Dementia in Bradford and Airedale

A Health Needs Assessment and Strategy for 2015-2020

Executive Summary
Strategic Summary

At the outset of this piece of work, it was designed to take a strategic overview, and structured to deliver evidence-based recommendations, informed by local stakeholders.

On completion of the Health Needs Assessment, it was decided by members of the Dementia Strategy Group that it should also constitute the 2015-2020 Dementia Strategy for the District, underpinned by a 5 year Action Plan under the supervision and direction of the Dementia Strategy Group. This approach has been approved by the Council Health and Social Care Overview and Scrutiny Committee, the three Clinical Commissioning Groups and Secondary Care partners. The Action Plan framework has been introduced at the Dementia Strategy Group and agreed by members, who are building up tasks with section leads to deliver the 83 recommendations.

Five key strategic aims for the strategy have been agreed

1. To keep people with Dementia in their homes for as long as possible
2. To increase the strategic focus on Dementia in Care Homes
3. Increase awareness of prevention of Dementia through healthy lifestyles
4. Provision of high quality end of life care for people with Dementia
5. To enable people to live well with Dementia

It is important to realise that this is a live piece of work. Evidence and policy will change over the next 5 years and we will ensure we are reactive as well as proactive in keeping the recommendations and strategic aims up to date and relevant. New sections will continue to be added over the lifetime of the strategy.
Dementia can occur at any age, however it is far more common in the elderly. One in six people over 80 and one in 14 people over 65 will dementia. The number of older people in our population is rising, therefore the number of people with both diagnosed and undiagnosed dementia will increase accordingly. In addition, if we also consider that people with dementia are living longer, all adding to this growing pool of need, it is clear that our services must develop in order to ensure the best quality of life and of care for our people with dementia.

As a direct result, the costs of caring for people with dementia across Bradford and Airedale can be expected to rise. There is a pressing need for robust forward planning, both to design effective and efficient services, and to make fiscal allowances for the resources required.

A detailed Dementia Health Needs Assessment (HNA) was identified by key stakeholders as a priority for the District. The HNA will be introduced into key strategic and commissioning structures and processes, and inform service redesign. The full HNA report is hosted on the Public Health Observatory website. It is not designed to be read from start to finish, rather sections are presented as discrete pieces of work that can be read and used individually, with signposts to other sections as required.
Section 2 – Epidemiology

The overall prevalence of dementia (i.e. diagnosed plus undiagnosed) in the over 65 population in the UK has previously been thought to be 8.3%, however this estimate has recently been reduced to 6.5%. Applying this figure to the over 65 population in Bradford and Airedale it would suggest an overall prevalence of around 5,000 cases in the District.

If we consider the numbers of diagnosed cases taken from GP Registers and set them against total prevalence estimates, we can estimate a “diagnosis deficit” of around 2,000 cases of Dementia for the Bradford and Airedale District.

There are four main types of dementia. Studies report different estimates, and a summary estimate is provided in the table to the right, along with estimates of local prevalence. Vascular dementia is particularly important as it is preventable through stopping smoking and reducing cardiovascular risk.

The table to the left outlines the projected increase in numbers of people with dementia across the district up to 2020. These estimates suggest that there will be an additional 700 cases over the next seven years. This may seem a small number, but an additional 100 cases per year will place a significant resource and financial burden on diagnostic and care services.

What does this mean for Bradford and Airedale?
The 5,000 people with dementia prevalence figure is a rounded estimate based on known diagnoses plus estimates of undiagnosed cases based on published research studies. The 3000:2000 split is a useful message. There are different methods and tools applied nationally for estimation, and it will be useful to set these figures against the rest of the findings of this report as we apply them to service redesign and commissioning development.

As we progress in finding people with undiagnosed dementia and offering them diagnosis and support, it is vital that we bear in mind differences between diagnosed and undiagnosed cohorts. The success of the pursuit of undiagnosed cases will ultimately determine the impact on services in respect of demand and capacity. Consideration of present and projected age profiles must be central to strategic planning in addition to knowledge of ethnic composition and socioeconomic deprivation across the district.

Recommendations
1. Work should continue to query and understand the methodologies in order that we use the appropriate measure in the appropriate circumstances
2. A local Steering Group should be established with a specific remit to develop and implement a case-finding action plan to increase diagnosis among the ~2,000 undiagnosed cases already living in the district as recommended in Section 6b – Memory Assessment and Treatment Services
3. The data contained in this report should be used to inform capacity:demand modelling as new services develop
Section 3 – Ethnicity

Bradford and Airedale has a rich ethnic diversity, with high numbers of people from BME communities, particular the South Asian community. This raises particular concerns about the increased risk of vascular dementia in this community, analogous with the better understood increased risk of cardiovascular disease (this also applies to the Black African community). Clearly there is potential for primary and secondary prevention in the vascular dementia BME community. The number/proportion of South Asian people living in the district is set to rise significantly to the year 2031 – a key factor for future service provision.

Key findings elsewhere in this report in respect of dementia and ethnicity include:

- The majority of BME groups live primarily in the City area, and are less likely to live in urban areas
- Work carried out as part of the qualitative analysis (see Section 8) indicated that community based activity in the 3rd sector is structured around five generalized ethnic groups; White, South Asian, African/Caribbean, Central Eastern European and Irish
- There is a relative underrepresentation of people from the South Asian community in hospital admissions
- Poor quality of ethnicity coding limits the applicability and robustness of local data
- Some South Asian people do not like being seen attending mental health services or follow up appointments for fear of stigmatisation
- Cultural attitudes to elders may be important in generating referrals
- Services should be culturally appropriate and staff culturally competent
- It was felt that across cultures there are diverse attitudes to carers/looking after elders.
- Cultural attitudes and norms in respect of dementia and mental illness may be preventing people from BME communities accessing dementia services
- South Asian families may be more reluctant to put elders into care
- The increased incidence and risk of cardiovascular disease and diabetes in South Asian people places them at an increased risk of developing vascular dementia

What does this mean for Bradford and Airedale?

