

North Wales Dementia Strategy Background data and information

This document has been produced as a discussion document to inform the development of the North Wales Integrated Dementia Strategy. Much of the information has been taken from the North Wales Population Assessment and updated as appropriate.

Contents

What we know about the population	3
Number of people living with dementia in North Wales	3
The dementia diagnosis rate	3
Number of people receiving care and support	4
The number of people with dementia is likely to increase	6
Young onset dementia	8
Mild cognitive impairment	8
People with learning disabilities	9
Sensory impairment	9
Physical health and other conditions	10
Carers	10
Risk reduction and delaying onset	11
Welsh language provision	12
Equality and human rights	15
Age	15
Disability	16
Marriage and civil partnership	16

Pregnancy and maternity	16
Race	16
Religion or belief	18
Sex	19
Sexual orientation and gender identity	19
Poverty	20
Amount spent on older people's services	21
References	22
Index of tables	
Table 1 Number of people in North Wales with dementia, by county, 2017 Table 2 Number of people diagnosed and estimated number undiagnosed	
dementia 2017-18	4
Table 3 Number of people aged 65+ receiving home-care services, 2017-	18 5
Table 4 Number of adults living in residential and nursing care homes, 20	17-18 6
Table 5 Care home placements in North Wales by type of care	6
Table 6 Number and percentage of people aged 65+ who speak Welsh, 2	011 13
Table 7 Percentage of local authority social services staff who speak Wels	sh 14
Table 8 Consensus estimates of the population prevalence (%) of late-ons	set
dementia	15
Table 9 Number of people aged 65 and over by ethnic group, North Wales	s17
Table 10 Number of people aged 65 and over by religion or belief, North V	Vales 19
Index of figures	
Figure 1 People aged 65+ receiving home care or living in a care home by care	, .
Figure 2 Projected increase in the number of people aged 65+ in North W to 2043	ales, 2018
Figure 3 Projected increase in the number of people living with dementia i	
Wales, 2017 to 2035 (Source: Daffodil Cymru)	8
Figure 4 Local authority spend on services for older people in North Wales support, 2017-18	

What we know about the population

Number of people living with dementia in North Wales

There are estimated to be between 10,000 and 11,000 people living with dementia in North Wales. The lower estimate is published in the Quality Outcomes Framework Statistics (Welsh Government, 2018a) and the higher estimate is used in the Daffodil projections (Institute of Public Care, 2017). Table 1 below shows the number of people estimated to be living with dementia in North Wales in each county based on the Daffodil prevalence estimates.

Table 1 Number of people in North Wales with dementia, by county, 2017

County	Total population aged 30-64 with young onset dementia	Total population aged 65 and over with dementia	Total
Anglesey	20	1,200	1,200
Gwynedd	32	2,000	2,000
Conwy	33	2,400	2,400
Denbighshire	26	1,500	1,600
Flintshire	42	2,100	2,200
Wrexham	37	1,800	1,900
North Wales	190	11,100	11,200

Source: Daffodil Cymru. Numbers may not add up due to rounding.

The Quality Outcomes Framework Statistics estimate that in North Wales there are 6,300 women with dementia and 3,700 men with dementia (Welsh Government, 2018a). These estimates were made by Welsh Government using prevalence rates published in a Lancet paper from the CFAS (Cognitive Function and Ageing Study) II study. Women live longer than men and age is the biggest known risk factor for dementia, which may explain this difference (Alzheimer's Research UK, 2015).

The age profile of North Wales is older than the average for Wales with a higher proportion of older people and a smaller proportion of younger residents in the region compared to Wales (Jones, Andrew and Atenstaedt, 2018).

The dementia diagnosis rate

There are around 5,100 people with a diagnosis of dementia in North Wales and an estimated 4,800 people undiagnosed with dementia (Quality and Outcomes

Framework, 2018). There are some issues with data collection around the number of diagnoses and Public Health Wales are working with GPs to improve the registration of diagnoses, but it is likely these figures are an undercount of the actual number of people with a diagnosis in North Wales.

The dementia diagnosis rate in North Wales was 51% and 53% in Wales (Welsh Government, 2018a). This is calculated by dividing the number of people diagnosed with dementia by the total estimated number of people living with dementia. The diagnosis rate for Wales is lower than the other countries in the UK: England 70%, Scotland 67% and Northern Ireland 73% (Alzheimer's Research UK, 2019). Table 2 shows a comparison with other regions in Wales.

