Kirklees Dementia Needs Assessment
# Contents

1 Summary............................................................................................................................................................ 3
2 Introduction...................................................................................................................................................... 4
3 Understanding Dementia........................................................................................................................................ 5
   3.1 Types of dementia............................................................................................................................................. 6
   3.2 The Impact of dementia...................................................................................................................................... 7
   3.3 Chewing and swallowing - Dysphasia................................................................................................................ 8
   3.4 Dying with Dementia........................................................................................................................................... 8
4 Carers................................................................................................................................................................... 9
5 Current and Predicted Prevalence in Kirklees................................................................................................. 10
   5.1 Severity.......................................................................................................................................................... 11
   5.2 Gender............................................................................................................................................................ 11
   5.3 Ethnicity.......................................................................................................................................................... 12
6 Dementia in primary care....................................................................................................................................... 13
   6.1 Prescribing data ............................................................................................................................................... 13
7 Dementia in Social care....................................................................................................................................... 14
8 Dementia in general hospitals.......................................................................................................................... 15
9 Spending on Dementia – now and in the future.............................................................................................. 16
   9.1 What does the future look like?...................................................................................................................... 16
10 Service requirements – now and in the future............................................................................................... 18
   10.1 Prevent......................................................................................................................................................... 18
   10.2 Diagnose........................................................................................................................................................ 18
   10.3 Support - Living well with dementia........................................................................................................... 19
11 Conclusions......................................................................................................................................................... 22
1 Summary

Dementia currently represents one of the greatest challenges to our economic, health and social care landscape. With no known cure and with limited treatments available, dementia is redefining our individual and collective experience of ageing, irrevocably changing the lives of ageing citizens across Kirklees.

Dementia describes a group of symptoms caused by the gradual death of brain cells, leading to the progressive decline of functions such as memory, orientation, understanding, judgement, calculation, learning, language and thinking. Dementia is a terminal disease where patients are expected to live between three to fifteen years after diagnosis.

There are several diseases that cause dementia. In late-onset dementia, Alzheimer’s disease is the most common disease, accounting for around 60% of all cases, followed by cerebrovascular disease (vascular dementia), and dementia with Lewy bodies which together account for 15-20% of cases. In young-onset dementia, fronto-temporal dementia is the most common disease, followed by Alzheimer’s. Less common diseases that may also cause dementia include Parkinson’s and Huntington’s, HIV and AIDS, Korsakoff’s syndrome, Creutzfeldt-Jakob disease, multiple sclerosis, and motor neurone disease, amongst others. There are also mixed cases of dementia have also been identified such as Alzheimer’s and dementia with Lewy bodies.

There are a number of potential pharmacological (e.g. cholinesterase inhibitors), and non-pharmacological (e.g. cognitive behavioural therapy) interventions that focus on treating the symptoms of dementia. Nevertheless, people with dementia are at an increased risk of physical health problems and become increasingly dependent on health and social care services and other people.
2 Introduction

The specific objectives of the needs assessment are to:

- Describe the population at risk of dementia, highlighting particular characteristics relevant to Kirklees.
- Estimate the current and future incidence and prevalence of dementia
- Summarise key service requirements as laid out in the national dementia strategy\(^1\) and consider their implications for Kirklees.

The ICD-10 definition 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.

The condition is complex and can cause extensive physical, psychological, emotional and financial stresses to those with dementia, their family carers and the wider community.

An increase in the population aged over 65 years, particularly those aged over 85 years, is likely to lead to an increase in the numbers of people with dementia. This will also increase the demand for health and social care services.

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3 Understanding Dementia

The term ‘dementia’ is used to describe a set of symptoms which result from the ongoing deterioration of the brain, caused by a number of diseases in which there is a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the ability to carry out daily activities.² There are individual differences in the speed and progression of dementia; people may live with it for up to 15 years after diagnosis, but it is a terminal illness. Each person is unique and will experience dementia differently.

Dementia progressively reduces a person’s ability to understand, remember, reason, communicate and function in daily life as they used to. A person with dementia becomes increasingly dependent on care and much of that care is, in many cases, provided by their spouse, child or other family members or friends. Consequently dementia also brings with it increased health problems for those family or friends who provide the care and support. People with dementia are high users of health care and of formal social care, in addition to the care provided informally by family or friends. The cost of dementia is large in every way.