Dementia tends to occur at a younger age in South Asian people, primary care staff, particularly in the City area should be aware of this to inform their index of suspicion of dementia in younger people.

This section raises particular concerns about the increased risk of vascular dementia in BME communities. Clearly there is potential for primary and secondary prevention in the vascular dementia BME community.

This report demonstrates at a number of points the underutilisation of dementia services by South Asian people, this should be investigated further in order to better understand the reasons for this and to identify broader lessons that can be learned.

The number/proportion of South Asian people living in the district is set to rise significantly to 2031 – this should be incorporated into strategic and operational planning.

Recommendations

1. Work should be undertaken with academic partners to develop culturally appropriate and robust screening and evaluation tools

2. Work should be undertaken with both clinicians and the South Asian community to promote primary and secondary prevention of vascular dementia

3. Efforts should continue to improve coding of ethnicity across all services

4. The Dementia Strategy should explicitly take into account the rising number of people from BME communities across the district
### Section 4 - Outcomes

One of the key elements of the changes in health and social care over the last five years has been a firm sharpening of the focus on outcomes as opposed to process and activity measures (‘outputs’), largely underpinned by the realisation that to deliver truly patient-centred care we must focus on what matters most to the patient and their carers. The publication of three key outcomes frameworks for health and social care has demonstrated this commitment nationally. The three outcomes frameworks are:

- The Public Health Outcomes Framework
- The Adult Social Care Outcomes Framework
- The NHS Outcomes Framework

The Dementia Health Needs Assessment Strategy Group met to derive a list of outcomes that reflect the work and direction of services, commissioners and other stakeholders across Bradford and Airedale. These outcomes were drawn from the frameworks outlined above.

#### Public Health Outcomes Framework

<table>
<thead>
<tr>
<th>Domain 1 - Improving the wider determinants of health</th>
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<tbody>
<tr>
<td>1.19 – Older people’s perception of community safety</td>
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<table>
<thead>
<tr>
<th>Domain 2 – Health Improvement</th>
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<tr>
<td>2.23 – Self-reported wellbeing</td>
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<tr>
<th>Domain 4 - Healthcare public health and preventing premature mortality</th>
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<tbody>
<tr>
<td>4.16 – Estimated diagnosis rate for people with dementia</td>
</tr>
<tr>
<td>4.13 – Health-related quality of life for older people</td>
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<tr>
<td>4.11 – Emergency readmissions within 30 days of discharge from hospital</td>
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#### NHS Outcomes Framework

<table>
<thead>
<tr>
<th>Domain 2 - Enhancing Quality of Life for People with Long-term Conditions</th>
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<tr>
<td>2.3 - Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)</td>
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<tr>
<th>Domain 4 - Ensuring that People have a Positive Experience of Care</th>
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<tr>
<td>4.6 - Bereaved carers’ views on the quality of care in the last 3 months of life</td>
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<td>4.7 - Patient experience of community mental health services</td>
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#### Adult Social Care Outcomes Framework

<table>
<thead>
<tr>
<th>Domain 1 – Enhancing quality of life for people with care and support needs</th>
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<tr>
<td>1D – Carer-reported Quality of Life</td>
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<table>
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<tr>
<th>Domain 2 – Delaying and reducing the need for care and support</th>
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<tr>
<td>2A – Permanent admissions to residential and nursing care homes, per 1,000 population</td>
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<tr>
<td>2B – Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services</td>
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<tr>
<td>2F – Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life</td>
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<thead>
<tr>
<th>Domain 3 – Ensuring that people have a positive experience of care</th>
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<tr>
<td>3C – The proportion of carers who report that they have been included or consulted in discussions about the person they care for</td>
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<tr>
<td>3D – The proportion of people who use services and carers who find it easy to find information about support</td>
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<tr>
<th>Domain 4 – Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm</th>
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<tr>
<td>4A – The proportion of people who use services who feel safe</td>
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Section 5 – Primary Care

Primary Care is that care which would normally represent a patient’s first point of contact with healthcare services in the community. In the UK it is generally considered to be general practices and the services they provide. Usually, primary care services refer on to secondary care services provided by hospital trusts. In Bradford and Airedale, primary care services are provided by three Clinical Commissioning Groups (CCGs):

1. Airedale, Wharfedale and Craven CCG (AWCCCG)
2. Bradford City CCG (BCCCG)
3. Bradford Districts CCG (BDCCG)

The table to the right shows the number of diagnosed cases of dementia by CCG, and also the proportion of the total population diagnosed with dementia.

<table>
<thead>
<tr>
<th>CCG</th>
<th>Diagnosed cases from QoF</th>
<th>% of total population with a diagnosis of dementia, from QoF</th>
</tr>
</thead>
<tbody>
<tr>
<td>AWCCCG</td>
<td>1106</td>
<td>0.71%</td>
</tr>
<tr>
<td>AWCCG</td>
<td>672</td>
<td>0.64%</td>
</tr>
<tr>
<td>BDCCG</td>
<td>2007</td>
<td>0.61%</td>
</tr>
<tr>
<td>BCCCG</td>
<td>281</td>
<td>0.24%</td>
</tr>
</tbody>
</table>

What does this mean for Bradford and Airedale?