Table 2 Number of people diagnosed and estimated number undiagnosed with dementia 2017-18

Health board	Number diagnosed	Estimated number	Number undiagnosed	Percentage diagnosed (%)
Betsi Cadwaladr	5,100	9,900	4,800	51
Powys	1,000	2,200	1,200	46
Hywel Dda	2,700	5,800	3,100	46
Abertawe Bro Morgannwg	3,800	6,500	2,800	58
Cwm Taf	1,600	3,300	1,700	49
Aneurin Bevan	3,900	7,100	3,200	55
Cardiff & Vale	3,200	5,000	1,900	63
Wales	21,000	40,000	19,000	53

Source: QOF data, CFAS II study prevalence, ONS mid year estimates. Numbers may not add due to rounding.

Number of people receiving care and support

There are 6,400 adults aged 65 and over who receive home-care services in North Wales. Around 60% of people receiving home-care services in Britain are living with dementia (Alzheimer's Society, 2007). This suggests around 3,800 people living with dementia could be receiving home-care support in North Wales.

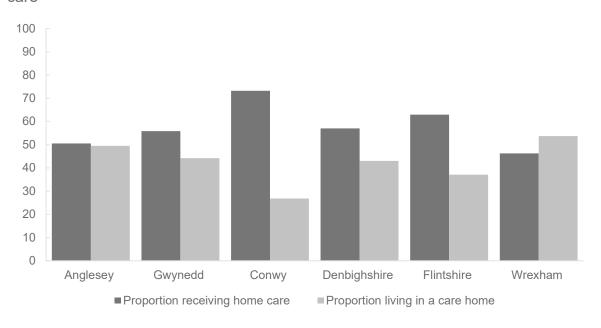
Table 3 Number of people aged 65+ receiving home-care services, 2017-18

County	Number receiving home care	Percentage of people aged 65+ receiving home care
Anglesey	480	2.7
Gwynedd	1,300	4.7
Conwy	2,100	6.6
Denbighshire	710	3.1
Flintshire	1,100	3.5
Wrexham	660	2.5
North Wales	6,400	4.0

Source: StatsWales. Numbers may not add up due to rounding.

Table 3 shows the number of people receiving home-care services by county. These figures show quite a wide variation between counties. This seems to be due to different approaches to providing care as shown in the figure below, which shows the proportion of people who aged 65+ who receive home care or are living in a care home as a total of all people who receive home care or live in a care home in each county.

Figure 1 People aged 65+ receiving home care or living in a care home by type of care



Source: StatsWales.

An estimated 69% of people living in care homes have dementia, 62% of men and 71% of women (Prince *et al.*, 2014). In North Wales a total of 4,800 people lived in

residential or nursing home placements in 2017-18 including 530 people aged under 65. This suggests that there could be around 3,300 people living with dementia in care homes in North Wales.

Table 4 Number of adults living in residential and nursing care homes, 2017-18

County	Residential	Nursing	Total
Anglesey	450	80	530
Gwynedd	820	300	1,130
Conwy	600	240	840
Denbighshire	490	140	630
Flintshire	580	180	760
Wrexham	750	130	880
North Wales	3,700	1,100	4,800

Source: Stats Wales. Numbers may not add up due to rounding.

A census carried out in 2016 found there were around 5,400 older people living in care homes in North Wales including 1,400 self-funded placements and 200 placements made outside of the region. Table 5 shows the breakdown of the 3,800 funded placements in North Wales by type of care.

Table 5 Care home placements in North Wales by type of care

County	Residential	Residential EMI (a)	Nursing	Nursing EMI (a)	Total
Anglesey	170	60	30	30	280
Gwynedd	290	70	110	50	520
Conwy	340	40	110	40	540
Denbighshire	180	100	50	30	350
Flintshire	200	150	60	40	440
Wrexham	240	180	40	40	500
BCUHB	<5	<5	760	440	1,200
North Wales	1,400	590	1,200	660	3,800

Source: May 2016 Care home placement census.

Numbers may not add up due to rounding.

(a) EMI: Elderly mentally infirm. Homes which care for people with dementia.

The number of people with dementia is likely to increase

The number of those aged over 65 is predicted to increase continually until 2038, where it will then start to decrease. The number of those aged over 65 in 2038, is estimated to be around 195,000 in North Wales. It is currently around 160,000, which

gives an increase of around 35,000 people. This increase is due to improvements in mortality rates, meaning that people are living longer, and also due to the ageing on of the large 'baby boomers' who were born after World War II. There was also a second 'baby boom' in the early 1960s, who are included in this age band towards the end of the projected period.

