Dementia

Ref HSCW 018

Why is it important?

Dementia presents a significant and urgent challenge to health and social care in County Durham, in terms of both numbers of people affected and the costs associated with it. Estimates suggest that in 2015 there were 850,000 people living with dementia in the UK (Dementia UK [2nd edition], Alzheimer's Society). This will cost the UK £26 billion a year (NICE Dementia Costing Commissioning Assessment). Over the last 20 years, deaths from dementia have nearly doubled (PHE Prevalence of dementia in population groups by protected characteristics).

Dementia is a progressive, terminal condition characterised by a widespread loss of mental function, severely impacting upon an individual's ability to carry out previously simple daily activities. It can affect people of any age but is most common in older people. Estimates suggest that prevalence after the age of 65 doubles every five years. However, dementia is not an inevitable consequence of ageing; the majority of older people will not develop dementia. Impacts include memory loss, language impairment, disorientation, change in personality, self-neglect and behaviour which is out of character. This is often accompanied by increasing reliance on family carers who may in turn see their own wellbeing deteriorate. Feelings of isolation are also common amongst people with dementia. Nationally, dementia is the main cause of mental health admissions to hospital amongst older people (Figure 1). Many people with dementia also suffer from depression and anxiety, with as many as 63% of people with dementia reporting depression or anxiety (Alzheimer's Society, 2013).

Figure 1: Selected key figures for dementia. Various sources.

ġġġġġġ	65%	Estimated increase in number with dementia locally
ŇŇŇŇŇ ŇŇŇŇ	63%	With dementia also suffer from depression and anxiety
	48%	Of those with dementia have a formal diagnosis or are in contact with specialist services
	20%	Dementia prevalence for those aged 80+

As one of the main causes of disability in later life, dementia has a huge impact on capacity for independent living. The varying degrees of symptoms and lack of specific diagnostic tests for some forms (especially Alzheimer's) may be a factor in why diagnosis of dementia is currently believed to be poor, with less than half (48%) of sufferers in England having a formal diagnosis or being in contact with specialist services. Dementia affects 5% of those aged 65+ and 20% of the over 80 year olds (Alzheimer's Society 2007). One of the effects of an ageing population will include an increase in the numbers of people living with dementia, their health and social care needs and the needs of their carers.

'Dementia 2014: Update' (Alzheimer's Society, 2014) estimated that in 2013:

- 815,827 people in the UK had dementia, 773,502 of whom were aged 65 years or over.
- The total cost of dementia in the UK was £26.3 billion, with an average cost of £32,250 per person.
- The estimated average cost of caring for a person with dementia was £32,242 per year. Of this:
 - 44.2% fell on unpaid care
 - o 39.0% social care
 - o 16.4% health care.
- Nationally, around 40% of people with dementia live in care homes; 1.0% have a hospital as a primary address. The remaining 59% live in the community, often supported by informal carers.

As the needs of those suffering with dementia are wide and varied, it presents a challenge when considering the personalised level of care and support required. The role of the health and social care systems in meeting the

multiple needs of people with dementia and their families is a key policy issue in the UK. The range of services needed include informal care, specialist services, residential care and community based support. Key issues include the difference between finance arrangements, roles and responsibilities, eligibility and differing ways of accessing both health and social care services. These issues can often increase confusion and distress to an individual and their family during a period of great change.

Carers play a vital role in supporting people with dementia. Unpaid care contributes more in financial terms than contributions from any other agency (45% of the total, with social care providing 39% [Dementia 2014 Update, Alzheimer's Society]). Carers are often older themselves, more likely to be women, and are likely to be providing a substantial number of hours of support. Carers for people with dementia often experience poorer physical and mental health, social isolation, fewer opportunities for employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

Durham data - the local picture and how we compare

There are over 4,800 people registered with dementia in County Durham (2014/15). Typical of the situation across the country, the observed prevalence in GP surgeries (the number of people registered with dementia), is around two-thirds of the expected prevalence. This has implications in terms of lack of treatment, care and unmet need.