Primary care is the key interface for clinicians and patients in respect of diagnosis of dementia and referral to specialist services, it is crucial that GPs and other practice staff are appropriately equipped to mange this process safely and effectively. It is also important to recognise that many patients live outside the CCG area when planning services. Prevalence of diagnosed cases varies across CCGs, likely due to demographic and epidemiological differences and there is evidence of statistically significant variation in diagnosed prevalence rates within CCGs themselves, further analysis of this may provide valuable information regarding local diagnosis and referral cultures and processes. There is some suggestion here that rates of diagnoses may be tailing off, may be evidence of a “mop up” effect as diagnosis rates rise and it is important that we continue to monitor trends.

Recommendations

1. Dementia must remain high on the list of strategic priorities for all CCGs
2. Clinical audit of practice prevalence within CCGs may provide valuable information
3. CCGs should plan robustly for coming rises in demand for diagnosis and treatment services
4. CCGs should support and develop work the continuing work on Memory Assessment and Treatment Services
Section 6 – Memory Assessment and Treatment Services

Memory Assessment and Treatment Services (MATS) are recommended as the single point of referral for those with a possible diagnosis of dementia. Providing a specialist diagnosis service ensures that those with dementia have access to the full range of assessment, diagnostic and therapeutic services to ensure a correct diagnosis of dementia is made and that other medical causes of memory loss are considered.

The figure to the left shows the number of referrals to Memory Services across Bradford District from 2005-6 to 2012-13. A clear sustained year on year rise in referrals from 2005 to the present is shown. with a more modest rise observed between 2012-13. The trend upwards suggests a need to build in rising capacity to services.

Local MATS Services

In Bradford and Airedale, the MATS services are provided by Bradford District Care Trust and are delivered within the localities of the provider Community Mental Health Teams which include, Bingley and North Bradford, Bradford South and West, Bradford City and Airedale and Craven. MATS services have been delivered across Bradford and Airedale since 2010, and differing commissioning arrangements have resulted in a variety of models being delivered. In 2012 a review was undertaken to identify a standardised, evidence-based model for equitable access to MATS across the District and for the early detection and diagnosis of dementia via the Acute and Care Home Liaison (ACHL) service to optimise quality outcomes for people with dementia delivered in a timely and efficient manner which should also deliver financial savings. The findings of this HNA will be used to inform the implementation of options presented in the review.

What does this mean for Bradford and Airedale?

There has been a steady rise in referrals to MATS services from all three CCGs over recent years. There is some indication of a slowing or plateauing of the rate of rise in referrals, however this must be taken in the context that the demographic projections remain that numbers of older people are expected to continue rising - there is a need to maintain and develop adequate provision for a prospective continuing rise in number of people with dementia.

It is important that all population groups are aware of and can access the services. There are likely to be factors influencing inequity of access, e.g. deprivation, fear of diagnosis; practical difficulties in attending; complexity of the system and lack of awareness among GPs.

Recommendations

1. An integrated, community and primary care focused model of MATS services is likely to best serve the identified needs of the local population.
2. A local Steering Group should be established with a specific remit to develop and implement a case-finding action plan to increase diagnosis among the ~2,000 undiagnosed cases in the district.
3. The data in this report should be used to inform capacity: demand modeling as services develop.
4. Services should be carefully advertised and described to minimise fear and stigma.
5. Services should be culturally appropriate and staff culturally competent.
6. Services should follow a district-wide common pathway.
7. Data collection and analysis processes should be developed to provide ethnicity figures.
Section 7 – Secondary Care

25% of hospital beds are occupied by somebody with dementia, rising to 40% patients over the age of 75. Being an inpatient in a general hospital can be detrimental to the well-being of a person with dementia. The figure to the right shows the rising numbers of admissions in dementia patients since 2009, by CCG. There has been a notable rise from 2011 to the present.

People with dementia stay far longer in hospital than other people who go in for the same procedure. The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and the individual’s physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used. The figure to the left shows a current average stay of 9-10 days with this having fallen up to 2012 and then rising again.

What does this mean for Bradford and Airedale?
This section has raised a number of key questions regarding people with dementia and secondary care across the district. For example:
- How can the transition to admission on mental health grounds be managed without the need for a crisis with patient distress?
- Is admission to acute medical care sometimes pursued because the most appropriate option is hard to access out-of-hours?
- How can we create and sustain pathways of care which cross smoothly between community and secondary care services, where admission to hospital is seen as a last resort?

Recommendations
1. Commissioners should continue to work with secondary care providers to ensure that admissions to hospital are short departures from community care pathways, rather than pathways in themselves
2. Priority should be given to agreeing jointly owned integrated discharge planning processes
3. The Dementia Strategy Group should oversee a focused piece of work, in partnership with Meri Yaadain, to better understand the reasons that determine when and why South Asian people with dementia are admitted to secondary care
4. The School of Dementia Studies at Bradford University should be approached to discuss analysis of the cohort of patients who are admitted to BDCT, as this may provide valuable insights into the dynamics of the relationship between community-based mental health care and reasons for admission
5. Work should be undertaken with local clinicians to better understand the relationship between dementia and delirium, and the measures that can be taken to both improve quality of life for people with dementia and their carers, and to reduce costs.
Section 8 – Voluntary and Third Sector Services

The Voluntary and Third Sector plays an important role in providing dementia services in the community. Some organisations serve a specific dementia client group and, although they may make a charge for their services, they are non-profit-making.

Note - It is not possible to cover all of the VTS organisations that contribute to dementia care here in Bradford and Airedale, however the activities two key organisations are summarized below.

Alzheimer’s Society
The Alzheimer’s Society is the primary voluntary sector organisation offering services to people with dementia primarily living in the community, carers, families and professionals. Services include:

Dementia Advisor Service - to ensure all people newly diagnosed with dementia, their carers and families get access to independent information about their condition.
Dementia Support Worker Service - ensuring people get continued access to information and support as required through an allocated caseworker system.
Peer Support Service - to provide activities and groups such as singing groups, cafes and discussion groups in order to provide both enjoyment and the opportunity to develop friendship and support networks with people in a similar situation.

