Surrey Heath Dementia Strategy 2016-2021
Our vision

Our vision is that residents of Surrey Heath will have improved health and wellbeing, helping to prevent, or reduce the risk of developing of dementia. That if dementia develops, they will receive a timely diagnosis with a clear pathway, regardless of their age, background or additional needs. With their family and carers, individuals will live in a supportive and accepting community with services that meet their personal wants and needs. We acknowledge that ‘one size doesn’t fit all’ and advocate a personalised approach.

Introduction

The Surrey Heath Dementia Strategy has been written in partnership with the Surrey Heath Dementia Group and engagement with people who have dementia and their carers. The Group consists of a membership from Surrey County Council, Surrey Heath Clinical Commissioning Group (CCG), Surrey Heath Borough Council, Alzheimer’s Society, Surrey and Borders Partnership (SABP), Virgin Care, the Arena Leisure Centre (Camberley), a carer of someone with dementia, and Age UK Surrey.

The strategy sets out our vision and how we will achieve this over the next five years. There is an accompanying action plan that will be implemented, reviewed and monitored at the Surrey Heath Dementia Group, with new actions to be added as appropriate. There will also be an annual review of achievements within the Group with strategic actions agreed for the latter years of the strategy. This strategy will be published on the Surrey County Council website, alongside strategies from the other areas of Surrey, and will be overseen by the Surrey Dementia Partnership Board, which is a countywide group.

Background

The Dementia and Older People's Mental Health Joint Commissioning Strategy 2010-15, set out Surrey's vision to modernise dementia and older people's mental health services and meet the needs of our population, allowing people to manage their mental health conditions as close to home and as independently as possible. In those five years a great deal has been achieved, including the following:

- Countywide public awareness campaign for Dementia Friendly Surrey
- Improved access to information and advice within the community and health settings through information boards, website reviews and developing local directory of services
- Established Dementia Local Implementation Groups responsible for developing local area responses to the Surrey strategy and developed a local pathway for each area.
• Worked in partnership with borough and district councils to increase community based support for people with dementia
• Increased access to dementia training for the community and health and social care workforce and established a dementia training consortium.
• Increased diagnosis rates across the county through local pilot schemes
• Supported partnership working with care homes with area care home forums
• Supported the increase of telecare for people with dementia by accessing demonstration sites in each of the live Wellbeing Centres
• Worked with acute trusts to establish clinical leads at all acute hospitals in Surrey
• Established the butterfly scheme
• Improved information and services for end of life care with end of life care planning document
• Established a pool of dementia navigators across the county responsible for providing 1:1 support for people living with dementia and their families
• In process of improving day care options for people with dementia to offer a more flexible service for people with dementia and their carers.

Gaps identified and work still to do

• Young Onset
• Access to specialist dementia training in care homes
• Parity for learning disabilities
• Clinical gaps
Surrey Heath – a local context

This strategy covers the Surrey Heath area, whose borough council and Clinical Commissioning Group (CCG) boundaries are not co-terminus, therefore some areas will be included that fall within other borough or CCG areas.

At the end of Quarter 4 in 2015/16 there were 747 people in Surrey Heath with a diagnosis of dementia, however as the table below demonstrates, the prevalence data is significantly higher with 1,251 people ages 65+ having dementia. Surrey Heath Carers support scheme reported that they were helping 181 carers who were primarily supporting a person with dementia in 2015/16.

<table>
<thead>
<tr>
<th>Area</th>
<th>2016 Age 30-64</th>
<th>2025 Age 30-64</th>
<th>% growth for 30-64</th>
<th>2016 Age 65+</th>
<th>2025 Age 65+</th>
<th>% growth for 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Surrey Heath CCG</td>
<td>25</td>
<td>29</td>
<td>12%</td>
<td>1,251</td>
<td>1,675</td>
<td>34%</td>
</tr>
<tr>
<td>Surrey Heath Borough Council</td>
<td>24</td>
<td>27</td>
<td>12%</td>
<td>1,587</td>
<td>1,167</td>
<td>36%</td>
</tr>
</tbody>
</table>

Table 1: Surrey Heath dementia prevalence and expected growth (Taken from the draft Dementia JSNA chapter, due for publication Dec 2016)

The Surrey Heath geography and objectives

The CCG’s role
People

Objective
To build and encourage communities where people can live happily and healthily.