Population

County Durham's population is ageing as a result of people living longer. The number of older people is increasing nationally and locally due to improvements in health and social care. Office for National Statistics (ONS) projections suggest that the proportion of County Durham's population aged over 65 years will rise from 18.8% to 26.1% by 2035 (Table 1). One of the effects of an ageing population will include an increase in the numbers of people living with dementia, i.e. the older people get, the more likely they are to have dementia (Figure 6).

Table 1: Population aged over 65 years, projected to 2035: County Durham Source: ONS subnational projections for England. ONS. 2014

	2014	2015	2020	2025	2030	2035
Total population	517,800	519,900	530,800	541,800	554,000	560,200
Population aged 65+	96,200	103,200	112,500	123,100	136,600	146,300
Population aged 85+	11,600	11,700	13,600	16,500	21,100	26,300
% population aged 65+	18.8	19.8	21.2	22.7	25.0	26.1
% population aged 85+	2.3	2.3	2.6	3.0	3.8	4.7

Table 2: Population by selected age groups: County Durham, North Durham CCG and constituencies, DDES CCG and localities (ONS, 2013)

		Total	Age ba	and	% a	ged
	Area	pop.	65+	85+	65+	85+
North Du	rham CCG	244,361	46,556	5,311	19.1	2.2
	Derwentside	92,690	17,987	2,176	19.4	2.3
	Chester-le-Street	54,434	11,356	1,168	20.9	2.1
	Durham	97,237	17,213	1,967	17.7	2
DDES CO	CG	273,412	54,915	6,314	20.1	2.3
	Durham Dales	90,623	19,479	2,285	21.5	2.5
	East Durham	95,075	17,763	1,989	18.7	2.1
	Sedgefield	87,714	17,673	2,040	20.1	2.3
County D	Jurham	517,773	101,471	11,625	19.6	2.2

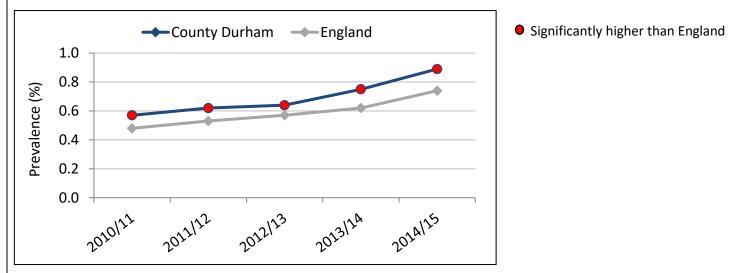
- The ageing population and changing demographic structures are likely to affect the scale of needs for health and social care services.
- The 65 years and over age group is projected to increase from almost one in five people in 2014 to over one in four people by 2035, with the proportion of the county's population aged 85+ predicted to more than double by 2035.

• There is slight variation in the distribution of people aged over 65 years in County Durham (Table 2). Proportionally more people aged over 65 years live in Durham Dales (21.5%) than Durham (17.7%).

Dementia prevalence

Recorded dementia prevalence, through the Quality Outcomes Framework (QOF), provides an indication of the concentration, within a population, of the number of people who have been diagnosed and who are now living with the condition. This indicator can be used to inform local service planning as to the scale of services required to provide treatment, care and support as needed, so those with dementia can be living well with the condition. QOF contains information to aid in the provision of quality care and helps to standardise improvements in the delivery of primary medical services. An important feature of the QOF is the establishment of disease registers. These are lists of patients registered with a GP who have been diagnosed with a disease (or risk factor).

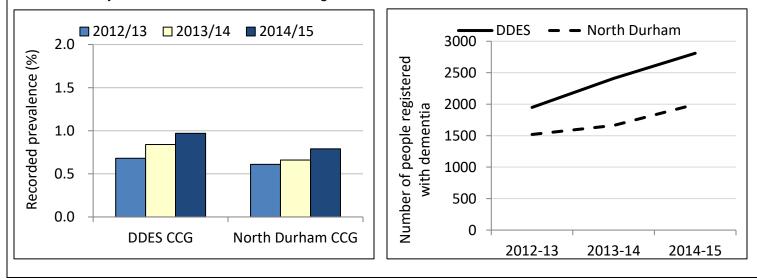
Figure 2: Recorded dementia prevalence (all ages), 2010/11-2014/15, County Durham and England Source: Public Health England (PHE) Dementia profile (based on QOF, NHS Digital)



• Dementia prevalence in County Durham is significantly higher than England, and has been rising over time both locally and nationally (Figure 2).