Meri Yaadain
Meri Yaadain (meaning My Memories) is a local initiative focused on addressing issues relating to dementia in Black and Minority Ethnic (BME) communities, and in particular the district’s large south Asian community. Services include:

- Community roadshows
- A quarterly newsletter
- Radio programmes
- Home visits
- Support Group
- Telephone Advice
- Work with Schools

To date, Meri Yaadain has supported approximately 220 individual and families, with a current caseload of about 80.

What does this mean for Bradford and Airedale?
There is a rich wealth of Voluntary and Third Sector services supporting people with dementia and their carers throughout Bradford and Airedale. It would not be possible to describe all of them and what they provide here, and we have focused on two of our key services in order to provide a picture of the role of the Voluntary and Third Sector in Bradford and Airedale.
Clearly the Voluntary and Third Sector occupies an enormous role and bears a significant responsibility in supporting people with dementia and their carers throughout the district. It would not be possible to consider dementia in the context of strategic and operational planning without explicitly acknowledging and incorporating activity from this sector.

Recommendations
1. Consideration should be given to undertaking a focused piece of work investigating further the extent and nature of activity in this sector for people with dementia and their carers, potentially in conjunction with colleagues from the Bradford University School of Dementia Studies.
2. We should ensure that commissioners and providers incorporate the activity of the Voluntary and Third Sector in all strategic and operational planning for dementia.
Section 9 – Wellbeing Cafes

The Wellbeing Café model is a setting in which “people with dementia and their carers can come together in a friendly and comfortable place to socialise and get information and support”. The literature available on the model asserts that the cafes are particularly beneficial to people in the early stages of dementia and that by encouraging people to find strategies to manage the cognitive changes of dementia, people with early stage dementia are encouraged to regain contacts within their community and to take up activities.

Bradford Metropolitan Council Adult Social Services funds a network of 21 Wellbeing Cafes located within communities and neighbourhoods across the Bradford and Airedale District through Wellbeing grants. Some provide for specific geographical communities for example the Queensbury area, and some provide for cultural communities such as the South Asian and Central & Eastern European communities. Their locations are shown to the left.

Under this local arrangement, the Cafes are expected to:

- Provide support for older people with mild to moderate mental health needs; this includes people with dementia, isolation, depression, bereavement and carers.
- Generate greater understanding of the needs and experiences of older people with mental health needs, particularly groups currently marginalised within existing service provision and using this knowledge to inform wider service developments.
- Signpost Users of Cafes to community, health and social care resources, ensuring ‘right help at the right time’. Appropriate signposting and crisis avoidance is expected to reduce pressure on early intervention services.

Recommendations

1. A review should be undertaken of the knowledge and skills that will best serve the staff working in the Wellbeing Cafes.
2. Consideration should be given to expanding the provision of Wellbeing Café service provision. This should include strategic consideration of geographical access to the Cafes and the developing rise in demand as outlined in Section 2.
3. The services provided by the Cafes should be reviewed in light of the different needs of different groups of people with dementia.
4. Work should progress to ensure that both Primary Care, Secondary Care and community providers ensure that all patients with dementia and their carers are made aware of the Cafes and the most appropriate ones for them to attend.
5. The Dementia Strategy Board should consider appropriate mechanisms by which the Cafes can have representation at strategic level.

What does this mean for Bradford and Airedale?
Wellbeing Cafes have become a vital resource in the post-diagnosis period. There are some geographical gaps in their provision, and though all cafes are open to people with Dementia and carers it is not known if all café staff have knowledge and expertise.

As rates of diagnosis and incidence of dementia rise, we may need to put more Cafes in place to meet needs. We should ensure that all people receiving a diagnosis of dementia, and their carers, are informed of the existence of the Cafes, what they offer and where they are located. There is also a need to explore strategic development of the network of Cafes and the services they provide. In undertaking this, we must consider whether our Cafes are suitable for all people with dementia, and if cafes link better to other services as part of the pathway of care.
Section 10 – Dementia Friendly Communities

A Dementia Friendly Community is one that shows a high level of public awareness and understanding of dementia so that people with dementia and their carers are encouraged to seek help and are supported by their community. A Dementia Friendly Community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

Evidence researched by the Alzheimer’s Society has shown that, to help support them to live well in their local area, people with dementia and their carers want a range of support. This evidence suggests that there is a good case for Dementia Friendly Communities addressing a clearly expressed need among people with dementia and their carers.

Dementia friendly communities could save £11,000 per person per year by helping people with dementia to remain independent, stay out of care for longer and have a better quality of life, according to Alzheimer’s Society. If just 5% of admissions to residential care were to be delayed for one year as a result of dementia-friendly communities, there would be a net saving of £55 million per annum across England, Wales and Northern Ireland. Pro rata this would equal ~£500,000 per annum for Bradford and Airedale.

Bradford Dementia Friendly Communities Project is run by the Alzheimer’s Society Bradford office and is funded by Joseph Rowntree Foundation and Bradford Metropolitan District Council initially for 2 years to support Bradford District’s work towards becoming a dementia friendly district and to develop and share good practice. This is a new project, but it builds on the work of the previous dementia friendly community work run by the Alzheimer’s Society in Bradford and funded by Bradford council from Nov 2011 to March 2013.

The Project aims are, through work with communities, businesses and organisations:

1. To develop good practice in developing dementia friendly communities
2. To share this learning with the wider dementia friendly community movement.

The strategic aim is to develop 20 Dementia Friendly Communities across the district.

