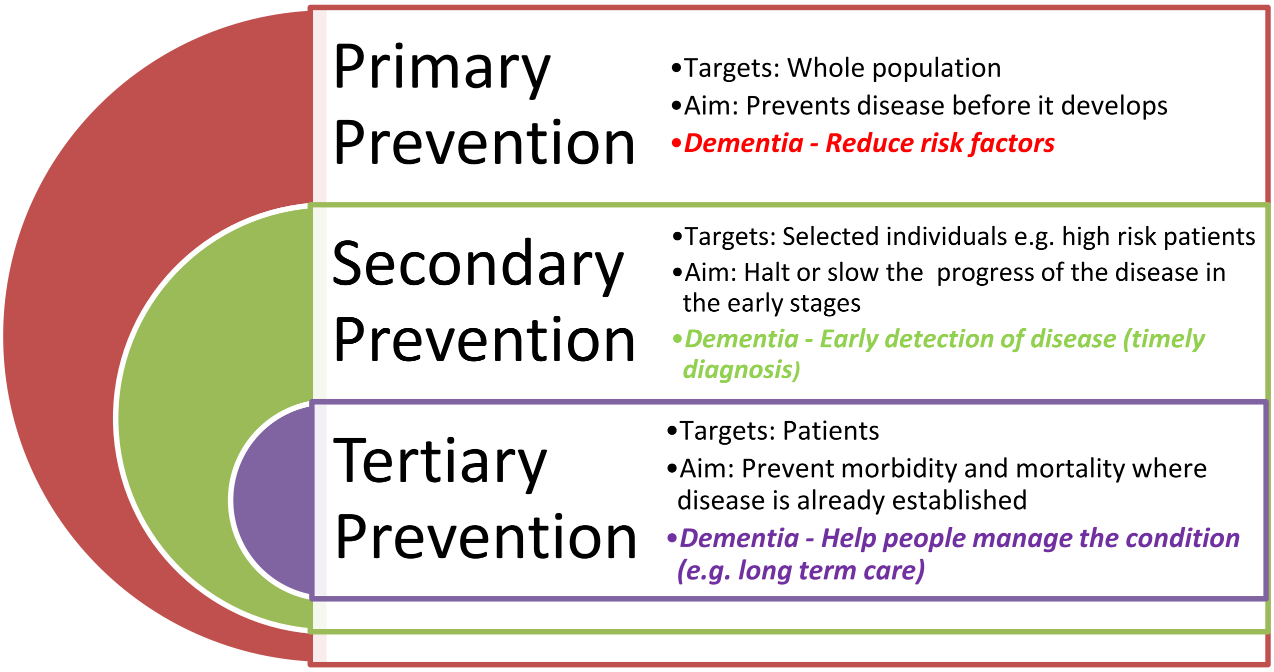
### Summary on primary prevention of dementia

## ‘What’s good for the heart is good for the brain’

### Levels of prevention

Promoting healthy ageing has many components. Types of prevention can be grouped in to primary, second, and tertiary prevention as illustrated in Figure 20. The majority of the national work around dementia to date has focused on secondary and tertiary prevention; this evidence review will focus on strategies for primary prevention of dementia. Secondary and Tertiary prevention of dementia will be touched upon and references to published reports will be provided.

**Figure 20. Levels of prevention**



**Primary Prevention**

- Targets: Whole population
- Aim: Prevents disease before it develops
- *Dementia - Reduce risk factors*

**Secondary Prevention**

- Targets: Selected individuals e.g. high risk patients
- Aim: Halt or slow the progress of the disease in the early stages
- *Dementia - Early detection of disease (timely diagnosis)*

**Tertiary Prevention**

- Targets: Patients
- Aim: Prevent morbidity and mortality where disease is already established
- *Dementia - Help people manage the condition (e.g. long term care)*

## Primary prevention of dementia

This section of the HNA will focus on the evidence base for the primary prevention of dementia. The approach will centre on community and social support.

> ***What is primary prevention?***
>
> *'Taking action to reduce the incidence of disease and health problems within the population, either through universal measures that reduce lifestyle risks and their causes or by targeting high-risk groups.'*

*Source: King's Fund*[39]

Risk factors for primary prevention of dementia can be categorised into three groups: behavioural risk factors (including alcohol, diet, physical activity, and smoking), intermediate risk factors (such as blood pressure, diabetes, obesity, and serum cholesterol), and fixed risk factors for example genetics and family risk. As modifiable risk factors, the behavioural and intermediate risk factors offer the greatest potential for reducing the burden of dementia and are well aligned with key existing public health messages.

In May 2014, the UK Health Forum published a science and policy discussion document called 'Promoting brain health, developing a prevention agenda linking dementia and other non-communicable diseases.' The report was split into a science review, focusing on four behavioural risk factors and four medical risk factors, and a policy review on prevention measures.

Due to the high quality of this recent review which was led by an expert group, this evidence base review will only consider the same risk factors. The search strategy and study selection for the UK Health Forum report was clearly documented; this allowed the same search terms to be used to identify research published since the evidence was reviewed for the UK Health Forum report (August – October 2013).

---

[39] http://www.kingsfund.org.uk/projects/gp-commissioning/ten-priorities-for-commissioners/primary-prevention

## Literature review methodology

To ensure the evidence base was up to date, each risk factor was assessed separately; the original search terms were used to search PubMed from 1st August 2013 to the end of September 2014, search terms are shown in appendix 5. Following screening of the titles and abstracts, relevant articles were identified and the full text was reviewed; inclusion criteria were then applied. Figure 21 and Figure 23 show the number of studies for each risk factor at each stage of the updated review. If a study met the inclusion criteria, three questions were assessed:

- Is the new systematic review based on different studies to the systematic reviews already included in the UK Health Forum report?
- Are any new ideas presented?
- Does the evidence support or contradict the summary evidence provided in the UK Health Forum report?

The summary findings from the UK Health Forum report and this update are included in the sections that follow.

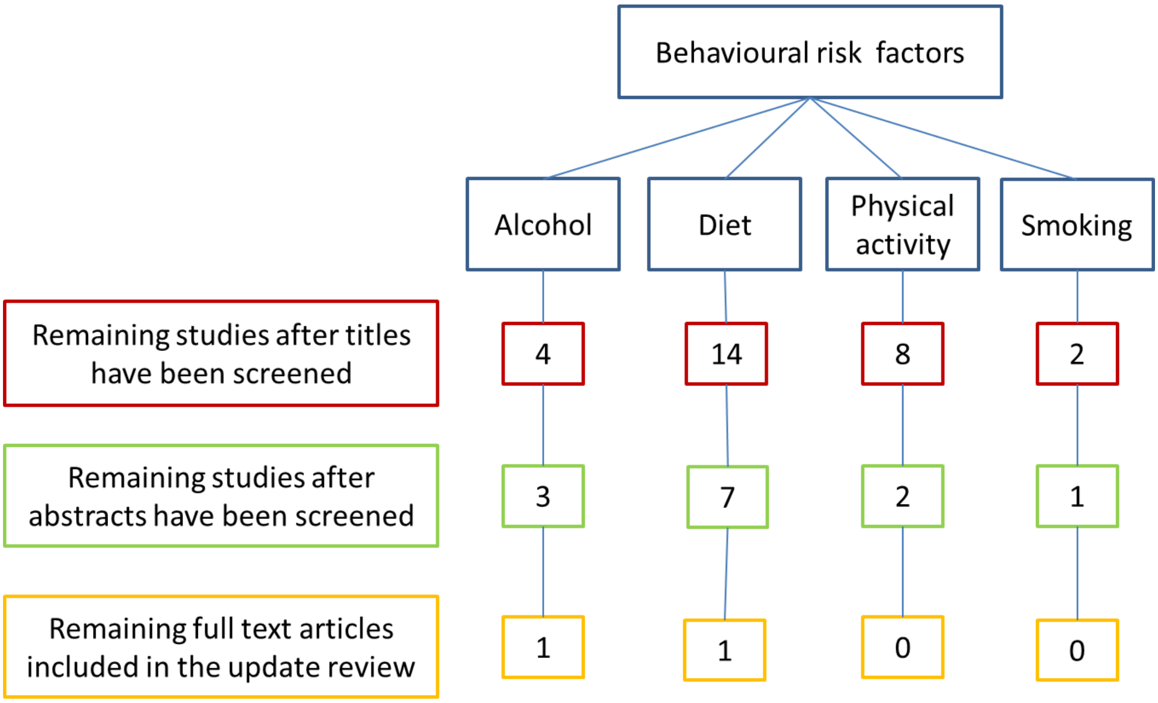
## Behavioural risk factors

Table 28 summaries the relationship between the behavioural risk factors and the effect on dementia. Each risk factor will be discussed in detail in the sections that follow.

**Table 28. The effect on dementia of key behavioural risk factors**

| | **Systematic reviews identified in UK Health Forum report** | **Effect on dementia** |
|---|---|---|
| **Alcohol** | 3 | U shaped relationship |
| **Diet** | 4 | Healthy diet may be protective |
| **Physical Activity** | 5 | Protective |
| **Smoking** | 4 | Increases risk |

**Figure 21. Flowchart showing the number of articles included at each stage of the updated review**



## a) Alcohol

What the UK Health Forum report said:

*‘The evidence does not consistently show that heavy alcohol consumption (compared to no alcohol consumption) is associated with excess risk of dementia. However, some evidence points to a U- or J-shaped relationship between consumption and risk of dementia. The clinical evidence also suggests that heavy alcohol consumption is likely to be linked to dementia. As with cardiovascular disease, it might therefore seem most appropriate to assume a U-shaped relationship with dementia.*

*As with cardiovascular disease, it could be sensible to put the emphasis on discouraging heavy consumption of alcohol, with less emphasis being given to the possible benefits of small or moderate consumption. It could also be helpful to use the term ‘alcohol-related brain damage’ for which there is a stronger body of evidence showing the dangers of excessive alcohol consumption, throughout the life course.*

*Policies that discourage harmful excessive alcohol consumption could be supported as measures to reduce the incidence of alcohol-related brain damage, including alcohol-related dementia.’*

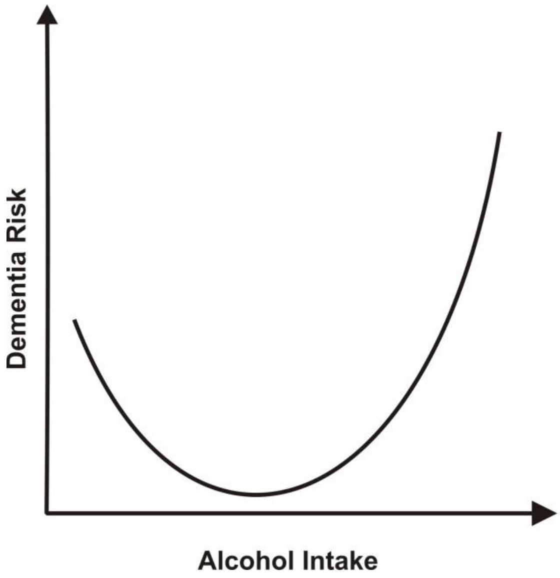
Updates since the UK Health Forum report:

One systematic review met the inclusion criteria, this review included 12 cross sectional and 18 cohort studies from 1996 to 2012. The sample size ranged from 314 – 30,499 covering populations in Europe, US, Australia, and China. The results were presented as summary results for the 12 cross sectional studies and summary results for the 18 cohort studies. As causality cannot be determined in cross sectional studies the results from the cohort studies are of more interest. The hypothesis of the study was 'moderate alcohol consumption is protective against cognitive function, higher rate of cognitive decline and dementia.' 8/18 studies found a 'U' or 'J' or linear relationship between alcohol consumption and dementia in the hypothesized direction, 2/18 found this for some outcomes, 4/18 for a subgroup of the population, one study found that alcohol was generally linked to poor cognitive outcomes and 3/18 found no significant associations. Overall the systematic review reported that alcohol in general was found to have a 'U' shaped association with the risk of decline.

**Summary on alcohol and risk of dementia**

The current evidence base suggests that the relationship between alcohol intake and dementia is similar to the relationship between alcohol intake and cardiovascular disease. This is described as a U shape relationship where individuals not drinking have a higher risk of dementia than those who are moderate drinkers; however the risk is highest for those who drink excessively. This relationship is demonstrated in Figure 22.

**Figure 22. The relationship between alcohol intake and dementia risk**



## b) Diet

What the UK Health Forum report said:

*‘There is some evidence that diet, particularly regular consumption of vegetables, can reduce the risk of dementia. In addition, diet is important in the development of other risk factors (e.g. diabetes and hypertension) for which the evidence is more established. Measures to promote healthy eating could be supported as part of a strategy to reduce the incidence of dementia.*

*However, one should be careful about over-interpreting these early studies (e.g. putting too much emphasis on a Mediterranean diet or on vegetables) as only a limited number of dietary factors and patterns have been studied. The broad message (and direction for policy) could be that a healthy diet may offer protection against dementia.’*

Updates since the UK Health Forum report:

One systematic review met the inclusion criteria however the studies that made up the systematic review had already been reported in one of the included systematic reviews, therefore no new evidence was presented.

### Summary on diet and risk of dementia

The current evidence base suggests that the relationship between diet and dementia is similar to the relationship between diet and other non-communicable diseases. As such, a healthy balanced diet should be promoted to individuals at all life course stages.

### c) Physical activity

What the UK Health Forum report said:

*‘There is consistent evidence to suggest that regular physical activity can prevent or delay the onset of dementia, including both Alzheimer’s dementia and vascular dementia. While the amount of physical activity that will yield benefits is uncertain, it would seem most prudent to continue to recommend the standard doses of physical activity for good health (i.e. in the UK, 150 minutes per week of moderate, or 75 minutes of vigorous physical activity, or combinations of both).*

*Given the very low levels of habitual physical activity in the UK (Townsend et al, 2012), increasing physical activity among adults appears to offer significant potential as a strategy to delay or prevent the onset of dementia. Policies that promote physical activity should be supported as measures to reduce the incidence of dementia.’*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria. However a study identified during the search for alcohol also covered physical activity. In this systematic review, 24 cohort studies and 4 cross sectional studies were examined for the relationship between physical activity and dementia. All but one cohort study found an association in the hypothesised direction that physical activity could be a protective factor for dementia.

**Summary on physical activity and risk of dementia**

The current evidence base suggests that the relationship between physical activity and dementia is similar to the relationship between physical activity and other non-communicable diseases as such increasing physical activity levels should be promoted to individuals at all life course stages. Emphasis should be placed on getting those who are inactive to gradually become more active.

### d) Smoking

What the UK Health Forum report said:

*'There is reasonable evidence that smoking is associated with dementia. Measures that discourage smoking could be supported as part of a strategy to reduce the incidence of dementia.'*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria. However a study identified during the search for alcohol also covered smoking. In this systematic review 29 cohort studies and 7 cross sectional studies were examined for the relationship between smoking and dementia. Some studies pointed to the difficulty of establishing an association between smoking and dementia as many smokers did not live to older ages where dementia is more prevalent. Overall, 20/29 of the cohort studies found an association in the hypothesized direction that smoking was a risk factor for dementia while eight found no association and only one found an association in the opposite direction to the hypothesis. Of the seven cross sectional studies four found an association in the hypothesised direction and three did not detect an association.

**Summary on smoking and risk of dementia**

Smoking is a well-known risk factor for stroke and other chronic diseases, the evidence base for the risk between smoking and dementia is growing. As such, activities to support people to quit their smoking habits should be promoted as good for the brain as well as the heart.

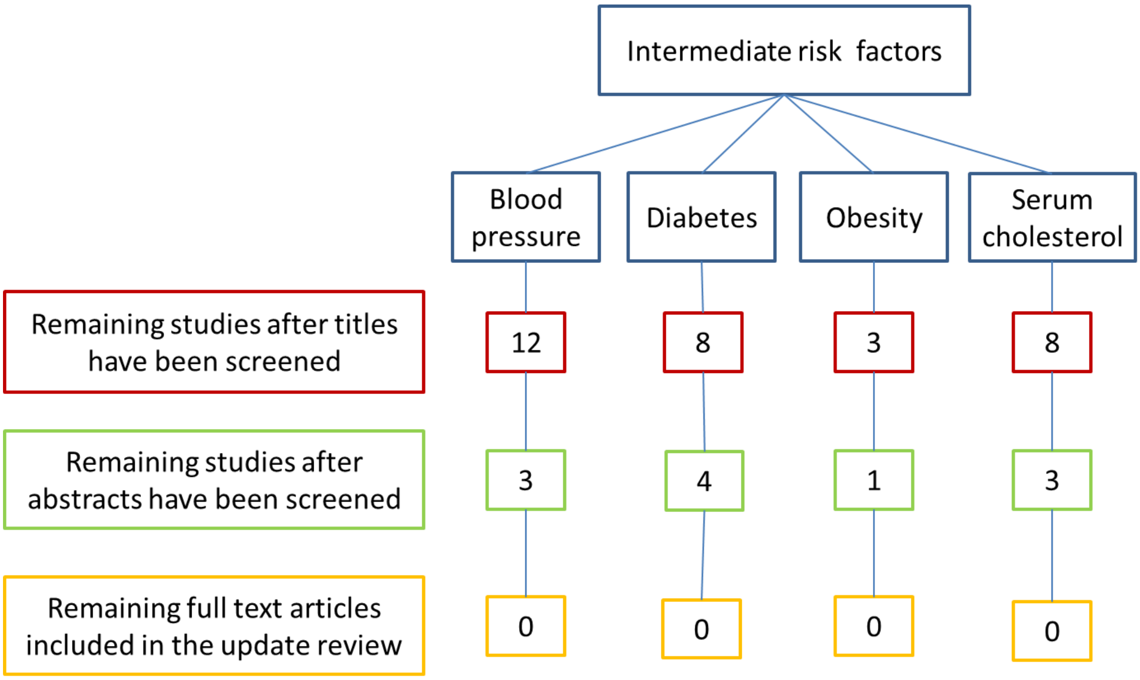
## Intermediate risk factors

Table 29 summaries the relationship between the intermediate risk factors and the effect on dementia. Each risk factor will be discussed in detail in the sections that follow. A flow chart illustrating the literature review is shown in Figure 23.