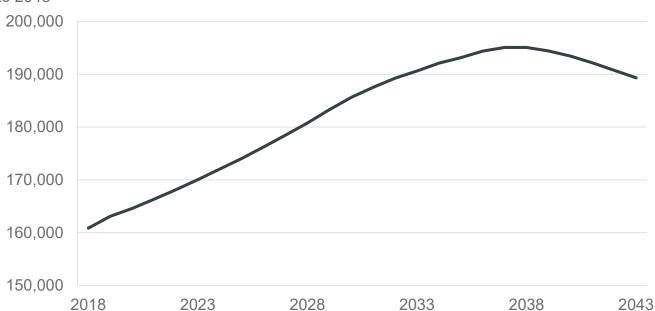


Figure 2 Projected increase in the number of people aged 65+ in North Wales, 2018 to 2043

Source: Knowledge and Analytical Services, Welsh Government

As people live longer, it is estimated that the number of cases of dementia will increase as age is the biggest known risk factor. Figure 3 shows the anticipated increase in the number of older people with dementia in North Wales based on this assumption. There is a 64% increase between 2017 and 2035, which would mean around 7,000 more people living with dementia in North Wales. However, a study suggests that the anticipated 'explosion' in cases of dementia has not been observed as the incidence at given ages had dropped by about 20%, mainly in men with women's rates decreasing less strongly (Matthews *et al.*, 2016). This means that as the number of people aged 65 and over has increased in the UK they found the number of people developing dementia each year had remained relatively stable. This may be due to improvements to health and more years spent in education, for example, fewer men smoking, eating less salt and doing more exercise. However, researchers have warned that an increase in less healthy lifestyles could overturn this trend in the future.

4,500 4,000 Flintshire Conwy 3,500 Number of people Wrexham 3,000 Gwynedd 2,500 Denbighshire 2,000 Isle of Anglesey 1,500 1,000 500 0 2017 2020 2025 2030 2035 Year

Figure 3 Projected increase in the number of people living with dementia in North Wales, 2017 to 2035 (Source: Daffodil Cymru)

Young onset dementia

The vast majority of people living with dementia are older people, and cases of young onset dementia (among people aged under 65) are relatively rare. Around 5% of people who have dementia are aged under 65, an estimated 520 people in North Wales (Prince *et al.*, 2014). The majority, around 410 people, are aged 60 to 65.

The Daffodil figures based on the lower prevalence estimates from 2007 show that the number of people with young onset dementia is projected to fall slightly in North Wales by about 20 people due to a projected decrease in the total number of adults aged under 65 (Institute of Public Care, 2017). However according to our local engagement work, the number of younger adults accessing support for living with dementia has been increasing gradually and this is a group that can find it difficult to access care appropriate for their age group.

Mild cognitive impairment

Mild cognitive impairment is a decline in mental abilities greater than normal aging but not severe enough to interfere significantly with daily life, so it is not defined as dementia. It affects an estimated 5% to 20% of people aged over 65. Having a mild cognitive impairment increases a person's risk of developing dementia. Estimates vary of the number of people with mild cognitive impairments who go on to develop

dementia each year from about 5% to 15% each year (Alzheimer's Society, 2019). Not everyone with a mild cognitive impairment will develop dementia.

People with learning disabilities

People with learning disabilities are more at risk of developing dementia as they get older (Ward, 2012). The prevalence of dementia among people with a learning disability is estimated at 13% of people over 50 years old and 22% of those over 65 compared with 6% in the general older adult population (Kerr, 2007). The Learning Disability Health Liaison Service in North Wales report that people with learning disabilities are four times more likely to have young onset dementia. People with Down's syndrome are particularly at risk and can develop dementia 30-40 years earlier than the general population with rates of 40% at around age 50 (Holland and others, 1998).

Sensory impairment

People living with dementia may also have a sensory impairment such as sight loss, hearing loss or both.

One in five people aged 75 and over are living with sight loss and the prevalence is slightly higher among people with dementia, especially those living in care homes. Dementia can also make it more difficult to identify sight conditions. An estimated 1,880 people are living with dementia and significant sight loss in North Wales (RNIB, 2018).

