

Dementia and dementia related conditions

July 2014

Headlines

Prevalence and incidence of dementia

- There are approximately 2,260 residents of North Lincolnshire living with dementia, with an estimated 30 people newly developing the condition each year. This number will rise as the number of people reaching older age accelerates.
- Late onset dementia affects approximately 7% of the North Lincolnshire population aged 65+.
- Early onset dementia is relatively rare, affecting an estimated 2.2% of people with dementia, or an estimated 50 people under the age of 65 years in North Lincolnshire.
- The number of people living with dementia is likely to increase in the next 10 years and at a faster rate than nationally, due to North Lincolnshire's older than average population.
- Women are more likely to be affected than men due to longer female life expectancy. Currently there are 882 men and 1378 women living with late onset dementia in North Lincolnshire, that is, almost two women (1.6) to every man affected. However, this gender difference will change as male life expectancy improves.
- People with learning disabilities may experience a higher risk of dementia because of premature ageing. In addition, people with Down's syndrome have an increased genetic risk of developing early onset dementia, with up to three quarters of people with Down Syndrome over the age of 50 likely to develop the disease.

Severity

- At any one time, about 55% of people with dementia (1240) will have a mild form of the disease, 33% a moderate form, (745), and 12% a severe form, (270), with severity increasing with age as the condition progresses.

Living arrangements

- Nationally it is estimated that nearly two thirds of people with dementia live in the community and a third in care homes. Applied to North Lincolnshire's population this would mean, an estimated 1490 people with dementia living in private households and 770 living in care homes

- In 2014, there were more than 1990 registered care home places in North Lincolnshire, of which at least 1400 were registered for people with dementia. This is a higher rate of care home beds per 1000 people aged 75+ in the population, than nationally, (140 per 1000 compared with 114 across the country as a whole) and is well in excess of the estimated number of people living with a severe form of dementia currently.
- The highest concentration of such beds is in Brigg and Wold, Crosby and Park and Ashby wards and the lowest in Axholme Central and Ridge wards.
- National research suggests that good housing (including specific aids and adaptations) for people living with dementia can reduce or delay demand for health and social care services.
- As public awareness of dementia increases, and access to earlier treatment and support in the community improves, we should expect an increasing number of people with dementia to be living at home for longer.

Social Care

- In 2013/14, a total of 2,524 older people (65+) were supported by the local authority in residential or community based services, of which 152 had a primary need of mental health, and 44 had a primary need of dementia. This equates to less than 10% of those estimated to have severe dementia with critical care needs. This is clearly an underestimate of the total number of people with dementia in receipt of these services during the year, suggesting the need to review the mental health/dementia element of Care First. In contrast, the largest primary need recorded amongst older people was physical disability.
- According to the national dementia prevalence calculator there are likely to be at least 780 people with dementia living in care homes in North Lincolnshire, ie a third of all people living with the condition. Most of this number are likely to have critical care needs, ie they require constant supervision. National data suggest that about 33% of care home places for dementia are self funded and about 47% are provided without top up from the local authority. The remaining 20% are either provided for by the local authority with top up or by NHS Continuing Healthcare.

Ethnicity

- A relatively small number of people with dementia are from Black and Minority communities in North Lincolnshire, currently estimated at less than 20 people. This is unlikely to increase substantially for at least a further two decades, as our BME community is still a relatively young population.

Prevalence in primary care

- In 2014 an estimated 51% of people living with dementia in North Lincolnshire had a diagnosis and were being treated in primary care. This is an improvement on previous years and compares with an estimated diagnostic rate of 46% nationally. Nevertheless this still means that almost half of people living with the condition have not yet been diagnosed.
- Some of the barriers to diagnosis include a perceived lack of support, stigma, the absence of a cure, and lack of understanding about the care pathways involved.
- To improve diagnostic rates, information about local memory services and, screening if appropriate is offered to all 65-74 year olds at their health check appointment.

Dementia in general hospitals

- Nationally, it is estimated that a quarter of general hospital beds are occupied at any one time, by people with dementia.
- Locally the number of people coded as having dementia at admission is much lower than this, although it is increasing and averages at just under 9% of all unscheduled admissions amongst 65+s in North Lincolnshire.
- **CQUINs** Commissioning for Quality and Innovation (CQUIN) payments enable commissioners to link a proportion of a provider's income to the achievement of local goals. In 2013/14 a national dementia CQUIN was developed with the aim of improving the identification of people with dementia when in hospital, to ensure referral to appropriate services and to improve care whilst in hospital. Northern Lincolnshire and Goole Hospital Foundation Trust is currently working towards delivering this standard.

Spending

- The total annual costs to the North Lincolnshire economy of dementia is estimated to be between £32 - £71 million a year, of which more than a third is accounted for by carer's lost earnings.
- Even small reductions in the incidence of dementia or delaying the age at onset could make a significant difference to the burden of the disease. Research suggests that the greatest impact in terms of prevention is likely to come from public health programmes which aim to improve education, at all ages, identify and reduce the risk of vascular diseases in middle age, improve heart health and reduce the risk of depression in older age.

Prescription costs

- Between 2010/11 and 2012/13 the number of dementia drug items prescribed by GPs in North Lincolnshire rose by 75%. In spite of this, dementia prescription costs fell during this period by 46%, due to a number of anti dementia drugs coming off licence.
- As more dementia drugs come off licence in the UK, prescription costs associated with early diagnosis of dementia should fall further.

End of life

- In North Lincolnshire, an average of 340 people die each year where there is a mention of dementia on the death certificate. Of these, 62% die in a care home, and 10% at home.
- One of the recommendations of the recent Experience Led Commissioning work with stakeholders on Dementia Care in North Lincolnshire was to improve awareness of and confidence in Advance Care Planning amongst the local population, including formal and informal carers.

User and carer voice

- Generally, people living with dementia and their carers feel the quality of services in North Lincolnshire is good, but that there are still some capacity issues. Generally speaking users and carers would like:
- More comprehensive awareness training across the health and social care sector and the development of Dementia Friendly Communities
- Development of a first aider model of training on dementia awareness for staff working in key public access points including supermarkets
- A one stop shop for information about where to get help, including for self funders.
- A centralised 'one stop shop' for assessment and diagnosis, with pharmacies potentially offering first instance screening to improve access to early diagnosis.
- The development of a joining pack or communication passport at the point of diagnosis to ease relatives' and carers' access to timely advice and support and to reduce crises.
- Development of a local campaign to improve the take up of advanced care planning for people with dementia
- Improved access to information about personal budgets
- Implementation of a minimum set of standards for dementia training and competencies of care home and home care staff
- Increased opportunities for integrating the commissioning and delivery health and social care services for people with dementia

Future need

- Assuming prevalence rates remain constant, the number of people living with dementia in North Lincolnshire could increase by as much as 20% between now and 2020, due to natural population growth and an ageing population, whilst the numbers are expected to double by 2040, whilst the costs are likely to treble.

- The effects of this growth are likely to vary geographically across North Lincolnshire, with increasing numbers of families, individuals and carers being affected in our rural areas, where the older population is increasing fastest.
- People with dementia are likely to have additional illnesses, disabilities and conditions (dual diagnoses). They may also be living alone in the community. An increasing number are likely to be from minority groups, such as BME communities or LGBT groups.

All of these factors will need to be considered in the delivery of person centred care.

Key issues

- The number of people affected by dementia will increase significantly over the next 20 years.
- Timely diagnosis can provide advice support and treatment for sufferers and their carers and prevent crises and avoidable admissions to care homes.
- The treatment costs associated with earlier diagnosis are falling and are likely to fall further as more dementia drugs come off licence.
- Currently less than half of people estimated to have dementia nationally, have a diagnosis and therefore do not have the benefits of early assessment and intervention.
- In North Lincolnshire diagnostic rates have improved significantly in recent years, but are still averaging at 50%.
- Barriers to early help- seeking and diagnosis include: lack of insight for the person with dementia; low levels of knowledge about dementia and where to get help, lack of confidence amongst GPs in discussing the diagnosis with potential sufferers.
- National research suggests a significant improvement in diagnostic rates since the launch of the national dementia strategy and the allocation of additional dementia funds to PCTs.
- However, it is difficult to ascertain how much has come as a direct result of this increased government funding, since two thirds of PCTs were unable to say how their dementia allocation had been spent.
- A more recent national survey of memory clinics has suggested that referrals to these services have increased with a corresponding increase in diagnostic rates, suggesting that 'rebadging' mental health services as memory clinics may have altered the public's perceptions and reduced any stigma that might be associated with approaching 'mental health' services for help. This suggests there is scope for promoting these rebadged services further.

Background

- The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.
- Dementia can affect people of any age, but is most common in older people. One in six people over 80 has a form of dementia, compared with 1 in 14 people over 65.
- Researchers are still working to find out more about the different types of dementia, and whether any forms of the disease have a genetic link. It is thought that many factors,

including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia.