**Table 29. The relationship between intermediate risk factors and the effect on dementia**

| | Systematic reviews identified in UK Health Forum report | Effect on dementia |
|---|---|---|
| **Blood pressure** | 7 | Midlife high BP likely increases risk<br>Later Life association unclear |
| **Diabetes** | 5 | Increases risk in both mid and late life |
| **Obesity** | 6 | Mid-life likely increases risk<br>Later life association unclear |
| **Serum cholesterol** | 5 | Mid-life raised total cholesterol likely increases risk<br>Later life association unclear |

**Figure 23. Flowchart showing the number of articles included at each stage of the updated review**



## a) Blood Pressure

What the UK Health Forum report said:

*'The evidence is tending to suggest that reducing raised blood pressure, particularly during mid-life, may help prevent dementia. However, it should be noted that the evidence from trials is not yet sufficient to recommend the use of anti-hypertensives to prevent dementia.*

*Policies and strategies (both behavioural and pharmacological) that reduce hypertension may reduce the incidence of dementia. Mid-life may be a more important period to target, but benefits may also occur from treatment in older age.'*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria when full text articles were reviewed.

**Summary on blood pressure and risk of dementia**

High blood pressure should be reduced to benefit brain health as well as physical health. While it may be important to target activities at those in mid-life to prevent the onset of dementia, strategies should also encourage older adults to take steps to reducing their blood pressure to benefit their overall health.

### b) Diabetes

What the UK Health Forum report said:

*‘Diabetes is associated with raised risk of dementia (both vascular and Alzheimer’s). Aggressive treatment of diabetes (or its vascular complications) may seem like an attractive strategy to reduce risk in those with diabetes, but at present there is no evidence that such treatment reduces the risk of dementia. Strategies and interventions that aim to prevent diabetes (such as promoting physical activity and improved nutrition) could reduce the incidence of diabetes and so could contribute to reducing the future burden of dementia.*

*Dementia due to diabetes is likely to become a greater issue, both because of the rising prevalence of diabetes in the UK and because people with diabetes are increasingly living to an older age.’*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria when full text articles were reviewed.

**Summary on diabetes and risk of dementia**

Diabetes is an established risk factor for dementia. The link between diabetes and dementia is likely to become more of a challenge as people with diabetes live longer – managing patients with comorbidities and dementia is a key area to focus on and will be discussed in section 7.

c) Obesity

What the UK Health Forum report said:

*‘Mid-life obesity is consistently associated with raised risk of dementia (both vascular and Alzheimer’s). Strategies and interventions that aim to prevent obesity in middle age (such as promoting physical activity and improved nutrition) could reduce the incidence of dementia.*

*Weight loss in people who are obese may have a role in prevention of obesity. However, sustained weight loss is difficult to achieve, and the effects of reversing weight gain on dementia risk have not been explored. This emphasises the importance of preventive strategies.*

*The independent effect of obesity may suggest that the excess risk associated with obesity cannot readily be managed by medical treatment (anti-hypertensive agents and anti-diabetic agents), which emphasises the importance of specific measures to prevent weight gain or to reduce body weight.’*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria when full text articles were reviewed. However in April 2015, a large retrospective cohort study was published that contradicted previous research. This research suggests that people who are overweight or obese have a lower risk of dementia compared with healthy weight people. Additionally the research suggests that underweight people were at the highest risk of dementia. Overall, the researchers concluded that the reasons for their findings and subsequent public health consequences of their findings would require further investigation. As such the public health advice should remain for people to be encouraged and supported to maintain a healthy weight. A review of this article by NHS Behind the headlines is included in appendix 5.

**Summary on obesity and risk of dementia**

Obesity should be reduced to benefit brain health as well as physical health. While it may be important to target activities at those in mid-life to prevent the onset of dementia, strategies should also encourage older adults to take steps to maintain a healthy weight to benefit their overall health. Research in this area should be reviewed frequently to ensure current policy is based on the best available evidence.

### d) Serum Cholesterol

What the UK Health Forum report said:

*‘Mid-life cholesterol appears to be an important risk factor for later development of dementia. Late-life cholesterol does not appear to be important in the development of dementia. There is very limited evidence, to date, to suggest that lipid-lowering therapy, in the form of statins, may prevent or delay the onset of dementia. However, such research has focused on older people, and the efficacy of statin therapy, particularly in mid-life, for the prevention of dementia has not been adequately tested.*

*Policies to lower lipid levels in mid-life, either behavioural or pharmacological, may reduce the incidence of dementia in later life.’*

Updates since the UK Health Forum report:

Using the search terms applied in the UK Health Forum report did not identify any further studies that met the inclusion criteria when full text articles were reviewed. A number of studies were found that focused on the association of statin use with the risk of dementia both in the short and longer term. Overall more research is needed in this area.

**Summary on serum cholesterol and risk of dementia**

The link between raised total cholesterol and increased risk of dementia in mid-life is established. Strategies should aim to reduce a person’s total cholesterol in mid-life to prevent the onset of dementia. However, older adults should also be encouraged to take steps to reducing their total cholesterol to benefit their overall health.

## Additional protective risk factors

### Depression

Of the psychological risk factors for dementia, depression is the most frequently cited and evidence based risk factor. Three explanations have been proposed to explain the link between depression and dementia; these are shown in Table 30.

**Table 30. Possible mechanisms explaining the association between depression and dementia**

| Proposed mechanism | |
|---|---|
| Depression is the result of early cognitive deficits. | Depressive symptoms may arise as a result of increasing awareness of diminishing cognitive function or in response to a diagnosis of dementia. This relationship could also arise from biological mechanisms (e.g. limbic and cortical atrophy, white matter lesions), which are common in both dementia and late onset depression. |
| Depression is a prodromal syndrome of dementia. | Depression may represent a predementia syndrome, which marks the beginning of an underlying disease process. The appearance of depression may then be driven by changes in brain structure and function that are part of the neuropathological course of dementia. In this case, symptoms of depression should appear just before or together with the onset of dementia. |
| Depression is an independent risk factor for dementia. | Depression preceding dementia may be a causal risk factor for its onset. Several biological mechanisms have been proposed for such a relationship. These include depression related predisposition to vascular disease, release of pro-inflammatory cytokines and chemokines, increased glucocorticoid production, amyloid deposition and neurofibrillary formation, all of which can lead to hippocampal injury. |

*Source: http://www.alz.co.uk/research/WorldAlzheimerReport2014.pdf*

## Educational attainment

Higher levels of educational attainment have been shown to be protective against dementia, several mechanisms have been proposed to explain this relationship, these are discussed in Table 31.

**Table 31. Possible methods explaining the association between educational attainment and dementia**

| Proposed mechanism | |
|---|---|
| Brain reserve: | A larger brain volume may be related to a delay in onset of clinical symptoms despite the presence of neuropathology, due to physical resources which can compensate. This may take the form of a greater number of neurons or synapses. People with larger brains may be more likely to stay in education for longer. |
| Cognitive reserve: | It may be brain function, rather than size, which helps protect against dementia. People with higher levels of education may develop a greater complexity and/or efficiency of neural networks, meaning as dementia-related pathology occurs in the brain, they can actively compensate by drawing on a greater reserve of cognitive processing approaches. |
| The ‘use it or lose it’ hypothesis: | Lifelong cognitive activity may be necessary to help prevent cognitive decline, and those with higher education may be more highly motivated to pursue intellectual stimulation throughout the life course. |
| The ‘brain-battering’ hypothesis: | People with higher educational attainment are likely to have a higher socio-economic status, to enjoy a healthier and more advantaged lifestyle, and to have greater access to superior healthcare. They may be exposed to fewer toxins, and their brains may be protected from insults such as cerebral infarct that contribute to dementia. |
| Ascertainment bias: | Some authors have suggested that individuals with lower educational attainment may simply perform more poorly on cognitive tests, and the apparent relationship between education and dementia would be an artefact of measurement. |
| Education is a proxy for third variables: | Education may be a marker for innate intelligence, which could be related genetically or environmentally to other protective factors. |

*Source:* *http://www.alz.co.uk/research/WorldAlzheimerReport2014.pdf*

## Summary of primary prevention for dementia

**Update to the evidence base for protective risk factors**

After this evidence based review was complete, a comprehensive review was published by Alzheimer's Disease International 'World Alzheimer Report 2014, Dementia and risk reduction, an analysis of protective and modifiable factors.' This high quality review included new meta-analyses and went into more detail than the review conducted as part of this health needs assessment.

The full report can be viewed online:
http://www.alz.co.uk/research/world-report-2014

Overall the conclusions presented in this health needs assessment reflect the conclusions of this more in depth report.

Key points regarding protective risk factors:

- What is good for the heart is good for the brain.
- Evidence for the prevention of dementia is based at a population level – individual lifestyle changes may not prevent dementia at an individual level.
- There are key stages within development (i.e. childhood, adulthood and older age) where the impact of ageing on brain health can be influenced.
- The signs and symptoms of dementia in later life may be buffered by regularly taking part in mentally stimulating activities, higher educational attainment, increased physical activity, and social interaction.
- While strategies should aim to prevent risk factors for dementia older adults should still be encouraged to adopt healthier behaviours.

These key points can be mapped against the three broad life-stages of the Public Health England strategy: Starting well, living well and ageing well as shown in Table 32.

**Table 32. Life stage, focus for preventing dementia and examples of how to achieve these aims**

| Life stage | Focus for preventing dementia | Examples of how to achieve aim |
|---|---|---|
| Starting well | Build cognitive reserve, imprint healthy habits | • Reduce the prevalence of low birth weight babies<br>• Promote breast feeding<br>• Improve childhood nutrition (improves cognitive function) |
| Living well | Maintain healthy habits, 'active body, active mind' | • Raise awareness about how prevention can help reduce the risk of dementia and other conditions<br>• Make it easier for people to make changes to their behaviours e.g. stop smoking<br>• Promote healthy workplaces<br>• Reduce psychological distress – early interventions and support for those affected |
| Ageing well | Older age, keep active body and active mind to buffer potential effects of dementia | • Raise awareness about the importance of seeking help when symptoms first arise<br>• Promote services such as NHS health checks |

## Section 6. Secondary prevention of dementia

### Summary of secondary prevention of dementia

There is a growing body of high quality evidence to promote a timely diagnosis of dementia; national resources are available to support local initiatives to increase the diagnosis rate.

Cognitive stimulation and peer support are also well evidenced and recommended to all people with dementia regardless of medication usage.

This section of the health needs assessment will focus on the evidence base for the secondary prevention of dementia.

### Secondary Prevention of dementia

***What is secondary prevention?***

*'Systematically detecting the early stages of disease and intervening before full symptoms develop – for example, prescribing statins to reduce cholesterol and taking measures to reduce high blood pressure.'*

*Source: King's Fund*[40]

Secondary prevention of dementia is concerned with targeting people who are more likely to be at risk of developing the illness. By identifying the illness in the earlier stages, the impact of the illness on the person with dementia and their families may be lessened. Three areas will be considered in this section of the evidence review: timely diagnosis, cognitive stimulation activities, and peer support.

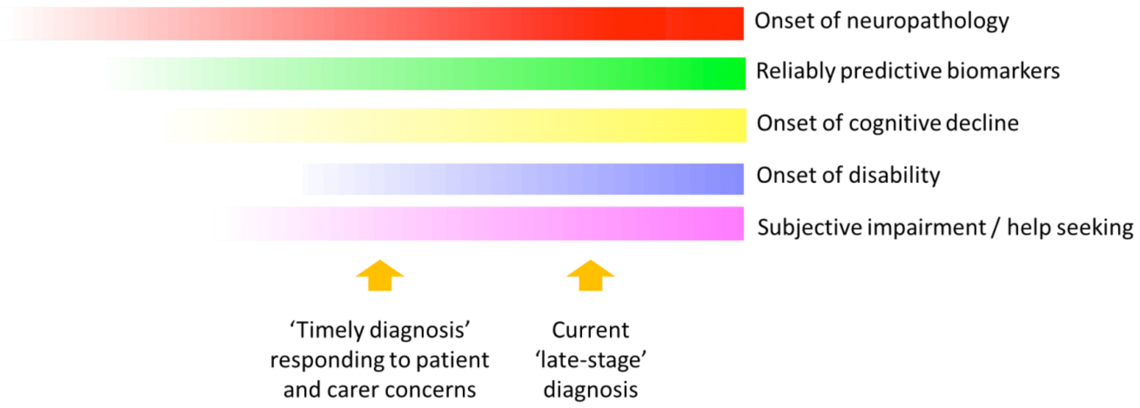
---

[40] http://www.kingsfund.org.uk/projects/gp-commissioning/ten-priorities-for-commissioners/secondary-prevention

## Timely diagnosis of dementia

A timely diagnosis of dementia often gets confused with an early diagnosis of dementia. The more appropriate terminology is a timely diagnosis. The natural history of the disease progression may take many decades to manifest into clinically detectable symptoms. Currently, the majority of people with dementia are diagnosed many years after they and their families first become aware of the signs and symptoms. A biomarker is a biological feature that can be used to measure the presence or progress of disease. A timely diagnosis of dementia aims to shift the diagnosis point to an earlier point in time. This is illustrated in Figure 24.

**Figure 24. Timeline of disease progression**



Dementia diagnosis rates in England are unreasonable; in 2011/12 the national diagnosis rate was only 45%[41] meaning less than half of the people with dementia received a diagnosis. This is comparable with other high income countries where only 20-50% of dementia cases are recognised and documented in primary care[42].

This under diagnosis has been recognised as a national priority with the Prime Minister's Challenge[1] on Dementia and NHS England agreeing a target of achieving a 67% diagnosis rate with appropriate diagnostic support by March 2015. International experience would suggest that diagnosis rates of between 60 and 80 per cent are achievable[43,44]. The most recent available data for England is shown in Table 33. This shows that over the past year there has been a significant increase in average dementia diagnosis rate in England. However, this is still below the target of

---

[41] http://goo.gl/GCqOPP
[42] http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf
[43] The Dementia Prevalence Calculator Project Steering Group, and Project Report (2012) concluded, and recommended that an upper threshold for maximum diagnosis rate should be in the range of 70-80%. This is also reflected in the World Alzheimer Report (2009).
[44] http://goo.gl/lb30zt

67% of all people with dementia receiving a diagnosis. Three key factors contributing to a low diagnosis rate are shown in Figure 25. Tackling each of these areas, should result in more people feeling that they can seek help and gain a dementia diagnosis.

**Figure 25. Three key factors contributing to low dementia diagnosis rates**

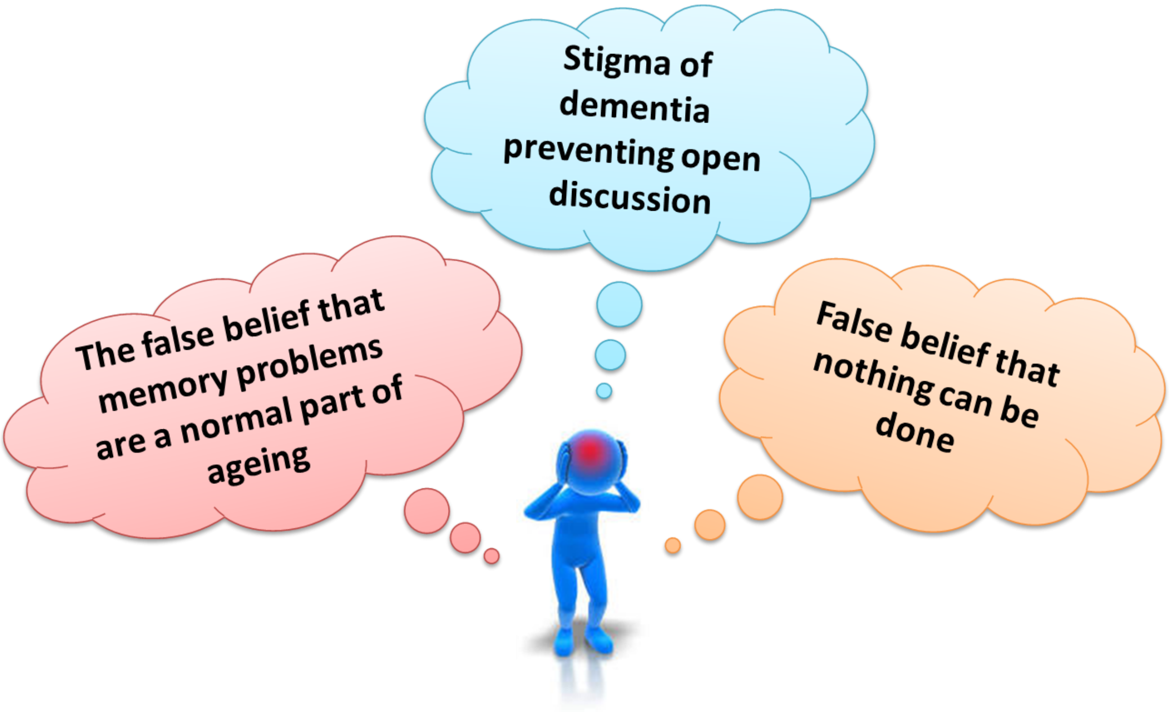


**Table 33. Dementia diagnosis rate in England**

| Year | National diagnosis rate (England) |
|---|---|
| 2011/2012 | 45% |
| 2012/2013 | 47.47% |
| 2013/2014 | 51.75% |
| 2014/2015 | 60.78% |

*Source: Dementia Prevalence Calculator*

> ***'You often feel like you are going mad, no one believing you but then you get a diagnosis and you are not mad, whatever mad is.'***
>
> Female with dementia

## Benefits of a timely diagnosis

There are many benefits of a timely diagnosis of dementia; this includes benefits to the person with dementia, their family, friends and carers, and local services.

### Benefits of a timely diagnosis

- A diagnosis should not be seen as an endpoint; instead a diagnosis of dementia can act as a gateway to access services and support.
- A diagnosis can reduce uncertainties and anxiety as the person with dementia and their carers are usually aware something is wrong but may be afraid of finding out the issue - Most patients wait an average of three years from the onset of symptoms to receiving a diagnosis.
- A timely diagnosis enables the person with dementia and their family carers to make informed choices about their care, both in the short, medium, and longer term. For example facilitating a person with dementia to stay in their home for longer.
- A timely diagnosis can promote specialist dementia services which provide support to the family, thereby reducing the likelihood of the person with dementia having a crisis, admission to hospital, and residential care. This would result is reduced costs to local services.

Overall timely diagnosis leads to a better quality of life for the person with dementia, their family, and carers; allowing services to better manage demand.

More details about the benefits of a timely diagnosis can be found in '*The benefits of early diagnosis and intervention.'* World Alzheimer Report 2011[45].

---

[45] http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

> ***‘He was thrilled to bits, thank goodness for that he said, he thought he had a brain tumour’***
>
> Female carer taking about her husband’s response to being giving a diagnosis of dementia

While there are many benefits to receiving a diagnosis of dementia, finding out you or a person you care for has dementia can be life changing. The impact of receiving a diagnosis of dementia can be made easier by using the eight elements of good practice, as shown in Table 34.