Priorities
- To work with partners and the community to keep Surrey Heath a clean, green and safe place.
- To work with Partners to deliver the Sustainable Community Strategy Action Plan.
- To deliver the Surrey Heath Health and Wellbeing Action Plan with the Surrey Heath Clinical Commissioning Group and Surrey County Council.
This strategy will follow the NHS England Transformation Framework ‘The Well Pathway for Dementia’

### NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

<table>
<thead>
<tr>
<th>Preventing Well</th>
<th>Diagnosing Well</th>
<th>Living Well</th>
<th>Supported Well</th>
<th>Dying Well</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of people developing dementia is minimised</td>
<td>Timely diagnosis, integrated care plan, and review within first year</td>
<td>People with dementia can live normally in safe and accepting communities</td>
<td>Access to safe high quality health &amp; social care for people with dementia and carers</td>
<td>People living with dementia die with dignity in the place of their choosing</td>
</tr>
</tbody>
</table>

**STANDARDS:**

- Prevention(1)
- Risk Reduction(2)

- Diagnosis(1)(4)
- Memory Assessment(1)(2)
- Concerns Discussed(3)
- Investigation(4)
- Provide Information(4)
- Care Plan(2)

- Integrated Services(1)(X)(5)
- Supporting Carers(2)(4)(5)
- Carers Respite(3)
- Co-ordinated Care(1)(5)
- Promote independence(1)(4)
- Relationships(3)
- Leisure(3)
- Safe Communities(5)(6)

- Choice(2)(X)(4)
- BPSD(2)(2)
- Liaison(2)
- Advocates(3)
- Housing(2)
- Hospital Treatments(2)
- Technology(2)
- Health & Social Services(5)

**COMMISSIONING GUIDANCE:**

- Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.
- Agree minimum standard service specifications, set business plans, mandate and resources.
- Work with ADASS, PHE & other ALBs on co-commissioning strategies to provide an integrated service.

**MEASUREMENT:**

- Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.
- Identify data sources and agree with HSCIC, et al on the extraction processes.
- Set ‘profiled’ ambitions for each metric, to form the basis of the transformation plan.

**TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:**

- Transformation: using CCG scorecard to set & achieve a national standard for Dementia services.
- Intervention: Intensive Support Team to provide ‘deep-dive’ support and assistance for CCGs that fall short.
- Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.

Contents

1. Preventing well ......................................................................................................................... 8
2. Diagnosing well ......................................................................................................................... 10
3. Supporting well ......................................................................................................................... 11
4. Living well ................................................................................................................................. 15
5. Living and Supporting Well: Black and Minority Ethnic communities .................................. 17
6. Living and Supporting Well: Young Onset Dementia ............................................................ 19
7. Living and Supporting Well: People with a learning disability ............................................. 20
8. Dying well ................................................................................................................................. 22
1. Preventing well

Our vision for Surrey Heath:

Ensuring that communities in Surrey Heath live well, are physically active and have improved health and wellbeing, reducing the likelihood of developing dementia and keeping those who already have dementia and their carers as healthy as possible.

1.1 Why is this a priority?

Around a third of Alzheimer’s disease cases might be attributable to potentially modifiable lifestyle risk factors. There is now good evidence that some forms of dementia have the same risk factors as cardiovascular disease and diabetes. These include high blood pressure, smoking, excess drinking, being overweight and obese and lack of physical activity. Evidence of the importance of psychosocial risk factors such as loneliness, isolation and depression is also emerging.

There is a form of Encephalitis called Wernicke’s that presents as acute confusion due to the Vitamin B Depletion in the brain caused by alcohol. It is vital to give patients high strength Vitamin B usually by IV infusion, if they are at risk of Alcohol Withdrawal as this can cause a form of dementia called Korsakoff’s Syndrome if untreated.

- 26% of adults are inactive which is the second highest in Surrey, but lower than the England average.
- Nearly 50% of residents drink sufficient excess alcohol to damage their health.
- Smoking prevalence in three out of seven Surrey Heath wards is higher than the England average
- 67% of adults in Surrey Heath have excess weight which is the highest in Surrey
- The prevalence for residents diagnosed with depression is lower than the England average (5.5% compared to 6.5%)2

1.2 How is Surrey Heath doing now?

- Local residents can access a general assessment of their cardiovascular disease risk through the free NHS Health Check at GP practices or some pharmacies, which is available to those between 40 - 74 years of age and not already on a disease register. It assesses an individual's risk of developing heart disease, stroke, diabetes, kidney disease and some forms of dementia. As part of the check advice and assistance is provided to help reduce the risk. Those over 65 years old presenting for their Health Check will have a brief talk about dementia. This will include: what the key signs and symptoms of dementia are; what can be done to limit the risk of developing some types of the condition; how to access support for care or further assessments for dementia.