The risk of developing dementia increases greatly with age. For people aged 60-69, the likelihood of having dementia is around one per cent for women and one and a half per cent for men; for those aged 90 or more around a quarter of men and one third of women live with dementia.³ The UK population is growing, and is projected to continue to grow, especially in the older age groups. Increasingly, age is the main risk factor but other factors include genetic background, medical history and health behaviours. About half of all cases of dementia have a vascular component (i.e. linked to the blood supply to the brain) and so are linked to smoking, diet and physical activity.

Dementia is the most feared illness in people over the age of 55⁴. The brain is the organ that we least understand. We don’t just fear the loss of memory - in a very real way, we fear the loss of who we are. Dementia is chronic brain failure and delirium is acute brain failure. Dementia is more than just about memory; it is a collection of difficulties that also includes the ability to manage our affairs and to plan things – often referred to as ‘executive functions’.

The symptoms of dementia include:

- Loss or lapses of recent memory
- Mood changes or uncharacteristic behaviour (in later stages this will be pronounced)
- Poor concentration

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² Alzheimer’s Society. from: http://www.alzheimers.org.uk/factsheet/401
⁴ PHE, Attitudes to dementia Findings from the 2015 British Social Attitudes survey, NatCen 2016
• Problems communicating
• Getting lost in familiar places
• Making mistakes in a previously learned skill (e.g. cookery)
• Problems telling the time or using money
• Changes in sleep patterns and appetite
• Personality changes
• Visio-spatial perception issues (i.e. the brain does not process images as normal).

3.1 Types of dementia

Alzheimer’s disease - This is the most common cause of dementia with around 2 in 3 dementia diagnosis’s falling under Alzheimer’s. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.

Vascular dementia - If the oxygen supply to the brain fails, brain cells may die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes.

Dementia with Lewy bodies - This form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue.

Fronto-temporal dementia - In fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory.

There are many other rarer causes of dementia, including progressive supra-nuclear palsy and Binswanger’s disease. People with multiple sclerosis, motor neurone disease, Parkinson’s disease and Huntington’s disease can also be at an increased risk of developing dementia.

Creutzfeldt-Jakob disease - Prions are infectious agents that attack the central nervous system and then invade the brain, causing dementia. The best-known prion disease is Creutzfeldt-Jakob disease, or CJD.

Korsakoff’s syndrome - Korsakoff’s syndrome is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory.

HIV-related cognitive impairment - People with HIV and AIDS sometimes develop cognitive impairment, particularly in the later stages of their illness.

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6 Dementia Revealed - What Primary Care Needs to Know, November 2014
Mild cognitive impairment - Mild cognitive impairment (MCI) is a relatively recent term, used to describe people who have some problems with their memory but do not actually have dementia. According to the Alzheimer's Society: It is estimated that between 5 and 20 per cent of people aged over 65 have MCI. It is not a type of dementia, but a person with MCI is more likely to go on to develop dementia.

Traumatic Brain Injury – Fibres (axons) connecting brain cells are snapped during impact and withdraw into “retraction balls”, with frontal areas most vulnerable because axons are longer.

Learning Disabilities - Individuals with learning disability (LD) are at higher risk of developing dementia and the specific association between Down’s syndrome and Alzheimer’s disease is well recognised. The assessment of cognitive impairment in LD needs special care, paying attention particularly to co-morbid physical and mental health disorders and less reliance of standard tests of cognition. People with Down’s syndrome are four times more likely to develop dementia and for it to begin at an earlier age.

3.2 The Impact of dementia

Nationally, it is estimated that 1 in 20 people over the age of 65 years are affected by dementia and 1 in 5 people aged over 80 years. By 2030 it is estimated that this will have increased by more than 60%. In Kirklees it is estimated that nearly 1 in 16 (4,800) people aged over 65 had dementia in 2015, and that this is projected to rise to nearly 5,500 or 1 in 14 by 2020. It is estimated that there are over 100 people locally with young onset dementia i.e. aged under 65 years and this is expected to increase slightly too around 110 by 2020.