**Table 34. The key elements to making the diagnosis well**

| Key elements to making the diagnosis well |
|---|
| 1. Preparing for disclosure |
| 2. Integrating family members |
| 3. Exploring the patient’s perspective |
| 4. Disclosing the diagnosis |
| 5. Responding to patient’s reactions |
| 6. Focusing on quality of life and wellbeing |
| 7. Planning for the future |
| 8. Communicating effectively |

*Source: Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'*[46]

> ***‘It’s devastating to hear the diagnosis, that word dementia, it’s devastating for them, for you.’***
>
> Female carer talking about her husband’s diagnosis

---

[46] BMC Health Services Research 2008, 8:95, available online http://www.biomedcentral.com/content/pdf/1472-6963-8-95.pdf

> ***‘It’s taken her time and adjustment to come to terms with the diagnosis’***
>
> Daughter talking about her mother with dementia

## Local diagnosis rates

Local dementia diagnosis rates are presented in section 2.

## Strategies to improve dementia diagnosis rates

> A key component of improving the dementia diagnosis rate is to enable people to seek help at an earlier stage when they begin to notice signs and symptoms

Several key resources have been published that suggest examples and ways to increase the dementia diagnosis rate; these key publications are listed in Table 35. Figure 26 shows the 10 key steps to improve diagnosis and diagnosis pathways from ‘*A resource pack for commissioners and general practices*’[47]; the full document includes actions, resources, and examples for each step.  This resource has been published by Dementia Pathways, a specialist knowledge portal for dementia in England.

---

[47] http://dementiapartnerships.com/wp-content/uploads/sites/2/DPC-resource-pack-v3.pdf

Table 35. Key NICE publications to support timely dementia diagnosis

| Publication | Website link to publication |
|---|---|
| NICE cost impact and commissioning assessment quality standard for dementia | http://www.nice.org.uk/media/7EF/1A/DementiaCostingCommissioningAssessment.pdf |
| CMG48 NICE support for commissioners of dementia care | http://publications.nice.org.uk/support-for-commissioning-dementia-care-cmg48 |
| QS1 Quality Standard for dementia | http://guidance.nice.org.uk/QS1 |
| QS30 Quality standard for supporting people to live well with dementia | http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30 |
| CG42 Dementia: Supporting people with dementia and their carers in health and social care | http://publications.nice.org.uk/dementia-cg42 |

In late 2013, Professor Alistair Burns (National Clinical Director for Dementia in NHS England) visited 17 CCGs that have successfully increased their dementia diagnosis rates to pull together themes for others to learn from. The key themes were:

- The local health and care community has a coherent, focused, and clearly led plan of work to improve dementia care.
- Commissioners and clinical leaders are active and visible in this pursuit, knowledgeable about what works, and proactively delivering a comprehensive strategy and action plan; working relationships are positive, and it appears that values and ambitions are shared.
- Work is proactive, systematic and sustained, rather than reactive and piecemeal.
- Dementia care is being mainstreamed within existing health and care services, rather than being framed as something associated with memory services alone.
- Ambitions to improve diagnosis are being progressed within the wider context of raising awareness about dementia; improving knowledge and skills of health and care staff; understanding the role of primary care in dementia care, including care of patients living in care homes.
- Voluntary and community sector organisations are key partners in the development of strategic plans and as service providers. Investments in this sector are key components of local dementia strategies.

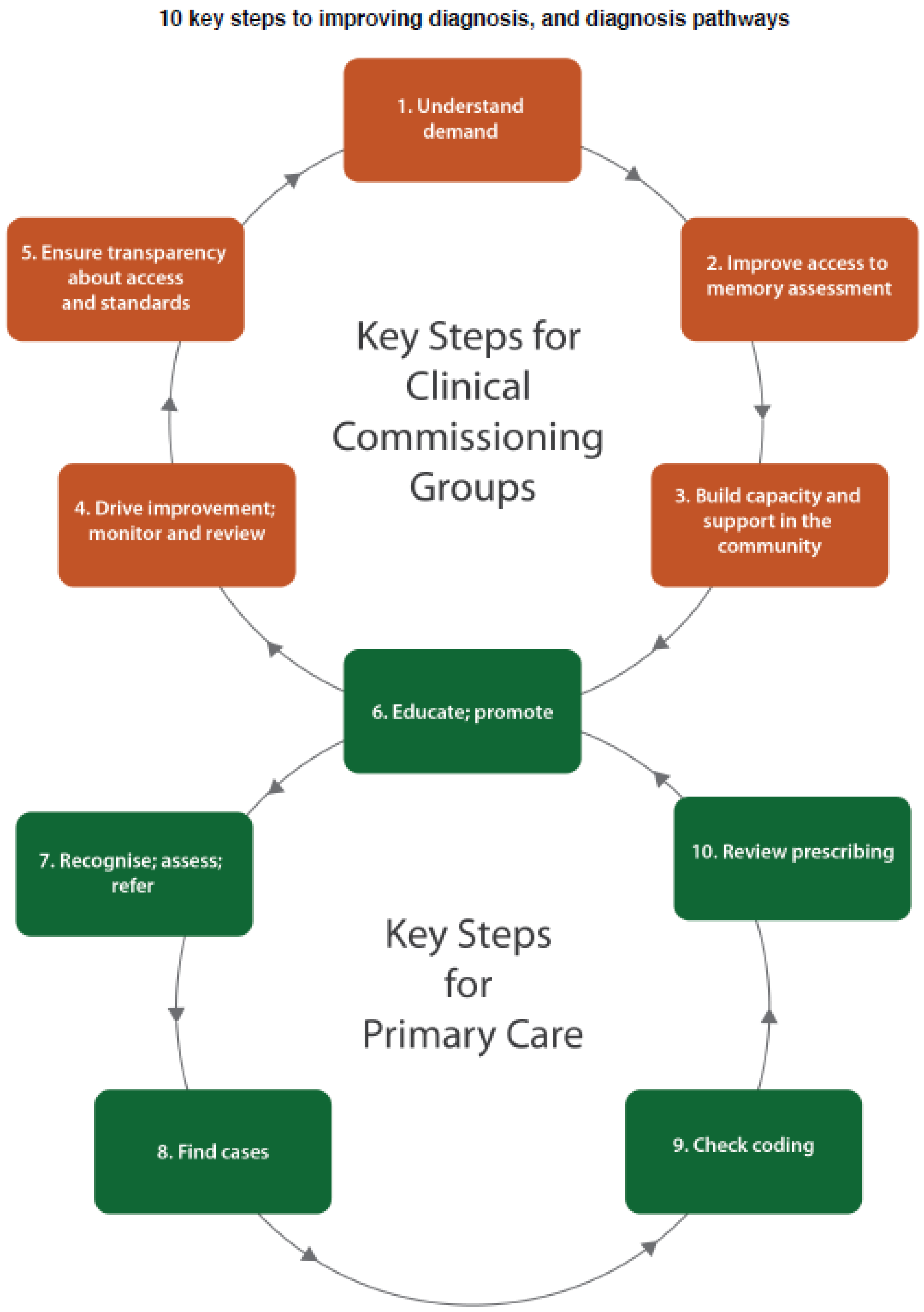
Interventions which were used in successful CCGs were:

- High levels of Enhanced Service for Dementia (DES) amongst GPs
- Coding reconciliation exercises and monitoring of QOF performance
- Commissioning dementia advisor services to support timely diagnosis and post-diagnostic support
- Training of health care professionals
- Training for carers
- Advance care planning
- Access to respite care

## Local strategies to improve dementia diagnosis

Bedfordshire CCG has been leading a project with key partners to help GP practices with low diagnosis rates increase their diagnosis rates. Bedfordshire CCG are also planning to work with care homes to increase dementia diagnosis among people living in care homes as this subgroup of the population are often underdiagnosed.

**Figure 26. 10 key steps to improve diagnosis and diagnostic pathways**



### National screening for dementia

Despite the push to increase the diagnosis rate of dementia, the National Screening Committee (NSC) does not recommend population wide screening for dementia. A summary from the latest NSC review in January 2015 is shown in the box below:

**Why is screening not recommended by UK NSC?**

About 7 out of every 100 people over the age of 65 have dementia. If this age group was screened using current tests about 18 people would receive a positive test result, but:

- only 6 of these people would actually have dementia
- 12 people would receive a positive result when they don't have dementia
- 1 person who does have dementia would be missed and be falsely reassured

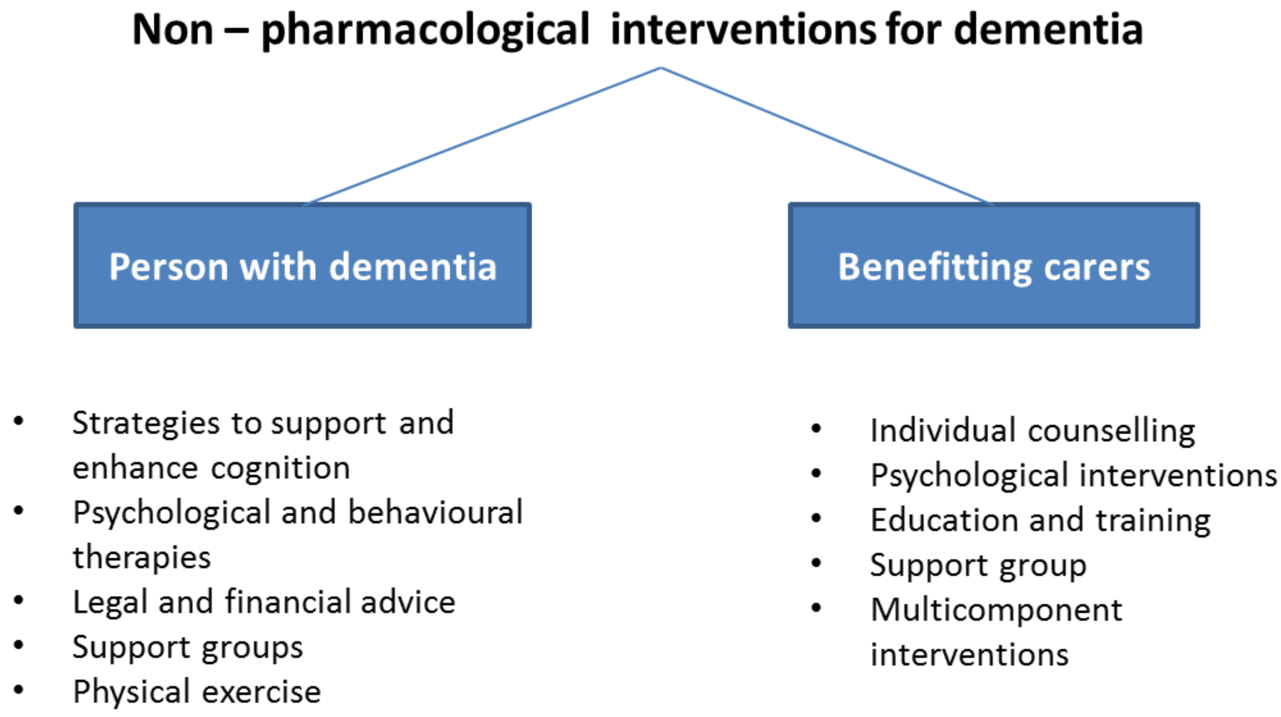
Between 7 and 17 out of every 100 people over the age of 65 demonstrate a mild cognitive impairment using current tests. But this does not always mean the person has or will develop dementia. Only about 5-10% of people with this condition will develop dementia each year. Because of this, many people would receive positive test results when they would not actually develop dementia.

*Source: http://www.screening.nhs.uk/dementia*

## Cognitive stimulation activities

Interventions for people with dementia can be split in to pharmacological and non-pharmacological interventions.  Pharmacological interventions are explored in NICE guidance CG42 (2011)[48]. Non-pharmacological interventions are illustrated in Figure 27. These include activities that aim to provide general stimulation for thinking, concentration, and memory; these are known as cognitive stimulation activities.

**Figure 27. Non-pharmacological interventions for dementia**



Many of the community services available to people with dementia include an element of cognitive stimulation. The benefits of cognitive stimulation for people with dementia have been reviewed as part of the 2011 World Alzheimer report ‘The benefits of early diagnosis and intervention.’ This report concluded that *‘Cognitive stimulation may also prove to be an effective therapy for people with early stage dementia.’*

In 2012, a Cochrane review ‘Cognitive stimulation to improve cognitive functioning in people with dementia’ supported this finding by concluding that *‘there was consistent*

---

[48] https://www.nice.org.uk/guidance/cg42

*evidence from multiple trials that cognitive stimulation programmes benefit cognition in people with mild to moderate dementia over and above medication effects.'*

Dementia NICE guidelines CG42[49] recommend the use of cognitive stimulation for people with mild to moderate dementia irrespective of drug treatment for cognitive symptoms. The cost effectiveness of cognitive stimulation has been evaluated by the NHS Institute of Innovation and Improvement, who published a report in October 2011[50]: 'An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia.' This report suggests that behavioural interventions are a more efficient use of public money than antipsychotic drugs and should be used as first line of treatment for behavioural and psychological symptoms among those with dementia.

### What is cognitive stimulation therapy?

Cognitive stimulation therapy is an evidence based treatment for people with mild to moderate dementia and is recommended by NICE Guidance irrespective of drug treatments received. It involves 14 sessions of themed activities, which run over a seven week period and aim to actively stimulate and engage people with dementia.

More information about the principles and structure of the sessions can be found online: http://www.cstdementia.com/

**Peer Support programmes**

In March 2015, the Health Innovation Network and the Academic Health Science Network for South London published a dementia peer support resource pack[51]. This pack aims to promote and encourage more peer support opportunities for people with dementia.

The resource pack introduces the concept of a 'Peer Support System' that recognises the value of social opportunities for people with dementia to meet others

---

[49] https://www.nice.org.uk/guidance/cg42

[50] http://www.aph.gov.au/DocumentStore.ashx?id=3207b0df-1063-4494-909f-9f8c2b431f37

[51] http://www.hin-southlondon.org/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_v12.pdf

in the community, whether they are informal or structured opportunities, dementia specific or available to everyone to enjoy.

The resource pack contains:

- Case studies and films of people with dementia and their relatives talking about how important peer support is for them.
- Films of group facilitators and volunteers who support people with dementia.
- Information on making existing groups dementia friendly with resources on improving the group environment and group activities.
- How to set up and run groups for people with dementia, including information on staff training, fundraising sources and evaluation aids.

The resource pack is designed for:

- Statutory, community and voluntary sectors who want to offer people with dementia the opportunity to meet others in a similar situation.
- People setting up, running or involved in peer support groups or community and activity groups which include, or could include people with dementia.
- People who are commissioning or funding services for people with dementia.

# Section 7. Tertiary prevention of dementia

**Summary on tertiary prevention of dementia**

There are many documented and evidence based ways to make the lives of people living with dementia and their carers easier. This can include strategies to help people manage the condition such as supporting people living alone, appropriate use of antipsychotic medication, supporting carers through education, and respite provision and advance planning for long term care.

This section of the health needs assessment will focus on the evidence base for the tertiary prevention of dementia.

## Tertiary prevention of dementia

***What is tertiary prevention?***

*‘The application of measures to reduce or eliminate long-term impairments and disabilities, minimising suffering caused by existing departures from good health, and to promote the patient’s adjustments to his/her condition.’*

*Source: Health Knowledge*[52]

Tertiary prevention in dementia aims to prevent and reduce morbidity and mortality in people who have dementia. Four key areas will be explored: helping people manage the condition, appropriate use of antipsychotic medication, support for carers, and long term care.

---

[52] http://www.healthknowledge.org.uk/public-health-textbook/research-methods/1c-health-care-evaluation-health-care-assessment/epidemiological-basis-pstrategies

## Helping people manage the condition

A key component to helping people manage the condition is to reduce the stigma of dementia and promote dementia friendly communities. These areas will be discussed in section eight.

As people age, they are more likely to be living with a medical condition or risk factor for dementia. In section two the term clustering was explained, this is where a person may have several interconnected risk factors for dementia but the overall effect of these risk factors may not be the sum of all of the risk factors combined.

Clustering is concerned with the risk factors and overall risk of dementia. Once dementia is established, if a person has other health problems such as diabetes, this is known as a comorbidity. An Alzheimer's Society report[53] found that 72% of people with dementia are living with another condition and another study reported that approximately 64% of people with dementia have three or more conditions[54].

Helping people to manage their condition needs to also take into account the management of other health conditions in addition to dementia. As a person's dementia progresses, their ability to manage other health conditions may deteriorate. The strongest evidence base to support this is for people with diabetes and dementia.

A recent review 'Comorbidity and dementia: a scoping review of the literature'[55] concluded that the prevalence of comorbid conditions in people with dementia is high. This review focused on diabetes, stoke, and visual impairment. The key issues identified in this review are shown in the box below:

---

[53] http://www.alzheimers.org.uk/dementiauk

[54] http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2812%2960240-2/abstract

[55] http://www.biomedcentral.com/1741-7015/12/192

**Key issues identified in the review:**

- Having dementia may impact on a person's ability to self-manage their health condition, for example a person with dementia and diabetes may forget to take medication or to monitor their blood glucose.

- People with dementia may be unable to communicate their concerns about their health effectively for example, if their dementia is severe they may not be able to communicate that their vision has deteriorated, this could worsen their confusion and increase their risk of accidents.

- Lack of communication between health professionals in different specialities may not promote a coordinated person centred care plan.

- A person with dementia may have multiple comorbidities.

- People with dementia may not have the same access to healthcare for comorbidities as people without dementia. This includes access to treatment and monitoring for conditions.

- Clinicians may be more reluctant to investigate comorbidities in people with dementia, this may be due to difficulties with patient cooperation or because the treatments are considered inappropriate for older people with multi-morbidities.

## People with dementia living alone

People living alone at home are more likely to become socially isolated with dementia and not seek help[56]. As the disease progresses, the risk of having an accident at home due to memory loss increases. This increases the chance of the person requiring hospital or residential care compared to someone living at home with another person. Some of the potential issues a person with dementia living alone may face are shown in the box below:

**Potential issues a person living alone with dementia may face:**

- forget to eat or take prescribed medication
- forget to bathe or change their clothes regularly
- lack awareness of potentially hazardous situations, such as fire or electrical appliances
- show poor judgement about who they let into the house
- have unrealistic ideas or suspicions, which can lead to trouble with neighbours, the police or the community
- forget to feed or care for pets

In order to help mitigate some of these risks, a person with dementia would need to have a diagnosis and be accepting of help. Services such as having meals delivered to the person with dementia or a carer visit the person could then be put in place to help the person with dementia living alone. Unfortunately, there are many people living alone that do not recognise they have signs and symptoms of dementia or are unable to access support. This hidden population is more likely to present to services in a state of crisis, for example when their behaviours have impacted others (e.g. neighbours).