- Surrey County Council’s Public Health has developed maps showing areas with a higher concentration of people likely to be at risk of social isolation which can be accessed here - http://www.surreyi.gov.uk/GroupPage.aspx?GroupID=61&cookieCheck=true. Age UK and Liverpool Public Health Observatory have also published best practice evidence3 to better

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2 Joint Strategic Needs Assessment
3 https://www.liverpool.ac.uk/media/livacuk/instituteofpsychology/researchgroups/lpho/LPHO,loneliness,final.pdf
understand “the prevalence of loneliness, its impact on health and wellbeing and effective interventions that can be used to ameliorate these effects.”

- Frimley Park Hospital employ two Alcohol Specialist Nurses who continue to raise awareness and educate patients of the types of dementia that can be caused by excess drinking and how they can try to improve their general health, reducing risk of patients developing this form of dementia.

The Surrey Heath Health and Wellbeing Strategy (Preventing avoidable illness and death) Prevention plan references a variety of initiatives that in improving the general health of the population may help prevent, or reduce the risk of developing of dementia.

Smoking cessation

- The Surrey Stop Smoking Service provider Quit 51 offers intensive face-to-face, group support and telephone support and advice, over a number of weeks, to any smoker wanting to stop. Behavioural support, along with the use of stop smoking pharmacotherapy, is provided by an advisor who has received training and supervision that complies with the DH ‘Standard for training in smoking cessation treatments’.
- Stop smoking contracts with General Practice and Pharmacies. Nine GP Practices and 4 Pharmacies have signed up to the PHA. There is currently one specialist one-to-one stop smoking clinic running at Frimley Green GP practice.

Substance misuse (drugs and alcohol)

- Current services range from prevention activities (e.g. awareness campaigns or alcohol education within PSHE curriculum), Tier 1 activities such as early identification and brief advice within primary care, Tier 2 services (more targeted advice and extended brief interventions) through to Tier 3/4 services which are treatment and recovery services for those with more serious alcohol-related problems.

Physical Activity

- 6 GP practices are currently signed up to the Exercise Referral Scheme. GPs and Health Professionals refer appropriate patients to a qualified exercise specialist. The specialist devises and delivers a 12 week tailored exercise programme for the patient, at a reduced price.
- The Mychett Centre runs a Stroke Clinic and a Cardiac Rehabilitation group as does the Arena Leisure Centre which also has a COPD session and Dementia session.
- There are a wide range of exercise and cultural activities available through the Borough Community Centres (list available on request) plus many opportunities for sport and physical activity through the leisure centres
2. Diagnosing well

Our vision for Surrey Heath:
People in Surrey Heath receive a timely diagnosis and are well supported through their dementia journey.

2.1 Why is this a priority?

At the end of Quarter 4 in 2015/16 there were 747 people in Surrey Heath with a diagnosis of dementia, however prevalence data demonstrates a significantly higher figure of 1,251 people aged 65+ who have dementia.

By receiving an early diagnosis people can access health and social care services at the right time, enabling them to plan and receive treatment and care earlier, preventing future crises, so reducing the gap between prevalence and diagnosis is vital.

Over half (56%) of people put off seeking a dementia diagnosis for up to a year or more, with dementia as the most feared health condition in the UK.

2.2 How is Surrey Heath doing now?

- Analysis by NHS England of our local population suggests that Surrey Heath’s prevalence for people over 65 with dementia is 1,251. The Prime Minister’s Challenge set a target of diagnosing 67% of the expected population by March 2016. As of March 2016 our GP practices have a dementia diagnosis rate of 65.1%.

<table>
<thead>
<tr>
<th></th>
<th>Number of people</th>
<th>% of expected population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual (December 2016)</td>
<td>786</td>
<td>66.4%</td>
</tr>
<tr>
<td>National Target</td>
<td>793</td>
<td>67%</td>
</tr>
</tbody>
</table>

Table 2: Surrey Heath diagnosis rate against the national target, Public Health England

Graph 1: Surrey Heath diagnosis rate, NHS Digital’s Monthly Dementia Register Publication 2016-17

- GPs and other professionals in Surrey Heath can diagnose dementia, or refer the individual to Surrey and Borders Partnership Memory Clinic that sits within the Community Mental Health Team for Older People(see Appendix 1 – Memory Assessment Pathway for

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People Over 65 Years).