- Dementia is also a progressive condition, which means that the symptoms become more severe over time. Understanding how this progression happens can be useful in helping someone with dementia anticipate and plan for change. The main types of dementia include:
- **Alzheimer's Disease, (AD)** is the most common type of dementia, accounting for about 62% of cases. It changes the chemistry and structure of the brain, causing brain cells to die.
- **Vascular Dementia (VD)** accounts for approximately 17% of dementia and is caused by strokes or small vessel disease which affect the supply of oxygen to the brain. Vascular dementia affects people in different ways. It can cause communication problems, stroke-like symptoms and acute confusion.
- **Mixed AD and VD** account for approximately 10% of dementia sufferers.
- **Frontal lobe dementia** is a rarer form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change. This accounts for an estimated 2% of dementia sufferers.
- **Dementia with Lewy bodies** is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills. This accounts for an estimated 4% of dementia sufferers.

Source: *Alzheimer's Society. Dementia UK: The Full Report (2007)*

Burden of disease

As people become very old they are more prone to develop chronic physical diseases affecting different organ systems, as well as mental and cognitive disorders. Dementia is one of the main causes of disability in later life, and has a disproportionate impact on capacity for independent living.

According to the World Health Organization's Global Burden of Disease 2002 report, disability from dementia carries a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer, contributing 11.2% of all years lived with disability amongst people aged 60 years and over; which is more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of non terminal cancer (2.4%).

National policy

The national dementia strategy for England was the first UK government initiative to focus on improving dementia care, although similar strategies have since been launched in Scotland and Wales. It sets out a range of requirements to improve dementia services across the country, including, in brief:

- Raising awareness and understanding
- Early diagnosis and support, including the commissioning of a dementia care advisor, as single point of contact
- Improving the range of services including person centred community based services
- To improve care support, including access to high quality short break services

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- Improve the quality of care for people with dementia in general hospital, including the identifying leadership for dementia within general hospitals and defining the care pathway for dementia
- To improve access to intermediate care
- That housing support commissioners consider the needs of people with dementia and their carers in the development of housing options
- The development of explicit leadership for dementia within care homes , and commissioning of specialist in reach community mental health services
- Improved end of life care
- There is also a recognition that people with dementia may have restricted access to mainstream community physical health services

It was launched in 2009, with £150 million allocated to PCTs to help achieve these objectives. National dementia awareness campaigns were also raised.

In 2012, the Prime Minister's Challenge was published. It established three champion groups to progress national developments in dementia services by 2015.

This included:

Driving improvements in health and care

- Increased diagnosis rates through regular checks of over 65s
- Financial rewards for hospitals offering quality dementia care
- Dementia Care and Support compact signed by leading care homes and home care providers

Creating dementia friendly communities that understand how to help

- Awareness raising campaign

Better research

- Doubling overall funding for research by 2015

Local policy

The latest Joint Strategy for dementia can be found at : <http://www.northlincs.gov.uk/people-health-and-care/shaping-services/health-and-care-consultations/dementia-information/>

Risk factors

In 2005, the Medical Research Council undertook a large UK based study into the factors associated with the incidence of dementia. The following were identified as key risk factors.

Age

Age is strongly correlated with developing dementia, with incidence rising from 6.7 per 1,000 at 65-69 years of age to 68.5 per 1000 at 85 years of age and older. After the age of 80, the exponential increase in incidence slows down. Currently national life expectancy for males at birth is 79.2 and for females it is 83.0 , (ie 2010-12). In North Lincolnshire the equivalent figures are 78.3 years and 82.8, respectively, (2010-12). By 2030 it is projected that national life expectancy

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will increase to 82.1 for males and 85.5 for females, which is likely to increase the size of the population at risk, and a larger male population with the condition than currently.

Gender

The MRC study also found gender to be a risk factor. The prevalence of dementia is higher for men than for women between the ages of 65 – 74 years. After this age there is a higher prevalence amongst women, largely due to women's greater life expectancy post 65. However, this pattern may change as male life expectancy increases over time.

Table 1: Prevalence of early onset dementia applied to mid 2013 population estimates

Age	Male rate per 100,000	Female rate per 100,000	Estimated no.s in North Lincolnshire
30-4	8.9	9.5	1
35-9	6.3	9.3	1
40-4	8.1	19.6	2
45-9	31.8	27.3	4
50-4	62.7	55.1	7
55-9	179.5	97.1	15
60-4	198.9	118.0	17

Source: Alzheimers Society. Dementia UK the Full report (2007)

Table 2: Prevalence of late onset dementia by age applied to mid 2013 population estimates

Age band	Male %	Female %	Estimated no.s in N Lincolnshire
65-9	1.5%	1.0%	131
70-4	3.1%	2.4%	207
75-9	5.1%	6.5%	352
80-4	10.2%	13.3%	525
85-9	16.7%	22.2%	550
90+	28%	33%	495
Total (no)			2260

Source: Alzheimers Society. Dementia UK the Full report (2007)

Stroke and Parkinson's Disease

A high proportion of people with dementia are thought to have a vascular component. The MRC study found that a history of stroke, heart disease and hypertension, showed a clear risk pattern for the incidence of dementia, with an estimated two thirds of vascular dementia thought to be caused by strokes, or TIAs. People with Parkinson's Disease also showed an increased risk of developing dementia. According to NICE guidance, dementia occurs in between 15-30% of cases of Parkinsons' Disease.

Registered prevalence of some risk factors for vascular dementia, including stroke, heart disease and hypertension are above the national average in North Lincolnshire, due to an older than average population and a higher prevalence of lifestyle risk factors in the adult population, including smoking, physical inactivity and excess weight.

Figure 1: Prevalence of long term conditions in North Lincolnshire

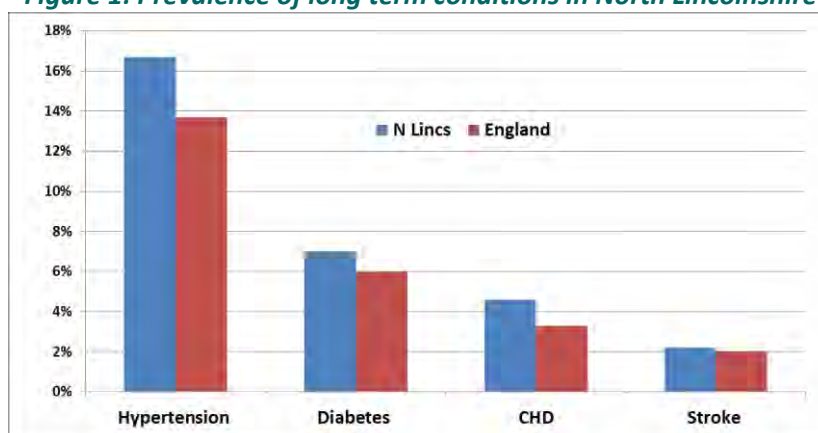
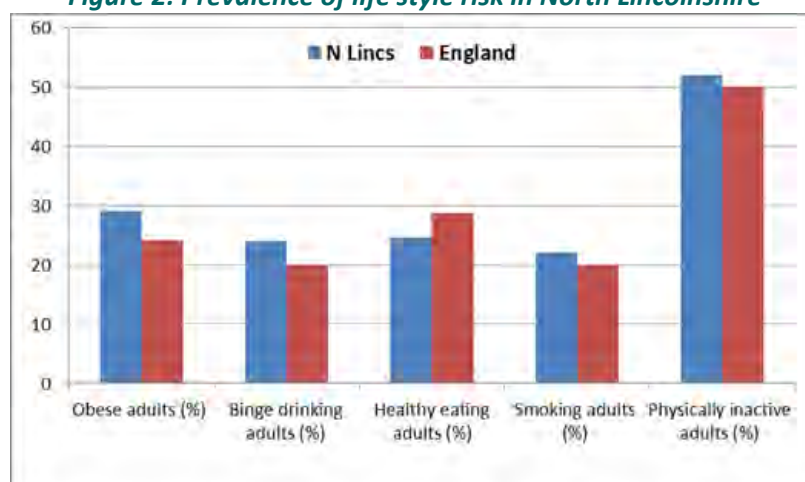


Figure 2: Prevalence of life style risk in North Lincolnshire



Source: Health Profiles, PHE, 2013

Learning Disability

People with learning disabilities may experience a higher risk of dementia because of premature ageing. In addition, people with Down's syndrome have an increased genetic risk of developing early onset dementia, with up to three quarters of people with Down Syndrome over the age of 50 likely to develop the disease. Additional specialist support and services may need to be provided to meet the increasing needs of the ageing learning disabled population.

Currently, there are an estimated 150 adults aged 50+ living with severe learning disabilities in North Lincolnshire.