This indicator is a measure of recorded prevalence and not actual prevalence and therefore under-reports groups who are less likely to be registered with a GP, such as ethnic minority populations, the homeless, migrants and travellers. QOF registers are constructed to underpin indicators on quality of care. Caution should be taken when interpreting this indicator, as higher than average value may mean that the prevalence of the condition is high in an area but it could also indicate that detection is better there - this is for local knowledge to determine.

Figure 3 and Figure 4: Registered dementia prevalence (**3**) and number registered with dementia (**4**), DDES CCG and North Durham CCG (all ages), 2012/13 – 2014/15 Source: Quality Outcomes Framework, NHS Digital



Registered dementia prevalence (Figure 3), and the number of people registered with dementia (Figure 4) is consistently higher in DDES CCG (0.97%, 2,809 patients registered, 2014/15) than North Durham (0.79%, 1,997 patients, 2014/15), and has been rising over time in both CCGs.

Estimated dementia prevalence

The Alzheimer's Society in its Dementia UK 2014 update report estimated dementia prevalence by type of dementia within the UK population. These estimates suggest over 6,600 people in County Durham having some form of dementia. The majority of estimated sufferers have Alzheimer's disease (62%). Alzheimer's and vascular dementia (or a combination of both) make up an estimated 89% of dementia.

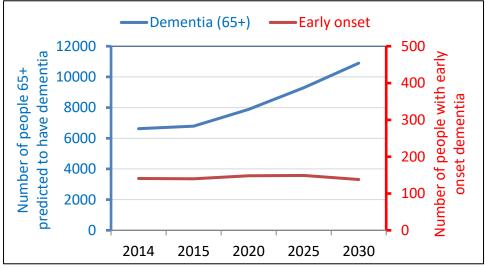
Table 3: Estimated dementia prevalence and number, by type, County Durham

 Source: Dementia UK 2014 update, Alzheimer's Society

Estimated %	Estimated patients
62	4,108
17	1,126
10	663
4	265
2	133
2	133
3	199
	62 17 10 4 2 2

Figure 5: Number of people a) aged 65+ projected to have dementia, and b) projected to have early onset dementia 2014-2030, County Durham

Source: POPPI, 2015

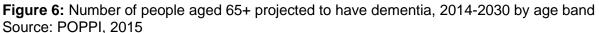


- Dementia prevalence is projected to increase over time (Figure 5).
- Projections suggest that the estimated 6,625 people affected in 2014 could rise to 10,896 by 2030, an increase of almost 65% (Figure 5). Therefore the observed prevalence in GP surgeries, in other words the number of people registered with dementia, (around 4,800 in County Durham) is around 40% of the expected prevalence. This has implications in terms of lack of treatment, care and unmet need.
- Prevalence of early onset dementia is not projected to increase over the same time period.

Age presents the greatest dementia risk factor. As the population ages and the proportion of those aged 65+ increases, then so will the number of people with dementia. Between 2014 and 2030 estimated dementia prevalence (Figure 6) is projected to increase by:

- 22% for those aged 65-74.
- 53% for those aged 75-84.
- 92% for those aged 85+.

Early diagnosis (sometimes called timely diagnosis) of dementia is essential in enabling patients and their carers to make choices about their future, to support their care. These choices, such as accessing specialist services providing care and support to the family, could reduce potential crises and hospital or residential care admission.



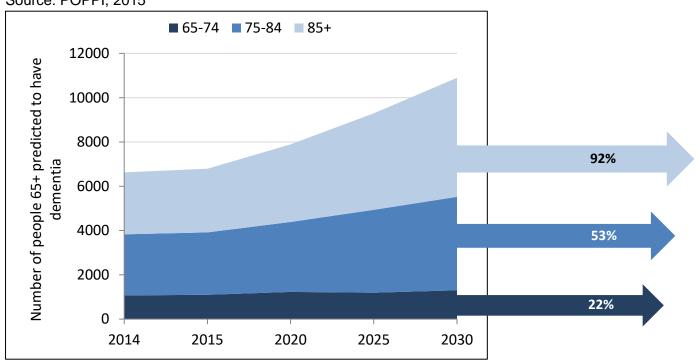
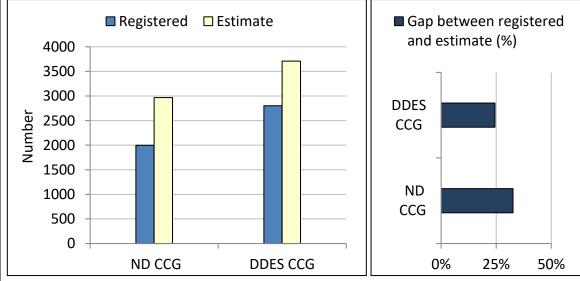