- Community Matrons, District Nurses (Community Nurses) are involved in the identification and diagnosis of people with dementia. Community Nurses are often able to identify people with the early stages of Dementia and carry out some screening. The screening involves blood tests, depression and anxiety scores and GP cognitive score test, these tests are then used by the GP to eliminate a medical cause for memory decline. The GP will then be able to refer the patient to the appropriate clinician to ensure they are supported with a correct diagnosis.

- Surrey and Borders Partnership has a dementia pathway for adults aged 65+ that clearly states the steps and procedures involved.
3. Supporting well

Our vision for Surrey Heath:

People with dementia and their carers have access to safe, high quality care, support, information and advice in Surrey Heath enabling them to live their lives as they wish.

3.1 Why is this a priority?

The key aspects of the 2020 Prime Minister’s Challenge are to improve quality and levels of care, so that every person with dementia, their families and carers should receive high quality, compassionate and culturally competent care.

People with dementia and their carers want to live well and stay in their community for as long as possible, which also requires support to be available to carers of people with dementia to enable them to continue in their caring role whilst having a life outside caring. There are a variety of day activities for people with dementia in Surrey Heath, but carers and professionals have told us that there is a gap in the provision of services for those with more complex needs, ‘out of hours’ service e.g. at weekends and in the evening, and also for emergency respite services to give carers a break.

The Mental Capacity Act 2005 gives provision for people to plan ahead and make decisions for a time where they may not be able to with provisions for Lasting Powers of Attorney, Advance Statements, Advance decisions and mental capacity assessments. Relevant and appropriate information and advice on the Act should be made available to individuals and their family/ carers early in their dementia journey from a range of professionals.

10% of one person households in Surrey Heath are someone over 65 living alone and 21% of households contain only people over 65, both of which are lower than the Surrey average. So having appropriate technology to support older people who have dementia or are at risk of developing it could enable more people to remain safe at home for longer, or enable safer discharges following a stay in hospital. A Global Positioning System (GPS) means that individuals at risk of ‘walking about’ can be supported, promoting individuals independence and reducing call outs to blue light services.

3.2 How is Surrey Heath doing now?

- There is a Dementia Navigator in Surrey Heath, jointly funded by health and social care to provide continuity of specialist 1:1 support and advice, actively facilitating access to services in the community in a personalised way to sustain and improve the quality of life of people with dementia, their carers and family, as and when they need it throughout their dementia journey. 85 people were supported in quarter 1 of 2016 (people with dementia and their carers).

- Surrey and Borders Partnership provide a number of individual and group interventions and support from diagnosis. Signposting to social care, voluntary organisations, carers support also takes place within the Memory Clinic and additional psychological help can be asked for if necessary.
The Intensive Support Team (IST) is a new service formed in January 2016 that supports individuals with dementia and highly complex behaviours that challenge. People may be living at home or in a care/hospital setting and are likely to possess continuing healthcare funding and/or 117 after care. The IST aims to prevent unnecessary hospital admissions, facilitate transfers of people using services across care settings and promote better understanding of the purpose/function that is served by distressed behaviours. In Surrey Heath data, 12 referrals have been received (Jan-July 2016). Of these, three have been accepted and admissions to hospital avoided.

- Staff in the Surrey Heath social care locality team have an awareness of the Mental Capacity Act and there are nominated staff to undertake Best Interest Decision work.

- Surrey Heath Carers Support service supported 1,342 carers in 2015/16 and of these 191 were carers of people with dementia. 70 carers of people with dementia were provided with “A Voice for Carers / Carers’ Awareness” training.

- The Frimley System Care Home Forum was established in with the aim to improve the safe care of people with dementia. 70 delegates attended the March 2016 forum that concentrated purely on dementia with topics such as Admiral nurses; depression, dementia and drugs, dementia and the senses, delirium, and quality outcomes for people with dementia with the aim to encourage and foster best practice for care homes in the area. The forum supports the Alzheimer’s Society’s Fix Dementia campaign and will submit best practice examples to be shared nationwide.

Community Alarms & Telecare
Number of active clients: 892 (July 2016)

- Alarm unit with pendant providing assistance at the touch of a button, linked to a 24 hour monitoring centre where support and assistance can be arranged.
- Telecare sensors further promote independent living
- Door sensors – alert when leaving the property
- Smoke detectors – automatically connect to monitoring centre if activated allowing fire service to be called if required
- Pill dispensers – can assist individuals to remember to take their medication
- Carbon dioxide detector – useful where an individual may leave a gas cooker on, or for gas central heating systems
- Heat detector – activates if cooker is left on (will activate prior to the smoke alarm)
- Care assist – an internal monitoring system for carers – telecare sensors can be connected to the care assist to alert carer within the property rather than the monitoring centre.