Protective factors

Education seems to be an important protective factor, although there is evidence that compensation in higher age groups may mask the clinical signs and symptoms of dementia. Participation in cognitively stimulating activities and an active socially integrated lifestyle have both been observed to delay the onset of dementia. A Mediterranean-type diet with high

consumption of vegetables and fish (n-3 polyunsaturated fatty acids) has been observed to reduce the risk of Alzheimer's disease.

Population structure and distribution

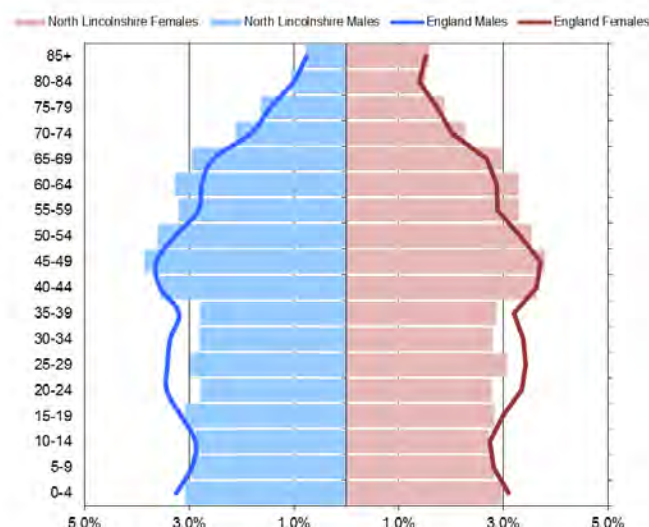
North Lincolnshire is a largely rural district, covering an area of 85,000 hectares. More than half of the resident population, 53%, live outside the urban areas of Scunthorpe and Bottesford. This is in contrast to 15 years ago, when more than half of our population lived in the main town of Scunthorpe.

The latest official mid-year estimates for 2013 suggest that 168,760 people live in the unitary authority district of North Lincolnshire. A slightly higher number are registered with North Lincolnshire GPs, 169,840 in 2013. This represents a population increase of more than 10% since 1991. Much of this growth has occurred amongst people in their mid 50s and older. Indeed, more than two thirds is accounted for by a growth in people aged 65 years and older. The figure below shows that currently, we have proportionately fewer residents aged 20-34 years than nationally, and more people aged 55+.

This means we should expect a faster than average growth in our older population, and as the life expectancy of men improves, a growing number of men amongst the very old.

Even assuming the annual incidence rate of dementia remains the same, we should expect a more rapid rate of growth in this client group in North Lincolnshire over the next two decades, compared with some of our peers.

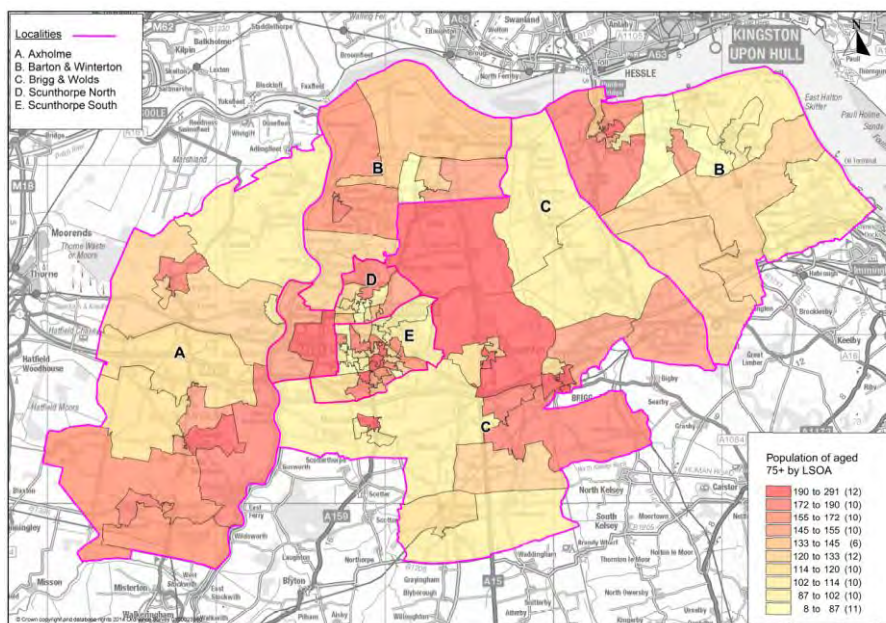
Figure 3: Population pyramid for mid 2013 North Lincolnshire compared with England



Source: ONS mid year population estimates, 2013

The age profile of our urban and rural areas is also changing, with a much younger population in our urban areas, and an older population in our rural areas, (see map below).

Figure 4: No of people aged 75+ by LLSOA in North Lincolnshire 2012



Source: ONS, 2012 Mid year estimates by LLSOA

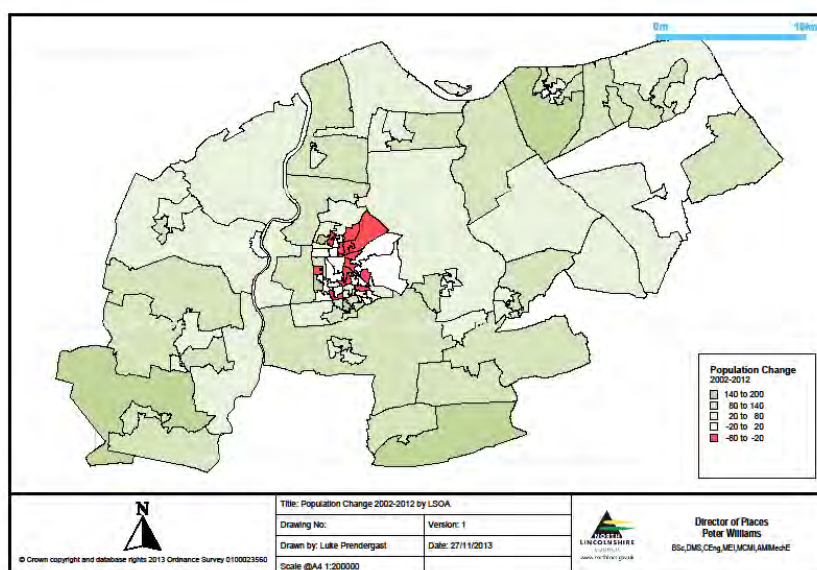
Table 3: %age change in the number of residents aged 75+ by locality 2001-12

		Axholme	Barton & Winterton	Brigg and District	Scunthorpe North	Scunthorpe South
2001-12 % change		29%	27%	24%	7%	20%
2012 no (% share of N Lincs total))		1977 (14%)	2768 (19%)	2918 (21%)	1889 (13%)	4646 (32%)

Source ONS population mid year estimates

Since 2001, the rural areas of North Lincolnshire have experienced the largest growth in the older population, with some urban areas showing signs of decline.

Figure 5: Percentage change in 65+ population 2001-12



Based on recent trends, it is anticipated that by 2020 the 75+ population will grow by a further 27% to approximately 18,000 people. Assuming the same distribution and growth of this population as in the previous decade, (ie no further movement of this age group in or out of the localities) more than half, (54%) of North Lincolnshire's older residents (ie those aged 75+) will reside in rural areas.

Table 4: % and number of resident aged 75+ projected to 2020 by locality

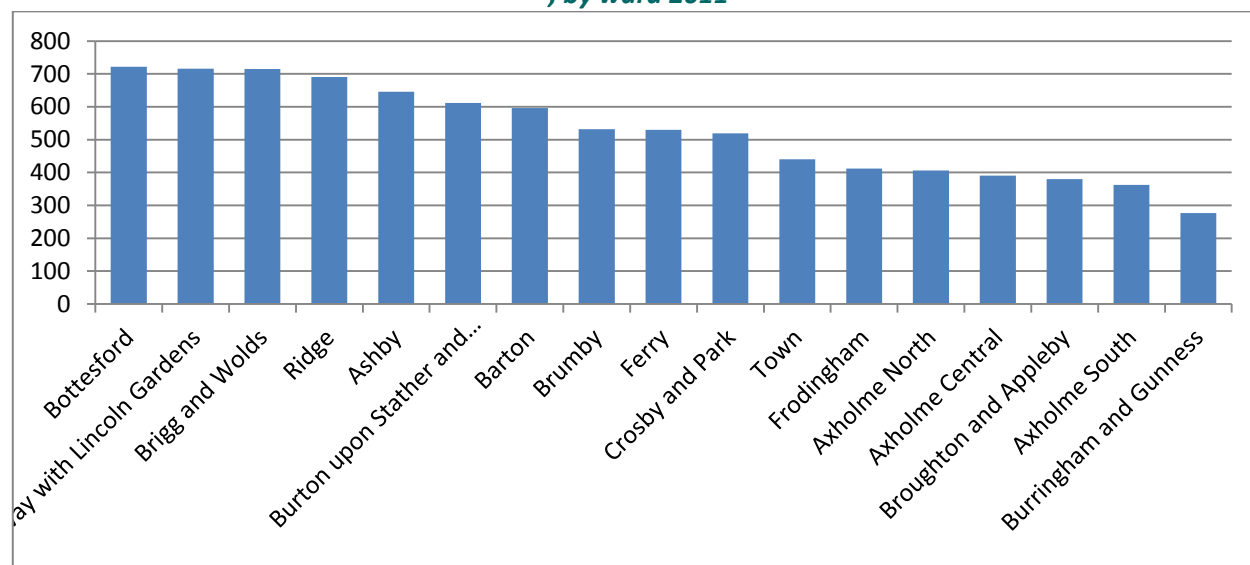
% projected change	Axholme	Barton & Winterton	Brigg and District	Scunthorpe Nth	Scunthorpe Sth
2012 – 20	+27%	+27%	+30%	+24%	+24%
Projected number 2020	2500	3420	3780	2340	5760