Figure 7 and Figure 8: Number on GP practice registers, estimates (7) and dementia gap, by CCG (8) Source: Primary Care Webtool

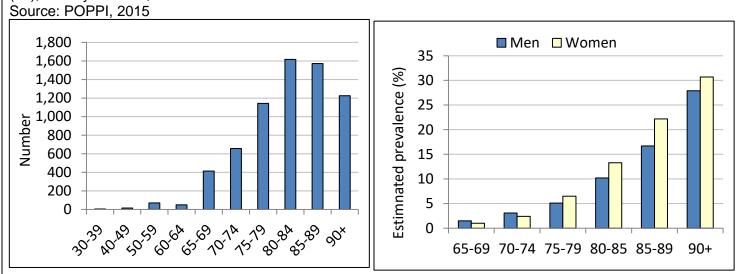


Patients with a recorded diagnosis of dementia can be compared to the estimated dementia prevalence amongst people registered with GPs, using the Dementia Prevalence Calculator (Dementia Partnerships). GP practice-based dementia disease registers only give numbers of those registered with a GP who have also been diagnosed. This enables health and care communities to gain a better understanding of estimated prevalence of dementia across the country and within local communities. The Dementia Prevalence Calculator estimates that in County Durham:

- Almost 1,900 people with dementia remain undiagnosed. This is a significant gap between the registered and estimated population with dementia (Figure 8).
- Estimates suggest a 24% difference in DDES CCG and 33% difference in North Durham CCG.

Diagnosis rates can be improved using a variety of interventions, as identified in national research and policy. Both North Durham CCG and DDES CCG have ambitious targets to increase diagnosis of dementia over the coming years. This ambition will result in increasing demand on the treatment services and the capacity to care for people with dementia in the community (e.g. social care).

Figure 9 and Figure 10: Estimated number of cases of dementia (9), and prevalence for over 65's by age group (10), County Durham, 2014



Within County Durham:

- There are relatively few estimated cases of early onset dementia in County Durham, with less than 200 cases estimated (Figure 9).
- The majority of estimated dementia cases occur in the 80-84 age band (Figure 9).
- Estimates suggest that, for those aged 75 years and over, prevalence in County Durham is higher for women than for men (Figure 10). National estimates from the Social Care Institute of Excellence's Dementia Gateway suggest that around two-thirds of people with dementia in the UK are women.

Hospital Admissions

People with dementia are substantial users of hospital care. Nationally, dementia is a significant challenge for the NHS, with an estimated 25% of hospital beds occupied by people with dementia (Dementia: A state of the nation report on dementia care and support in England, DH, 2013). Dementia patients:

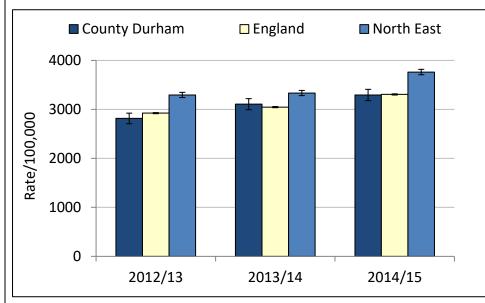
- Are sometimes admitted to hospital for conditions which would not ordinarily require an admission.
- Stay in hospital for longer than those admitted for the same reason without dementia.
- Are often subject to delays in discharge. The longer someone stays in hospital, the worse the effect on the symptoms of dementia and the person's physical health. Longer admissions often result in discharge to a care home and the prescribing of antipsychotic drugs.
- Are more likely to be readmitted than those without dementia.
- Are more likely to die, than patients without dementia admitted for the same reason.