GPS Location Service
Five devices currently in use (September 2016) in Surrey Heath

- Pendant alarm that can be activated at the touch of a button if help and assistance needed when out and about in the community, ideal for people who would like to maintain their independence out in the community but may get lost or disorientated while out.
- Pressing the button alerts Safer Runnymede – a 24 hour monitoring centre, where trained staff will speak to the client and reassure them whilst they pinpoint their location. If assistance is needed the clients’ nominated responder will be contacted or if required, the emergency services.
- A safe zone can also be set up: a set radial area within which the client is able to travel freely. If the safe zone is breached, a SMS alert is sent to Safer Runnymede who will locate
the client and contact their nominated responder. They will continue to monitor until their responder reaches them or the client no longer needs assistance.

- There were 149 unplanned Geo Zone breaks between 1st January 2016 to 8th August 2016. This is across 11 clients who have breached their Geo Zone at least once. In these instances, staff have had to respond to the alert and identify the reason, using the GPS device to locate the client. Of these 149 breaches, 35 were to one client residing in Surrey Heath. Each of these alerts, could have potentially led to police input had the GPS device and Geo zone alert not have been in place.
4. Living well

Our vision for Surrey Heath:

Surrey Heath is a safe and accepting place for individuals with a diagnosis of dementia and their carers to live and enjoy their lives. Communities and businesses are well educated on dementia and support their residents in their cultural and religious needs.

4.1 Why is this a priority?

There are approximately 1,200+ people with dementia (diagnosed and undiagnosed) living in Surrey Heath. Individuals and their carers want to stay at home, but communities need to have an awareness of how best to support these individuals to do this – 5% (4444 people) considered their day to day activities limited by long term illness or disability, one of the highest rates across the County and only 48% of Surrey Heath residents receiving adult social care support felt they were able to do the things they value or enjoy (compared to 68% Surrey average). If we can get it right for people with dementia, this will also positively impact upon other groups within the area e.g. Surrey House has almost 17,000 older people and almost 6,000 people with a physical disability (JSNA).

People working in settings that are used by people with dementia and their carers should:

- Have an awareness of dementia
- Know how to signpost people to services if they think it’s needed
- Improve awareness of the benefits of early diagnosis

4.2 How is Surrey Heath doing now?

- Since the Dementia Friends programme began in 2013, over 2,220 people have become Dementia Friends with the postcodes of the Surrey Heath area.

<table>
<thead>
<tr>
<th>Dementia Friends Champions</th>
<th>34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Friends Information Sessions run within postcodes</td>
<td>93</td>
</tr>
<tr>
<td>Dementia Friends Created at above Information Sessions</td>
<td>1,508</td>
</tr>
<tr>
<td>Digital Dementia Friends (created via the online route)</td>
<td>591</td>
</tr>
<tr>
<td>Total</td>
<td>2,226</td>
</tr>
</tbody>
</table>

Table 3: Number of people trained as a Dementia Friend in Surrey Heath 2013-2016 (Alzheimer’s Society)

- Surrey County Council has funded a number of Carers Information Support Programmes (CrISP) in Surrey Heath run by Alzheimer’s Society that aims to improve the knowledge, skills and understanding of people caring for a person with dementia, by providing effective support and up-to-date and relevant information.
  - CrISP 1 has been designed specifically for carers, family members and friends of people with a recent diagnosis of a dementia. Topics include: Understanding dementia, Legal and money matters, Providing support and care, Coping day-to-day and Next steps
  - CrISP 2 has been designed specifically for carers, family members and friends of people who have been living with dementia for some time. Topics include: Understanding how dementia progresses, Living with change as dementia progresses, Living well as dementia progresses, including occupation and activities.
May 2014 | CrISP 1 | 11 carers attended
March 2015 | CrISP 2 | 9 carers attended
October 2015 | CrISP 2 | 10 carers attended

Table 4: Number of people who attended a CrISP course in Surrey Heath (Alzheimer’s Society)

- Dr Gemma Jones, chair of the Alzheimer’s Café UK Charity, has led the following training courses within the last year:
  - Dementia Awareness: Reaching Communities
    - March 2015 - 23 attended
    - March 2016 – 40 attended
  - March 2015 Mayor's Dementia Awareness Review - 92 attended
  - March 2015 ‘About the Alzheimer Café: how to help’ 20 attended

- The Surrey Heath Museum ran two reminiscence events for people with dementia at the Century of Sound music festival 2015 using videos and objects spanning music from the 1950s-1990s and overall 30 people attended.