While some of these behaviours may be life threatening there is also a concern about the quality of life for a person with dementia living alone. Research for the Alzheimer's Society[57], found that 62% of people with dementia living alone feel lonely.  This is compared to 38% of all people with dementia who responded to the survey.

---

[56] Alzheimer's Society: People with dementia living alone http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=550

[57] Alzheimer's Society:  The hidden cost of loneliness, http://www.alzheimers.org.uk/dementia2013

***'When you are at home alone you miss out on what's going on but groups like this really help.'***

Female with dementia, living alone

It is also worth remembering that some people with dementia want to live alone. These people should be supported to do so for as long as possible. The Canadian Alzheimer's Society has a useful webpage[58] that offers advice for people living alone with dementia and everyday strategies to support someone with dementia living alone.

***'I like to remain independent, I've lived by myself at home for 60years, I don't want to rely on others'***

Female with dementia, living alone

## Appropriate use of antipsychotic medication

90% of people with dementia experience some form of behavioural and psychological symptoms of dementia (BPSD).  BPSD can include aggression, agitation, loss of inhibitions, and psychosis (delusions and hallucinations). BPSD is more common in the later stages of the illness and in care home settings.  While anti-psychotic medication may be useful for some patients, a large number of people with dementia do not benefit from anti-psychotic medication and these prescriptions are not appropriate.

Inappropriate prescribing of anti-psychotic medication in dementia patients was described in a report to the Department of health in 2009 by Professor Sube Banerjee, since this report there have been national audits and recommendations to decrease the usage of anti-psychotic medication in people with dementia.

---

[58] http://www.alzheimer.ca/en/Living-with-dementia/Staying-connected/Living-alone

**Why are anti-psychotic medications inappropriate for people with dementia?**

- People with dementia are at a high risk of dangerous side effects
- Behavioural and psychological symptoms can be the result of unmet needs that require different solutions
- Anti-psychotic drugs only have modest benefits for specific symptoms and for a short period of time

Source: Alzheimer's Society Antipsychotic drugs, updated April 2013[59]

**BCCG Medicine Management Audit – Anti psychotic use in dementia.**

BCCG Medicines management designed a local audit which was first used in 2013 and modified for use in 2014. The purpose of this audit was to gain a representative overview of anti-psychotic medication use in Bedfordshire CCG following an East of England publication in 2012 that only included data from 22% of BCCG practices.

The audit criteria used in 2013 are shown in Appendix 7.

The response rate in 2013 was 67% and for 2014 the audit was incentivised with 100% of practices taking part. Three questions were added for 2014:

- Antipsychotic initiated by GP or secondary care subdivided into hospital / mental health services
- Was there a documented treatment plan at initiation?
- If yes to 10 is there documentation of risk/benefit discussion?

The comparative results for 2013 and 2014 are shown in Table 36. The key findings are that the percentage of dementia patients with no psychosis co-morbidities prescribed antipsychotic medication dropped from 8.1% in 2013 to 7% in 2014. In 2014, the vast majority (86%) of patients receiving antipsychotics were initiated by secondary care or the Community Mental Health Team (CMHT), with only 47% documented as receiving 3 monthly reviews of antipsychotic medication.

---

[59] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=548

**Table 36. Comparative results for 2013 and 2014 BCCG medicines management audit**

| Results 2013 | Results 2014 |
|---|---|
| • 37 practices audited (67%) | • 55 practices audited (100%) |
| • 1629 patients on dementia register (2.4% of population 60+) | • 2544 patients on dementia register (Did not measure) |
| • 182 patients prescribed antipsychotic (15.4% not READ coded for dementia) | • 236 patients prescribed antipsychotic (6% not READ coded for dementia) |
| • 24.7% had co-morbidity of psychosis | • 28% had co-morbidity of psychosis |
| • 8.1% of dementia patients with no psychosis co-morbidities prescribed antipsychotic | • 7% of dementia patients with no psychosis co-morbidities prescribed antipsychotic |
| • 70% of patients READ coded for dementia are in care homes | • 73% of patients READ coded for dementia are in care homes |
| • 68% antipsychotics initiated by secondary care and 14% unclear initiation | • 86% antipsychotics initiated by secondary care or CMHT |
| • Most commonly prescribed antipsychotics: quetiapine 36%, 22% risperidone 22%, and haloperidol 12.5% | • Most commonly prescribed antipsychotics: quetiapine 31%, risperidone 26%, and haloperidol 15% |
| • 39% patients prescribed antipsychotics had CV co-morbidities | • 58% patients prescribed antipsychotics had CV co-morbidities or risk factors |
| • 59% documented as receiving 3 monthly reviews of antipsychotic and 5.5% newly prescribed | • 47% documented as receiving 3 monthly reviews of antipsychotic and 11% newly prescribed |
| • 37% of dementia patients prescribed an antipsychotic for > 2 years; for 12% the length of treatment could not be determined | • 46% of dementia patients prescribed an antipsychotic for > 2 years,; for 6% the length of treatment could not be determined |

## Support for carers

Carers play a vital role in helping people with dementia stay healthier for longer. Carers are often family members with no formal care qualifications or training. There are two key ways to support carers. The first one is the provision of information, support, and training to enable them to care safely and effectively for their loved one; this may include support and activity groups. The second area is to provide respite care, whether in the form of day centre provision or overnight respite care.  This section will focus on the evidence base for these two key areas with local examples detailed in section nine.

> ***‘Things change daily, weekly, you need to add to your routine, not everyone understands, caring is a 24hour job, no breaks, no schedule.’***
>
> Female caring for husband with dementia

### Education and support

People with dementia and their carers need information and support to help them come to terms with the diagnosis of dementia and what it may mean for them. Practical information may include details about what benefits they are entitled to and how to apply.

Activity groups may be designed for the person with dementia to attend alone or with a carer. Often groups will be organised to allow some time together then split into activities for the person with dementia and information and advice sessions for carers. Supportive groups allow carers to meet other people experiencing the same challenges and promote learning from each other.

The Alzheimer’s Society runs two courses for carers of people with dementia. The CrISP (Carer Information and Support Programme) is broken down into CrISP1 and CrISP 2:

CrISP1 - a four session programme aimed at family members and friends who support a person with a recent diagnosis of dementia. Topics covered include; understanding dementia, legal and money matters, providing support and care and coping day to day.

CrISP2 - a three session programme covering issues that arise as dementia progresses. Topics covered include; understanding change as dementia progresses, living with change as more help is needed, and living well as dementia progresses.

Locally these courses are well regarded; however some carers did state that they had difficulty attending as they needed to find alternative care arrangements for the person they cared for. Providing advice and support to carers can better equip carers to enable them to care for their loved one at home for a longer period of time; ultimately resulting in cost savings and decreased need for residential care places from local authorities.

However, it is estimated that 40% of carers of family members with dementia have clinically significant depression or anxiety, in addition to this 40%, other carers have significant psychological symptoms[60]. While key policies recommend psychological therapy for carers, the evidence base is limited.

One Randomised Control Trial (RCT), the START (STrAtegies for RelaTives)[61], assessed the clinical and cost effectiveness of a manual based coping strategy. The intervention consisted of eight sessions delivered and supervised by psychology graduates to carers of family members with dementia. The programme consisted of:

- psychoeducation about dementia,
- carers' stress and where to get emotional support,
- understanding behaviours of the family member being cared for and behavioural management techniques,
- changing unhelpful thoughts,
- promoting acceptance.
- assertive communication,
- relaxation,
- planning for the future,
- increasing pleasant activities,
- maintaining skills learnt.

Carers practised these techniques at home, using the manual and relaxation CDs.

Overall, the intervention was effective in reducing affective symptoms and case level depression in carers of family members with dementia. The carers' quality of life also improved. The cost effectiveness review found that the intervention is cost effective when added to usual care, when costs are measured from the perspective of the health and social care system, and when outcomes are measured in terms of carer's affective symptoms and health related quality of life over an eight month period.

---

[60] http://www.bmj.com/content/347/bmj.f6276
[61] http://www.journalslibrary.nihr.ac.uk/hta/volume-18/issue-61#abstract

The Centre of Reviews and Dissemination have conducted a critical appraisal of the cost effectiveness of this study, this can be shown in Appendix 7.

### Admiral Nurses

Admiral Nurses are specialist dementia nurses who give expert practical and emotional care and support for family carers, as well as the person with dementia. They work in the community, in care homes, in hospices and in a variety of other settings. More details can be found online https://www.dementiauk.org/how-we-help/admiral-nursing/ successful schemes in the East of England include the Norfolk Admiral nurses service.

### Respite care

Caring for a loved one with dementia is an exhausting task; as the illness progresses, carers require more support as their care duties increase. In the early stages of dementia, respite may be sought in the form of activity groups, while as the illness progresses, day centre provision or overnight respite care may be more appropriate. The aim of day care should be to maintain and strengthen remaining skills and to enhance confidence and self-esteem in the person with dementia.

**What is respite care?**

Respite care is the temporary provision of care for a person with dementia at home or in a care home by people other than the primary informal caregiver.

> ***'Carer's in Bedfordshire provide support for seeing respite care, it's important to me to have someone to trust that can help with my husband if I am ill, someone I know that knows him and will look out for him if I am ill and away'***
>
> Female caring for husband with dementia

**Figure 28. Potential benefits of day centres for people with dementia and their carers**

**Table 37. Services that may be on offer at a day centre**

| Services that may be on offer at a day centre |
|---|
| • Counselling<br>• Advice about benefits<br>• Health services (e.g. podiatry, nurse led clinic)<br>• Nutrition – snacks and lunch are often provided<br>• Personal care (e.g. hairdressing, help eating and using the toilet, etc.)<br>• Activities – daily programme of activities (e.g. music, art, games, quizzes).<br>• Trips out (e.g. museums, gardens, etc.)<br>• Therapy (e.g. physiotherapy, occupational therapy, speech therapy, etc.) |

## Day centre versus day support

Attending a group may not be suitable for every person with dementia. Some forms of dementia may result in behaviours that are not acceptable in group environments such as sexual behaviour. The ratios of staff to people with dementia are important to ensure a good quality experience for the person with dementia. Attending day centres may be less appropriate for people in the early stages of the illness who want to continue with their current activates, younger people who may prefer one to one support, and people from different ethnic backgrounds.

Table 38 combines ideas from several sources (see appendix 7 for references) about what makes a good day centre. This could be adapted into a checklist to be used by commissioners assessing local day centre provision for people with dementia.

**Table 38. What makes a good day centre**

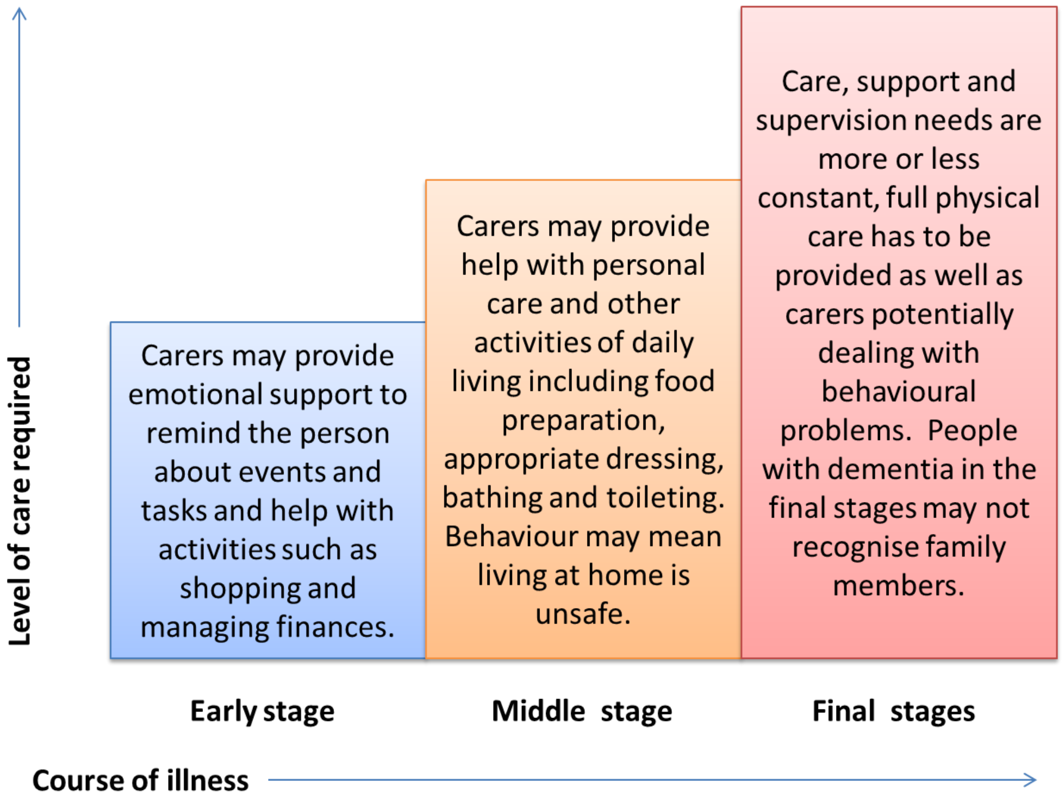
| Practical aspects | Staff aspects | Management aspects |
|---|---|---|
| A centre that is designed to be dementia friendly | Friendly, compassionate staff that take time to build rapport and trust with service users. | Staff that are well supported and motivated to learn more about dementia. |
| A centre where centre staff accompany service users to and from the centre if transport is provided | Staff that can manage behaviours commonly associated with dementia. These may include wandering, incontinence, hallucinations, sexually inappropriate behaviour or speech difficulties. | Having a variety of activities on offer in small groups to ensure cognitive stimulation. |
| | | Having the resources available to tailor cognitive stimulation activities to current events (e.g. seasonal and cultural celebrations). |
| A centre that offers rehabilitation and a range of health and social services | Improving access and engagement of people with more severe dementia. | Having the flexibility to allow service users to attend for special reasons on days outside of their normal care plan. |
| | Low staff turnover. | Frequently reviewing care plans with health professionals and carer involvement. |
| | | Supporting the carer through the dementia journey, signposting and advising when step up care packages may be beneficial. |

> ***'I like coming here, it's a break from home, Wendy is great, she does quizzes and plays games, it keeps you amused.'***
>
> Male with dementia talking about attending Greenarce day centre

## Long term care

Unfortunately dementia is a degenerative condition with no known cure. Gradually the symptoms such as memory loss, cognitive impairment and difficulty in communicating become worse. People with dementia have specific needs for care, these needs can start early in the disease course and change as the disease progresses. This is illustrated in Figure 29.

**Figure 29. Disease progression and care needs for a person with dementia**



Carers may provide emotional support to remind the person about events and tasks and help with activities such as shopping and managing finances.

Carers may provide help with personal care and other activities of daily living including food preparation, appropriate dressing, bathing and toileting. Behaviour may mean living at home is unsafe.

Care, support and supervision needs are more or less constant, full physical care has to be provided as well as carers potentially dealing with behavioural problems. People with dementia in the final stages may not recognise family members.

*Source: Adapted from WHO*

## What is long term care?

*‘The system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity.’*

Planning for long term care can help the person with dementia take control of their future and help carers to cope with their changing role. The term long term care encompasses a number of options including informal (family) or formal (paid) care at home or care in a care home. There are three main types of care homes for people with dementia[62]:

- Residential care or assisted living facilities, staffed by care assistants, which provide assistance with activities of daily living, and supervision, but no onsite specialist medical or nursing care.
- Nursing homes, staffed by registered nurses as well as nursing and care assistants, and able to attend to medical and nursing care needs, as well as high levels of personal care.
- Dementia special care units, staffed by specialist dementia nurses, and attended by multidisciplinary care teams, capable of providing specialist care for those with advanced dementia, behavioural problems, psychological symptoms, and complex medical comorbidities.

A 2013 survey by Alzheimer’s Society[63] identified the most common reasons carers turned to care homes for the person they cared for:

- 33% unable to cope with increasing care demand
- 26% could no longer live independently / needed 24hr care
- 23% safety issues
- 16% advised by health or social care services
- 14% challenging behaviour (abusive, aggressive, etc.)
- 14% caregiver had issues of their own (e.g. failing health)

---

[62] http://www.alz.co.uk/research/world-report-2013

[63] Alzheimer’s Society: Low expectations. Attitudes on choice, care and community for people with dementia in care homes (2013).

- 11% personal care or hygiene issues (e.g. incontinence)

As participants could select more than one reason, the results do not sum to 100%. In addition to the options for long term care already discussed, respite care can also help carers cope with looking after a person with dementia. Respite care was discussed earlier in this section.

The WHO states that every person with a progressive illness has a right to palliative care. Palliative care is not often associated with dementia, however end of life care is an important consideration for people with dementia, their carers, and health and social care organisations. Advance care planning (ACP) may help a person with dementia to plan their future knowing their wishes will be taken in to consideration when they may be unable to communicate.

**What is Advanced care planning?**

Advanced care planning is ‘a process to make clear a person’s wishes and that will usually take place in anticipation of future deterioration of an individual’s condition, with loss of capacity, to make decisions and/or ability to communicate wishes to others’

**What can ACP include?**

Lasting Power of Attorney (LPA) - The nomination in a prescribed form of a person responsible for taking decisions on the behalf of an individual with dementia on economic, health or personal matters, in case of loss of capacity. Any decisions taken by the appointed person have to be made in the patient’s best interests.

Advance Decision to Refuse Treatment (ADRT) in specific future circumstances - The decision to refuse treatment should loss of capacity ensue. This decision should be made under the supervision of someone who understands the intricacies of the process, and by someone who has mental capacity at the time of the decision.

Ultimately, by discussing the available options with the person with dementia while they still have the capacity to understand and communicate their wishes the long term care for the person with dementia and for their family can be improved. The 2013 World Alzheimer report[64] focused on ‘An analysis of long-term care for dementia’ this resources discusses in more detail some of the ideas presented in this section.

---

[64] http://www.alz.co.uk/research/world-report-2013

# Section 8. Reducing stigma and increasing community support

## Summary of reducing stigma and increasing community support

Reducing the stigma of dementia and promoting dementia friendly communities should be at the forefront of any dementia strategy. Stigma attached to dementia and wider mental health conditions puts people off seeking a diagnosis and accessing help. This worsens their health outcomes, quality of life, and the quality of life of their families.

When people feel stigmatised they are more likely to present for help in the later stages of disease or at a time of crisis. This is damaging for the person with dementia and their families but also more resource intensive for health and social care teams.