Local analysis for 2015/16 indicates that within County Durham admissions of people very often come with other conditions which require treatment, or are a factor which may influence the care or recovery of the person with dementia (Figure 11). Around two thirds of people with dementia admitted to acute hospitals will usually have dementia recorded as a secondary condition (i.e. secondary to the cause of admission). If dementia is listed as one of the first few recorded diagnoses, this should represent the condition being a significant contributor to causing admissions, or having a significant impact on patient care.

Figure 11: Dementia diagnoses as a proportion of admissions, County Durham, 2015/16 Source: NHS Digital Secondary Uses Service (SUS), North East Commissioning Support (NECS), 2016

	Of all admissions admitted to hospital with a primary diagnosis of dementia
27%	Of admissions had dementia coded in the first three recorded diagnoses
62%	Of admissions had dementia coded as one of the five most relevant diagnoses recorded

Figure 12: Dementia emergency admission rates per 100,000, with 95% confidence intervals, aged 65+, 2012/13 to 2014/15, County Durham, North East and England Source: Dementia Profile, PHE Fingertips

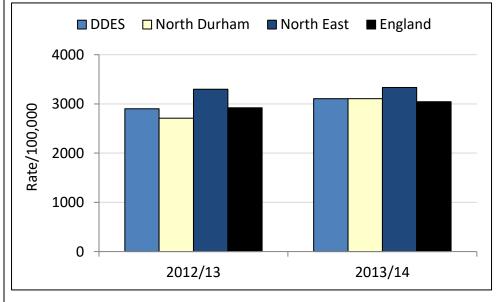


NB. These directly age standardised rates of emergency inpatient hospital admissions relate to those aged 65 years and over with a mention of dementia in any of the diagnosis code positions.

- Emergency admission rates in County Durham for those aged 65+ are not significantly different to England (Figure 12). Rates in the North East are significantly higher than both County Durham and England.
- Local, regional and national emergency admission rates for those aged 65+ increased between 2012/13 and 2014/15. This increase over time was higher in County Durham (17%) than the North East (14.2%) and England (13.1%).

Figure 13: Admissions to hospital with a dementia diagnosis per 100,000, County Durham, men and women, aged 75+, 2012/13 to 2013/14

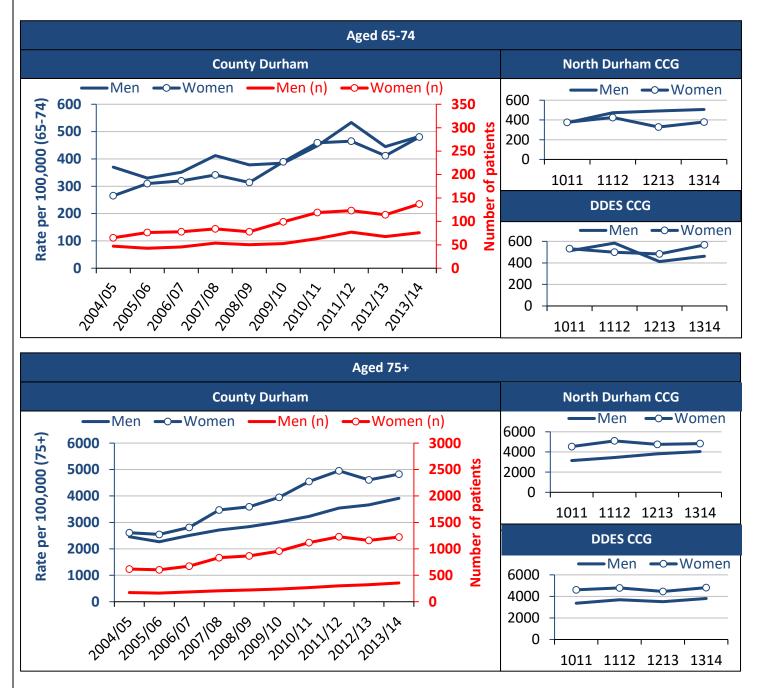
Source: Hospital Episode Statistics, Local Knowledge and Intelligence Service (LKIS) North East, Public Health England, 2015



- Admission rates to hospital with a dementia diagnosis for those aged 75+ are similar in DDES CCG, North Durham CCG and England (Figure 13).
- Local admission rates (75+) are lower than the regional average for the North East.