Source ONS population mid year estimates and 2012-based population projections

Living arrangements

More than a quarter of people aged 65+ (29%) live alone in North Lincolnshire, accounting for 13% of all households. . The largest proportion of lone pensioners are women aged 80+, the highest risk age group for late onset dementia. The highest concentration is in Bottesford, Brigg and Wolds and Kingsway and Lincolns Gardens wards.

Figure 6: Number of older people (aged 65+) who live alone in North Lincolnshire , by ward 2011



Source : ONS, 2011 Census,

Table 5: No (%) of older people aged 65+ who live alone by locality, 2011

Population aged 65+	Axholme	Barton and Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
Who live alone	1159 (20%)	1738 (26%)	1785 (36%)	1236 (29%)	3028 (36%)

Source : ONS Census, 2011

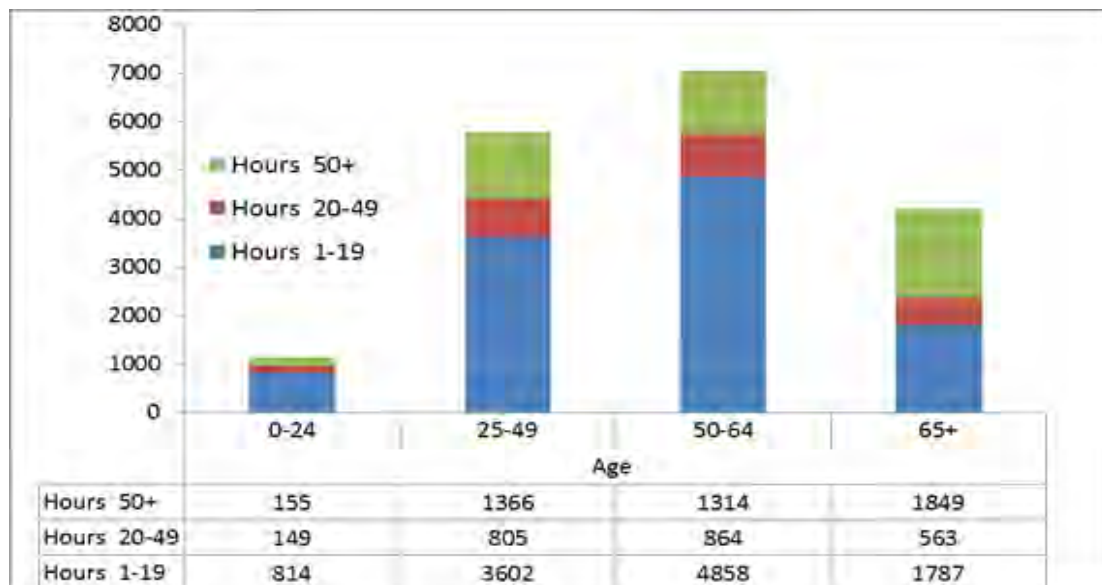
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Carers

According to the 2011 Census there are more than 18,000 people providing unpaid care for relatives or friends in North Lincolnshire. This represents 10.8% of the population, a rate similar to the national average. Whilst this is a similar proportion to 2001, when the rate was 11%, the rapid growth in the middle aged and older population in North Lincolnshire locally means that the actual number of carers has grown by 14% in the last 10 years. This is a faster rate of growth than nationally.

People aged 65+ provide the largest number of unpaid care hours a week. In 2011, 6% of people aged 65+ provided 50+ hours of unpaid care a week, for a relative or friend.

Figure 7: Provision of unpaid care in North Lincolnshire by age of carer, 2011



Source : ONS, Census 2011

It should be noted that the figures for carers relate to care for anyone with any long-term physical or mental health problem, a disability or problems associated with old age, and would thus include looking after someone with dementia alongside those with other needs.

Incidence and prevalence of dementia

Prevalence

At any one time there are estimated to be around 2,260 people living with dementia in North Lincolnshire. Young onset dementia is relatively rare, accounting for just 2.2% of all people with dementia across the country. Locally it is estimated that there are approximately 57 people with early onset dementia in North Lincolnshire. This may understate the actual number of people living with the condition, as prevalence of early onset is based on referrals to services.

Age

The prevalence of both early onset (under 65) and late onset (65+) dementia increases with age, doubling with every five year age increase across the age range. 69% of people living with the condition are over 80 years. Prevalence rises from 6% of all people aged 65+ to 33% of those aged 95+.

Table 6: Prevalence of early onset dementia applied to North Lincolnshire mid 2013 population estimates

Age	Male rate per 100,000	Female rate per 100,000	Estimated no.s
30-4	8.9	9.5	1
35-9	6.3	9.3	1
40-4	8.1	19.6	2
45-9	31.8	27.3	4
50-4	62.7	55.1	7
55-9	179.5	97.1	15
60-4	198.9	118.0	17

Source: Alzheimers Society. Dementia UK the Full report (2007)

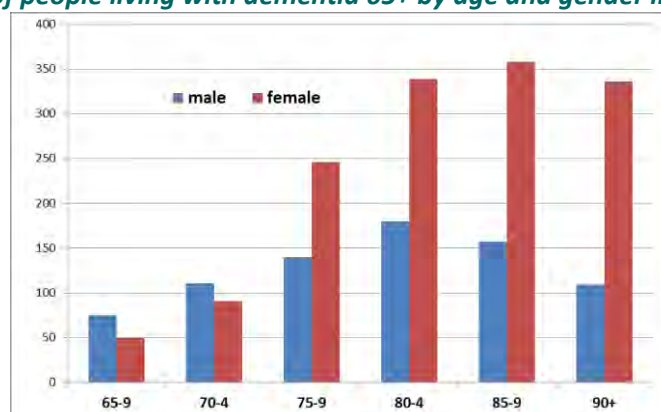
Table 7: Prevalence of late onset dementia by age applied to mid 2013 population estimates

Age band	Male %	Female %	Estimated nos in N Lincs
65-9	1.5%	1.0%	131
70-4	3.1%	2.4%	207
75-9	5.1%	6.5%	352
80-4	10.2%	13.3%	525
85-9	16.7%	22.2%	550
90+	28%	33%	495
Total (no)	882	1378	2260

Source: Alzheimers Society. Dementia UK the Full report (2007)

Overall, we estimate that there are 882 men and 1378 women living with late onset dementia in North Lincolnshire, more than 1 woman to every man (1.6:1) affected. The higher premature mortality rate and lower life expectancy of men accounts for much of this gender difference.

Figure 8: Estimated no of people living with dementia 65+ by age and gender in North Lincolnshire, 2013



Of these, it is estimated that approximately 1370 have Alzheimers' Disease. The remaining 830 have vascular and other forms of dementia.

Table 8: Estimated no of sufferers by type of dementia

Type of dementia	Proportion of people with dementia	Estimated no. in North Lincolnshire 2012
Alzheimers Disease	62%	1401
Vascular dementia	17%	384
Mixed (AD and VD)	10%	221
Dementia with Lewy bodies	4%	90
Frontotemporal dementia	2%	45
Parkinsons dementia	2%	45
Other	3%	68
Total	100%	2260

Source: Alzheimers Society. Dementia UK, 2007, applied to 2012 mid year estimates.

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Incidence

The number of new cases of late onset dementia per annum across the country as a whole is estimated to be 0.3% of the population as a whole, or 1.43% of the population aged 60 plus. Applied to North Lincolnshire's 60+ population, there are estimated to be at least 30 new cases of dementia each year in North Lincolnshire. This incidence increases significantly with age, from 6.7 per 1000 people at age 65-9 years, to 68.5 per 1000 people aged 85 years and older.