By reducing stigma and promoting dementia friendly communities, individuals are able to lead happier, healthier lives, and plan for their futures.

Across the three levels of prevention for dementia, a common theme is to reduce the stigma associated with dementia and increase community support. The benefits of reducing the stigma of dementia include people seeking an earlier diagnosis and by living in a dementia friendly community people can lead happier, healthier lives.

> *‘Stigma is something which causes an individual to be classified by others in an undesirable, rejected, stereotype. Misconceptions of dementia and the people who are affected by it are a problem around the world. Stigma prevents people from acknowledging symptoms and obtaining the help they need. It causes individuals and organisations to behave in ways that are unhelpful; emphasising the symptoms of dementia rather than supporting the abilities that people with dementia have.’*

*Source: Marc Wortman, Executive Director, Alzheimer’s Disease International*

***'Word dementia is a taboo, my wife does not accept she has dementia.'***

***'Weller wing has bad connotations, "only mad people go there I'm not mad so I don't need to go" she says'***

Husband caring for wife with dementia

In 2012, the Wold Alzheimer's Report was dedicated to 'Overcoming the stigma of dementia'[65]. The key recommendations from this report are summarised in the box below:

**Ten key recommendations to overcome the stigma of dementia:**

1. Educate the public
2. Reduce isolation of people with dementia
3. Give people with dementia a voice
4. Recognise the rights of people with dementia and their carers
5. Involve people with dementia in their local communities
6. Support and educate informal and paid carers
7. Improve the quality of care at home and in care homes
8. Improve dementia training of primary healthcare physicians
9. Call on governments to create national Alzheimer's disease plans
10. Increase research into how to address stigma

The world Alzheimer report lists six examples of ways to reduce the stigma of dementia:

1. People with dementia speaking out
2. Dementia friendly communities
3. Dementia experiences
4. Outreach programmes
5. Promoting earlier diagnosis
6. Art and physical activity.

---

[65] http://www.alz.co.uk/research/world-report-2012

Dementia friendly communities is a concept that has its origins in the WHO Age-Friendly movement. The 2012 Prime Minister's Challenge on Dementia included a challenge for 20 cities to become dementia friendly by 2015. There are numerous resources available to support communities to become a dementia friendly community. A dementia friendly community does not have to be bound geographically. The Alzheimer's Society has identified ten key areas that can lead to a dementia friendly community.

**What are Dementia-Friendly Communities?**

Dementia-Friendly Communities (whether cities, towns, villages or streets) do as much as possible to remove the barriers to everyday living that people with dementia and their carers face. They also help people with dementia to make the most of their own capabilities, encouraging them and including them in what is going in the community.

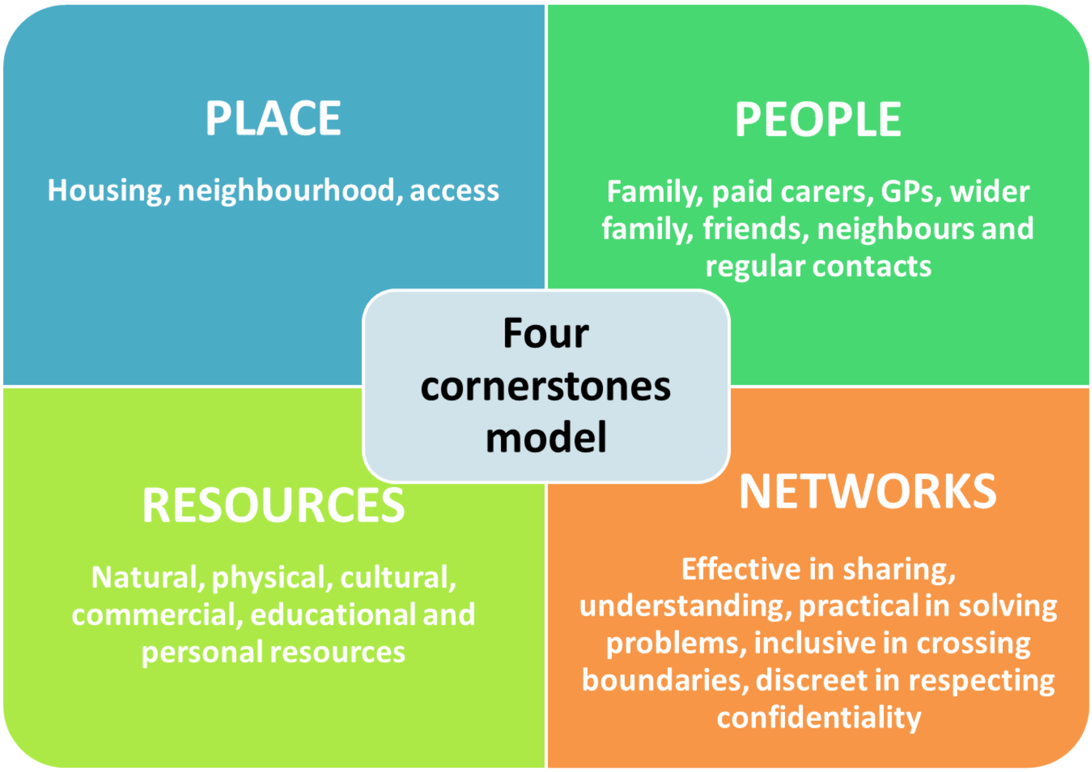
In addition to the resources available from the Alzheimer's Society, the Local Government Information Unit[66] have produced a helpful briefing for local authorities to enable them to develop dementia friendly communities. This is based on the four cornerstones model as illustrated in Figure 30.  Table 39 and Table 40 show how different local authority departments and elected members can support dementia friendly communities.

Section 9 details how dementia friendly communities are being implemented in Central Bedfordshire.

---

[66] http://www.lgiu.org.uk/wp-content/uploads/2013/02/Dementia-Friendly-Communities.pdf

**Figure 30. Four cornerstones model, Local Government Unit**



## Creating a dementia friendly community:

### 1. Involvement of people with dementia:

Shape communities around the needs and aspirations of people living with dementia alongside the views of their carers. Each community will have its own diverse populations and focus must include understanding demographic variation, the needs of people with dementia from seldom heard communities, and the impact of geography (e.g. rural versus urban locations).

### 2. Challenge stigma and build understanding:

Work to break down the stigma of dementia, including in seldom heard communities, and increase awareness and understanding of dementia.

### 3. Accessible community activities:

Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.

### 4. Acknowledge potential:

Ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities. Build on the goodwill in the general public to make communities dementia-friendly.

### 5. Ensure an early diagnosis:

Ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.

### 6. Practical support to enable engagement in community life:

Deliver a befriending service that includes practical support to ensure people with dementia can engage in community life as well as offering emotional support.

### 7. Community-based solutions:

Support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive quality care homes. Community-based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.

### 8. Consistent and reliable travel options:

Ensure that people with dementia can be confident that transport will be consistent, reliable, responsive, and respectful to their needs.

### 9. Easy to navigate environments:

Ensure that the physical environment is accessible and easy to navigate for people with dementia.

### 10. Respectful and responsive businesses and services:

Promote awareness of dementia in all shops, businesses and services so all staff demonstrate understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business.

Table 39. How different local authority departments can support dementia friendly communities

| Ideas and examples of how different departments can support dementia friendly communities | |
|---|---|
| **Public Health** | Leading on awareness of the demographics of dementia, its growing prevalence, and understanding how to 'live well' with dementia. |
| **Adult Social Care** | Leading on awareness of different types of dementia, the needs of carers, training for non-specialists who may provide services to people with dementia. |
| **Children's Social Care** | Raising awareness of intergenerational issues in families, helping children to understand dementia. |
| **Education** | Working with schools to help children and young people understand dementia, inviting people with dementia and carers in to schools to talk about their experience and their memories. |
| **Planning** | Leading on place, understanding how the planning process can help people with dementia to access and use places safely and well. |
| **Transport/Highways** | Assessing the impact of transport plans on people with dementia, promoting their needs with transport partners. Making places clear through signage. |
| **Housing** | Ensuring that people with dementia are well housed and that their housing is adapted to support changing needs. Protecting residents from harassment. |
| **Environmental Services** | Enabling people with dementia to keep their environment clean and tidy and to recycle waste. |
| **Leisure** | Enabling people with dementia to maintain their health and fitness and to enjoy a range of activities with their families and friends. |
| **Cultural Services** | Supporting people with dementia to enjoy theatre, music, and cinema and to continue to participate in these. Enabling access to library services, adapting to meet changing needs. Promoting information about dementia to the wider community. |
| **Customer Access** | Ensuring that people with dementia can access local services how they choose. Providing training to front line staff about the particular needs of people with dementia. |
| **Payment Services** | Ensuring that people with dementia and their carers understand and can access payment systems, and that changing needs are responded to. |
| **Economic Development** | Working with the local business community to help them to provide better services to people with dementia, including the promotion of 'Dementia-Friendly' rated services if appropriate. Helping to identify people with dementia as contributors to the local economy. |
| **Corporate Services** | Ensuring that people with dementia are part of the Equalities Scheme for the council. Promoting the council as a Dementia-Friendly organisation, including the impact of caring from a person with dementia on staff. |

**Table 40. Five ways elected members can support dementia friendly communities**

| **Five ways in which elected members at all levels and in the variety of their roles can support Dementia-Friendly Communities** | |
|---|---|
| Budget planning and scrutiny | Be clear about how your investment locally is supporting people with dementia and making your community more Dementia-Friendly. Know the facts about dementia in your area, and ask for analyses about which services support people and what the gaps are. Monitor and challenge expenditure in terms of outcomes for people with dementia and their families, not just in terms of amount spent. Consider ways of reinvesting in community services to help more people earlier, and reduce the costs of responding to crises |
| Partnership working | Consider your investment in people with dementia alongside that of other partners in the NHS; voluntary and private sector. Identify the big opportunities to transform services together to get the most out of joint investment and to co-ordinate change. Look for ways to influence and encourage partners to do things which are Dementia Friendly because this is a good thing in itself, but also because there are benefits to be gained. |
| Dementia Champion | Become a ‘dementia champion’, either formally through involvement in a local Dementia Action Alliance, or informally by speaking out about dementia whenever you can. Raise awareness of dementia and its impacts on individuals, carers and families and tackle stigma, discrimination and harassment where it arises. |
| Promote what works | Find out about and promote those things that work well for people with dementia and their carers and that offer good value for money. Share your good practice with others in your own area and across local authorities, building your knowledge and that of others about what a Dementia –Friendly Community really means. |
| Listen to people with Dementia and their Carers | People with dementia have a voice, sometimes not always as we conventionally think of it – listen to it. Get to know people with dementia and their carers when you visit them in their own homes or meet with them in the community, or in hospital. If people cannot speak, listen to their carers and families who can often express their wishes. A person is there throughout the stages of a dementia life, so if they cannot speak, make contact in another appropriate way. |

# Section 9. Existing local services

## Summary of existing services

This section details some of the local services available in Central Bedfordshire, including health services, social services, and other support services for people with dementia and their families. Overall Central Bedfordshire is making good progress towards becoming a dementia friendly community with seven towns leading the way and over 5000 dementia friends and champions.

## Strategic overview

In Central Bedfordshire there is a joint dementia steering group between Central Bedfordshire Council and Bedfordshire CCG. In addition to this group there is a wider stakeholder group. Membership of the stakeholder group includes:

- Central Bedfordshire Council
- Bedfordshire CCG
- Luton and Dunstable Hospital Trust
- Carers in Bedfordshire
- Stroke Association
- Pohwer
- Alzheimer's Society
- SEPT
- Dementia Friend champion representative
- Tibbs Dementia Foundation
- St Andrews Care home

## Working towards Central Bedfordshire becoming a dementia friendly community

Reducing the stigma attached to dementia and creating dementia friendly communities has already been highlighted as a key area to help improve the lives of those living with dementia and their carers. In Central Bedfordshire, the council can provide support for communities wishing to become dementia friendly, so far there has been good progress made, although the communities themselves need to take ownership of becoming dementia friendly. The numbers of dementia friendly communities, dementia champions and dementia friends is shown in Table 41.

**Table 41. Central Bedfordshire working towards becoming a dementia friendly place to live**

| Measure | Progress to date |
|---|---|
| Communities interested in becoming dementia friendly | Dunstable, Sandy, Potton, Aspley Guise, Slipend, Flitwick and Biggleswade |
| Dementia Friends Champions | 139 |
| Dementia Friends (attended face to face session) | 3322 |
| Dementia Friends (completed online session) | 1898 |
| Total Dementia Friends and champions | 5359 |

*Source: Regional Volunteering Support Officer - Dementia Friends, Alzheimer's Society 23/04/15*

## Dementia in primary care

For most people concerned about the signs and symptoms associated with dementia, their first point of call will be their GP. GP's are often described as the gateway to secondary care. GP's may diagnose patients with dementia themselves or refer to the Memory Assessment Service (MAS). Timely diagnosis of dementia is currently a national priority, as such, there have been many publications aimed at increasing the number of people receiving a diagnosis of dementia. This has been previously discussed in section 2: the prevalence of dementia and in section 6: secondary prevention for dementia.

Once a patient has been diagnosed with dementia, their ongoing clinical management is usually the responsibility of their GP. This could include liaising with secondary care and social care.

Dementia activity in primary care is measured by three systems, which are descripted in Table 42. In addition to these indicators, in 2013/14, NHS England introduced a new directly enhanced service (DES) to encourage GPs to identify patients at clinical risk of dementia, offer an assessment to detect possible signs of dementia in those at risk, offer a referral for diagnosis where dementia is suspected, and support the health and wellbeing of carers for patients diagnosed with dementia.

**Table 42. Measures of dementia care in primary care tools.**

| Quality and Outcomes Framework (QOF) | NHS Outcome Framework | Public Health Outcomes Framework |
|---|---|---|
| Dementia Register | Indicator 2.6ii (in development for 2015/16) | Indicator 4.16 |
| The proportion of people with dementia reviewed in the previous 15 months | A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life | The number of people diagnosed with dementia as a percentage of estimated number of people with dementia |

The NHS health check programme for 65-74 years old now includes raising awareness about dementia by asking about signs and symptoms and if the person would like a referral to their GP to explore this further. National NHS health check resources include a dementia leaflet and a web based dementia training tool for staff.

Primary care also includes pharmacies and dental surgeries. Staff from these two key access points should be included when staff training is provided to primary care providers.

## Dementia in secondary care

### Memory assessment services (MAS)

The memory assessment service is currently provided by the East London NHS Foundation Trust (ELFT). The service aims to meet the needs of people who are concerned that they may have a memory problem. The initial stage will be to assess and diagnose the nature of the person’s memory difficulties, report this to their GP, and advise on further treatment or intervention. The team is made up of specialist doctors, nurses, occupational therapists, and psychologists. The team will continue to be involved after diagnosis when appropriate and can offer information, advice, and support to the person with memory problems and their family.

Services are currently located in the following locations:

- Central Bedfordshire Memory Assessment, The Lawns Resource Centre, Biggleswade
- South Bedfordshire Memory Assessment, Townsend Court, Houghton Regis

Both have recently been accredited as excellent under the Memory services national accreditation programme. Information about the number of people seen by the MAS and outcomes have been shown in section two.

> ***‘The process for diagnosis is good, there is good support from Dr Schoeman, he takes the time to explain things, he is excellent, you also get information from the Alzheimer’s Society and Carers in Bedfordshire.’***
>
> Female carer caring for husband

## Hospital inpatient services for people with dementia

A 2009 report by the Alzheimer’s Society[67] found that up to 25% of hospital beds are occupied by people with dementia at any one time. The average length of stay for a person with dementia is longer than for a person without dementia. The Alzheimer report also found that half of the people with moderate dementia admitted with an acute illness such as a hip fracture or pneumonia will die within eight months. The costs associated with dementia in hospital are discussed in section four.

Locally, both the Luton and Dunstable Hospital and Bedford Hospital take part in the Butterfly scheme[68]. This scheme is organised slightly differently in each hospital. Generally, a blue butterfly is put on the patient’s notes and above their bed so staff are aware the person has dementia and can adapt how they engage with the person. The Luton and Dunstable Hospital also has a dedicated Dementia Nurse Specialist, who can advise and support staff, patients, and carers. At Luton Hospital the emphasis is on training all staff in all areas to be able to care for people with dementia across the hospital. Whereas in Bedford Hospital in December 2014, the Harpur Ward and Elizabeth Ward were adapted to provide improved dementia friendly environments.

---

[67] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1199

[68] http://butterflyscheme.org.uk/

Since October 2012, a national CQUIN (Commissioning for Quality and Innovation Framework) has been in place for dementia to financially incentivise the diagnosis / identification of dementia patients on acute wards. The target is for 90% of patients over the age of 75 admitted for at least 72 hours to be assessed for dementia using a case finding question and diagnostic assessment tool. A further target is for 90% of people found to be positive on these assessments to be referred to the memory assessment service.

End of life care has been explored in section seven. Locally the Bedfordshire Partnership for Excellence in Palliative Support (PEPS) Coordination Centre and Central Bedfordshire council can offer advice and support on matters including; palliative care, end of life (palliative) care, funeral and cremation advice, bereavement support, making a will, power of attorney, and independent financial advice.

## Support services for the person with dementia and their families

### Local services

A number of voluntary sector organisations provide dementia specific services across Central Bedfordshire; this includes some services that Central Bedfordshire Council commissions directly. Services may include dementia support workers, befriending services, carer support groups, dementia cafes, and courses for family carers. The services provided by the Alzheimer's Society are shown in Table 44 and the services provided by Carers in Bedfordshire are shown in Table 45.

In addition to services specifically tailored for people with dementia there are many services that people with dementia and/or their carers are welcome to attend but are not dementia specific. These include carers cafes organised by Carers in Bedfordshire and services / groups organised by Age UK. Central Bedfordshire council has led a project to capture what is available locally and produced four locality leaflets, these were given to GPs to give to patients and available to download online.

**Quotes about local services from people with dementia:**

*'Groups like this are great, I like getting out, keeping busy.'*

*'People understand what you are going through at these groups.'*

*'This is lovely, everyone is so friendly, you get to know people, have fun, there is usually something different on'.*

*'Dementia can be a problem but it's nice to meet people.'*

**Quotes about local services from carers:**

*'Carers in Bedfordshire have been a tremendous support, I cannot fault them, they even gave support to past carers, they help with paperwork and when a carer is in a mess'*

*'Carers in Bedfordshire are great, they have talks from people like the fire service, the police, all offering help, they had my eyes, they knew what I was going through, with their help I got through it.'*

*'There is a gap between Central Bedfordshire Council and the Alzheimer's Society, why can't the Alzheimer's Society pay Central Bedfordshire Council to do more work with dementia, it's in the news enough.'*

*'The Alzheimer's Society CrISP course was very useful, more people should do it, I learn a lot there like power of attorney.'*

### National services

A number of national organisations provide advice lines that people with dementia or their carers can access, these are shown in Table 43. This list has been generated by using information provided by stakeholders, people with dementia, and their carers and may not capture all available services.