Generally, only 1 in 3 people nationally with dementia ever receive a formal diagnosis or have contact with specialist services at any time in their illness. However diagnosis rates have improved in Kirklees and now almost 2 in 3 people predicted to have dementia have a diagnosis and are known to services. In North Kirklees diagnosis rates are 68.2% and Greater Huddersfield is 66.8%.

Up to half of all people with dementia also have depression. People with both dementia and depression have higher rates of disability and higher rates of hospital admission than people with dementia alone. People with dementia are also at greater risk of social isolation, particularly as the condition increases in severity.

8 POPPI. Available from: http://www.poppi.org.uk
10 CCG Diagnosis Data – November 2016
11 Dementia - A state of the nation report on dementia care and support in England, Department of Health, 2013
3.3 Chewing and swallowing - Dysphasia

A person with dementia may have difficulties with chewing food. They may forget to chew or they may hold food in their mouth. Certain foods, such as sweetcorn or dry biscuits, may be more difficult for the person to chew or swallow. These should be avoided if chewing is an issue. Good oral hygiene is important. If the person is feeling pain in their mouth, chewing will be uncomfortable and difficult. If the person wears dentures, they should be comfortable and fitted properly. People with dementia can get tired easily. Eating soft, moist food that needs minimal chewing can help.

As dementia progresses, swallowing difficulties (called dysphagia) become more common, although they can vary from person to person. If a person is having difficulty with swallowing, a referral to a speech and language therapist can help. Difficulties can include holding food in the mouth, continuous chewing, and leaving foods that are harder to chew (e.g. hard vegetables) on the plate. Swallowing difficulties can also lead to weight loss, malnutrition and dehydration.\textsuperscript{12}

3.4 Dying with Dementia

Nationally two-thirds of people say they would prefer to die at home. The majority (58\%) of deaths with a mention of dementia occurred in care homes. By comparison a much lower proportion (25\%) of all deaths in the general population aged 65+ happen in a care home.

Only 8\% of people who die with dementia pass away at home, compared to 21\% of the general population aged 65+. They are less likely to die at home than people dying with cancer, circulatory or respiratory diseases.

Nearly a third (32\%) of people who die with a mention of dementia die at a hospital, a lower proportion than in the general population (49\%) or amongst those dying with cancer, circulatory or respiratory diseases. Only 1\% of deaths with dementia happen in a hospice, compared with 5\% of deaths in the general population aged 65+. People with dementia are less likely to die in a hospice than people dying of cancer.

People who die with dementia are more likely to die younger if they reside in more deprived areas. The proportion difference is small but significant and is more pronounced for people with vascular dementia.

End of life care can pose difficulties because dementia is not always predictable. Ideally, patients with dementia should be asked about their end of life wishes before they lose capacity. Relatives and carers continue to have a very important role if a patient is in hospital or has gone into care and need to be listened to carefully. An end of life plan, incorporating the known wishes of the patient, is important.

\textsuperscript{12} https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=149
4 Carers

Carers are a valuable asset within our communities, providing not just voluntary, unpaid care to assist the person they care for to remain independent, but also love, friendship, reassurance and connection. Carers have good knowledge of the person they care for and their health issues, often co-ordinating and managing their care.

Although we know that caring for someone with dementia can have a significant impact physically, emotionally, socially and economically on a person’s life, information about how many unpaid family carers care for someone with dementia is not clear locally.

Informal carers do nearly all of the work of caring for patients with dementia, so looking after carers is vital. Most GPs and practice nurses know that taking the time to listen, empathetically, is highly valued by carers and primary care has a key role in supporting carers. For many carers, the development of dementia in someone they love is a deep and long drawn out living bereavement. They may want to talk about it from time to time and some may need formal counselling.