- Surrey Libraries have organised a number of coffee mornings and afternoons for people with dementia and their carers across the county and two in Surrey Heath in 2016. Representatives from the Alzheimer’s Society and Age UK Surrey attended to help with questions, plus information on library services offered relating to dementia e.g. reminiscence sessions.

- Across Surrey there are 230 families and 460 students taking part in the Alzheimer’s Society’s “Time for Dementia” programme that partners a person with dementia and their carer with a professional in training for two years. Preliminary findings are that student knowledge, attitude and understanding of dementia has significantly improved since the start of the programme. Students have reported that their previous perceptions of dementia have been challenged, they had developed new skills and that they feel that this learning will impact on how they work with people with dementia and their carers in the future.

- The Surrey Dementia Roadmap (http://dementiaroadmap.info/surrey/) provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care to support people with dementia and their carers.

- Frimley Health Foundation Trust (including Frimley Park Hospital) aims that all hospital staff receive a Tier 1 Dementia awareness session. 65% of the current hospital staff have received the face to face training and this is a continuing process until 100% compliance is achieved. This is a more comprehensive acute based training compared to the Dementia Friends session from The Alzheimer’s Society, although the Trust has 4 Dementia Friends Champions that also deliver Dementia Friends sessions.
5. Living and Supporting Well: Black and Minority Ethnic communities

**Our vision for Surrey Heath:**

Dementia is demystified for people from black and minority ethnic communities, and individuals and carers are supported to receive an early diagnosis with appropriate support to their cultural and religious needs.

### 5.1 Why is this a priority?

- 85% of the population of Surrey Heath is White British, 5% is White Other, 3% Asian, 2% Indian, 1% Caribbean, 0.75% Pakistani.  
- 5% of Surrey Heath residents do not speak English as their main language
- Nepalese and Polish are the most commonly spoken languages amongst those whose main language is not English
- 504 armed forces personnel live in households in Surrey Heath

11.75% of Surrey Heath residents are from Black Minority Ethnic communities, part of which is a result of the historic armed forces presence in the area. This is a relatively small percentage of the population, but within these groups there are factors that mean they are at risk of developing dementia and receiving an early diagnosis.

The risk of developing vascular dementia is more likely in these communities due to other prevalent health conditions resulting from diet and lifestyle: high blood pressure and diabetes.

Once someone has developed dementia, it can be difficult to obtain a clinical diagnosis due to a range of issues:

- Amongst many BME communities, there is a **lack of knowledge** about dementia, so people are therefore unlikely to seek help because they don’t know what they are asking about and to whom
- There is often a **stigma** about the disease.
- Differences in **culture** can mean that elders in some BME communities are unlikely to seek help e.g. Mother and Father are the law in families and trying to persuade a visit to the GP is almost impossible, not asking an older person a questions is a mark of respect, elders decide how help is sought, one shouldn’t tell people older than you what to do. There may also be a belief about the involvement of ‘spirit’ – people not well because they’ve been put under a spell. All of these factors may cause a delay which affects early diagnosis.
- **Language.** For example there is no word for dementia in Nepali, the word ‘pagal’ is used, but that means ‘mad’ which isn’t accurate. Use of professional interpreters is essential, but can be difficult to arrange and to decide on how it’s funded.
- **Education.** Reading and writing can be an issue for elders as; even memory tests in Nepali are difficult because older adults haven’t been to school. Current tests in the UK can be 4 pages long which would be impossible. Presentations will have more of an impact than leaflets.

Once a diagnosis has been obtained, other difficulties can arise:

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5 2011 Census via Surrey JSNA, rounded up to nearest whole number for Surrey Heath CCG and Borough Council areas
“In the UK there is an immediate cure for everything, so dementia should be a quick fix.”
It can be hard to give the carer a break due to cultural issues, so more likely to have a crisis.

5.2 What is happening in Surrey Heath now?

- The Nepalese community across the Frimley System meet together monthly in Aldershot as organised by Alzheimer’s Society in North East Hampshire. Interpreters, Rushmoor Health Living and Rushmoor Citizens’s Advice Bureau help to facilitate some of these sessions.

- Citizen’s Advice Bureau has four interpreters working the Camberley branch to provide information and advice on managing the implications of loss of capacity.