Table 9: Incidence of late onset (60+) dementia by age and sex

Age group	Incidence rate male per 1000	Estimated no of new cases	Incidence rate female per 1000	Estimated no. of new cases	Total no of estimated new cases per year in North Lincs
65-9 years	6.9	2	6.3	1	3
70-4 years	14.5	1	6.1	1	2
75-9 years	14.2	2	14.8	2	4
80-4 years	17.0	9	31.2	3	12
85+	58.4	5	71.7	3	8
Total		19		10	29

Source: MRC Cognitive Function and Ageing Study, 2005, applied to 2013 mid year estimates, ONS.

As this population grows we can expect the number of new cases to increase incrementally each year.

Estimated prevalence by locality and ward

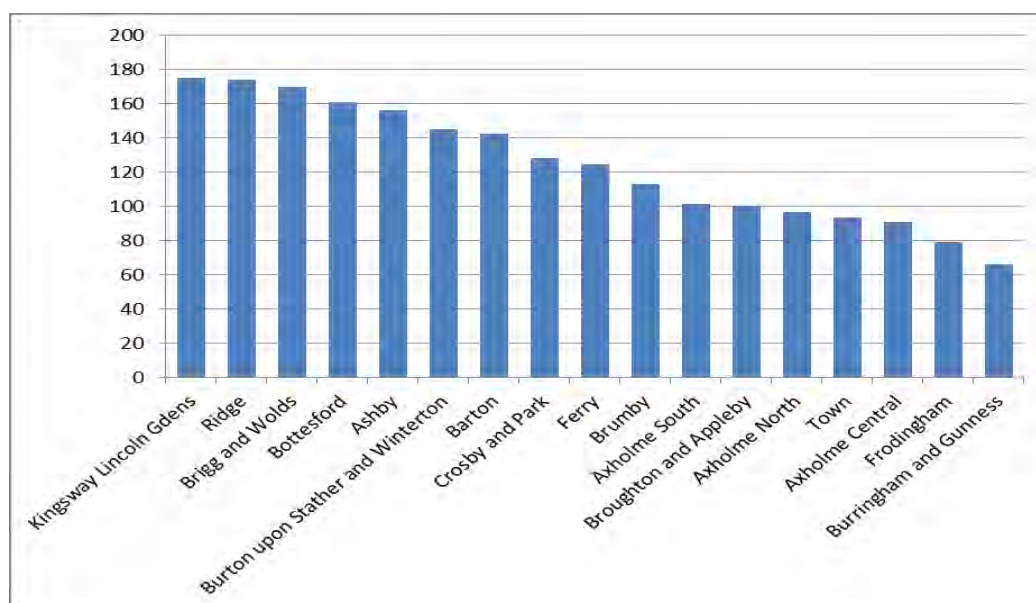
Overall, the rural localities of North Lincolnshire have a larger population of people aged 65+. We would therefore expect the numbers of people with dementia to be higher in these areas. As the table below shows, Brigg locality has the highest concentration of older people in North Lincolnshire. However, Scunthorpe South has the largest numbers in this age group, with just over 9000 residents aged 65+, and so it is likely that it is also has the largest number of older residents living with dementia. Even so, more than half, (54%) of those estimated to be living with dementia live outside the urban area of Scunthorpe and Bottesford.

Table 10: estimated numbers of people aged 65+ living with late onset dementia by locality of residence and locality of GP practice

Locality	% 65 + resident in the population (2013)	Estimated numbers with late onset dementia by residence (2013)	Estimated numbers with late onset dementia by locality of GP practice (2013)
Axholme	19%	300	320
Barton and Winterton	19%	460	380
Brigg and Wolds	21%	450	440
Scunthorpe North	16%	290	370
Scunthorpe South	17%	760	803

Source: Alzheimers Society. Dementia UK, 2007, applied to 2013 mid year estimates, and Dementia Prevalence Calculator, NHSE, 2014

Figure 9: Estimated prevalence of late onset dementia by ward



Severity

The severity of dementia is generally categorised as mild, moderate or severe. At any one time, about 55% of the affected population will have a mild form of the disease, 33% moderate and 13% severe, with severity increasing with age as the disease progresses.

Table 11: % of people with mild, moderate and severe late onset dementia

Age group	Mild	Moderate	Severe
65-9	62%	32%	6%
70-4	63%	30%	7%
75-9	57%	31%	12%
80-4	57%	32%	11%
85-9	54%	33%	13%
90+	49%	33%	18%
Total	55% (1240)	33% (745)	12% (270)

Source: *Alzheimers Society. Dementia UK, 2007, applied to 2013 mid year estimates*

Living arrangements

Nationally it is estimated that almost two thirds, 64%, of those with late onset dementia, live in the community, and 36% in care homes.

Assuming this same pattern applies to North Lincolnshire one might expect an estimated 1410 people in North Lincolnshire with dementia to live in private households and 790 to be cared for in care homes. The proportion living in care homes rises steadily with age, from 27% of those aged 65-74 with dementia, to 61% of those aged 90+ with dementia.

Table 12: Percentage of people with late onset dementia living at home or in care homes

	% living in the community	% living in care homes
65-74	73%	27%
75-84	72%	28%
85-9	59%	41%
90+	39%	61%
Total	64%	36%

Source: Alzheimer's Society, 2007

Residential status

Nationally, the prevalence of dementia is estimated to be 79.9% amongst residents of EMI registered care homes, 67% of nursing homes and 52% of residential homes.

Most people with dementia with critical or substantial needs will be living in nursing or care homes. However, the majority of people living in either residential or nursing care homes will have some form of dementia, moderate or otherwise, often with multiple co morbidities.

Nationally, the demand for residential care seems to be falling due to:

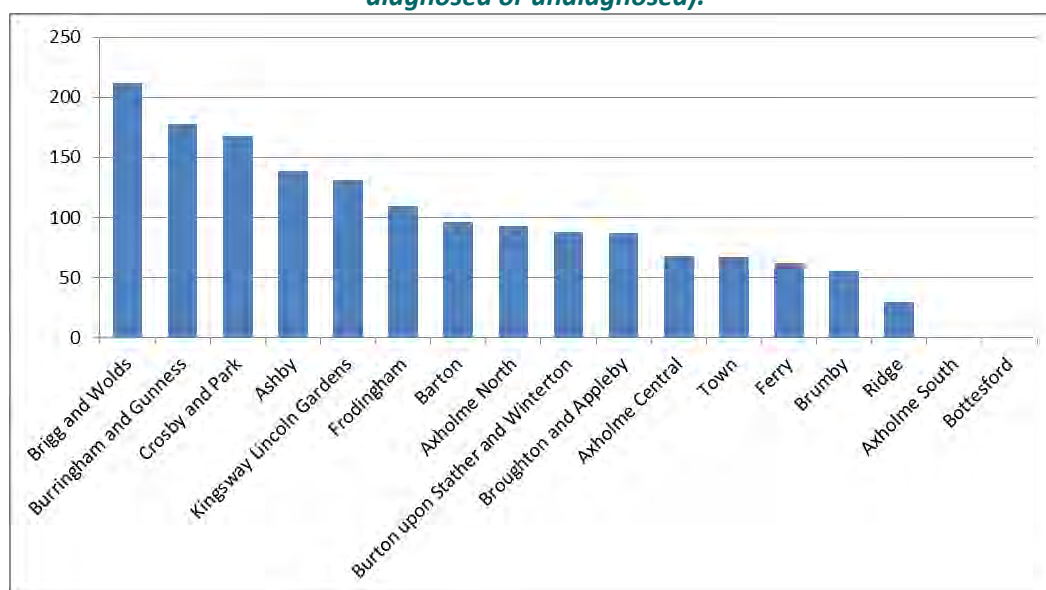
- Increases in the number of people with severe dementia and palliative care needs, who require nursing care
- Tighter council eligibility criteria
- Expansion of primary and community based support services, including assistive technology
- Expansion of extra care housing

Taking the national figure of 36% with late onset dementia living in a care home, we can estimate that in North Lincolnshire, there are likely to be at least 780 people with late onset dementia living in care homes, of which most will have a severe form of the disease, and 1140 living in the community, either with relatives or alone.

Currently, there are more than 1987 registered care home places in North Lincolnshire, of which at least 1400 are registered for people with dementia. This is a higher rate of care home beds per 1,000 people aged 75+ in the population, than nationally, (140 in North Lincolnshire, compared with 114 nationally.)

Although the occupancy rate of these care home beds is not known, this level of provision is in excess of the estimated numbers of people with dementia living in care homes in North Lincolnshire, giving a rate of 88 beds per 100 people estimated to have any form of the disease. The highest concentration of these registered beds relative to the size of the estimated population in potential need, is in Brigg and Wolds Burringham & Gunness, and Kingsway and Lincoln Gardens and the lowest in Ridge, (Axholme Central and Bottesford wards have no beds within the wards).

Figure 10: No of registered care home beds by ward per 100 estimated to have dementia (whether diagnosed or undiagnosed).