Most carers have a legal right to an assessment of their own needs. The Local Authority will examine what help is needed with caring. This may be provided as part of a Community Care Assessment for the individual with dementia. It is helpful to ensure that both carer and the individual with dementia are assessed. The Carer’s Assessment covers help required to maintain the carer’s own health and balance caring with other aspects of their lives, such as work and family.
## 5 Current and Predicted Prevalence in Kirklees\textsuperscript{13}

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2015</th>
<th>2030</th>
<th>% Change in population</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-64</td>
<td>107</td>
<td>116</td>
<td>+8%</td>
</tr>
<tr>
<td>65-69</td>
<td>299</td>
<td>325</td>
<td>+9%</td>
</tr>
<tr>
<td>70-74</td>
<td>470</td>
<td>600</td>
<td>+28%</td>
</tr>
<tr>
<td>75-79</td>
<td>802</td>
<td>1,055</td>
<td>+32%</td>
</tr>
<tr>
<td>80-84</td>
<td>1,129</td>
<td>1,962</td>
<td>+74%</td>
</tr>
<tr>
<td>85-90</td>
<td>1,150</td>
<td>1,828</td>
<td>+59%</td>
</tr>
<tr>
<td>90+</td>
<td>957</td>
<td>1,870</td>
<td>+95%</td>
</tr>
<tr>
<td>65+</td>
<td>4,807</td>
<td>7,640</td>
<td>+59%</td>
</tr>
</tbody>
</table>

\textsuperscript{13} POPPI & PANSI Data 2016
5.1 Severity\textsuperscript{14}

Estimated Case Prevalence in 2015 (Kirklees)

- **Mild Dementia**: 2,700 (55%)
- **Moderate Dementia**: 1,570 (32%)
- **Severe Dementia**: 600 (13%)

5.2 Gender\textsuperscript{14}

There are variances between women and men when it comes to dementia. The most robust way of looking at this is by understanding how many cases of dementia there are in every 1,000 people in the population.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male dementia prevalence per 1000 population</th>
<th>Female dementia prevalence per 1000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-69</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>70-74</td>
<td>31</td>
<td>24</td>
</tr>
<tr>
<td>75-79</td>
<td>51</td>
<td>65</td>
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<tr>
<td>80-84</td>
<td>102</td>
<td>133</td>
</tr>
<tr>
<td>85-89</td>
<td>169</td>
<td>220</td>
</tr>
<tr>
<td>90+</td>
<td>295</td>
<td>318</td>
</tr>
<tr>
<td>Total 65+ by gender</td>
<td>53</td>
<td>76</td>
</tr>
</tbody>
</table>

It can be seen that dementia is actually more prevalent in men until they reach 75-79. Then it becomes 20-30% more common in women until the 90+ age group when it is 7% more prevalent in women. We know that women on average live longer than men, but they also live longer in ill health or with a disability than men.

\textsuperscript{14} POPPI Data, 2016
5.3 Ethnicity

There are increasing indications that the prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white UK population and that the age of onset is lower for Black African-Caribbean groups than the white UK population. Since these groups are also more likely to experience high blood pressure, it is suggested that the increased risk of vascular dementia contributes to increased prevalence.

We need to understand the shape of ethnicity in Kirklees to understand the future potential growth in dementia within these groups. There may be a stigma connected with dementia and diagnosis in some cultures or communities, and some languages and cultures do not recognise. The revised NHS dementia data collection tool, which advises of diagnosis rates locally and nationally, now pulls data referring to ethnicity. Once this information has started to come through, meaningful data with regards to BAME communities will be available to shape both strategy and service development.

Currently 1 in 20 (5%) of older people are from an Asian or Asian British background, in the 0-17 population this grows to 1 in 4 (25%). As this cohort and the mixed/multiple ethnic background group ages they will account for around 1 in 3 of all older people. If current data and thinking is correct we could see increasing incidence of vascular dementia in proportion to Alzheimer’s disease.

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**2014 Population estimate by ethnicity - ONS**

- 0-17 Years old: 67% White, 25% Asian/Asian British, 9% Mixed/multiple ethnic group, 5% Black/African/Caribbean/Black British
- 18-49 Years old: 76% White, 18% Asian/Asian British, 9% Mixed/multiple ethnic group, 5% Black/African/Caribbean/Black British
- 50-64 Years old: 89% White, 9% Asian/Asian British, 9% Mixed/multiple ethnic group, 5% Black/African/Caribbean/Black British
- 65+ Years old: 93% White, 7% Asian/Asian British, 9% Mixed/multiple ethnic group, 5% Black/African/Caribbean/Black British

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15 Black, Asian and Minority Ethnic Communities and Dementia – where are we now? David Truswell, A Race Equality Foundation Briefing Paper, 2013
Dementia in primary care

Dementia is a clinical syndrome which affects the intellectual functions of the brain – remembering, thinking, and deciding. Each GP will have about a dozen patients with the disorder. There can be opportunities and challenges at all stages of the illness, whether in relation to prevention, or at the end of life. People may present later in the illness, often in crisis, so timely diagnosis is important in that it can allow support to be provided for people and their families and help to avert emergency admissions to a hospital or a care home. There is a range of approaches to care. Clinical Commissioning Groups (CCGs) hold legal responsibility for assessing and delivering NHS Continuing Healthcare (CHC) to individuals with Dementia.