Figure 14: Admissions to hospital with a dementia diagnosis per 100,000, men and women, (1) aged 65-74 and (2) aged 75+, 2004/05 to 2013/14, County Durham, (directly age standardised rates per 100,000 and number of patients admitted) and North Durham and DDES CCGs (rates per 100,000 only)

Source: Hospital Episode Statistics, Local Knowledge and Intelligence Service (LKIS) North East, Public Health England, 2015



Readmission of people with dementia to non-mental health providers

Taking necessary steps to reduce the readmission of patients with dementia remains a key focus. As previously mentioned, many admissions to non-mental health providers concern a co-morbidity of dementia with other conditions requiring treatment, or where dementia is a factor which may influence the patient's care or recovery. This presents a challenge not only for the community and acute providers but also for local services in taking steps to avoid unnecessary readmission to hospitals within 30 days.

In County Durham during 2015/16, 18% of patients with dementia were readmitted to non-mental health providers within 30 days of discharge from a prior admission. There was little variation within County Durham by CCG over this period (Table 4).

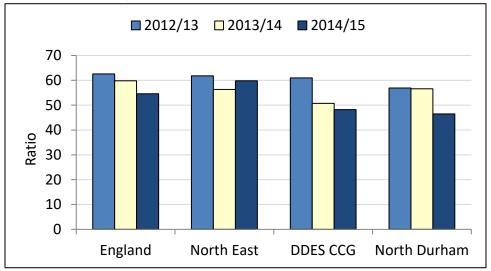
Table 4: Admissions within 30 days of discharge from a prior admission, 2015/16, County Durham, DDES CCG and North Durham CCG

Source: NHS Digital Secondary Uses Service (SUS), North East Commissioning Support (NECS), 2016

CCG / Type of Admission	Total emergency admissions	Admission within 30 days of discharge from prior admission	Admission NOT within 30 days of discharge from prior admission	% of dementia related admissions in month which are 30 day readmissions
DDES	186	34	152	18.3%
Acute	181	33	148	18.2%
Community Hospital	5	1	4	20.0%
North Durham	125	22	103	17.6%
Acute	124	22	102	17.7%
Community Hospital	1	0	1	0.0%
County Durham	311	56	255	18.0%

Within England, there is variation in the ratio of admissions for dementia (with a mention in the diagnosis code) compared to dementia primary care registers. This will identify areas where the ratios are both higher and lower than the national average. Areas identified of both types might warrant further investigation, to establish the underlying causes for either higher or lower ratios and thus gain an understanding of where improvements might be required.

Figure 15: Ratio of inpatient service use to recorded diagnoses, County Durham and England, 2014 Source: Dementia profiles, PHE



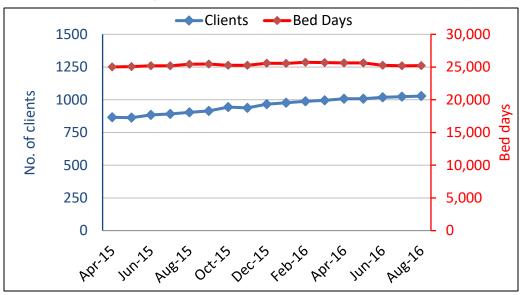
Rising dementia prevalence places an additional impact on social services. The Alzheimer's Society estimates that nationally around 40% of people with dementia live in care homes and that 80% of all care home residents have some form of dementia. Local data indicate that around one third of all residential clients in County Durham have a registered diagnosis of dementia (Table 5).