Hearing impairment affects the daily lives of 42 per cent of people over 50 years (123,900 people in North Wales) and 71 per cent of over 70 year olds (over 82,000 people in North Wales) (Action on Hearing Loss, 2015; Welsh Government, 2018b). Hearing assessment is recommended for all those with suspected dementia (NICE, 2018b) as it has been shown that 80% to 90% of those accessing memory assessment services have hearing impairment and this can mask or exacerbate the symptoms of dementia. Hearing rehabilitation, such as using hearing aids, is known to improve communication and wider engagement in those living with dementia (Mamo *et al.*, 2017) and reduce cognitive decline (Maharani *et al.*, 2018). Hearing aids are available from NHS Audiology services in North Wales at no cost to the person through a referral from primary care services.

There is also a link between hearing loss and increased risk of dementia in adults over 55 years old, with hearing impairment being described as the largest modifiable

risk factor for dementia in midlife (Livingston *et al.*, 2017). A long-term study found an increased risk of dementia in people with hearing loss who did not use hearing aids, although no increased risk was found in the participants that used hearing aids (Amieva *et al.*, 2018). Further research suggests that people who wear a hearing aid for age-related hearing problems maintain better brain function over time than those who have hearing problems but do not seek help for this (Brooker *et al.*, 2019). With hearing impairment affecting so many aspects of daily life, it is very important that hearing assessment and rehabilitation are also accessed by those caring for or supporting those living with dementia.

Physical health and other conditions

People with dementia may have other conditions which need equivalent access to diagnosis, treatment and care as people who do not have dementia (NICE, 2018a). This can include pain, falls, diabetes and incontinence. People with dementia who are admitted to hospital have an increased risk of delirium and will need an assessment that balances their current medical needs with the additional harms they may face in hospital (NICE, 2018a).

People with dementia will also need support with oral health. Studies show that older people living in nursing homes have more than double the amount of tooth decay as those living in the community, and for those living with dementia it is twice as high again (Thompson, 2014). This is a growing issue as more people are keeping their own teeth for longer.

Carers

It is estimated that of the cost of health and social care overall for people living with dementia, 16% is for healthcare, 39% for social care and 44% for unpaid care (Prince *et al.*, 2014). The percentage cost of unpaid care is 75% for people with dementia living in the community and the contribution of unpaid carers has been increasing (Prince *et al.*, 2014). Approximately two-thirds of people with dementia live in the community, with the remaining one-third living in <u>care homes</u> (Prince *et al.*, 2014).

The population assessment identified that around 73,000 people provide unpaid care in North Wales, about 11% of the population and the number of carers is increasing. Overall, more women provide unpaid care than men: 57% of carers in North Wales are women, and 42% are men, which is similar to the proportion across Wales and in

each local council area. People aged 50 to 64 are the most likely to provide unpaid care. Around half of all carers are in employment and 30% of carers are retired.

A report by Alzheimer's Research UK (2015) found that between 60% and 70% of all unpaid dementia carers are women. They highlighted that 2.5 times more women than men provide intensive on-duty care for someone 24-hours a day. They are also 2.3 times more likely than men to have been providing care to someone with dementia for more than five years and therefore make up a large portion of the carers who are supporting someone with advanced dementia. The report highlights research that women who care for people with dementia feel less supported than their male counterparts.

The North Wales Carers' Strategy sets out a vision and offer for carers in North Wales so that individual carers' needs, including language needs, are met in the best way and that carers come to mind as soon as the person cared for. This includes early identification of carers and involving carers in decision making and planning processes.

Risk reduction and delaying onset

Welsh Government recommend <u>six steps</u> that people can take to reduce their risk of dementia. These are:

- Step 1: Be physically active
- Step 2: Maintain a healthy weight
- Step 3: Be socially and mentally active (follow the <u>5 ways to wellbeing</u>).
- Step 4: Avoid drinking too much alcohol
- Step 5: Stop smoking
- Step 6: Commit to review your health

Data from the Public Health Outcomes Framework shows that in North Wales:

- 52% of adults do the recommended 150 minutes of exercise each week, which is similar to the Wales average of 53%.
- 22% of adults eat five portions of fruit or vegetables a day, which is lower than the Wales average of 24%.
- 41% of working age adults are a healthy weight, which is similar to the Wales average of 39%. Also 40% of older people are a healthy weight which is higher than the Wales average of 36%.

- 53% of people say they feel a sense of community, which is higher than the Wales average of 50% and 16% of adults say they feel lonely, which is similar to the Wales average of 17%.
- 18% drink more alcohol than the guidelines, which is similar to the Wales average of 19%.
- 19% of adults smoke, which is similar to the Wales average of 19%.

These risk factors are closely linked with deprivation and other social causes of poor health. For example, adults living in the most deprived areas in Wales are 2.4 times more likely to smoke than those in the least deprived areas (Public Health Wales, 2018).