6.1 Prescribing data

- **Donepezil** – Used for Alzheimer’s disease, mild and moderate
- **Rivastigmine** – Used for Alzheimer’s disease mild and moderate and Dementia in PD
- **Galantamine** – Used for Alzheimer’s disease, mild and moderate
- **Memantine** – Used for Alzheimer’s disease, moderate to severe

% Drug therapy in registered dementia population

<table>
<thead>
<tr>
<th>Drug</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donepezil</td>
<td>69%</td>
</tr>
<tr>
<td>Rivastigmine</td>
<td>5%</td>
</tr>
<tr>
<td>Galantamine</td>
<td>8%</td>
</tr>
<tr>
<td>Memantine</td>
<td>18%</td>
</tr>
</tbody>
</table>

There is no specific drug treatment for vascular dementia but GPs are familiar with the lifestyle changes and drug therapies that reduce vascular risk.

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16 Dementia Revealed - What Primary Care Needs to Know, November 2014

17 Health Informatics Service (October 2016)
7 Dementia in Social care

Social and community support services are of great importance in the care of people with dementia. The services commissioned by the local authority range from the provision of information to practical help such as day, domiciliary and respite care.

The numbers of people with dementia are increasing; diagnosis and early intervention helps people with dementia to live well and delay premature admission to long term care. Providing high quality support to people with dementia, from staff who are fully ‘dementia aware’, will become an increasing focus in all commissioning activities for older people and we will be looking towards providers who can demonstrate they are able to support people with dementia as part of their on-going service offer.\(^\text{18}\) We are currently reviewing our dementia commissioning plan to ensure it is meeting the needs of both users and carers. This may mean we identify gaps in provision which we will be looking to source from the market. Finding quality solutions which support people to remain at home and delay the need for long term care will be a priority.

It is estimated that up to 90% of people in care homes have dementia, and Care Quality Commission studies show that people with dementia in care homes are more likely to go into hospital with avoidable conditions such as dehydration than similar people without dementia.

\(^\text{18}\) Common Core Principles for Supporting People with Dementia – Skills for Care and Skills for Health, 2010
8 Dementia in general hospitals

Patients with dementia, who have to go into hospital, are particularly vulnerable. It is very helpful for staff to know what a patient’s baseline function is before admission, and to know a patient’s likes and dislikes as well as some personal details such as what they prefer to be called. Patients and carers should be encouraged to complete the ‘This is me’ document, available on the Alzheimer’s Society website, and bring it with them to hospital and other places.¹⁹

Patients with cognitive impairment are at risk of developing delirium when ill. This is increasingly recognised as a serious condition that carries a high mortality risk. Falls and injuries occur when patients try to climb out of bed or go wandering. Delirium delays hospital discharge. Patients who have delirium may take several weeks to recover and some will never recover their previous cognition. Between forty and sixty per cent of patients are not fully recovered at the time of discharge. Disturbing vivid hallucinations may be remembered long after the patient is better and may disturb previously trusting relationships. Patients may remain puzzled and shaken about what has happened to them.

Hospitals are highly detrimental environments for people with dementia. Inevitably, there will be changes of wards and changes of staff. The benefits and risks of hospital admission in late stages of dementia require careful conversations with relatives, and knowledge of a patient’s prior wishes can be very helpful. There needs to be a discussion of what can realistically be achieved by hospital admission, and decisions may be complicated by feelings of guilt on the part of relatives, or fear of allegations of neglect on the part of care home staff. However, many relatives do take the view that the interests of the patient are not best served by another admission, and that they would prefer that their relative receives palliative support at home.

9 Spending on Dementia – now and in the future

The human cost of dementia is greater than any monetary value; however there is a growing body of national evidence about the costs of care and support relating to those with dementia.