Table 5: Number of dementia clients as a proportion of total clients, by care type, Durham County Council, as at 3rd October 2016

Source: Durham County Council Social Services Information Database (SSID)

Care Type	Dementia	Total	% with client type recorded as Dementia
Day Care	102	1,353	7.5
Home Care	319	3,895	8.2
Residential	1024	3,256	31.4
Total	1445	8,504	17.0

Figure 16: Number of dementia clients in residential and nursing care, and total bed days for older people accessing residential and nursing dementia care



Source: Durham County Council Social Services Information Database (SSID)

Carers

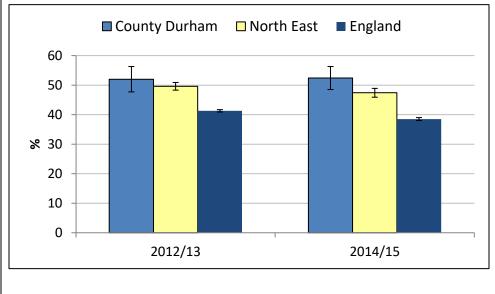
Dementia places a particular responsibility on carers and family members who have a vital role in supporting people with dementia. The links between loneliness and poor mental and physical health are clear. Those caring for people with dementia often experience poorer physical and mental health, as well as social isolation. Indeed, carers of people with dementia report greater levels of stress than carers of people with other kinds of need.

Tackling loneliness and social isolation, supporting people to remain independent, connected to their communities and developing and maintaining connections to their friends and family is a key driver for social care. Promoting wellbeing and independence, and improved support for carers, should enable people to maintain their independence for longer and avoid crisis. Whilst data are not available for carers looking after people with dementia, an overarching outcome measure for carers in the Public Health Outcomes Framework has been used as a proxy.

• Over 52% of carers in County Durham report that they have as much social contact as they would like (2014/15). This is significantly higher than England (Figure 17).

Figure 17: Social Isolation: % of adult carers who have as much social contact as they would like, 2012/2013 and 2013/14, with 95% confidence intervals

Source: Adult Social Care Users Survey, Public Health Outcomes Framework, PHE

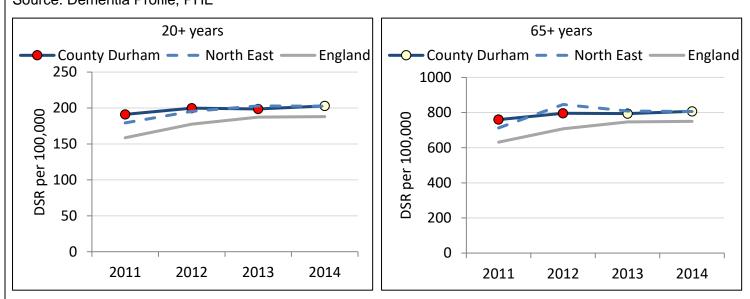


Mortality

In England, approximately 480,000 people die each year. One in 10 of these people will have dementia. One in three people who die after the age of 65 have dementia. All health and care staff who support dying people must be capable and compassionate in treating people with dementia. Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death (NICE, 2015).

Dementia mortality rates have steadily risen since 2011 for both 65+ years and early onset, with both the North East and County Durham having higher rates than England (Figures 18 and 19).

Figure 18 and Figure 19: Mortality rates for people with dementia, aged 20+ (**18**) and aged 65+ (**19**), directly standardised rates per 100,000 Source: Dementia Profile, PHE



• Significantly higher than England • O Not significantly different to England

Place of death

In England, the North East and County Durham, the most common place for a person with dementia to die is in a care home.

Since 2012, the proportion of those dying in care homes has declined for the North East (56.4%) and both Durham CCGs (DDES 56.5%, North Durham 60.1%) but for England has risen over the same period.

Hospital is the second most common place of death for those with dementia – 31% for England, 35% for the North East and 33% for County Durham. This percentage has remained fairly steady over the last few years (Figure 20 and Table 6).

There is a relatively low percentage of deaths at home, with 8% for England, 7% for the North East and 6% in County Durham. Across England there has been a 31% increase between 2011 and 2014, a 35% increase in the North East as a whole, but only a 10% increase for County Durham - which has even seen a decrease from 2013 to 2014.