Welsh language provision

We need to make sure there is enough provision and specialist assessment is available through the medium of Welsh, including an active offer. An active offer simply means providing a service in Welsh without someone having to ask for it. This was also identified as a concern in the national research of the Older People Commissioner in her report 'Dementia: More than just memory loss'.

The Alzheimer's Society Cymru have released a <u>report</u> with the Welsh Language Commissioner about access to care in Welsh for people living with dementia. Recommendations are being taken forward by Welsh Government and the Alzheimer's Society. Some of the areas where they will be working with local authorities and health boards include the following.

- Assessments of the range and level of services required to meet the care and support needs of people in their area, including the outcome 'I get care and support through the Welsh language if I need it'.
- Developing a Welsh language care pathway.
- Developing a national platform to share Welsh language diagnostic tests as well as resources, expertise and information about dementia and the Welsh language.
- Developing national and local forums to share experiences of delivering care and volunteering in Welsh.
- Make sure that specialist Welsh learning provision is available for workers involved in the care package for people living with dementia and where possible staff are released for extended periods to develop Welsh language skills.

According to the 2011 Census, 31% of the population of North Wales are able to speak Welsh, ranging from 65% in Gwynedd to 13% in Flintshire and Wrexham. The proportion of Welsh speakers is higher again in some areas of North Wales, with some electoral divisions (wards) where 88% of the population are able to speak Welsh such as Llanrug and areas of Caernarfon. The proportion of people aged 65 and over who speak Welsh is slightly lower and is shown in the table below.

Table 6 Number and percentage of people aged 65+ who speak Welsh, 2011

County	Number	%
Anglesey	7,745	54
Gwynedd	14,590	62
Conwy	6,245	24
Denbighshire	4,211	21
Flintshire	2,136	9
Wrexham	2,673	9
North Wales	37,600	27

Source: StatsWales (2011 Census).

The overall percentage of staff in local authority social services departments who speak Welsh in North Wales is 20% which is lower than the percentage of people aged 65 and over who speak Welsh but higher than the Welsh average of 16%. The percentage of Welsh speaking staff ranges from 4% in Wrexham to 86% in Anglesey. The areas in North Wales with the greatest gaps between the number of older people who speak Welsh and the number of Welsh speaking social care staff are Conwy, Denbighshire and Wrexham. However this data only includes staff directly employed by local authorities, not staff working for organisations commissioned by the local authority to provide care and support.

Table 7 Percentage of local authority social services staff who speak Welsh

County (a)	% of staff
Anglesey	86
Gwynedd	77
Conwy	9
Denbighshire	17
Flintshire	11
Wrexham	4
North Wales	20

Source: StatsWales (Staffing of local authority social services data collection).

Dementia can affect a person's linguistic ability, as it affects that part of the brain. Language decline is common. Evidence shows that bilingual people can lose their ability to speak one of their languages. It is vital that people living with dementia can access services in their chosen language. Services not being available, means that diagnosis can be delayed unnecessarily and there may be shortcomings when providing for their care needs.

Research published in the Journal of Neuropsychology has found that Welsh speakers are diagnosed an average three years later than those who only speak English. Their cognitive condition was also found to be much worse at the point of diagnosis. Language was likely to be a key factor causing this. Morgan and Crowder (2003) found that language was a factor when bilingual people were completing the Mini Mental State Examination. Their score in Welsh would be different to when it was completed in English. Further details can be found in Welsh Speakers' Dementia Care.

This makes language choice a clinical need, which is supported by national level policies and guidance, such as in More than just words and Dementia Action Plan for Wales.

Equality and human rights

Where available data has been included above to try to highlight the needs of people with protected characteristics living with dementia and their carers. This section summarises the issues that will need to be considered in the strategy to make sure that it meets the public sector duty in the Equality Act 2010 to tackle discrimination, advance equality of opportunity and promote good relations between people who share a protected characteristic and those who do not. In addition to the data collected we will consult with people with protected characteristics about the strategy and complete an equality impact assessment.

Age

People are more likely to experience dementia as they get older as shown in Table 8 below. In total 7.1% of all people over the age of 65 have dementia which rises to 17% of those over the age of 80 (Prince *et al.*, 2014).

Table 8 Consensus estimates of the population prevalence (%) of late-onset dementia

Age in years	Women	Men	Total
60 to 64	0.9	0.9	0.9
65 to 69	1.8	1.5	1.7
70 to 74	3.0	3.1	3.0
75 to 79	6.6	5.3	6.0
80 to 84	11.7	10.3	11.1
85 to 89	20.2	15.1	18.3
90 to 94	33.0	22.6	29.9
95 and older	44.2	28.8	41.1

Source: Dementia UK 2014.