Source: CQC, 2014, ONS population estimates, 2013

Ethnicity

Locally there are estimated to be just 16 people from BME communities with dementia living in North Lincolnshire, one with early onset dementia. The proportion with early onset dementia (6%) is higher than it is for the White population, due to the much younger age profile of these communities. As this population ages, we should expect the numbers of people from BME communities living with the disease to grow.

The number of older people from lesbian, gay, bisexual, or transgender communities (LGBT) is also likely to increase in the future.

Inequalities in access to services

Nationally there is some evidence that people from BME groups are less likely to access dementia services than the white British population, because of stigma and lack of awareness. This group of people are more likely to be single, live on their own, and have fewer support networks than heterosexual people and so may have difficulties accessing services.

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The All Party Parliamentary Group on Dementia published 'Dementia Does not Discriminate,' and recommended that Health and Wellbeing Boards should encourage joint working between services and the local BME communities.

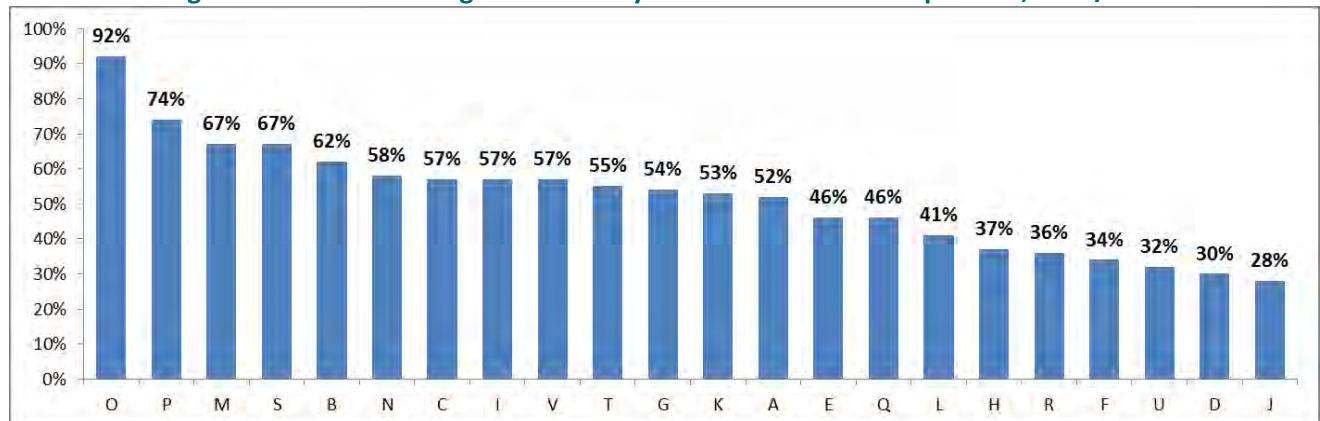
People who live in rural areas may be at greater risk than urban dwellers of poorer access to services due to public transport links or cost, especially if they live alone.

Diagnosed dementia

Currently there are an estimated 2260 people living with dementia in North Lincolnshire, of which an estimated 12% (270), will have the most severe form of the disease. This compares with 1,117 currently registered North Lincolnshire patients with a diagnosis of dementia on GP QOF registers, (2013/14), whose condition is being treated and managed within primary care. This is a significant improvement since 2010/11 when the number was 771, and represents a diagnosis rate of 50.7%.

Whilst not everyone with dementia would be expected to appear on GP registers, because many would be in the early stages of the disease, with relatively mild symptoms, the current coverage amounts to just over half of people estimated to have the condition. This is a significant improvement on 2010 and 2011, when the diagnostic rates were 41% and 43% respectively, and compares with a local and national rate in 2012/13 of 46%. There are significant variations by GP practice, as the figure below shows.

Figure 11: Dementia Diagnostic Rate by North Lincolnshire GP practice, 2013/14



Source: QoF, 2014, and estimated numbers of patients with diagnosed and undiagnosed dementia, dementia prevalence calculator

There are many reasons why primary care registers may vary in their level of recording dementia in the patient population. These might include factors relating to the overall level of service provision in the practice area, including access to memory clinics, (the density of care home beds for people with dementia may also raise levels in the catchment area), as well as the level of diagnosis and care. The highest diagnostic rates are in Scunthorpe South and the Isle of Axholme and the lowest in Scunthorpe South, and Barton, Winterton and District.

Table 13: estimated diagnostic rate by locality of GP practice

	Diagnostic rate
Axholme	57%
Barton Winterton and district	37%
Brigg and Wolds	44%
Scunthorpe North	34%
Scunthorpe South	59%

Source: QoF, 2012/13, estimated nos of people living with dementia based on 2012 MYE

In addition, some patients with dementia may be excluded from the QoF register. The reasons for this may include:

- Patients have been recorded as refusing to attend a review despite having been invited three times in the previous 12 months;
- Patients may have terminal illness or extreme frailty;
- Patients may be newly diagnosed or who have recently registered with the practice.

The table below shows the distribution of these registered patients in 2013/14.

Table 14
Number of people with a diagnosis of dementia on GP QoF registers by locality of GP practice, (provisional data for 2014)

	Axholme	Barton & Winterton	Brigg & Wolds	Scunthorpe North	Scunthorpe South
QoF Dementia register 2014	179	156	187	125	480
Estimated numbers with dementia on GP registers	316	383	436	367	803

There appears to be no association between living in a rural area and being diagnosed, nor does appear to be a link with deprivation.

Prescribing data

There are a number of drug treatments for cognitive or memory related difficulty in people and these are often part of a package of care alongside non pharmacological approaches, such as psychological therapies.

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Analysis of prescribing data shows that over 7352 dementia related drug items were prescribed to North Lincolnshire registered patients in 2012/13. This equates to 3342 prescription items per 1000 people estimated to have dementia in North Lincolnshire per annum, and 7100 items per 1000 people registered with a diagnosis of dementia on primary care registers. This represents a 75% increase in prescribed items for dementia since 2010/11.

However, at the same time the total spent has fallen due to a number of drugs for dementia coming off patent. In 2012/13, North Lincolnshire PCT spent £224,690 on GP prescribed dementia drugs, compared with £327,946 in the previous year.

Service needs

The concept of interval levels of care provides a framework for assessing the different levels of care required for people with dementia.

The table below is adapted from work developed by the London Dementia Centre in 2009, and applied to North Lincolnshire estimates, suggesting 750 people with dementia with critical care needs.

Table 15: Estimated number of people with dementia with care needs

Care interval description	Requirement	% people with dementia	No in North Lincolnshire in 2013
Critical	Constant care required	34%	770
Substantial	Care needed at regular intervals	48%	1100
Moderate	Care needed once a week	11%	250
Low	Care considered	6%	140

Those with critical care needs are likely to have severe dementia, be aged 85+, and consist largely of White British women. Many of these will live in care homes.

The remainder living in the community, some with informal support, although many will be living alone with packages of care. The other half will be living in care homes.

Prevention

According to national research conducted by the Alzheimer's Society UK and published in August 2014, more than a fifth of people do not think it is possible to reduce their risk of developing dementia. This is in spite of growing evidence that simple lifestyle changes, such as stopping smoking, weight management, improved Vitamin D intake, improved heart health, increased social activities and taking regular exercise, can improve our chances of reducing the risk/ delaying the onset of dementia.

Indeed, provisional studies from other developed nations suggest that the incidence of dementia amongst those in their 60s may be falling, as a result of improved heart health and improvements in the detection and treatment of cardiovascular disease.

User and Carers' views

National research suggests very mixed experiences in the range and quality of care and support available for people with dementia and their carers across the country.

In developing a local Dementia Commissioning Strategy North Lincolnshire CCG, North Lincolnshire Council and partner agencies wanted to understand better local peoples' experiences of living with dementia, and to make sure their views were reflected in any review of local services.

User and carers' insights were gathered through the Experience Led Commissioning Programme. The aim of this programme is to develop a person centred approach to service delivery which reflects those outcomes that matter most to users and carers, to improve people's experience of care and deliver better outcomes for users.

Suggestions for improving local services included:

- More comprehensive awareness training across the health and social care sector and the development of Dementia Friendly Communities
- Development of a first aider model of training on dementia awareness for staff working in key public access points including supermarkets
- A one stop shop for information about where to get help, including for self funders.
- A centralised 'one stop shop' for assessment and diagnosis, with pharmacies potentially offering first instance screening to improve access to early diagnosis.
- The development of a joining pack or communication passport at the point of diagnosis to ease relatives' and carers' access to timely advice and support and to reduce crises.
- Development of a local campaign to improve the take up of advanced care planning for people with dementia
- Improved access to information about personal budgets
- Implementation of a minimum set of standards for dementia training and competencies of care home and home care staff
- Increased opportunities for integrating the commissioning and delivery health and social care services for people with dementia

This work has informed the development of an integrated Dementia Commissioning Strategy and Action plan, which will be monitored by North Lincolnshire CCG and North Lincolnshire Council.