**Table 43. Advice lines available to people with dementia and their carers**

| Organisation | Number | Opening hours |
|---|---|---|
| The Alzheimer's Society National Dementia Helpline | 0300 222 1122 | 9am - 8pm Monday to Wednesday<br>9am - 5pm on Thursday and Friday<br>10am - 4pm on Saturday and Sunday |
| Dementia UK / Admiral Nursing DIRECT | 0845 257 9406 | Monday 9:15 - 16:45<br>Tuesday 9:15 - 16:45<br>Wednesday 9:15 - 16:45, 18:00 - 21:00<br>Thursday 9:15 - 16:45, 18:00 - 21:00<br>Friday 9:15 - 16:45 |
| Age UK advice line | 0800 169 6565 | 8am-7pm, 365 days a year. |
| Carers direct | 0300 123 1053 | 9am-8pm Monday to Friday, and from 11am-4pm at weekends. The helpline is closed on bank holidays |
| Carers UK | 0808 808 7777 | Open Monday to Friday, 10am to 4pm.<br>*Note: listening service available Mondays and Tuesdays, from 9am to 7pm.* |
| The Samaritans | 08457 909090 | 24 hours a day, 365 days a year |
| Rethink Mental Illness Advice Service | 0300 5000 927 | Mon-Fri, 10am-2pm |
| MIND | 0300 123 3393 | Open Monday to Friday 9am to 6pm (except bank holidays). |
| Sane line | 0845 767 8000 | Open 6pm - 11pm every day |
| The Silver Line | 0800 470 8090 | 24 hours a day, 365 days a year |

## Mental health services

From the 1st April 2015, East London NHS Foundation Trust (ELFT) took over the provision of mental health services in Bedfordshire. Previously this was provided by South Essex Partnership University NHS Foundation Trust (SEPT). A number of services in addition to memory assessment services may be suitable for people with dementia, these are summarised in Table 46 towards the end of this section.

## Social care services

Central Bedfordshire Council offers a number of services to people with dementia and their carers. Access to these services is often determined via assessments.

> ***'Without Alexis (Carer's support work, Central Bedfordshire Council) I would have drowned, she is quick at responding and helping to find an answer.'***
>
> Female, caring for her husband with dementia

### Direct payments

Direct payments and personal budgets are offered to give people more flexibility over how their care and support is arranged and provided. They are given to both people with care and support needs, and also to carers.

A personal budget or direct payment will be created after an assessment by social services. If the council decides that either the person with dementia or their carer need any kind of support, they will receive a personal budget and can choose a direct payment instead of letting the council arrange services on their behalf.

### Day centres

People with dementia are able to access day centres specifically for people with dementia such as Greenacres day centre or generic day centres for older people including Ampthill day centre, Houghton Regis day centre, Leighton Buzzard day centre, and Biggleswade day centre.

### Domiciliary care

Domicilliary or home care is available to help a person with dementia getting up, getting washed, and getting dressed.

### Carer's break

Carers can receive either carers direct payment or carers vouchers to be used for a carers break, this could be for an hour, a week, several hours or even overnight.

### Respite Care

Respite care refers to overnight carer to facilitate the carer to take a break from their caring role.

### Extra care and sheltered housing

Sheltered accommodation is purposely designed to meet the needs of older people who may need a little extra support to continue living independently. Central Bedfordshire has a number of extra care and sheltered housing schemes available.

### Care homes

Care homes include residential care homes and nursing homes. Homes may also specifically cater for people with dementia. Residential care homes have staff that can help with personal care, meals and going to the toilet whereas nursing home also offer 24 hour care by trained nursing staff. Central Bedfordshire council operates a number of care homes across the area.

## Bereavement services

Carers in Bedfordshire and Age UK both offer bereavement services to people who have been caring for a loved one who has recently passed away. People who have cared for someone with dementia will have gained a vast amount of knowledge and skills that can be shared to benefit current carers. A number of people will go on to become volunteers imparting their knowledge and experience on other carers. This knowledge base was recognised during this needs assessment and the views of people who had previously cared for a loved one with dementia are included in section 10.

> ***‘It’s important to have continued support after husband’s death to help deal with grief.’***
>
> ***‘I felt excluded, I couldn’t see the friends I had made because my husband had died when I needed support, I was vulnerable.’***
>
> Widow who used to care for her husband who had dementia

Table 44. Dementia specific services provided in Central Bedfordshire by the Alzheimer's Society

| Activity | Description | Audience | Chiltern Vale | Ivel Valley | Leighton Buzzard | West Mid Beds | Notes |
|---|---|---|---|---|---|---|---|
| Dementia Support | One to one dementia support for anyone who has received a diagnosis of dementia and for those who care for a person with a dementia diagnosis. | People living with dementia and / or their carers. | At home or at another alternative and suitable environment. | | | | |
| Dementia Information points | No appointment necessary, come along to speak with a support worker for a range of information and support issues relating to dementia. | People living with dementia and / or their carers. | Yes | No | Yes | No | |
| Activity Groups | Activity group offering activities and support for people with dementia and their carers. | People living with dementia and their carers. | Yes | Yes | Yes | No | Access to these groups is by referral |
| Cognitive Stimulation group | Cognitive Stimulation Group suitable for people in the early to moderate stages of dementia, to help develop coping strategies for living well with dementia and moving forward in a positive way, through a range of planned cognitive activities in a supportive environment. | People living with dementia | No | Yes | No | Yes | Runs at same time as carers peer support group.<br>Access to these sessions is by referral as spaces are limited |

| Activity | Description | Audience | Chiltern Vale | Ivel Valley | Leighton Buzzard | West Mid Beds | Notes |
|---|---|---|---|---|---|---|---|
| Carers peer support group | Peer support group designed to provide carers with an opportunity to talk to others and receive information in a supportive environment. The groups are facilitated by a support worker. | Carers | No | Yes | No | Yes | Runs at same time as Cognitive Stimulation group.<br>Access to these sessions is by referral as spaces are limited |
| CrISP Carers Information and Support Programme | The Carer Information and Support Programme (CrISP) is a course in a group environment which is facilitated by a trained member of staff. The course provides support and up to date information to carers of a person who is in the early stages of, and recently diagnosed with, any form of dementia. | Carers | Various locations, rotating throughout the year between localities. | | | | Access to these sessions is by referral only. |
| Singing for the brain | Singing for the Brain© sessions are designed to be an enjoyable, fun, activity group where those attending are able to seek peer support, combined with active participation through song and gentle movements. | Suitable for people with dementia who are able to participate in and benefit from the joy and stimulation of singing. | Available in all localities | | | | Access to these sessions is by referral. |

| Activity | Description | Audience | Chiltern Vale | Ivel Valley | Leighton Buzzard | West Mid Beds | Notes |
|---|---|---|---|---|---|---|---|
| Dementia Cafes | Dementia Cafés provide an opportunity to meet regularly and talk about living with dementia in an informal social environment. The dementia café also provides information about dementia and practical tips about coping with dementia. | People with dementia, families and carers | Yes | No | No | No | They provide opportunities to ask questions of professionals and learn from the experiences of others. |
| National telephone helpline | Provides information, support, guidance and signposting to other appropriate organisations. Callers speak to trained Helpline Advisers. | People living with dementia and their carers. | Available via telephone. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm. |  |  |  |  |

Source: http://www.alzheimers.org.uk/site/custom_scripts/branch.php?branch=true&branchCode=13214&areaBC=EAEA

**Table 45. Dementia specific services provided in Central Bedfordshire by Carers in Bedfordshire.**

| Activity | Description | Audience | Chiltern Vale | Ivel Valley | Leighton Buzzard | West Mid Beds | Notes |
|---|---|---|---|---|---|---|---|
| Understanding Dementia Course | Offers information on dementia (the different types of dementia, coping strategies, communication, living well with dementia, a person centre approach and help available). | People with dementia, families and carers | Across all localities | | | | Three half day course |
| Dementia befriending service | Trained volunteers give carers short respite, whilst befriending the person with dementia. | People with dementia, families and carers | Across all localities | | | | This can help reduce isolation and provides a short break for carers. |
| Carers rest | For carers who look after a family member or friend who has dementia. | | Across all localities | | | | Cared for welcome with their carer |
| Dementia focus group | Bi-monthly meeting for carers on their own or with the person they are caring for. | | Yes | No | Yes. | No | |
| Dementia Gateway | A support / information gateway for the carers of newly diagnosed people living with dementia, and their cared for.<br>This monthly service is being piloted. | | Yes | No | No | No | Each month there will be core information about the condition, and services available, through talks and information stands from key providers. |

Source: http://www.carersinbeds.org.uk/

**Table 46. Mental health services accessible to people with dementia**

| Service | Base | Description |
|---|---|---|
| Older People Community Mental Health Teams (Older People CMHTs | Mid Bedfordshire (Biggleswade) and South Bedfordshire (Houghton Regis) | Older People Community Mental Health Teams (Older People CMHTs) are multi-disciplinary, multi-agency assessment teams for adults over the age of 65 who require specialist mental health services in Bedfordshire and Luton. Patients under the age of 65 with early onset dementia may also be cared for within this team.<br>Older People CMHTs are comprised of community psychiatric nurses, occupational therapists, psychologists, approved social workers, support workers, psychiatrists, and doctors. |
| Older People Continuing Care Inpatient Service | Fountains Court Bedford Health Village | Older People Continuing Care Inpatient Service is provided for adults over the age of 65 years with dementia or other organic mental illness, in Bedfordshire and Luton. Patients under the age of 65 years with early onset dementia may also be accepted. Organic mental illness mostly describes dementia as well as other conditions which result from brain injury.<br>The service offers the following treatments and therapies available:<br>● Art and Crafts ● Ball Games ● Hand Massage<br>● Music Therapy ● Religious Services ● Reminiscence |
| Older People Assessment Inpatient Services | Fountains Court – Organic Mental Illness and Chaucer Ward – Functional Mental Illness<br>Weller Wing | Older People Assessment Inpatient Services are provided for people over the age of 65 years with a functional or organic mental illness. Functional mental illness describes conditions of acute psychiatric illness such as depression, anxiety or psychosis. Organic mental illness mostly describes dementia as well as other conditions which result from brain injury.<br>The service offers:<br>• 24 hour service, 365 days a year<br>• Active involvement of the patient, family and carers<br>• Assessment, intensive treatment, intervention and support in the early stages of a mental health crisis<br>• Choice and patient autonomy<br>• Practical support and assistance with problems of daily living<br>• Rapid response following referral to the ward<br>• Recovery planning with patient focused outcomes<br>• Time-limited care that is responsive to patient need |

# Section 10. Views of stakeholders

**Summary of stakeholder views**

- Overall it was felt that stakeholders were having to deliver more for less.
- Unmet need includes managing dementia and co-morbidities.
- Gaps in treatment include support for people with dementia and more challenging behaviour.
- A number of hidden populations were identified, including: people with more severe dementia who cannot communicate, people living in rural communities, living alone, and couples where both husband and wife have dementia.
- Barriers to treatment include the person with signs and symptoms not realising or admitting that they have signs and symptoms of dementia.
- Stakeholders recognised that younger people face specific challenges and that a virtual support group could be created to help support younger people with dementia.
- The key challenge identified by stakeholders for people from different ethnic backgrounds was a tendency to forget English and revert back to their native language.
- Stakeholders reported that people with learning disabilities and dementia are well supported by a specialist memory assessment service at Twinwoods Resource Centre.
- A wide range of suggestions were given by stakeholders regarding how to improve care for people with dementia have been grouped into support for the person with dementia, support for the carer, health and social care, emergency care, and partner services.

As part of this health needs assessment, the author attended several of the stakeholder meetings, initially to introduce the work then to report findings back to the group. All members of the stakeholder group were emailed to ask for comments and examples of what work had already taken place in the area. See section 9.1 for membership of the stakeholder group.

In addition to email contact with stakeholders identified in section 9.1, face to face interviews were held with the following stakeholders:

- Consultant Psychiatrist, East London Foundation Trust
- Clinical group manager, East London Foundation Trust
- Dementia Nurse Specialist, Luton and Dunstable Hospital
- Associate Specialist in Learning Disabilities, Twinwoods Medical Resource Centre
- Services manager, Alzheimer’s Society
- Adult services manager, Carer’s in Bedfordshire

- Tibbs Dementia Foundation Directors
- Day Centre manager, Central Bedfordshire Council
- Carer’s support work, Central Bedfordshire Council
- Adult Learning Disability team, Central Bedfordshire Council

All stakeholders were asked the same set of questions; these can be found in appendix 10. The author met with the stakeholders below several times during the development of this health needs assessment to understand the local picture of dementia care:

- Project Manager, Commissioning Central Bedfordshire Council
- Commissioning Officer, Central Bedfordshire Council
- Mental Health project manager, Bedfordshire CCG

Themes emerging from the interview will stakeholders will now be presented.

1. *What are the current unmet needs across the system?*

The responses to this question focused around five main themes: getting a diagnosis, communicating with people with dementia, accessing support, managing comorbidities, and understanding the Mental Capacity Act (2005) and the Mental Health Act (1983 amended 2007).

- Getting a diagnosis

It was felt that more work is needed to understand why people do not access support, particularly people with dementia that are carers themselves or people with dementia that do not have carers (a person could belong in both of these groups). Ideas to support this included re-establishing links between voluntary organisations, memory clinics, and social care teams to provide better pre-diagnostic information and support for people concerned about signs and symptoms of dementia in themselves or a contact (family member / neighbour).

- Communicating with people with dementia

Communication arose as one of the most important unmet needs. In order to truly help someone to live well with dementia people need to understand how to communicate with a person with dementia. In the later stages of the illness this is particularly important as a person with dementia may not understand the content of a conversation but they can still understand the tone. Most issues arise when good communication breaks down.

- Accessing support

Many stakeholders reporting that there was an unmet need for support services for people with dementia living alone. Some stakeholders knew of individuals that were not able to access groups without a carer present and others where attending day centres was challenging. Issues included people with dementia having to organise transport themselves on a weekly basis which in the latter stages of dementia becomes more of a challenge. Living alone means that the person with dementia has to get him or herself up, dressed and ready to attend a group or rely on carers to visit before they can attend groups / day centres. The person with dementia may also be confused regarding what activities they are doing each day.

Attendance at groups was also highlighted as a problem for people with dementia that relied on a family member to take them to a group or attend with them as most groups take place Monday to Friday between 9am and 5pm, which is a time when carers often work. Additionally some support groups exclude people from attending alone, which compounds this issue.

- Managing dementia and comorbidities

While training for dementia awareness is increasing, there is a gap in educating health professionals about managing people with dementia and its comorbidities. An example of this, is the management of a person with dementia who also has cancer. The person with dementia may be under the care of an older people's team or their GP for their dementia and under the care of an oncologist for their cancer, with little coordination and understanding of how one condition may affect the other. A suggested solution was for the GP to ensure that all other health professionals working with the person are aware of the diagnosis of dementia.

There was also a perception among stakeholders that there was a generation of health professionals that have missed out on dementia training. While it was acknowledged that caring for patients with dementia is in the curriculum for new staff, it was felt that older, higher grade staff may have missed out on dementia training and may not have access to it as current training is aimed at lower grade staff.

- Understanding the Mental Capacity Act (2005) and the Mental Health Act (1983 amended 2007).

Stakeholders reported poor uptake and knowledge of these acts. Ideally these should be discussed when a person has had time to accept a diagnosis of dementia but still have the capacity to understand. Putting plans in place ahead of when they are needed is also less stressful and cheaper for the family. Recommendations included GPs having an agreement to do an assessment for capacity; this would involve training for GPs to support this.

2. *Where are there gaps in the treatment system?*

Gaps identified by stakeholders have been split into five areas: close support for the person with dementia, accessing support, transport, longer term care, and support for people with dementia and more challenging behaviour.

- Close support for people with dementia

The person with dementia may not be aware they have signs and symptoms of dementia, without a regular carer, the early stages of dementia can be harder to identify in people living alone. Without a diagnosis a person living alone may not be in receipt of any external assistance. Even if the person with dementia has family close by, support may not be available or suitable.

- Accessing support

Stakeholders reported that in order to attend certain support groups a person had to meet eligibility criteria, this could include having a diagnosis before support could be put in place, this may be a barrier for people concerned about signs and symptoms of dementia. It was felt that specific support is not available for people with all sub types of dementia. Stakeholders commented that the understanding of the subtypes of dementia was not well known in all care settings, which could be detrimental to people with rarer forms of dementia or more challenging symptoms.

Stakeholders reported that boundary issues made it harder for some people with dementia to access support. Examples included when people lived in one local authority area but were geographically closer to services provided by another or when the GP for the person with dementia was in a CCG area other than Bedfordshire CCG but they were a Central Bedfordshire resident.

Overall it was agreed that a clear pathway between diagnosis and what services are available at each stage of dementia would be helpful to people with dementia, their families, and stakeholders. Stakeholders shared examples of where patients have been told they cannot access services until their symptoms are worse.

Lack of out of hours support was raised as a major gap in dementia care in Central Bedfordshire.

- Transport

Transport is an issue for people with dementia and their carers. Stakeholders knew of many examples of elderly couples where only the person with dementia drives. When the person with dementia is no longer able to drive the couple can quickly become isolated. Understanding public transport routes and timetables can be challenging for a person in the later stage of dementia. Transport is a key area where stakeholders felt improvements could be made. This included driving assessments for people with dementia and support for carers when it was felt the person with dementia should no longer be driving. Stakeholders also reported difficulties for people with dementia using services including the Buzzer bus and South Beds dial a ride. This included the process for making bookings in advance and for arranging pick-ups; for example arranging a pick up at a set time after visiting the supermarket.

- Longer term care

Residential care for people with dementia with challenging behaviours is lacking in Central Bedfordshire. Stakeholders shared examples of when people with dementia have been admitted to hospital because their care home cannot cope and refuses to take the person back when they are discharged from hospital. This can add confusion for the person with dementia and prove stressful for family members especially when the person with dementia has to move out of area for specialist dementia residential care.

- Support for people with dementia and more challenging behaviour

Stakeholders reported fewer residential placements for people with more challenging behaviours. More support is needed to help carers and care home staff to manage people with dementia in a state of crisis at home.