- http://www.carehome.co.uk/ provides information on whether nursing homes have staff with additional language capabilities

- Nepalese Community coffee mornings at High Cross Church

- Nepalese health check days at GP surgeries.

- There is a Gypsy Roma Travellers liaison officer at Surrey Heath Borough Council who engages with these communities in Swift Lane and Kalima regularly and facilitates other statutory bodies e.g. health, social care and borough councils to impart information about health and wellbeing.
6. Living and Supporting Well: Young Onset Dementia

Our vision for Surrey Heath:
For people with young onset dementia to have a timely diagnosis and for personalised information, care and support to be available so that individuals, their families and carers are able to live well with dementia.

6.1 Why is this a priority?

Young onset dementia refers to people under the age of 65 who develop dementia. In 2016, there are 25 people aged 30-64 in the Surrey Heath CCG area with a diagnosis of dementia which is set to increase by 12% in 2025 to 29 (taken from the draft Dementia JSNA chapter, due for publication Dec 2016).
The types of dementia that affects this younger cohort are often more rare, so awareness of these are lower. This can lead to a significant delay in the diagnosis as other conditions are ruled out and more specialist advice is sought.
Once a diagnosis is given, services that are more relevant to individuals under 65 are rare. So, personalised support services need to be available to take the age of the individual into consideration, given the huge impact the condition has on the lives of those diagnosed with young onset dementia (and their families and carers) who are likely to be in employment and may have responsibilities such as mortgages, children and a long life of plans ahead of them.

6.2 What is happening in Surrey Heath now?

- In 2016, SABP started to accept referrals for people under 65 years, and diagnosis can take longer due to the complexity of factors involved.
- 1:1 post-diagnostic support and signposting is offered.
- The day opportunities available in the area are aimed at older people with dementia and tend to focus on a day centre setting.
- Age UK Surrey support adults from 50 years old.
- The Dementia Navigator service can provide personalised support and information.
- The Surrey Heath Museum ran two reminiscence events for people with dementia at the Century of Sound music festival 2015 using videos and objects spanning music from the 1950s-1990s. Younger people with dementia attended the event, enjoying the more modern approach and overall 30 people attended.
7. Living and Supporting Well: People with a learning disability

Our vision for Surrey Heath:

To understand the prevalence of dementia for people with a learning disability, ensuring this is diagnosed early, and people are supported appropriately.

7.1 Why is this a priority?

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability.

People who are over 60 yrs old with a learning disability are most at risk
- Those with Down Syndrome have 50% chance of developing dementia by 60, and need to be checked from the age of 30
- In 1930, men with Down’s syndrome lived on average for 10 years and women for 12 years, this compared to a life expectancy of mid-50s now.
- 1 in 7 people with other learning disabilities may get dementia and should be checked at 60 yrs.
- By comparison, the number of people among the population without learning disability aged 60-69 years who develop dementia is about 1 in 756
- People with learning disability also susceptible to dementia due to higher levels of diabetes as a result of poor dietary habits

Based on Surrey wide population statistics, indicatively, in the Surrey Heath CCG area population of 90,000 (70,000 adults and 20,000 children) there are:
- 1,700 adults 18 + with learning disabilities and 720 with autism

The table below indicates the number of those who have Down’s Syndrome and a diagnosis or suspected dementia

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of Adults with Down’s Syndrome</th>
<th>Adults with Down’s Syndrome with diagnosed or suspected dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>South West Surrey</td>
<td>North West Surrey</td>
</tr>
<tr>
<td>70 +</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>60 - 69</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>50 - 59</td>
<td>25</td>
<td>22</td>
</tr>
<tr>
<td>40 - 49</td>
<td>35</td>
<td>23</td>
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<tr>
<td>30 - 39</td>
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<td>5</td>
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<tr>
<td>18 - 29</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>96</td>
<td>64</td>
</tr>
</tbody>
</table>

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6 Services for People with Learning Disabilities, Surrey and Borders Partnership NHS Foundation Trust
Table 5: Number of adults with Down’s Syndrome, with a diagnosis of, or suspected dementia (Surrey and Borders Partnership 2016)

7.2 What is happening in Surrey Heath now?

- Only 10% of people with a learning disability received a health check in Surrey in 2013/14.7 Surrey Heath CCG are preparing an operational plan 2017-2018 including targets regarding annual health checks on GP registers for people with learning disabilities.