Source: Experience Led Commissioning Dementia Strategy 2014

Social Care caseloads

- In 2013/14, a total of 2,524 older people (65+) were supported by the local authority in residential or community based services, of which 152 had a primary need of mental health, and 44 had a primary need of dementia. This equates to less than 10% of those estimated to have severe dementia with critical care needs. This is clearly an underestimate of the total number of people with dementia in receipt of these services during the year, suggesting the need to review the mental health/dementia element of Care First. In contrast, the largest primary need recorded amongst older people was physical disability.
- According to the national dementia prevalence calculator there are likely to be at least 780 people with dementia living in care homes in North Lincolnshire, ie a third of all people living with the

condition. Most of this number are likely to have critical care needs, ie they require constant supervision. National data suggest that about 33% of care home places for dementia are self funded and about 47% are provided without top up from the local authority. The remaining 20% are either provided for by the local authority with top up or by NHS Continuing Healthcare.

Recent research highlights some of the barriers and facilitators for older people, including those with dementia, from taking up and benefiting from personal budgets. This may include:

- Lack of choice about local services
- Lack of complete information about what services are available
- Need for additional support to help people make decisions about their care

In fact all of the research evidence suggests that having access to information, advice and support is the most important factor in making personal budgets and direct payments work for older people. This includes awareness arising

North Lincolnshire Council is currently a national pilot site for Direct Payments in Care homes. The aim being to give users and potential residents increased control and greater independence, including people with dementia. The outcomes of this pilot work are not yet available...

Dementia in general hospitals

Nationally it is estimated that at any one time a quarter of acute hospital beds are in use by people with dementia. Locally the number of people coded as having dementia at admission is much lower than this, although it is increasing and averages at just under 9% of all unscheduled admissions amongst 65+s in North Lincolnshire.

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Table 16:

Number of admissions to hospital for Dementia and Dementia related conditions by Diagnosis column on admission record, North Lincolnshire, 2010-13

	(F01) Vascular dementia	(F03) Unspecified dementia	(G30) Alzheimer's disease	(R54) Senility	All Conditions
Diagnosis code 1	14	31	32	130	207
Diagnosis code 2	240		83	40	363
Diagnosis code 3	358		109	22	489
Diagnosis code 4	51	343	76	7	477
Diagnosis code 5	35	274	72	9	390
All Admissions with a diagnosis recorded	698	648	372	208	1,926

Source: NHS North Lincolnshire

Below are listed the primary conditions for those admissions where dementia or a dementia related condition, was a sub code. There were six primary diagnoses that featured in the top ten for each of the four co-morbidity diagnosis columns. They were:

- J18 - Pneumonia
- R55 - Syncope and collapse
- S72- Fractured neck of femur
- J22 - Unspecified acute lower respiratory infection
- N39 – Urinary tract infection
- G459 - TIA
- R410 – Disorientation/ Other symptoms & signs involving cognitive function and awareness

The national Dementia Audit collects data on patients with dementia admitted into hospital. In 2012, 40 Scunthorpe General Hospital case files were audited by an independent national audit team, led by the Royal College of Psychiatrists, on behalf of the Healthcare Quality Improvement Partnership. These 40 cases were selected as they were known to be patients with a diagnosis of dementia. In general the quality of assessments and case recording of these 40 case files was felt to be of a high standard. However, in common with other general hospital trusts, the assessment and recording of some conditions, including delirium was often missing. 15% of these patients were prescribed antipsychotic drugs during their stay in hospital. Whilst in 14% of cases, patients were discharged from hospital with less than 24 hours notice.

The National Audit recommends that all hospitals should have a care pathway in place under the leadership of a senior clinician by June 2014. Other recommendations in this 2nd national audit report include:

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- Dignity leads, dementia champions and dementia specialist nurses should be employed in all hospitals.
- Ward managers should ensure that there is clear leadership and supervision available to staff on the ward regarding the care of people with dementia, and that this is supported with appropriate training and learning resources. A skills gap analysis should be conducted in each hospital, across different staff groups, and an action plan drawn up.
- A personal information document (such as *This is Me*, published by the Alzheimer's Society) should be in use throughout the hospital to ensure that staff are aware of each patient's individual needs and preferences.
- Any instances of discharge of people with dementia from hospital after midnight, or when carers/family receive less than 24 hours notice, should be reported to and reviewed by Trust Boards.
- Hospital chief executives should ensure routine audit of in-hospital antipsychotic prescribing is carried out, allowing for comparison of practice between wards and departments.
- The Director of Nursing in each hospital should regularly review protected mealtimes in the hospital.

CQUINs Commissioning for Quality and Innovation (CQUIN) payments enable commissioners to link a proportion of a provider's income to the achievement of local goals. In 2013/14 a national dementia CQUIN was developed with the aim of improving the identification of people with dementia when in hospital, to ensure referral to appropriate services and to improve care whilst in hospital. Northern Lincolnshire and Goole Hospital Foundation Trust is currently working towards delivering this standard.

Medicines review services

There are several community services available to help people with dementia and their carers manage medications. The Medicines User Review service is a free service offered by pharmacists. It enables people with dementia and/or their carer to discuss their medication and enables the pharmacist to offer advice and support, including signposting and advice on referral pathways if appropriate.

End of life

Dementia is a progressive condition, so all people who develop dementia will have this until the end of their lives. All people with dementia are likely to have additional complications at end of life, regardless of what disease they die of, because of limited and diminishing mental capacity and difficulty with communication. Service providers may not recognise the signs of approaching death of people with dementia, and may not be used to supporting people with dementia to make decisions about the sort of care they would like at end of life.

Because of this it is important that people with dementia and their carers consider the type of care they would want as early as possible. Indeed, it is a national objective that by 2014, *'Every person with dementia living in England should agree with the statement, 'I am confident my end of life wishes will be respected and I can expect a good death'.*

There is little national research on the provision of specialist palliative care support services and the integration of support for people dying in care homes. However we do know that the high proportion of care home residents with dementia means that end of life care for people with dementia often take place in a care home, where staff may be taking on quite complex roles, which in other context would likely be provided by more senior and professionally qualified staff.

Between 2011-13 there were an average of 340 deaths of older people per year, where dementia was mentioned as a cause of death, primary or otherwise, in North Lincolnshire, of which almost two thirds, (62%) occurred in care homes, a quarter, (26%) in hospital and 10% at home.

Table 17: Average no of annual deaths in North Lincolnshire where dementia mentioned on the death certificate by place of death (2011-13)

Place of death	Males	Females	Persons
Home	12	23	34
Care/Nursing home	58	158	216
Hospital	34	51	85
Other	<10	<10	

Source: North Lincolnshire PCMD, 2014, based on deaths where dementia codes were evident in the first five causes of death.

In comparison with people with time-limiting illnesses whose ability to communicate is not affected by their condition, few people with dementia will be able to express their needs and preferences for end of life care at the time they require it. This means that staff in care homes need to rely on a combination of information from advance care planning (ACP), information about a person's preferences from their own knowledge and that of other people who know the person with dementia well, such as family carers, and their own observations of levels of comfort and absence of pain.

The overall median survival time from diagnosis to death is between 4.1 to 4.6 years. The later the stage in the disease when the diagnosis is made, the shorter will be the length of survival

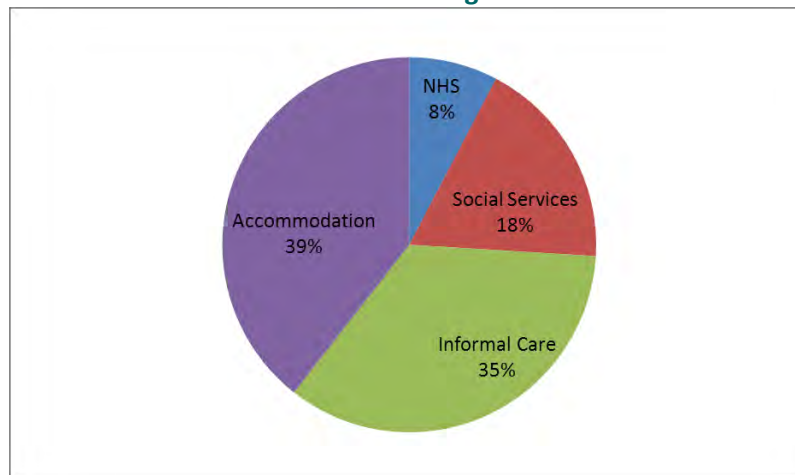
The National Institute for Health and Clinical Excellence (NICE) Quality Statement 3 for end of life care states that 'people should be given the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment. Moving into a care home provides an opportunity to develop or revise an advance care plan. However a lack of training and lack of confidence in working with the Mental Capacity Act, amongst staff can act as a barrier to the development of Advance Care Plans. The additional health needs of people with dementia may also be complex making it more likely that they will be admitted to hospital at the point of death.