Figure 20: Place of death for people with dementia, aged 65+, DDES CCG, North Durham CCG, North East and England, 2014 Source: Dementia Profile, PHE

Care home Des North Durham North East England

Table 6: Place of death for people with dementia, aged 65+, DDES CCG, North Durham CCG, North East and England, 2011-2013

Source: Primary Care Mortality Database (PCMD), NHS Digital

		% deaths in care home	% deaths in hospital	% deaths at home
2011	DDES	51.9	39.3	3.6
	North Durham	53.3	38.1	8.0
	North East	52.3	40.8	5.3
	England	56.3	35.9	6.4
2012	DDES	57.3	34.2	3.9
	North Durham	62.9	29.7	5.4
	North East	57.0	36.1	5.2
	England	58.1	33.4	7.1
2013	DDES	56.5	33.1	7.0
	North Durham	60.1	31.9	6.8
	North East	56.4	35.8	6.4
	England	58.6	32.6	7.4

Groups most at risk

Anyone can develop dementia but some people are more at risk than others. Dementia prevalence is associated with a number of factors, such as:

- Age
- Gender
- Social class and educational achievement
- Unhealthy lifestyles
- Learning disabilities
- BME groups

Older people

The main risk factor for dementia is growing old and ageing. Development of dementia, particularly Alzheimer's disease and vascular dementia, is strongly linked to increased age. Beyond the age of 65, the risk of developing Alzheimer's disease doubles around every five years.

Gender

Dementia is more common in women. Women also have a slightly higher risk of developing Alzheimer's disease but have a lower risk than men of vascular dementia. This is because men are more prone to stroke and heart disease, which can cause vascular and mixed dementia.

Those living in deprived communities

Socio-economic position has long been seen as an independent predictor of dementia. Those with a low socioeconomic position have an increased prevalence of Alzheimer's disease. The reason for this is not clear, as it appears to be, in part, independent of educational status. However, it is also known that education remains protective against developing dementia (PHE Prevalence of dementia in population groups by protected characteristics).

People with unhealthy lifestyles

There is overwhelming evidence that our lifestyle choices affect our risk of developing dementia. Some research suggests that vascular disease and its risk factors (namely smoking, hypertension and hypercholesterolemia) are influential in the development of both vascular dementia and Alzheimer's disease and efforts to reduce the prevalence of these may therefore be effective in reducing rates of dementia overall. Although there is no certain way to prevent all types of dementia, a healthy lifestyle is likely to help lower your risk of developing dementia when you are older.

Research indicates that most success lies with modifying cardiovascular risk factors. The NICE guidance 'Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset' covers mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life. This aims to increase the amount of time that people can be independent, healthy and active in later life and makes recommendations to:

- Eating a healthy diet
- Regular physical activity
- Managing conditions like type 2 diabetes
- Managing high blood pressure
- Avoiding smoking and excessive drinking.

People with learning disabilities

People with learning disabilities may have a higher risk of dementia because of premature ageing and, in the case of Down's syndrome, genetic factors. Approximately 20% of adults with a learning disability have Down's syndrome and the predicted incidence rate of dementia is even higher. People with learning disabilities are generally affected by dementia in similar ways to those without learning disabilities (Alzheimer's Society, 2015). However, there are some important differences.

People with a learning disability:

- Are at greater risk of developing dementia at a younger age particularly those with Down's syndrome. The early stages of dementia are more likely to be missed or misinterpreted in this population.
- Are more likely to show different symptoms in the early stages of dementia.
- Are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis.
- May experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis.
- Are more likely to have other physical health conditions which are not always well managed.

BME groups

It is widely acknowledged that people from BME groups are generally under-represented in dementia services. They may have specific needs in relation to differing levels of vascular risk, access to services and awareness / stigma attached to the condition.

How does this topic link to our strategies and plans?

Dementia has been identified as a key workstream of the County Durham Dementia Strategy Group and the County Durham Mental Health Partnership Board.

Dementia is a cross-cutting theme which is reflected and referenced in many strategies and plans for County Durham. For example:

- <u>County Durham Joint Health and Wellbeing Strategy 2016-2019</u>
- <u>The County Durham and Darlington Dementia Strategy 2014-17</u>

Author:	Approver:

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Data sources: Public Health Outcomes Framework, Public Health England Dementia 2014: Update. Alzheimer's Society, 2014 Quality and Outcomes Framework, NHS Digital Dementia profile, Public Health England Projecting Older People Population Information System (POPPI), Institute of Public Care, Oxford Brookes University Dementia Primary Care Webtool Secondary Uses Service (SUS), North Commissioning Support (NECS) Hospital Episode Statistics, NHS Digital Adult Social Care Users Survey, Public Health England Primary Care Mortality Database (PCMD), NHS Digital Social Services Information Database (SSID), Durham County Council