It is thought there are around 4,900 people in Kirklees in 2015 with some degree of dementia. The overall economic impact of dementia in the UK is £26.3 billion. This works out at an average annual cost of £32,250 per person. It is estimated that dementia costs £158m per year in Kirklees, using national benchmarks the severity of dementia is likely to have the following pattern locally.20

The estimated costs in monetary terms for 2015 are outlined below, this is based on the total estimated dementia population rather than those confirmed with a diagnosis locally. These costs are broken down by proportion for each person or agency providing support:

9.1 What does the future look like?

If current trends in prevalence and spending continue at the same pace, it is thought that there will be around 5,600 people locally with dementia and a total cost of over £181m, with £100m being spent across health and social care alone

### Predicted Spend by agency/carer (2015)

<table>
<thead>
<tr>
<th></th>
<th>Healthcare</th>
<th>Social care</th>
<th>Unpaid care</th>
<th>Other costs</th>
<th>Total Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild dementia</td>
<td>£8.0m</td>
<td>£14.5m</td>
<td>£48.4m</td>
<td>£0.3m</td>
<td>£71.3m</td>
</tr>
<tr>
<td>Moderate dementia</td>
<td>£12.3m</td>
<td>£33.8m</td>
<td>£15.5m</td>
<td>£0.2m</td>
<td>£61.9m</td>
</tr>
<tr>
<td>Severe dementia</td>
<td>£5.7m</td>
<td>£13.6m</td>
<td>£5.8m</td>
<td>£0.1m</td>
<td>£25.2m</td>
</tr>
<tr>
<td>All severity levels</td>
<td>£26.0m</td>
<td>£61.9m</td>
<td>£70.0m</td>
<td>£0.6m</td>
<td>£158.6m</td>
</tr>
</tbody>
</table>

As the table above indicates the care and support of those with dementia is dominated by unpaid carers. When the costs of unpaid care and privately funded social care are removed the cost to the public sector is clearer. The total predicted costs of dementia locally are around £51.5m rising to £58.8m in 2020.

There is also likely to be a proportion of social care costs that are paid solely by self-funders. A self-funder is someone who pays for all of their social care or support from their own private resources (including social security benefits such as state pension or attendance allowance), or tops up their local authority residential or home care funding with additional private spending.

In future, the number of people who will fund their own care will grow. While accurate local data is lacking, national studies suggest that between 15% and 57% of older people currently fund their own care in residential care (depending on local levels of deprivation), equating to around 45% of all registered care home places. In addition, around 40% of people currently fund their own care at home entirely, with 21% topping up public funded care.  

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10 Service requirements – now and in the future

10.1 Prevent

Raising public awareness about dementia, reducing the stigma and fear associated with dementia, raising awareness of the modifiable risk factors and encouraging people to seek help and obtain a diagnosis are all important elements. Keeping vascular risk factors under control is always going to be worthwhile, as is keeping weight down and exercising. Keeping mentally active and retaining social networks is also good.

Focusing on prevention and encouraging or enabling people to behave in ways which will improve their health outcomes (for example, relating to heart disease and stroke which increase the risk of vascular dementia) to reduce those risk factors associated with some dementias which we can do something about, e.g. alcohol use.

10.2 Diagnose

In Kirklees we have a robust clinical pathway for diagnosis, outlined below.
In addition to GP and Memory Monitoring Services, which are key elements on the local Dementia pathway, there is currently a Dementia Information, Advice and Support service. This service sits on the Dementia pathway following formal diagnosis and acts as a point of contact for service users and carers. Kirklees also has an active Dementia Action Alliance provider whose work focusses on promoting Dementia-friendly communities and businesses across the whole of Kirklees, linking into local innovations such as the Safe Places Scheme and roll out of the Herbert Protocol.

We also need to ensure dementia is diagnosed as early as possible, to ensure the best outcomes for the person and their carer’s.

10.3 Support - Living well with dementia

Access to advice and support

When a diagnosis of dementia is given it is often the start of the journey for many people. They may have some early symptoms but some of the long term impacts may not have materialised yet. There is a need to provide a range of high-quality, post diagnostic support from a range of agencies for those people with dementia and their carers so they are able to plan and take greater control over their own lives and maintain a good quality of life for longer and in their own homes.