The strategy will need to make sure it covers the different needs of younger and older people living with dementia. As cases of <u>young onset dementia</u> are relatively rare there is a risk that services are not designed with this group in mind so they may experience direct or indirect discrimination when accessing services.

It's also important that the strategy protects and promotes the rights of older people living with dementia who may also experience age discrimination and be at risk of

abuse. It should be based on the UN Principles for Older Persons (UNPOP): there are 18 principles which can be grouped under five themes: independence, participation, care, self-fulfilment and dignity

Disability

People with <u>learning disabilities</u> are more at risk of developing dementia.

People with dementia may also have a physical and/or sensory impairment.

The United Nations Convention on the Rights of Disabled People 2006 (UK) also promotes and protects the rights of disabled people including a person with dementia.

Marriage and civil partnership

The Equality Act 2010 says people must not be discriminated against in employment because they are married or in a civil partnership.

See <u>sexual orientation section</u> for more information about marriage and civil partnership for people identifying as lesbian, gay or bisexual (LGB).

Pregnancy and maternity

The strategy will need to make sure that it doesn't have an adverse impact on care workers and unpaid carers who are pregnant, on maternity leave or in the 26 weeks after giving birth. This includes treating someone unfavourably because they are breastfeeding for as long as they are breastfeeding. This can be addressed by making sure providers of services have good workplace policies and having appropriate support in place for unpaid carers.

Race

Research has found that dementia diagnosis was 25% higher among black women than white women and 28% higher among black men than white men. Asian women and men were 18% and 12% less likely than white women and men, respectively to have a dementia diagnosis (Pham *et al.*, 2018). They also found that the rates of people receiving a diagnosis may be lower than the actual rates of dementia in certain groups, particularly among black men. The research highlighted the messages that dementia is best diagnosed early and diagnostic services need to be

tailored to different groups as people's cultural background can influence how willing or unwilling they are to seek help.

Other studies have highlighted the risk factors for dementia, including high blood pressure, diabetes, stroke and heart disease tend to be higher in several black, Asian and minority ethnic groups (Prince *et al.*, 2014). People from Black, Asian and minority ethnic (BAME) communities are less likely to be diagnosed or receive post-diagnosis support (All-Party Parliamentary Group on Dementia, 2013).

According to the 2011 Census in North Wales, there were around 800 people from BAME groups aged 65 and over, making up 0.6% of the population. Table 9 below shows the number of people aged 65 and over by ethnic group in North Wales.

Table 9 Number of people aged 65 and over by ethnic group, North Wales

Ethnic group	Number
	of people
White	140,000
Asian/Asian British	360
Mixed/multiple ethnic group	330
Black/African/Caribbean/Black British	70
Other ethnic group	50

Source: Census 2011.

The proportion of people from BAME groups is higher for people aged under 65 at around 2.7% so the number aged 65 and over may rise as these younger people age. Although around 29% of people from BAME groups age 16 and over living in North Wales are full-time students (compared to 7% of white people), a highly mobile population who may move out of the area and be replaced by other students moving to the area rather than remaining as they grow older.

Based on an estimated prevalence rate of 7.1% of people aged 65 and over having dementia this suggests that there are around 60 people from BAME groups living with dementia in North Wales (Prince *et al.*, 2014). As this is such a small group of people care needs to be taken that any specific requirements are not overlooked when planning services by making sure services are based on the needs of the individual.

Being able to provide services in a person's first language is also very important in dementia care as people may lose other languages acquired later in life. According to the 2011 Census there were 82 different languages spoken in North Wales. After Welsh and English, the most commonly spoken language is Polish with around 5,100 speakers, mainly living in Wrexham (2,600 speakers) and Flintshire (1,300 speakers). Chinese languages are the next most common with 1,700 people speaking a Chinese language including Cantonese Chinese and Mandarin Chinese. Then Arabic with 790 speakers, Portuguese with 750 speakers and Tagalog/Filipino with 560 speakers.

The most commonly spoken languages are similar for people aged 65 and over in North Wales too, with Polish the most commonly spoken language (150 speakers), around 90 Chinese speakers and then French (30 speakers), Portuguese (20 speakers) and Bengali with Sylheti and Chatgaya (15 speakers).