3. *Who are the hidden populations and what are their risks?*

The hidden populations in Central Bedfordshire as identified by stakeholders are shown in Table 47.

**Table 47. Hidden populations and their risks as identified by stakeholders**

| Population | Risk |
|---|---|
| People with more severe dementia who cannot communicate. | Most support groups rely on the person being able to communicate, some music therapy may be suitable but there is a risk of isolation. |
| People living in rural communities. | Some Central Bedfordshire villages are often perceived to be affluent but there are hidden populations that may be self-funders who are not aware of what support they can access.<br>Risk of social isolation, particularly those living alone in rural areas or those without private transport. |
| People living alone. | Living alone may result in the person slowly getting worse with no one to notice the changes, they may have low level support from neighbours but may refuse to access formal support. In addition to their dementia becoming worse, their general health may suffer and they may suffer from social isolation only coming to the attention of services at the point of crisis. |
| Couples where both husband and wife have dementia. | The couple may not be known to services or access support until they reach a point of crisis. |
| People in care homes | A common misconception is that a diagnosis of dementia in a person living in a care home is meaningless. Stakeholders identified this group as a hidden population with several stakeholders querying the number of diagnosed people with dementia in care homes in Central Bedfordshire. |
| Younger people with dementia. | The majority of services tailor their support for older people with dementia, a number of stakeholders were unsure who they would refer a younger person with dementia to as they felt current services would not be appropriate. |
| Self-funders | There were concerns among stakeholders that self-funders may not have access to the same levels of out of hours support as those supported by social care teams. |
| Recent immigrants. | May not be able to access social care funding or have the resources available to self-fund care. |
| Traveller communities | Travelling communities are known to have poor contact with health and social care services which could result in a lower diagnosis rate for dementia in this community. |
| Prisoners | As the prison population ages the number of prisoners expected to have dementia will increase. Some stakeholders raised this as a concern. |

4. *What are the enablers and barriers to treatment / management of the dementia pathway?*

Stakeholders felt that there have been improvements made in dementia care in Central Bedfordshire over the past few years, including work by the stakeholder group as shown in Appendix 1 and with partner organisations such as a police scheme to help identify people at risk of going missing before they go missing. Barriers identified are shown in Table 48.

**Table 48. Barriers to treatment and management of the dementia pathway**

| Barriers to treatment and management of the dementia pathway |
|---|
| • The person with dementia or their carer may not admit that there is an issue; this can result in the person not accessing services until they reach crisis point. |
| • Carers are given multiple leaflets at the point of diagnosis, but depending on the care needs of the person with dementia they may not have time to read all the information to find out what support is available. |
| • Carers and befrienders change frequently, people with dementia need consistency to enable the carer to understand what is normal for the person with dementia and what their hobbies and interests are. Multiple carers can be confusing for a person with dementia. |
| • There is a lack of follow up after diagnosis, people with medications are generally followed up better than people not prescribed any medications but even medication reviews do not always happen at the optimum frequency. |
| • People with dementia may have to wait to access day centre support. Stakeholders reported examples of carers having to make numerous calls to clarify arrangements and the number of days allocated may not be adequate. A lack of specialist day centre care was reported in some areas of Central Bedfordshire and nowhere offered day centre provision seven days a week. |
| • Day centres may have limited resources for cognitive stimulation activities; this could be improved by providing a clear budget for cognitive stimulation activities for example to buy new games, craft materials, and seasonal activities. |

5. *What improvements can be made to improve future service provision?*

All stakeholders were able to offer suggestions of improvements that could be made to future service provision. The suggestions have been grouped into support for the person with dementia, support for the carer, health and social care, emergency care, and partner services.

Support for the person with dementia

- Concerns were raised about people with undiagnosed dementia not attending appointments with the memory assessment service. A suggestion was to link up a person suspected of having dementia with a partner organisation before their memory assessment service. The role of the partner organisation would be to provide advice and reassurance to the person and if appropriate accompany them to their memory assessment appointment. This may help to reduce the number of people that do not attend, particularly those living alone.
- Stakeholders shared how people with dementia often report feeling 'dumped by the NHS' after the point of diagnosis. While some valued the support from charities and other organisations, some patients and stakeholders felt that these groups could not answer the more medical questions or people did not feel comfortable asking certain questions to non-health professionals. The recommendation was for a medical follow up.
- Day centres and support groups should provide small activity groups with planned activities that can cater to individual need, ability and preferences.

Support for the carer

- Planning respite care in advance can be less unsettling for the person with dementia and their carer, especially if the person with dementia is able to become familiar with the environment prior to their stay, for example by attending for the afternoon.
- Give carers a greater voice – allow carers to report concerns without the person with dementia being present.

Health and social care

- Stakeholders commented that when planning how to care for people with dementia, there were lessons to be learnt from cancer services, such as giving each person with dementia a named key worker and support surrounding end of life care. This idea was expanded on by a number of stakeholders who recommended the Admiral nursing model.

- It was also suggested that a more appropriate time to discuss matters such as end of life and power of attorney is needed rather than including details for this in information provided at the time of diagnosis.
- Some stakeholders had concerns that mental health teams were not always conducting face to face assessments, the concern was related to when individuals with dementia may try to hide their symptoms and this could be easier to do over the phone than in person. The recommendation was for all assessments to be face to face.
- Some stakeholders suggested that GPs should have more involvement in people with dementia, for example by offering regular follow up and dementia medication reviews.

### Emergency care

- Many stakeholders suggested that a single point of access for out of hours and emergency care would be beneficial to people with dementia and their carers. However, a number of stakeholders raised concerns about capacity of a single point of access and the ability of staff to refer to the most appropriate service in a timely manner.

### Partner services

- Specific training for frontline partners, for example community police teams including information about different types of dementia.
- Improving transport for people with dementia particularly in the rural areas frequently arose as a recommendation. One stakeholder recommended a scheme used in Glasgow under the Scottish Dementia working group. In Glasgow taxi drivers have been trained in dementia awareness and offer extra services to people with dementia such as carrying their shopping to their front door and checking they can get into their house. The scheme also offers a subsidised taxi fare of £1 to anyone producing a dementia card which allows them to travel within the city boundaries.

### 6. *Younger people with dementia*

Stakeholders were aware that current services are tailored to older people with dementia with no specific services for younger people with dementia in Central Bedfordshire. The population of younger people with dementia are geographically spread which makes having local services more challenging. Younger people with dementia are likely to be an isolated population who may have problems seeking a diagnosis and are often diagnosed away from the memory assessment service or after they have reached crisis. This can result in them not being made aware of available support. GP's may not consider a referral to the memory assessment service for younger people with signs and symptoms of dementia due to a lack of awareness. Younger people with dementia may be misdiagnosed as having anxiety, depression and / or stress.

Stakeholders commented that there is a lack of appropriate day centre, respite, and residential care for younger people with dementia especially in the early stages of the illness. Care staff may be unable to cope with physically active and sometimes sexually uninhibited younger people with dementia.

Support is also lacking for the families of a younger person with dementia. Direct payments and personalised 1:1 care were seen as positive ways to support younger people with dementia however knowledge about how to apply for this and what direct payments could be used for was poor. This knowledge should be improved among stakeholders and younger people with dementia and their families to enable the person with dementia to remain as active as possible doing the activities that they would normally take part in. A virtual service for younger people with dementia may be able to bridge this gap by linking up younger people with dementia and providing information and support.

### 7. *People with dementia from different ethnic backgrounds*

In Central Bedfordshire stakeholders reported that there are people from different ethnic backgrounds with dementia but this population is geographically spread. The key challenge identified by stakeholders for people from different ethnic backgrounds was a tendency to forget English and revert back to their native language. The understanding of dementia in different cultures varies and can be stigmatised forcing families to keep a person with dementia at home and hidden from the wider community. There was also a perception among stakeholders that people from different ethnic backgrounds do not use care homes and day centres as widely. This can result in the family only seeking help at a time of crisis.

### *8. People with learning disabilities and dementia*

Within Bedfordshire there is one memory assessment service for people with learning disabilities and dementia based at Twinwoods Resource Centre. Stakeholders felt that this service was invaluable as the staff at Twinwoods have expertise in working with people with learning disabilities which staff in other memory assessment services may not have.

While stakeholders commented that people with learning disabilities and dementia would be welcome to attend support groups for people with dementia very few did. This may be due to a lack of knowledge about the services or because the person with dementia and a learning disability is already in an assisted living placement.

# Section 11. Qualitative research - Using unstructured interviews to increase local understanding of the views of people with dementia, their carers, and people that have previously cared for a person with dementia.

## Summary of the qualitative research

Views of residents of Central Bedfordshire living with dementia or caring for a person with dementia were captured using unstructured interviews. Emerging themes include:

**Diagnosis** – The person with dementia may be a carer themselves so may delay seeking help over concerns about the welfare of the person they care for.

**Knowledge about services** – Too much information is provided at the point of diagnosis, this overloads carers and is daunting for people with dementia.

**Access to services** – Appropriate transport was frequently raised as an issue.

**Support for the person with dementia** – Driving assessments were a key area of concern for people with dementia

**Support for the carer** – Carers valued existing services but often felt lost between health and social care teams, particularly with out of hours support.

**Day to day support** – Not every person with dementia has a carer, they may require additional support for example with information about benefits or how to attend groups.

**Community support** – Better support included small groups and planned activities.

**Residential support** – Carers have fears about respite care, made worse by recent high profile documentaries.

**Emergency support** – It is unclear who to contact out of hours, carers often feel guilty for dialling 999.

**Quality of life both for the person with dementia and for the carer** – The importance of having consistent care was highlighted. For carers, consistent care allows trust to be developed for example by not having to repeat histories, and likes and dislikes. For people with dementia, having a consistent care package can cause less confusion. Overall, if hired carers really know the person they are caring for they will be better placed to know when something is wrong.

In conclusion, the qualitative aspect of this health needs assessment provided a unique insight in to the lives of people with dementia and their carers in Central Bedfordshire.

## Background:

During discussions with stakeholders it became apparent that while there was a wealth of local anecdotal evidence capturing the views of local people with dementia and their carers there had been no recent qualitative research. The aim of this section of the health needs assessment was to capture the views of people with dementia, their carers, and people who had recently cared for a loved one with dementia in order to increase the understanding of the experiences of people with dementia and their family / carers in Central Bedfordshire.

## Methodology:

A brief literature review identified some of the challenges of interviewing people with dementia. Key areas are summarised in Table 49 and references are shown in Appendix 11. After researching several different qualitative methodologies, the use of unstructured interviews was deemed the most appropriate for this population group. Unstructured interviewing allows the participant to tell their own stories in their own words, with prompting by the researcher if required.

**Table 49. Potential challenges of interviewing people with dementia**

| Potential challenges of interviewing people with dementia |
|---|
| Rigid questioning may lead to participants becoming agitated as they could feel there is a right and wrong answer; this could also lead to participants trying to please the research by answering in a manner they perceive will please the researcher. |
| Using devices such as dictaphones can be off putting and increase stress among participants. |
| People with dementia may respond differently if their carer is also present at the time of the interview. |
| Interviews may take considerable time as the person with dementia may forget what they are saying or move on to a new topic. |
| People with dementia may not fully understand what is asked of them |

The aim of unstructured interviews has been described by Lofland *(1971:76)*[69]*:*

*'to elicit rich, detailed materials that can be used in qualitative analysis. Its objective is to find out what kind of things are happening rather than to determine the frequency of predetermined kinds of things that the researcher already believes can happen'*

The prompts chosen for this analysis are shown below, depending on the natural course of the conversation they may not all be included:

- Diagnosis
- Knowledge about services
- Access to services
    - Support for the person with dementia
    - Support for the carer
    - Day to day support
    - Community support
    - Residential support
    - Emergency support
- Quality of life both for the person with dementia and for the carer.

Based on this, each interview was expected to be of a different nature and duration. In some, the focus was only on one or two of the prompts above while others included all of the above prompts. The ordering of the prompts also varied depending on the direction of the participants' story. In some cases it was not appropriate to ask about some of the prompts.

As part of the interview, the researcher tried to use open ended prompting in order to avoid yes / no answers and to encourage the participant's to share their experiences.

Information about consent, how the data was to be used, and what was required of participants was provided to activity leaders and discussed with all participants. An information sheet about the research that was provided to group leaders can be found in Appendix 11.

People with dementia, their carers, and people who had previously cared for someone with dementia were invited to take part in the research while attending established groups in Central Bedfordshire. This included services operated by the

---

- [69] Lofland J (1971). Analyzing social settings. Wadsworth, Belmont.

Alzheimer’s Society, Carers in Bedfordshire, and Central Bedfordshire Council. These services were geographically spread across Central Bedfordshire and encompassed a range of services available to people with dementia and carers. At the start of the session, the research introduced herself and invited participants to talk to her on a one to one basis or in small groups. The researcher had a small notebook to capture comments and short quotes form participants. At the end of the conversation, the researcher read back these notes to the participant to check she had accurately captured the participants comments.

## Limitations of this approach:

This approach did suffer selection bias (the results may not be representative of the whole population of people with dementia and their carers in Central Bedfordshire) as only people with dementia or carers that attended the chosen groups and were present on the day the researcher attended the group were eligible to be included in this research and within the chosen groups only motivated individuals volunteered to take part.

This approach also excluded people with the most severe forms of dementia as only people who could communicate were included. Younger people with dementia were also not included; this was not by choice but a result of no people with dementia under the age of 65 accessing services on the chosen days. In an attempt to capture the views of younger people with dementia and their carers a request for volunteers was made on Young Dementia UK’s social media pages. Unfortunately this did not result in anyone living in Central Bedfordshire getting in touch with the researcher.

## Analysis:

The analysis was based on thematic content arising from the interviews. After the period of data collection, the researcher’s notes were analysed for emerging themes and recommendations that can be included in the health needs assessment. Small quotes that were captured were transcribed.

## Validation of analysis:

In addition to reading the notes back to participants to check understanding, the researcher also shared the thematic analysis with a number of group leaders to ensure that what had been captured was representative of wider people with dementia in Central Bedfordshire.

## Presenting the results:

The results of this qualitative research will be presented in three ways in this health needs assessment:

1. Throughout the health needs assessment small quotes from research participants will be included where relevant.
2. The thematic analysis will be presented.
3. A number of personal stories will be documented through a series of quotes.

## Thematic analysis

Table 50 summarises the key themes arising for each of the included prompts. To be included as a theme, the view had to be reported by at least two independent participants; this was to ensure that the views captured were reflective of a wider population rather than isolated issues. Any isolated issues arising were followed up with a relevant stakeholder, for example a dementia support worker or dementia nurse. The views presented are the views of participants.

Table 50. Key themes arising from participants views and supporting quotes

| Prompt | Themes arising from participants views | Supporting quotes |
|---|---|---|
| **Diagnosis** | • The person with dementia may be a carer themselves; this could delay diagnosis due to fears about who will support the person they care for.<br>• It can take the person with dementia or their carer a long time to admit they have a problem and seek medical help or to come to terms with a diagnosis.<br>• People with a stronger academic background that are accustomed to remembering facts may find it easier to score well on the memory tests despite showing other symptoms of dementia; this could result in a delayed diagnosis.<br>• The level of support given to people with dementia and their carers may vary depending on where the diagnosis is made.<br>• Information needs to be presented in a way that people with dementia and their carers can understand for example there is too much jargon used. | *‘You go in, it’s just like having a baby, no handbook or manual, you just leave the hospital and have to learn what works for yourself, but children learn and progress, they don’t.’*<br>*‘It’s devastating to hear the diagnosis, that word dementia; it’s devastating for them, for you.’*<br>*‘We left as a wreck, no support, cried on the way home, just left to get on with it, at least we had each other.’*<br>‘It’s taken her time and adjustment to come to terms with the diagnosis.’<br>‘Some cleaver people can forge the tests, you get better treatment at the vets.’ |

| | | |
|---|---|---|
| **Knowledge about services** | - At the point of diagnosis, people with dementia and their carers are given too much information, this results in information overload for carers and can be daunting for person with dementia.<br>- While some participants praised the local services including the diagnostic process and support, a lot of participants reported finding out about services through word of mouth.<br>- Overall it was felt that there is a good ranges of services available, if you know where to find them, particularly if you include non-dementia specific services such as the Rotary club, WI, Age UK, Village groups, and Church groups. | *'There are fragmented services, it is unclear who you are dealing with, who does what, the assessment is NHS, the support council but the boundaries and cross over in care services are unclear.'*<br>*'I had more support at the start but not so much now, I think it's there but I'm not sure how.'*<br>*'You have to be determined to find out what there is.'*<br>*'Nobody tells you anything, if you need support and who to turn to, you need to find it out yourself.'* |
| **Access to services**<br>**General** | Access to services will be split into general themes and transport specific themes.<br>- There are few dementia specific day centres in Central Bedfordshire.<br>- Carers had heard of Admiral nurses in other areas and thought these would be a great benefit in Central Bedfordshire.<br>- Activities and groups should be planned for the afternoons as it makes tasks easier for carers such as getting a person with dementia washed, | *'We would benefit from admiral nursing, nothing like it offered here, they are specifically trained.'* |

| | | |
|---|---|---|
| **Transport specific** | dressed, fed, and to the venue; particularly if using public transport.<br>• According to participants, some groups had waiting lists to join.<br>• Some participants felt they faced extra challenges due to boundary issues within Central Bedfordshire. Examples given included:<br>○ People being asked to travel further to attend a group or day centre in their local authority area when an alternative was available geographically closer but the alternative was a different local authority area.<br>○ A patient may be registered with a GP in one CCG area but live within a different CCG or local authority area.<br>• The timings of public transport and activity groups may not always match up, this can either put people off attending or force them to find expensive alternatives.<br>• It was commonly reported that using public transport with someone with dementia is extremely difficult, particularly if changes were required for example a route that requires two bus journeys. | *'Not all people with dementia have someone who can drive, this makes travelling a massive barrier, it's not easy getting someone with dementia on and off buses.'*<br>*'I can't start to explain how hard it is to get someone on a bus, they can be confused, difficult and anxious.'* |