What does this mean for Bradford and Airedale?

There is a strong national drive to promote Dementia Friendly Communities, focusing on developing a shared understanding and tolerance among people in communities, and also within businesses and services which people with dementia and their carers continue to use. Bradford and Airedale has been at the forefront of this initiative from its outset and progress is extremely encouraging. There is considerable scope to build on this progress in innovative and imaginative ways, for example in terms of transport and building design as referred to in Section 8 – Qualitative Study.

Recommendations

1. The local Dementia Friendly Communities project should continue to be supported at every level, including political, clinical, commissioning, provider and local community groups and area committees.

2. The Dementia Strategy Board should work with leaders of the Dementia Friendly Communities projects, particularly with a view to developing innovation and support from experts within the group.
Section 11 – Qualitative Study

This part of the HNA is designed to capture the insights and opinions of key stakeholders in a meaningful way that can be used to contribute to the conclusions and recommendations. In order to undertake this section of the report, the key stakeholders were contacted and asked to take part in an interview which would:

1. Give them the opportunity to communicate their experience and knowledge in a manner which would contribute to the findings of the HNA.
2. If they were a service provider, involve a number of questions specific to their service being asked, and they may be asked to provide some data on service activity where appropriate.

In total 49 people were interviewed, including elected members, patients, carers, service providers and commissioners. All were asked the same 5 questions:

1. What comes to mind when you think of dementia in Bradford and Airedale?
2. What do you think is the biggest challenge we face in respect of dementia in Bradford and Airedale?
3. What do you think is the biggest asset we have in Bradford and Airedale in respect of dementia?
4. What is the single most important priority for action currently in respect of dementia in Bradford and Airedale?
5. If you had £1,000,000 to spend to achieve the answer set out in question 4., how would you spend it?

Responses were analysed using standard qualitative techniques, with the following results:

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Recurring Themes</th>
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<tbody>
<tr>
<td>1. Dementia in public</td>
<td>1. Goodwill across the District</td>
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<tr>
<td>2. Fragmented services</td>
<td>2. School of Dementia Studies</td>
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<tr>
<td>3. Impact of ethnicity</td>
<td>3. Funding</td>
</tr>
<tr>
<td>4. Need for training</td>
<td>4. Post-diagnosis care</td>
</tr>
<tr>
<td>5. Keeping patients at home</td>
<td>6. Importance of 3rd sector</td>
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<tr>
<td>7. Need to reduce stigma</td>
<td>8. Need to spread information</td>
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What does this mean for Bradford and Airedale?

There is a huge amount of information contained within this section, and its use should be approached carefully and systematically. It is important that quotes and summary sections are not used in isolation unless discussions take place with those who produced this report.

Since the focus groups facilitated by the Alzheimer’s Society took place, the Society has been contacted by many people with dementia and their carers, who are eager to continue the process of feedback. This has also been expressed through social media. This is an extremely positive step, and its use in informing service planning must be facilitated carefully.

Recommendations

1. The Dementia Strategy Group should lead work to ensure that the information provided in this section is made available to commissioners, providers and all those involved in planning dementia services.
2. The use and application of the information contained here should be taken through members of the Dementia Strategy Group who governed the production of this report.
3. The Dementia Strategy Group should continue to support the Alzheimer’s Society in developing this work.
Section 12 – Comorbidities and Frailty

As people get older, their probability of being diagnosed with multiple diseases (‘comorbidities’) rises considerably. A recent large UK study found that the prevalence of people with more than one disease increases substantially with age and is present in most people aged 65 years and over, the age at which dementia is most prevalent. Frailty, or “infirmity - the state of being weak in health and body” is a key element of this.

Primary Care registers were searched for patients on the Dementia register who also appear on other disease registers. The proportions observed in this study compared to prevalence figures reported in research literature to estimate areas where we are underdiagnosing comorbidities. Examples of findings are shown left.

17 comorbidities were analysed in total, the tables to the left and right show the total numbers for patients with dementia and their respective comorbidities. Note - The 305 patients receiving palliative care are mostly receiving it for diseases other than dementia.

What does this mean for Bradford and Airedale?

Management of comorbidity is an important element of any holistic care package for a person with dementia. There is some evidence that certain comorbidities may be underdiagnosed in people with dementia, in particular depression which is a growing problem among older people. Some differences across CCGs were observed, and further work to understand these may provide valuable insights.

This section throws an important light on a key issue in the important area integration of care to address the health and social care needs of people with dementia and their carers. It is important to understand that dementia will affect how their other long term conditions are managed and this needs to be taken into account by primary care commissioners and providers as these patients can be ‘missed’ or ‘exempted’ by the Quality Outcomes Framework as they are house bound with poor access to service.

Recommendations

1. The Dementia Strategy Group should lead work to highlight the findings of this section to primary care commissioners and providers and also to secondary care clinicians
2. The Dementia Strategy Group should help facilitate research being undertaken at the Bradford Institute for Health Research to better understand frailty in the district
3. The Adult Social Services Department at Bradford Metropolitan Council should work in partnership with healthcare services and academics as frailty is also closely allied to social circumstances
4. Further analysis of comorbidities across CCGs should be undertaken, incorporating factors such as deprivation and ethnicity, potentially with partners at the University of Bradford School of Dementia Studies
5. Work should be undertaken with primary care commissioners to better understand the Quality Outcomes Framework process in relation to dementia and comorbidities
Section 13 – Dementia in Care Homes

It is estimated that up to 90% of people in care homes have dementia, and Care Quality Commission studies show that people with dementia in care homes are more likely to go into hospital with avoidable conditions such as dehydration than similar people without dementia. At the outset of this work it was agreed that the project should contain a funded research project the focus of which should be Dementia in Care Homes. Funding was obtained from the Leeds, York and Bradford Collaboration in Leadership for Applied Health Research and Care (CLAHRC), and it was agreed that this work would form the basis of a pilot study for research being undertaken by the Bradford University School of Dementia Studies.