Research about dementia in Gypsy and Traveller communities found that campaigns to raise awareness about how to reduce risk often don't reach these communities (Rattigan and Sweeney, 2018). They also found people avoid seeking support because they felt they wouldn't receive culturally appropriate care as well as a strong preference for care workers from within the Gypsy and Traveller communities.

Religion or belief

Around 82% of people aged 65 and over in North Wales identified as Christian in the 2011 Census. Table 10 below show the number of people aged 65 and over by religion or belief. As with ethnic background above, care needs to be taken that any specific needs are not overlooked when planning services by making sure services are based on the needs of the individual.

Table 10 Number of people aged 65 and over by religion or belief, North Wales

Religion	Number
	of people
Christian	110,000
No religion	12,000
Religion not stated	12,000
Other religion	280
Buddhist	180
Muslim	95
Jewish	90
Hindu	70
Sikh	10

Source: Census 2011. Numbers may not add up due to rounding.

Sex

More women than men are <u>living with dementia</u> and women are more likely to be <u>carers of people living with dementia</u>. There is more information about the difference in prevalence rates between women and men in Table 8.

Sexual orientation and gender identity

Lesbian, gay, bisexual and trans (LGBT) people can face additional challenges when living with dementia. They may be less likely to have family and children to support them and have experienced discrimination that makes them feel unsafe when accessing health and social care (National Care Forum, 2016). A report of the Older LGBT Network in Wales highlighted concerns around prejudice and treatment from other older people; care providers and health professionals making the assumption they are heterosexual; and not having their wishes around who they consider to be their family and next of kin respected (Age Cymru, 2009).

Estimates about the number of LGBT people in the population vary and data was not collected in the last Census. Recent estimates suggest around 0.7% of the population aged 65 and over in the UK identify as LGB, whereas for 16 to 24 year olds this was 4.2% (Office for National Statistics, 2017). It's suggested this could be because younger people could be more likely to explore their sexuality combined

with more social acceptability of sexual identities today and the ability to express these.

In 2017, around 69% of those identifying as lesbian, gay or bisexual (LGB) stated they had never married or entered into a civil partnership (Office for National Statistics, 2017). This is a higher percentage than those identifying as heterosexual or straight (34%).

Trans people may face unique challenges when living with dementia, for example around feeling safe and expressing their identity. BCUHB have developed Supporting me to be the person I want to be, a guide to understanding, reflecting and responding to transgender issues in dementia care.

Poverty

Many of the risk factors for developing dementia are associated with living in poverty as described in the section on <u>risk reduction and delaying onset</u>.

People living with dementia may also be more likely to experience poverty, if they and/or their carers are no longer able to work or to do the same hours or kind of work as they used to. There are reasonable adjustments that employers can make to help people living with dementia and carers to continue in employment.

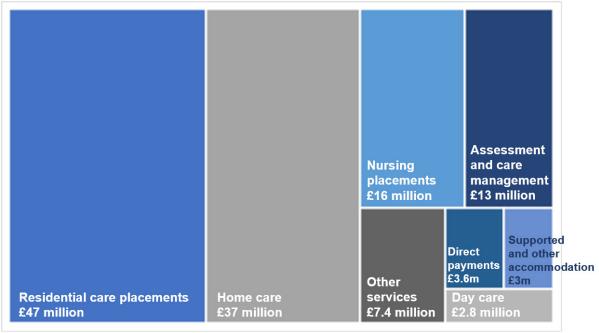
The welfare benefits system and the way that social care is funded are responsibilities of the UK Government and Welsh Government so are outside the scope of this strategy, although they do have a significant impact on the well-being of people affected by dementia.

Amount spent on older people's services

There is no data available about the amount of funding spent by local authorities on care and support for people living with dementia. In 2017-18 around £130 million was spent in total on older people's services by local authorities in North Wales, which will include a high proportion of people living with dementia. The greatest proportion of spend is on residential care, home care and nursing placements as shown in Figure 4 below.

In 2017-18 Betsi Cadwaladr University Health Board (BCUHB) spent £56 million in the category of 'elderly mental illness' of which £2.9 million is spent in primary care and £53 million is spent in secondary care (Welsh Government, 2019).

Figure 4 Local authority spend on services for older people in North Wales by type of support, 2017-18



Source: StatsWales

References

Action on Hearing Loss 2015. Hearing Matters. London: Action on Hearing Loss.

Age Cymru 2009. A report of the Older LGBT Network into the specific needs of older lesbian, gay, bisexual and transgender people.

All-Party Parliamentary Group on Dementia 2013. Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities.