Access to adaptations and appropriate accommodation

The use of technology to support people to stay in their own homes and communities also needs to be embraced, the costs of technology have dropped over the past decade and this should be capitalised upon.

Improvements to the provision of intermediate care and rehabilitation to reduce unnecessary or prolonged hospitalisation would also be a positive achievement.

It is also beneficial to engage with housing and third sector providers to deliver lower level support to maximise independence and maintain skills for as long as possible.

Access to treatment and therapy and end of life care

Therapeutic approaches to tackling the symptoms of the illness are essential in order to address cognitive impairments, functional limitations and behavioural problems. Dementia-specific therapies aim to delay deterioration, enhance coping, maximise independence and improve quality of life. Therapies include reality orientation, reminiscence therapy, cognitive rehabilitation, validation therapy and cognitive stimulation therapy.

People with dementia need to be able to access day services delivered specifically for those with dementia and generic day services for older people.
People with dementia need access to enabling and rehabilitation services to maximise independence – people with dementia have rehabilitation potential and some skills can be relearned or new skills developed to compensate.

People with dementia need access to good quality care and support to ensure people with dementia have a good death in their preferred place of choice at the end of their life.

**Access to dementia friendly environments**

People with dementia need to have dementia friendly environments by default, having dementia friendly design in care homes is positive, but as more people stay at home and in their own communities these design principles need to be more broadly applied. The Dementia Strategy in Kirklees has a key focus on creating and maintaining dementia-friendly communities.

**Access to carer support**

People with dementia often need the support of informal carers to live well. This impacts the life of many carers who can find it a struggle to care for the person with dementia. Supporting carers to understand dementia, its effects, and coping strategies is essential to helping people with dementia live well.

Additionally, as carers are focused on supporting the person with dementia they ignore their own needs; for example many will not go to their GP with their own health problems as they feel they can’t leave the person they care for. Coupled with the high levels of stress and anxiety which carers of people with dementia typically feel this can have a substantial negative impact on carers lives. Often carers of people with dementia care ‘around the clock’ and more than 70% of carers who provide care around the clock have suffered mental ill health. (KJSA)

Carers need support to cope with this situation. This includes the provision of appropriate advice, information, respite care, and peer support.

Respite care is an important way of helping the carer to have a break and think about themselves. This can be regular short breaks of a few hours a week, and longer respite care of a week or more at a time allowing the carer time to look after their own physical, emotional, and social needs. Breaks may mean time away from the person with dementia, or may mean a change of scene or more help for a period of time where the carer and person with dementia can spend quality time together.

Appropriate information and advice about dementia, about how to cope with dementia, and about how to look after yourself are important to maintaining a healthy carer relationship. Peer support can be effective to reduce isolation, show carers they are not the only one’s feeling as they do, and encourage people to share ways to get by. Without respite and
proper understanding the caring role is much more difficult, stressful, and likely to breakdown then it needs to be.

**Developing the workforce**

People with dementia need a workforce that is able to deliver high quality care: As the care of people with dementia has an impact across many different health and social care services, it is crucial that the workforce is trained in the common core principle for supporting people with dementia.
11 Conclusions

Dementia is a complex condition which, although national prevalence statistics suggest a decline, is increasing in incidence as the number of people who are 65+ continues to grow. This increasing incidence impacts on individuals, their carers, their communities and society as a whole. However, individuals with dementia deserve to live their lives as independently as possible, for as long as possible.

Those who provide unpaid care for people with dementia need to be supported and have access to outlets of support and breaks from the intense nature of caring for someone with dementia. Those who provide paid care for people with dementia need to be fully aware of the needs of individuals with dementia, receiving dementia training appropriate to their role.

We also need to embrace research and technological advancements that mitigate the effects and impacts that dementia has on those affected by it.

This dementia needs assessment forms part of a suite of documents which, collectively, aims to improve the experience of someone with dementia living in Kirklees along with the people who are caring for them. Please consider the contents of this document along with:

1. The Dementia Challenge in Kirklees: A Joint Dementia Strategy 2015 – 2020
2. The Dementia Strategy Action Plan (See Appendix 1 of the above)
3. The Kirklees Market Position Statement (which includes dementia)
Live life to the full
The dementia challenge in Kirklees