| | | |
|---|---|---|
| **Hospital care** | - Carers reported bad experiences of inpatient hospital care. This included the person with dementia becoming institutionalised and their condition deteriorating.<br>- Carers reported that hospital staff do not always address the person with dementia, instead the person with dementia has been talked over. This is upsetting for the carers as well as the person with dementia. | *‘We had a bad experience of L&D, he became institutionalised and forgot family members.’*<br>*‘I was furious, is he? Does he? Such as a cold fish, they ignore the person with dementia.’*<br>*‘Staff at hospital do not acknowledge the person with dementia, they just talk to me.’* |
| **Support for the person with dementia** | - The person with dementia may be a carer themselves.<br>- Both people with dementia and carers felt it was important for there to be services that the person with dementia can attend on their own – this allows them to come out of their shell but also gives carers a much needed break.<br>- Some people with dementia found attending groups where there are people with all stages of dementia quite daunting and would prefer to attend groups with people at a similar stage of cognitive ability. | *‘When you are at home alone you miss out on what’s going on but groups like this really help.’*<br>*‘Groups like this are great, I like getting out, keeping busy.’*<br>*‘The worst thing is Im limited in driving, Ive been involved in driving all my life, all sorts of vehicles.’*<br>*‘She couldn’t understand why I wanted to stop driving.’* |

| | | |
|---|---|---|
| | • Driving was a major issue among people with dementia and some carers. People with dementia did not always understand why they could no longer drive and others felt they were letting down their partner, especially if their partner did not drive. Some people with dementia went as far as saying that their carers had put pressure on them to continue to drive against medical advice. Some carers however reported having terrible problems convincing the person with dementia not to drive. | |
| **Support for the carer** | • Carers frequently reported feeling reluctant to accept financial help, for example attendance allowance, some were concerned that this was a sign that they could no longer cope and others reporting feeling guilty asking for help.<br>• The vast majority of carers felt that peer support was vital, especially as family support may not be available or appropriate. However some past carers reported that they were not always welcome to attend groups after the person they had cared for had died.<br>• Carers would like more information about the specific subtypes of dementia, the subtype of dementia can have a big impact on the behaviour of the person with dementia and the subsequent help a carer may require, for example dealing with aggression and /or hallucinations. | *‘I was reluctant to accept financial help, it was the knock on effect that helped the most, now I can get help with things around the house.’*<br>*‘Family are not always best, especially when you don’t see them often, they fly in with their suggestions and ideas but they don’t know what works, they don’t know how the person is, what their limits are and they can make things worse whereas other carers do understand, what I say wont shock them, it will shock the family, especially when the person is not how they remember them to be, or rather how they want the person to be.’*<br>*‘I felt excluded, I couldn’t see the friends I had made because my husband had died when I needed support, I was vulnerable.’*<br>*‘I feel torn, who do I see, who do I care for?’* |

| | | |
|---|---|---|
| | - Specific courses such as the Alzheimer's Society CrISP course were highly praised and recommended however a lack of support to find care for the person with dementia to be looked after so the carer can attend the course is not always available.<br>- Cares wanted to be kept informed about the care of their loved one and involved in any decision making process.<br>- Carers may have complex health conditions themselves. And / or also be caring for other relatives (with or without dementia, or children).<br>- Carers reported a lack of support to help them manage a physically bigger and / or stronger person with dementia.<br>- Carers felt that support was lacking for dealing with certain tasks such as how to remove a driving licence from a person with dementia. | *'I struggle as my daughter is also in a care home, but he doesn't accept that.'*<br>*'It was such an arduous process, removing his licence, that's what upset me the most, I didn't know what to do, I didn't want him to drive, I knew he wasn't safe but I knew it would devastate him to lose his licence. In the end I had to trick him in to letting me drive.'* |
| **Day to day support** | - Transport was frequently cited as a major barrier for people with dementia. In Central Bedfordshire buses may not be suitable for people with dementia and several carers were critical of the Buzzer bus due to operational management. | *'Carers are so important, we need support but it needs to be consistent, not constantly swapping, we need to build rapport, this means I can trust them with my husband and I don't have to keep repeating his history, likes and dislikes. It helps if carers are interested and really know the patients, what their* |

| | | |
|---|---|---|
| | - Carers frequently reported that it was unclear who carers could contact at different times of the day for support. | *interests are, and then they can know when something is wrong.'* |
| **Community support** | - Dementia friendly communities and environments were seen very positively, as were community schemes such as the police tagging scheme for vulnerable people, although it was often commented that schemes like this need more advertising.<br>- Generally there were positive comments about support services and groups, although a number of carers felt that recent changes to one organisation had had a negative impact on service delivery as eligibility criteria to attend groups had changed.<br>- It was felt that people with dementia and carers could gain a lot from non-dementia specific services and that these should be promoted more to people with dementia to help them remain part of the wider community.<br>- When speaking to carers, there was a widespread general misconception about who funds services. | *'The dementia gateway meetings are excellent, there are lots of people there from different organisations, it was through these meetings that I found out about Age UK, they helped me to find out about attendance allowance.'*<br>*'It's nice to know you are not lone, it makes me it makes you feel better, just speaking, you may not be caring for someone with the same issue but by hearing what others are going through it make you feel better, you are all different but you are all caring for a loved one.'*<br>*There is a gap between Central Bedfordshire Council and the Alzheimer's Society, why can't the Alzheimer's Society pay Central Bedfordshire Council to do more work with dementia, it's in the news enough.'* |
| **Residential support** | - Carers often reported either first or second hand experiences of when someone with dementia had had a negative experience in a hospital or respite care setting, this increased their fears about using respite care. Common perceptions included that the person | *'I am reluctant to try care centres etc due to previous bad experiences.'* |

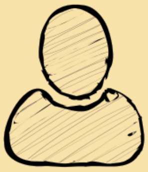
| | | |
|---|---|---|
| | with dementia would not have their basic care meets met, would come out worse than they went in or have issues with their regular medication. | *'It's the small things, teeth cleaning and changing clothes not done in respite care.'* |
| **Emergency support** | • As mentioned above, carers had little trust in hospital care; this was particularly felt for A&E.<br>• The vast majority of carers reporting not knowing who to contact when they required emergency support, for example in a care situation not a medical emergency like getting someone out of a bath or chair. | *'A&E was not the place for her, all that noise and business, I needed help but not A&E that was not right not appropriate.'*<br>*'It's horrible when you desperately need support but there isn't anything, anyone.'*<br>*'I didn't need an ambulance but I didn't know who else to turn to, I felt guilt that I couldn't cope, you see it on the news, not using ambulances right'*<br>*'My husband attacked me at 10pm, there was no help from the 24hour line, I was forced to call the police and my husband was taken in to hospital.'* |
| **Quality of life for the person with dementia** | • People with dementia reported feeling frustrated, confused, isolated and a burden to others. They felt they benefitted from attending groups and socialising with others.<br>• Giving up driving frequently came up as an issue, particularly for males with dementia.<br>• Situations were reported where the person with dementia was talked over and not included in the conversation despite being present. | *'8am looks like 8pm, I've got out of bed at 9pm but I've not known if its am or pm so I got dressed and then I realised it was not morning.'*<br>*'One day I couldn't remember how to tie my shoe laces, the next day I could, I just kept going until I did them.'*<br>*'The hardest part for me is knowing that I won't get my mind back, I might get worse and worse, a downward spiral.'* |

| | | |
|---|---|---|
| | | *‘I feel frustrated, I can’t help but be late because my carer is late, it annoys me.’*<br>*‘I found I was nervous, I tried to find a way that way not so difficult, I wouldn’t drive at night. In the end I was selfish, I gave it up. I got frightened, I thought this is silly I stopped.’* |
| **Quality of life for the carer.** | • Peer support from groups including services like Carers in Bedfordshire, and the Alzheimer’s Society is crucial to help support and inform carers.<br>• One of the hardest things carers reported having to deal with was when the person they cared for no longer recognised them or other family members.<br>• Some carers found it hard to make use of schemes such as using carers vouchers at the weekend to enable them to catch up with their friends or take part in activities while the person they cared for was being looked after.<br>• The importance of having consistent care was highlighted. For carers consistence care allows trust to be developed for example by not having to repeat histories, likes and dislikes. For people with dementia, having a consistence care package can cause less confusion. Overall if hired carers really | *‘Carer’s in Bedfordshire have been a tremendous support, I cannot fault them, they even gave support to past carers, they help with paperwork and when a carer is in a mess.’*<br>*‘You have to watch someone you love living in a another world, sometimes there is violence, you could see it in his eyes, he didn’t know who I was in his life.’*<br>*‘They lose their sense of awareness, she was in the middle of the road, cars coming but she didn’t understand that she should be there.’*<br>*‘As a carer, I feel sad, bereaved, I’m on duty 24 hours a day, I can’t move quickly enough, time doesn’t mean anything to them.’*<br>*‘You have to be alert all the time, you don’t know what they are going to do next, finding time for yourself like when to have a shower is difficult, if I* |

| | | |
|---|---|---|
| | know the person they are caring for they will be better placed to know when something is wrong. | *leave him I don’t know what will happen even for a short while so I can wash or use to toilet’* |

## Personal stories

Eight personal stories are presented on the pages that follow. Each story takes the format of a series of short quotes by the same people. To protect the persons identify, the person will only be identified by their sex, if they are a person with dementia, a carer or past carer and their living arrangements; this is to provide some context to the quotes.



**Male with dementia**

**Cared for at home by his wife**

***‘I'm not happy that she is doing everything, its wearing her out, I feel guilty asking her for help’***

***'She had a heart attack, my son came to help but she wouldn't have carers in the house, she is too proud'***

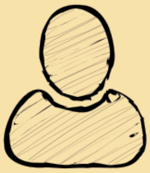
***'I want to come to respite so I can give her a break but the place is full'***

**Female with dementia living alone**

*‘Little things, I forgot to start with, but now I'm nervous about driving’*

*‘Its strange, its getting worse, I'm conscious that I'm forgetting things’*

*‘I found cooking a chore, I was getting bad, I couldn't think what to cook, I ate bacon and eggs everyday as I can't remember what I like to eat, I was worried about how to cook, now I eat ready meals'*



**Male with dementia**

**Cared for at home by his wife**

*‘The worst thing is I'm limited in driving, I've been involved in driving all my life, all sorts of vehicles.’*

*‘I'm embarrassed, I've taught so many people to drive and now I can't, I'm as sick as a parrot.’*

*‘I don't know if there is a cure’*

**Female carer, caring for husband at home**

*‘I didn't really want it (benefits) there are more people in need than me, I was talked into it, I guess its right as I do everything for him, and it would cost more if I wasn't here but it doesn't really feel right with the state the country is in’*

*'I've never really liked driving, he always used to do that, to drive but now he can't I've been forced to drive, I started off driving with someone but now I can drive short distances by myself or with only my husband'*

*'Im lucky I have plenty of help from family and friends, if I didn't it would be much harder’*

**Male with dementia**

**Cared for at home by his wife**

*'I'm not very good at remembering things'*

*'Coming here brings us back into things, I can get things out of it'*

*‘It suddenly comes to you, I've seen that it comes back, not worry about it, you get into it'*

*'I love it here, its tremendous' (referring to a Carer's In Bedfordshire support group)*

**Female with dementia living alone**

*'I feel frustrated, I can't help but be late because my carer is late, it annoys me'*

*'The hardest part for me is knowing that I won't get my mind back, I might get worse and worse, a downward spiral to death'*

**Female carer, previously cared for husband at home, husband has now died**

*‘He wouldn't admit he had a problem, it took a long time to get a diagnosis, we went to hospital every six months, he had hallucinations, then we were sent to another hospital where he was diagnosed with lewy body dementia’*

*‘You have to watch someone you love living in a another world, sometimes there is violence, you could see it in his eyes, he didn't know who I was in his life’*

**Female carer, caring for husband at home**

*'The dementia gateway meetings are excellent, there are lots of people there from different organisations, it was through these meetings that I found out about Age UK, they helped me to find out about attendance allowance'*

*'I was reluctant to accept financial help, it was the knock on effect that helped the most, now I can get help with things around the house'*

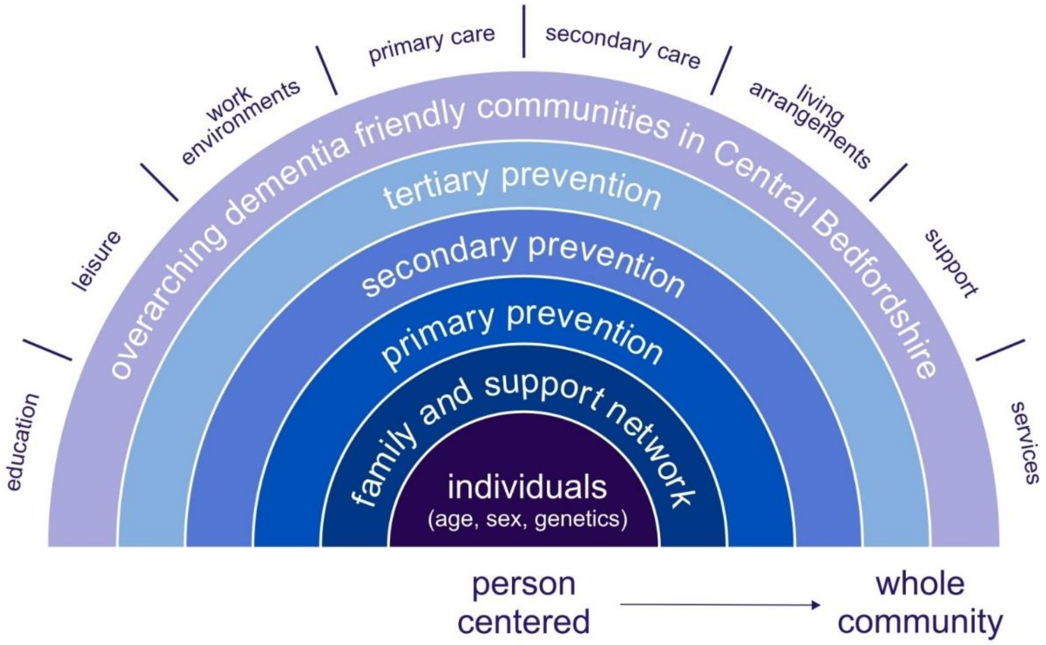
*'I don’t know how to change a light bulb but Age UK can send someone I can trust that wont rip me off'*

# Section 12. Recommendations

The recommendations presented build on the previous sections of this health needs assessment; including the views of people with dementia, their carers, past carers, and stakeholders. Dementia is a complex illness that has significant impact on the person with dementia and their support network. Figure 31 illustrates the key areas where recommendations have been made in this health needs assessment. These recommendations are for the Central Bedfordshire Dementia steering group to consider and should be reviewed in six months.

This figure has been designed specifically for dementia in Central Bedfordshire, it is loosely based on the Wider determinants of health model by Dalgren and Whitehead. At the centre of the model is the person with dementia, the immediate factors such as age, sex, and genetics are out of their control but will influence an individual’s risk of dementia. Moving from the inner rings to the outer rings the recommendations shift from focusing on the individual person and factors within their control such as behavioural risk factors to overarching recommendations to support dementia friendly communities.

**Figure 31. Key areas where recommendations have been made**



1. **Information, support and training is needed throughout the dementia pathway, providing a single point of contact early in the patient journey would be beneficial.**

Rationale: People with dementia and their carers will need different information at different stages of the disease. A single point of contact can greatly support people with dementia and their carers in managing their own dementia journey. Training carers can equip carers with knowledge and techniques to better support the person they are caring for while being mindful of their own health and wellbeing needs. Ultimately this can lead to better health outcomes for the person with dementia and their carer.

*Key sections in HNA and examples:*

- *Support for Carers, including training for carers: Section 7 Page 104.*
- *Single point of contact (e.g. similar to Admiral nurses model): Section 7 Page 106, Section 10 Page 140-1*
- *Out of hours support: Section 10 Page 136.*

2. **Services for people with dementia and their carers should utilise a person centred care approach to ensure the support provided is tailored to the individual's needs.**

Rationale: Each person with dementia will experience their own unique disease characteristics and progression. The experience for carers will also vary and the level of support a carer needs will be unique to their situation. Offering the right support at the right time to the person with dementia and their carer can improve the quality of life for both.

*Key sections in HNA and examples:*

- *Services should recognise the different types of dementia and how the symptoms may manifest in people with different types of dementia: Table 10, page 32.*
- *The needs of younger people with dementia and their families present different challenges and that should be catered for by support services: Section 4 Page 58, 61, 64 and 66.*
- *Support services should cater for people with dementia that do not have a dedicated carer: Section 7 Page 100 and Section 10 Page 138.*
- *Evidence based interventions to support people with dementia and their carers: Section 6 Page 95 and Section 7 Page104.*
- *Support should consider providing the opportunity for carers to share their knowledge either during their experience or after the person they have cared for has passed away: Section 11 Page 153.*

3. **Health and social care providers should look to ensure staff training about dementia is appropriate and helpful to increase the patient and carer experience whether inpatient or outpatient.**

Rationale: Identifying issues early can result in better care for people with dementia and access to support services. This can increase the quality of life for the person with dementia and help them remain in their own homes for longer if the appropriate support is provided.

Key sections in HNA and examples:

- *Correctly recording the status of people with dementia: Section 2 Page 37.*
- *Appropriate training for different staff groups: Section 8 Page 113 and Section 10 Page 141.*
- *Successfully managing patients that do not attend appointments: Section 10 Page 140.*
- *Supporting patients with dementia while inpatient e.g. notifying a dementia nurse specialist on admission for dementia specific actions to be completed conducting a nutritional needs assessment): Section 11 Page 152.*

4. **CBC and BCCG can be a catalyst for dementia friendly communities. This could include:**
    - **Increasing awareness of preventive measures e.g. linking dementia to existing key public health campaigns and services.**
    - **Increasing awareness of dementia across public services and with private organisations.**

Rationale: By raising awareness this should help to decrease stigma associated with Dementia, improving quality of life for people dementia and their carers.

*Key sections in HNA and examples:*

- *Promoting an integrated approach to key public health messages 'What's good for the heart is good for the brain' and understanding the early signs of dementia and where to seek help: Section 5 Page 82 and Section 8 Page 113.*
- *Consider Best practice from other parts of the UK for supporting communities to become dementia friendly: Section 8 Page 112-114, and Section 10 Page 139-141.*
- *It is important to keep people with dementia involved in the community and provide support to encourage this: Section 4 Page 66 and Section 8 Page 112, Section 10 Pages 139-141 and Section 11 Pages 152 and 155.*

The recommendations in this section should be considered with the Local Government Information Unit's recommendations for local authorities Table 39 in Section 8 of the full report and recent publications, including the Alzheimer's Society Dementia 2014: Opportunity for change, and the Department of Health Primer Minister's challenge on dementia 2020. Summaries of the key recommendations in both of these reports can be found in Appendix 12.

**A great place to live and work**

**Contact us…**

by telephone: 0300 300 8301
by email: customer.services@centralbedfordshire.gov.uk
on the web: www.centralbedfordshire.gov.uk
Write to Central Bedfordshire Council, Priory House,
Monks Walk, Chicksands, Shefford, Bedfordshire SG17 5TQ