Alzheimer's Research UK 2015. Women and dementia: A marginalised majority.

Alzheimer's Research UK 2019. Dementia Statistics Hub.

Alzheimer's Society 2007. Home from home: A report highlighting opportunities for improving standards of dementia care in care homes.

Alzheimer's Society Cymru and Welsh Language Commissioner 2018. Welsh Speakers' Dementia Care

Alzheimer's Society (2019) *About dementia*. Available at: https://www.alzheimers.org.uk/about-dementia.

Amieva, H., Ouvrard, C., Meillon, C., Rullier, L. and Dartigues, J.-F. (2018) 'Death, Depression, Disability, and Dementia Associated With Self-reported Hearing Problems: A 25-Year Study', *The Journals of Gerontology: Series A*, 73(10).

Brooker, H, Severin, J., Sander, M., Corbett, A., Aarsland, D., Hampshire, A., Wesnes, K and Ballard, C. 'Use of Hearing Aids in Older Adults with Hearing Loss Is Associated with Improved Cognitive Trajectory', *Alzheimer's Association International Conference*, Los Angeles, USA.

Holland, A. J., Hon, J., Huppert, F. A., Stevens, F. and Watson, P. (1998) 'Population based study of the prevalence and presentation of dementia in adults with Down's syndrome.', *British Journal of Psychiatry*, 172, pp. 493-498.

Institute of Public Care (2017) *Daffodil: Projecting the need for care services in Wales*. Available at: http://www.daffodilcymru.org.uk/ (Accessed: 04/06/2019.

Jones, C., Andrew, R. and Atenstaedt, R. 2018. Mental health and wellbeing in Betsi Cadwaladr University Health Board (BCUHB). Public Health Wales.

Kerr, D. 2007. Understanding Learning Disability and Dementia: Developing Effective Interventions. London: Jessica Kingsley Publishers.

Livingston, G, Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J. and Cooper, C. (2017) 'Dementia prevention, intervention, and care', *The Lancet*, 390(10113), pp. 2673-2734.

Maharani, A, Dawes, P., Nazroo, J., Tampubolon, G., Pendleton, N., SENSE-Cog WP1 group, Bertelsen, G., Cosh, S., Cougnard-Grégoire, A., Delcourt, C. and Constantinidou, F. (2018) 'Longitudinal relationship between hearing aid use and cognitive function in older Americans', *Journal of the American Geriatrics Society*, 66(6), pp. 1130-1136.

Mamo, S.K., Nirmalasari, O., Nieman, C. L., McNabney, M. K., Simpson, A., Oh, E. S. and Lin, F. R. (2017) 'Hearing care intervention for persons with dementia: A pilot study', *The American Journal of Geriatric Psychiatry*, 25(1), pp. 91-101.

Matthews, F. E., Stephan, B. C. M., L. Robinson, L., Jagger, C., Barnes, L. E., Arthur, A. and Brayne, C. (2016) 'A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II', *Nature Communications*, *Published online:* 19 April 2016; | doi:10.1038/ncomms11398.

National Care Forum 2016. Dementia care and LGBT communities.

NICE 2018a. Dementia: assessment, management and support for people living with dementia and their carers. *NICE guideline [NG97]*.

NICE 2018b. Hearing loss in adults: assessment and management. *NICE guideline NG98.*

Office for National Statistics 2017. Sexual orientation, UK. *Experimental statistics on sexual orientation in the UK in 2017 by region, sex, age, marital status, ethnicity and socio-economic classification.*

Pham, T., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N. and Cooper, C. (2018) 'Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data', *Clinical Epidemiology*, 10.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A. and Salimkumar, D. (2014) *Dementia UK: Second Edition - Overview.* Alzheimer's Society.

Public Health Wales 2018. Health and its determinants in Wales.

Rattigan, S. and Sweeney, S. 2018. 'We look after our own': Dementia in Gypsy and Traveller Communities.

RNIB 2018. Sight Loss Data Tool.

Thompson, W. M. 2014. Epidemiology of oral health conditions in older people.

Ward, C. 2012. BILD Factsheet: Older people with a learning disability. British Institute of Learning Disabilities.

Welsh Government 2018a. General Medical Services Contract: Quality and Outcomes Framework Statistics for Wales, 2017-18.

Welsh Government 2018b. Mid-year population estimates (1991 onwards), by Welsh local authorities, English regions and UK countries, for single year of age and gender.

Welsh Government 2019. NHS expenditure by programme budget category.

Welsh Government 2020. 2018-based local authority population projections for Wales.