Other key findings include:

- Vascular dementia was the most prevalent type of dementia in Care homes, unlike in the community where Alzheimer’s Disease is most prevalent.
- Loss of ability to live independently was the primary reason for admission for 43.2% of the total care home population, 42% of these having dementia and 25% admitted because carers could not cope with caring for them at home.
- Telemedicine was felt by those homes who used it to be a positive tool.
- 83% of Care Homes had established contact with Palliative Care services.
- 86% of Care homes report that they do not screen patients for dementia on admission although 80% reported that they actively refer on if cognitive impairment is seen.

The table to the left shows the key figures for dementia patients in care homes. Almost 2,000 people with dementia in Bradford and Airedale live in care homes, 40% of the district total of people with dementia. Of all care home residents, 63.1% have dementia.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>64 yrs &amp; under</td>
<td>27</td>
<td>22</td>
<td>49</td>
<td>1.6%</td>
</tr>
<tr>
<td>65 yrs &amp; over</td>
<td>479</td>
<td>1285</td>
<td>1764</td>
<td>57.7%</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>12</td>
<td>116</td>
<td>3.8%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>508</td>
<td>1319</td>
<td>1929</td>
<td>63.1%</td>
</tr>
</tbody>
</table>

What does this mean for Bradford and Airedale?
There is a general need to raise awareness that that 40% of our dementia patients are in care homes and that their diagnostic status varies. To reduce demand, we should ensure that community palliative care services are fit for purpose to keep people at home as long as possible. There is a growing problem for those who develop challenging behaviours as homes may be reluctant to take them, demonstrating a need to train and skill up care home staff. Care homes should take a leadership role in developing services to match need and demand, with standardisation according to best practice guidance. Nurses have a good understanding of dementia and this must be built upon.

Recommendations

1. The District needs to increase its strategic focus on people with dementia in care homes.
2. A partnership committee should be set up with the specific remit of dementia in care homes.
3. Work should continue with the Bradford University School of Dementia studies to inform their training research.
4. Work should be undertaken to better understand the reasons for admission to care homes in people with dementia, particularly non-elective admissions.
5. The possibility of incentivising care homes to better treat and manage dementia should be explored.
6. Diagnostic pathways in care homes should be formalised and agreed with primary care staff.
Section 14 – Use of Antipsychotic Medication

Antipsychotics are a range of medications that are used for some types of mental distress or disorder - mainly schizophrenia and manic depression (bipolar disorder). The use of antipsychotics in patients with dementia has been highlighted as dangerous in a number of detailed analyses and the first warning against their use in the UK came in 2004. The danger arises from sedation, increased risk of pneumonia and death among other risk factors. In 2012, reduction in their use was included in the NHS Operating Framework for the first time.

In Bradford and Airedale, work has been going on to address this issue for a number of years, with the first antipsychotics prescribing audit published in 2011. Work is currently focusing on identifying, developing and implementing alternative approaches to antipsychotic prescribing in patients with dementia who exhibit challenging behaviour.

The evidence base in respect of alternatives to antipsychotic prescribing in dementia, both pharmacological and non-pharmacological, has evolved considerably in recent years and there is a growing body of research that highlights approaches that can be used both in care homes and in the home environment. The key elements of effective approaches are shown to the left:

- A preventive approach that is mindful of the living environment
- An individual care planning approach
- Individualised psychological interventions
- Developing the skills of carers
- Involving family and carers
- Single task and one to one approaches
- Sensory stimulation
- Exercise

The 2011 local audit showed an estimated 16.5% of persons with dementia in Bradford and Airedale were prescribed antipsychotic medication, lower than that estimated nationally. The 2012 audit found that 10.8% of persons with dementia within Bradford and Airedale are prescribed antipsychotic medication, a reduction of 5.67%. This is an overall reduction in local prescribing of 34%. This work is overseen by the Antipsychotic Working Group (AWG).

What does this mean for Bradford and Airedale?
Management of challenging behaviour in people with dementia is a significant issue to commissioners, provider organisations, clinicians and carers. Most of all, we must be mindful of the patient experience and keep our focus on those in distress who must be managed with respect.

The AWG and its workstreams have delivered substantial progress and it is a significant achievement to have lowered prescribing rates by the extent shown in our local audits. It is crucial to build upon this, maintaining the audit process, and continuing to work closely with clinicians to ensure that they share ownership of the process. It must be recognised, however, that this transition may face difficulties in maintaining commitment to addressing the issues without clear and manageable alternatives to antipsychotics when faced with a patient who is at risk of harming themselves or others.

Recommendations
1. The AWG should continue to progress work to date and to add in additional workstreams as highlighted
2. Continued collection of evidence, both local data and review of published evidence and guidance
3. Benchmarking with performance feedback across CCGs, GP practices and Hospital Trusts
4. Clinical Leads should be identified in each General Practice, Hospital Trust and Care Home
5. A local Education Package for clinical/care staff should be established
6. Explore defining antipsychotic prescribing in contracts and incentive mechanisms
7. Develop a Pharmacy Support Strategy covering GP practices, Care Homes and local pharmacists
8. Clear, accessible Care Plans available for all people with dementia who are prescribed anti-psychotic medication, including paper and electronic copies
9. Improved coding of prescribing in people with dementia, focused on building a register
10. Record the views of people with dementia and their carers in respect of antipsychotic prescribing and to take these through the Dementia Strategy Group
11. Formalise clear, effective communication links between primary and secondary care
12. Redo the antipsychotic prescribing audit for 2014
Section 15 – Palliative Care

The course of dementia is characterised by a progressive worsening of symptoms up to the point of death. The World Health Organisation has stated that ‘the last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious.’ Life expectancy with those diagnosed between the ages of 60-69 is 6.7 years, and with those diagnosed at age 90 or over 1.9 years.