- The psychology service within the Community Team for People with a Learning Disability in Surrey and Borders Partnership NHS Foundation Trust operates a county-wide screening, assessment, monitoring and support service for people with Down’s syndrome and dementia. The team have produced a range of information for users, carers and staff and also provides training to care staff in Surrey on learning disability and dementia.

http://digital.nhs.uk/pubs/gpprac1415
8. Dying well

Our vision for Surrey Heath:

People with dementia and their carers are supported to have conversations and make advanced decisions to personalise their future care, enabling the individual to die with dignity in a place of their choosing.

8.1 Why is this a priority?

There are considerable differences between the place of death for people who have dementia and the general population nationwide. People with dementia are considerably more likely to die in hospitals and care homes and less likely to die at home or in end of life care settings such as hospices.8

As the table below demonstrates, people with dementia in Surrey Heath are also much more likely to die in a care home or hospital, than in their own home, with only 4% of people with a mention of dementia in their death record dying at home in 2013. This compares to 12.5% of people who did not have dementia who died at home.

<table>
<thead>
<tr>
<th>NHS Surrey Heath CCG</th>
<th>% of Deaths by Location</th>
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<tr>
<td></td>
<td>Place of Death</td>
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<tr>
<td>All Deaths</td>
<td>Home deaths</td>
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<tr>
<td></td>
<td>Care home deaths</td>
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<td></td>
<td>Hospice deaths</td>
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<tr>
<td></td>
<td>Hospital deaths</td>
</tr>
<tr>
<td>Dementia</td>
<td>Home</td>
</tr>
<tr>
<td></td>
<td>Care Home</td>
</tr>
<tr>
<td></td>
<td>Hospital</td>
</tr>
</tbody>
</table>

Table 6: Percentage of deaths of people with a mention of dementia in the death record by Place of Death (Public Health England NEoLCIN Profiles)

The National Dementia Intelligence Network cites two potential explanations for these inequalities. Firstly that dementia is not routinely identified as a terminal illness for end of life care and as a result people have less access to specialist palliative care services compared to people with other terminal illnesses. This factor may influence where people with dementia die. It is reasoned that the disease trajectory for people with dementia makes it harder to identify the terminal phases. However, end-stage dementia predictors have been identified such as more frequent infections and physical decline.

Secondly that the differences in the place of death for people with dementia compared with other conditions may also be due to a potential gap in advance care planning discussions. This process is important for ascertaining the responsibilities of different

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professional groups and ensuring that people’s preferences are expressed and where possible adhered to

8.2 What is happening in Surrey Heath now?

- There is an Advance Care Plan that individuals and their families are encouraged to think about and fill in by GPs, nurses and other practitioners.

- Surrey Heath has an End of Life pathway for practitioners to follow, but this is currently focussed around cancer support and does not include considerations around mental capacity.

- Surrey Heath CCG is able to place individuals in the Phyllis Tuckwell hospice in Farnham and Sam Beare Woking Hospice that provide end of life care, or these charities can provide palliative care for individuals within their own homes.

- Clinical and Health Psychologists from Surrey and Borders Partnership help support people with pain management and the psychological aspects of long term conditions such as dementia.

- Dementia Navigators and District Nurses have early conversations about end of life with individuals in the community, offering Advanced Care paperwork, but these conversations can be difficult and individuals and their families are often reticent about discussing end of life.

- Surrey Heath carers group and the Camberley Alzheimer's Café provide support for carers of people with dementia on topics such as end of life.
Conclusion

By working together the organisations supporting dementia sufferers and their families and carers are able to provide wrap around care in the community that meets the needs of the dementia sufferer at every stage of their journey, by working together we will be able to achieve better outcomes than working in isolation. To this end the Surrey Heath Dementia Partnership Group has been set up to deliver the strategy document and the action plan that will support delivery of local improvement in services.

With particular thanks to the following individuals who supported the Surrey Heath Dementia Group to understand how dementia affects a wide range of individuals: Rajen Chhetri, Pippa Stanley, Rob Stanley, Dr Jill Rasmussen, Jo Gavins, carers from the Bagshot Wellbeing Centre’s Saturday Club.

Appendix 1

Memory Assessment Pathway for People Over 65 Years

Appendix 2

Terms of Reference for the Surrey Heath Dementia Partnership Group

Appendix 3

Dementia Strategy Action Plan
<table>
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<th>Description of changes made</th>
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<td>03/05/2016</td>
<td>Sarah Wimblett wrote BME section</td>
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<td>13/05/2016</td>
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<td>27/06/2016</td>
<td>Sarah Wimblett changes from SH Dementia Group meeting</td>
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<td>Sarah Wimblett final amendments and formatting</td>
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