Spending

Nationally, the total annual costs of both paid and unpaid care for people with late onset dementia are estimated at between £14.5k to £31.3k per person per year, (at 2008 prices), depending on the stage of the disease and where the person lives. By contrast people with cancer stroke or heart disease cost less than half this.

Accommodation accounts for 40% of the total. A third is estimated to be due to informal care inputs by family members and other unpaid carers. Included in this amount is the estimated lost income for those carers who have to give up employment or cut back their work hours. The cost to the NHS is estimated to be in the region of 8% of all costs.

Figure 12
Estimated distribution of costs of caring for someone with dementia



Source: Dementia UK Summary, 2010

Applied to North Lincolnshire's estimated population of people with dementia (n= 2260), this suggests a total cost to the local economy, NHS, social care and unpaid carers of at least £32 million per annum, (at 2008 prices), and as much as £71million.

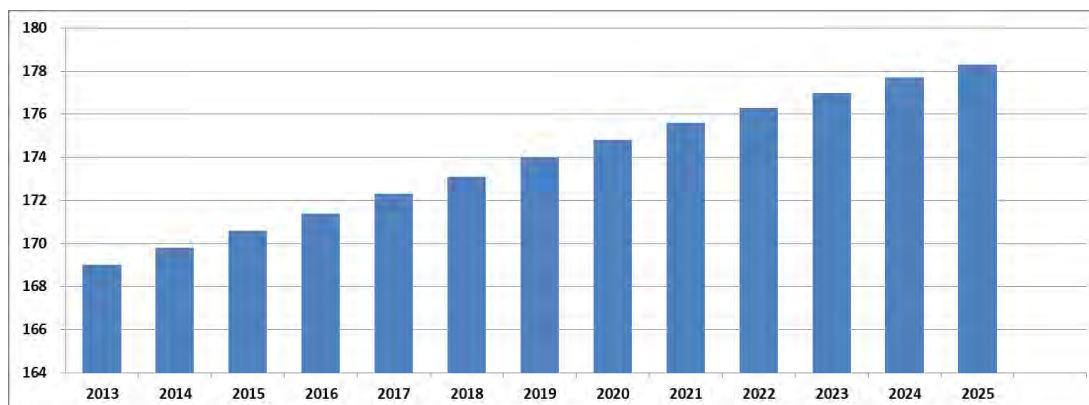
Even small reductions in the incidence of dementia or delaying the age at onset could make a significant difference to the burden of the disease. Research suggests that the greatest impact in terms of prevention is likely to come from public health programmes which aim to improve education, at all ages, identify and reduce the risk of vascular diseases in middle age, improve heart health and reduce the risk of depression in older age.

Population projections

Life expectancy has risen by an average of 3 years over the last decade and a half, and shows no signs of slowing down, with rates increasing fastest amongst men. Between now and 2020, the resident 65+ population of North Lincolnshire is projected to rise by almost 20%.

If life expectancy continues to rise each decade at current trends, we should expect an average annual increase amongst the 65+ population of almost 1,000 between now and 2025, with the largest increase expected amongst people aged 75. We should also expect a modest growth in the younger adult population, (20-34 year olds). Although it remains uncertain how many younger adults will remain living in the area, official projections suggest a 5% growth in people aged 20-44 years of age living in our area between now and 2025.

Figure 13: Population projections in North Lincolnshire, 2013– 2025 (all ages)



This growth will have an impact on the number of people presenting each year with the disease, with a 19% projected increase in new cases each year in North Lincolnshire between 2013 and 2020.

Figure 14: Population projections in North Lincolnshire amongst people aged 65+, 2013-2025

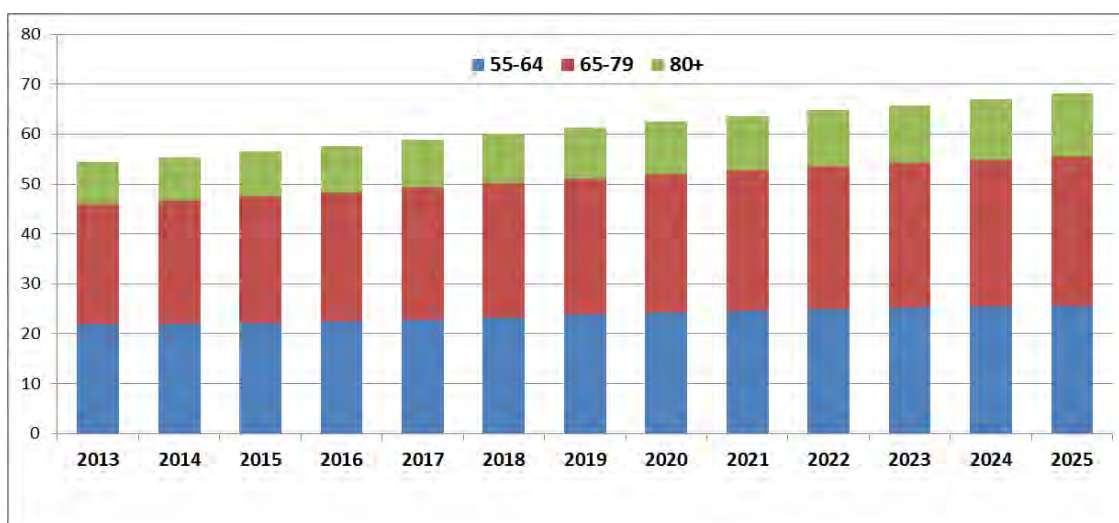


Table 18: Projected increase in older population and annual incidence, (new cases) of late onset dementia.

Age group	Incidence rate male per 1000	Estimated no of new cases 2015	Estimated number of new cases 2020	Incidence rate female per 1000	Estimated no. of new cases 2015	Estimated no of new cases 2020
65-9 years	6.9	35	35	6.3	38	32
70-4 years	14.5	58	73	6.1	25	31
75-9 years	14.2	43	43	14.8	44	60
80-4 years	17.0	34	34	31.2	94	94
85+	58.4	60	117	71.7	215	289
Total		230	302		416	506

Source: Alzheimers Society, 2007 applied to 2012 mid year population estimates for North Lincolnshire.

These projections are based on existing age and sex incidence and prevalence in the national population. These suggest at least a 20% increase in the number of people presenting with dementia in the five years between 2015-20, and a 20% increase in the number of people living with the disease. Improvements in treatments for dementia may alter these projections.

Table 19: Projected increase in older population and point prevalence (existing cases) of late onset dementia.

Age group	Prevalence rate male per 1000	Estimated no of cases 2015	Estimated number of cases 2020	Prevalence rate female per 1000	Estimated no. of cases 2015	Estimated no of cases 2020
65-9	1.5%	75	75	1.0%	55	55
70-4	3.1%	124	155	2.4%	100	120
75-9	5.1%	153	170	6.5%	220	250
80-4	10.2%	204	245	13.3%	350	370
85-9	16.7%	167	217	22.2%	370	445
90+	28%	112	167	33%	370	460
Total		835	1030		1465	1700

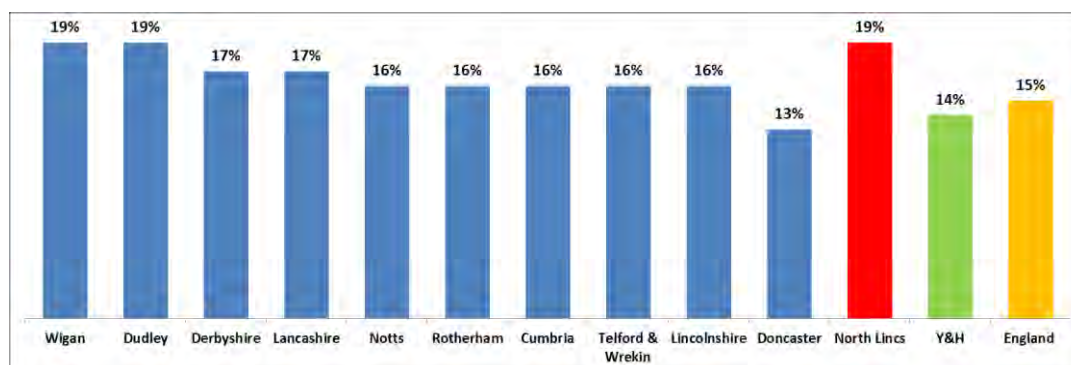
Source: Alzheimers Society, 2007, applied to ONS mid year estimates for 2013

This growth is likely to occur fastest in our rural areas. By 2020, all things being equal, more than 55% of those older people who are projected to have dementia will live in our rural localities.

This rate of growth is larger than nationally and greater than that in near neighbour authorities with a similar population profile.

Figure 15:

% Projected increase in prevalence of late onset dementia in North Lincolnshire and compared with Local Authority peers, 2015 and 2020



Source: www.poppi.org.uk

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