Evidence shows that patients with dementia compared to those without are less likely to be referred to palliative care teams, prescribed fewer palliative care medications and are infrequently referred or denied access to hospice care – this is NOT unique to our District and is an issue in many developed countries.

It is estimated that there are 986 people with advanced dementia in Bradford and Airedale

The table to the right outlines estimates calculated by NICE, in respect of the possible cost savings to the district if we reduce the number of hospital deaths in people with dementia, a goal which can be achieved through better palliative care in the community

<table>
<thead>
<tr>
<th>Percentage of hospital deaths avoided</th>
<th>Potential number of hospital deaths avoided</th>
<th>Potential reduction in admission costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.00%</td>
<td>17</td>
<td>£47,710.50</td>
</tr>
<tr>
<td>30.00%</td>
<td>52</td>
<td>£145,938.00</td>
</tr>
<tr>
<td>50.00%</td>
<td>87</td>
<td>£244,165.50</td>
</tr>
</tbody>
</table>

The table to the left outlines estimates calculated by NICE, in respect of the possible cost savings to the district if we reduce the number of hospital deaths in people with dementia, a goal which can be achieved through better palliative care in the community

Recommendations

1. Work should be undertaken between Adult Social Care and Palliative Care specialists to develop local Advanced Care Planning programmes.
2. Consideration should be given to developing a non-clinical model of advice and signposting, similar to the Dementia Advisers model
3. The potential role of MATS services in EOLC planning should be explored
4. Clear distinction should be drawn between the roles of generalist and specialist palliative care
5. Consideration should be given to providing regular, holistic palliative care assessments in the community
Section 16 - Carers

Family members who care for relatives with dementia perform an important service and save the healthcare system a considerable amount of money. However, many do so at substantial cost to themselves, with carers having a higher rate of depression, anxiety, impaired health, and mortality than adults without this caring role.

There are ~50,000 carers identified in the district with around 16,500 carers aged 50-64 years and 8,500 over 65 years of age. It has been estimated that 670,000 family and friends are acting as primary carers to someone with dementia in the UK - pro rata this is ~5,800 in Bradford and Airedale.

Local Services

Alzheimer's Society
- Bradford Dementia Support – provides information, face to face and telephone support
- Carer Information Programme - this service has been designed specifically for carers

Wellbeing Cafes
These are covered in detail in Section 7a – Wellbeing Cafes

Relate Bradford – Caring and Sharing
A free, specialist counselling service originally set up to support carers of people who were becoming confused or had received a diagnosis of dementia for carers aged 50+
Between June 2010 and September 2013, support was delivered to 308 carers in 839 sessions, 35% of carers were male and 65% female

Healthwatch Bradford and District
HealthWatch Bradford and District is currently undertaking a review of hospital care for people with dementia in the district

What does this mean for Bradford and Airedale?
Our health and social care systems are becoming increasingly reliant on unpaid carers as people live longer and more people have chronic illnesses. More carers are potentially at risk of poor health and wellbeing themselves, which could result in possible carer breakdown and an increased demand on statutory provision to meet the gap in services.

Local services are key to supporting carers and helping them to be as healthy as possible themselves.
A considerable burden is placed on health services due to the incidence of chronic illness in carers. Managing this will both save money, improve carers’ health and quality of life, and potentially improve the quality of life of their loved ones.
Information from carers can improve both the evidence base and the investment of limited resources in health and social care, so it is notable that HealthWatch has become involved in promoting the needs of carers for people with dementia.
There is clear evidence that carer support can create savings for health and social care services, and that carer support in the context of major care pathways such as hospital discharge, falls, dementia and stroke could generate systems-wide efficiencies. This is significant in the context of rising numbers of older people and people with dementia across the district.

Recommendations

1. Targeted local interventions should be developed and implemented to improve the health of caregivers of people with dementia.
2. Awareness of the different needs of different groups of carers should be incorporated into strategic and operational plans.
3. Appropriate Information should be provided to carers of people with dementia at all stages of the journey as outlined above.
4. Bradford Strategy Group should consider leading a work programme to develop a Bradford Carer’s Pathway.
5. The expertise available at The Bradford University School of Dementia Studies should be accessed wherever appropriate.
6. Application of the figures provide by Relate Bradford where appropriate.
7. Formal involvement of Healthwatch at strategic level through the Dementia Strategy Group.
Section 17 – Early Onset Dementia

Early Onset Dementia (EOD) is generally held to mean dementia which is diagnosed in someone under the age of 65. EOD has been known to develop between the ages of 30 and 40 but this is very uncommon. It is more usual to see people in their 50s with the disease. It is important to appreciate the difference between Early Onset Dementia which describes the age at which the disease develops, and Early Stage Dementia which describes the initial phase of the disease, regardless of the age at which it first developed. People who have EOD may be in any stage of dementia – early, middle, or late stage.

The QoF dementia register for Bradford and Airedale records 131 people with diagnosed EOD in the district as at November 2013. The true figure may be significantly higher, on the basis that data based on referrals to services, but not all those with young-onset dementia seek help in an early stage of the disease.

<table>
<thead>
<tr>
<th>Age</th>
<th>2012</th>
<th>2014</th>
<th>2016</th>
<th>2018</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>40-49</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>50-59</td>
<td>60</td>
<td>60</td>
<td>60</td>
<td>60</td>
<td>60</td>
</tr>
<tr>
<td>60-64</td>
<td>40</td>
<td>40</td>
<td>41</td>
<td>41</td>
<td>42</td>
</tr>
<tr>
<td>Total</td>
<td>119</td>
<td>121</td>
<td>122</td>
<td>125</td>
<td>127</td>
</tr>
</tbody>
</table>

The table to the left applies estimates from recent UK research to demonstrate projected rises in EOD for Bradford and Airedale. Although figures are slightly lower than QoF, it does indicate that rises to 2020 are likely to be small.

Local Services

Local services for people with Early-onset dementia have undergone a number of changes in recent years and are now focused at Woodward Court in Allerton and Holme Wood Older Peoples Home in Keighley. The service has been funded by social services, with referrals coming mostly from social workers and also from the Alzheimer’s Society. In addition, Odsal Top Kew Gardens Cafe has one evening a month for younger people, with 30 to 40 people attending per session. A number of Wellbeing Cafes also provide EOD services.

What does this mean for Bradford and Airedale? 130 may seem a relatively small number of patients, however it is a significant number to have clearly identified needs which are separate from the wider group of patients. It must also be emphasised that this cohort of patients will translate in due course into the wider group of dementia patients as they age.

It is difficult to measure service provision against need in this case. Current services have responded to an expressed need and are well attended and popular, however discussions with service providers and advocates suggest that current capacity does not reflect the diagnosed prevalence, and could not cope with an expansion in numbers should diagnosis increase in this group.

The services available have relocated on a number of occasions and there must be some concern regarding ability to embed in a stable location and build services on a long-term basis.

Recommendations

1. Dedicated events and evening sessions should take place more often.
2. Consideration should be given to providing dedicated services in the home/day care environment.
3. There should be specific care home provision available to manage difficult presentations in this group.
4. Provision should be made for respite care for under 65s - currently they go to old people’s services which can lead to deterioration.
5. Efforts should be made to maintain continuity of staff who work with people with Early-onset dementia in order that they can develop and maintain skills and knowledge in this area.
6. Discussions should take place at strategic level to make long-term plans to embed services and identify a stable location for these.
Section 18 – Economics

Dementia in the UK extracts a significant amount of both financial and human cost.

How does Dementia cost the District Money?

| Primary Care | Nurse home visits; Nurse practice visits; GP home visits, GP practice visits |
| Secondary Care | Outpatient visits; A&E visits; Inpatient care; Day Cases; Medications |
| Palliative Care | Inpatient hospice care; Home care |
| Private Healthcare | Various care providers/insurance providers |
| Social care | Long Term Care; Nursing Homes; Residential Care Homes |
| Non-Health/Social Care | Informal Care (carers); Mortality (Productivity loss due to premature death); Morbidity (Productivity loss due to workplace absence while alive) |

How much does Dementia cost the District?

Applying figures from UK research to Bradford and Airedale on a pro rata basis:

- Dementia costs the local economy ~£200 million per year: more than cancer and heart disease combined
- Long term institutional social care makes up the majority of the £200 million figure
- Most of the cost of dementia (£115 million per year) is met by unpaid carers
- 37% of all dementia patients in the UK are in long-term care institutions costing an estimated of £80 million per year in social care in Bradford and Airedale
- Health care costs are ~£10 million per year, of hospital inpatient stay 44% of this)
- Productivity losses are ~£250,000 per year
- Every dementia patient costs the economy £27,647 per year, for Bradford and Airedale this equates to ~£138 million in respect of all dementia patients – the difference with the £200 million estimate above is possibly due to the impact of a recent key report and its downscaling of estimated dementia prevalence in the UK (patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year)

What does this mean for Bradford and Airedale?

Numbers of older people are rising and accordingly numbers of people living with dementia, either diagnosed or undiagnosed, is increasing. Increased demand is likely to lead to escalating costs which cannot be met within existing budgets or service configurations. It is important design dementia services which ensure that existing investment is used to the greatest effect, identifying and removing inefficiencies within the system to free up resources to be re-invested elsewhere.

A lack of reliable financial benchmarking processes places a burden on us locally to develop a better understanding of how our financial need: demand relationship works and can be addressed.

Recommendations

1. A cross-organisational strategic drive to keep people with dementia in their homes if possible
2. Workstreams with both commissioners and academics to further develop our understanding of the appropriateness of our degree of financial spend on dementia in both health and social care.
3. All financial analyses should recognise the importance of supporting carers
4. Use of NICE guidance and other commissioning guides to inform integrated commissioning and service provision through the Dementia Strategy Group
5. Promotion of this report within integration processes, through partnerships and key committees
6. Work with secondary care providers and hospitals, to ensure that admissions to hospital become short-term departures from community care pathways, rather than pathways in themselves.
**Section 19 – Next Steps**

Following the publication of this report and the installation of the full sections on the Bradford Public Health Observatory website, the Dementia Strategy Group will begin to develop its action plan for 2014-19. The recommendations, data and intelligence contained within this report will form the basis of this action plan which will be owned by the members of the Dementia Strategy Group.

Formal presentations of the Dementia Health Needs Assessment will be delivered to key organisations and committees over the next year, including providers, commissioners and key Local Authority committees. This process will generate knowledge and awareness of the report, and also the key discussions and debate that will help to deliver the recommendations in this report and the action plan outlined above.

The Bradford Metropolitan District Council Department of Public Health will be responsible for keeping the Health Needs Assessment updated and delivering updates to the Dementia Strategy Group.

Three additional sections will be added to the HNA over the next year, under the direction of the Dementia Strategy Group, these being:

- Social Care Needs Assessment and associated community service provision
- Prevention of Dementia
- Prescribing in Dementia