

APPENDIX 1

HEALTH SCRUTINY COMMITTEE
DATE OF MEETING 17 DECEMBER 2015
TITLE OF AGENDA ITEM DEMENTIA
REPORT OF HELENE DENNESS, CONSULTANT IN PUBLIC HEALTH

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1. Purpose

Nottingham City has a growing number of citizens with dementia. Statutory and voluntary sector partners, across Nottingham City, are continually working together to improve the health and well-being of citizens with dementia and their Carers'. It is thus timely that work is scrutinized.

2. Action required

The Committee is asked to scrutinize the local strategic approach to supporting citizens with dementia in Nottingham and recommend ways to ensure their needs are met. The Committee is also asked to consider the support available to Carers'.

The Consultant in Public Health and colleagues will outline how statutory and voluntary partners across Nottingham City are working together to improve the health and wellbeing of citizens with dementia, and their Carers', in order to inform discussion.

3. Background information

The term "dementia" is used to describe a number of illnesses in which there is a progressive impact on a person's ability to take part in day to day activities. These include memory loss, reasoning, communication skills and the ability to carry out day-to-day activities. In addition, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering.

There are currently 700,000 people in the UK with dementia. The number of people with dementia is set to double to 1.4 million in the next 30 years (1).

Dementia is very much an age-related condition with both prevalence and incidence rising exponentially with age between ages 65 and about 90. Overall, 5% of people over 65 years of age may have dementia. The most common type of dementia is Alzheimer's disease (62%) followed by Vascular Dementia (17%). A further 10% of people have a combination of Alzheimer's and vascular dementia and the remaining 11% have more rare forms of the disease (2).

Dementia prevalence is associated with a number of factors including (3):

- Age
- Gender
- Social class and educational achievement
- Learning disabilities
- Ethnicity

Dementia is one of the main causes of disability in later life exceeding the burden of disease for stroke, cancer and heart disease (4) and as such is associated with significant

costs. Dementia is thought to cost the UK economy in the region of £26 billion a year which is more than the combined costs associated with cardiovascular disease and cancer. Unpaid Carers' save the UK economy £11 billion (5).

These costs are spread across health and social care services, as well as individual costs to citizens with dementia and their Carers' through loss of earnings and payment for personal support.

Recognising the needs of Carers' supporting people with dementia is crucial as supporting these Carers' enables citizens with dementia to remain independent and live at home for longer (6,7). The challenges associated with caring for someone with dementia is compounded when Carers' are older themselves, often with their own long-term health condition or disability.

National evidence (1) suggests that:

- Dementia is often underdiagnosed or overlooked
- People with dementia experience increased delay in discharge from, and readmission to, hospital and are more likely to be admitted prematurely to a care home

3.1 Policy Context

3.1.1 National Policy

Dementia is a national priority. A new "*Prime Minister's Challenge, 2020*" (8) was published in February 2015. It sets the agenda for the next 5 years and identifies new priorities for Clinical Commissioning Groups (CCGs) and Health and Wellbeing Boards to improve the commissioning and provision of services so that more people with dementia receive a timely diagnosis and appropriate post-diagnostic support.

The priorities are:






- Improved public awareness of the risk factors for dementia and the launch of a new *Healthy Ageing* campaign
- Access to diagnosis with an initial assessment within 6 weeks
- GPs' role in co-ordinating care via a named GP
- Meaningful care after diagnosis, for example, good information about local services, Carer support, respite, education and training
- Education and training for NHS and social care staff and the new 'Care certificate' for unqualified care and support workers
- Hospitals and care homes to become 'dementia friendly'

- Dementia Friends and Dementia Friendly communities campaign to continue, including business
- National and local government to encourage all organisations to become dementia friendly
- Increase in dementia research funding

The *NHS England Dementia Pathway Transformation Framework* (2015), (9) shown in figure 1 below, visualises the interventions needed to prevent and diagnose dementia and to support those with dementia to '*live and die*' well.

Figure 1

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 Risk of people developing dementia is minimised	 Timely diagnosis, integrated care plan, and review within first year	 Access to safe high quality health & social care for people with dementia and carers	 People with dementia can live normally in safe and accepting communities	 People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"Those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Care Plan ⁽²⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁶⁾ Health & Social Services ⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
COMMISSIONING GUIDANCE:				
<ul style="list-style-type: none"> • 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:				
<ul style="list-style-type: none"> • 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:				
<ul style="list-style-type: none"> • 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. 				
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.				

The *Blackfriars Consensus Statement* (2014) (10) was drawn up following a meeting held by the UK Health Forum and Public Health England (PHE) in Blackfriars, London. Fifty-nine organizations and experts from across the dementia and public health community signed the consensus statement which was supported by a correspondence in the Lancet.

The agreement, known as the *Blackfriars Consensus Statement*, highlights the need for a new national focus on dementia risk reduction. Specifically, it advocates action to tackle smoking, drinking, sedentary behaviour and poor diet which could reduce the risk of dementia in later life alongside other conditions such as heart disease, stroke and many cancers.

3.1.2 Local Strategy

Nottingham City Dementia Strategy (2011-15) (11) highlights the importance of:

- Prevention. Specifically, in vascular dementia where up to 50% of cases may be prevented by healthier lifestyle including stopping smoking
- Early diagnosis
- Having choice and control
- Keeping healthy, independent and safe
- Making a positive contribution
- Improved quality of care in hospitals and care homes
- Supporting Carers'
- Ensuring citizens with dementia experience freedom from discrimination

Nottingham City Health and Wellbeing Strategy (2013-16) (13) highlights that the experience of citizens with dementia who use health and social care services could be improved. The strategy commits to improving citizens experience of care through the delivery of more integrated primary, secondary health and social care services including the development of locality based teams with the flexibility to respond to differing needs in local populations.

The Nottingham Vulnerable Adults Plan (2012-15) (14) focuses on the need for more joined up community-based health and care services alongside community support for people with dementia.

3.2 Prevalence of dementia in Nottingham

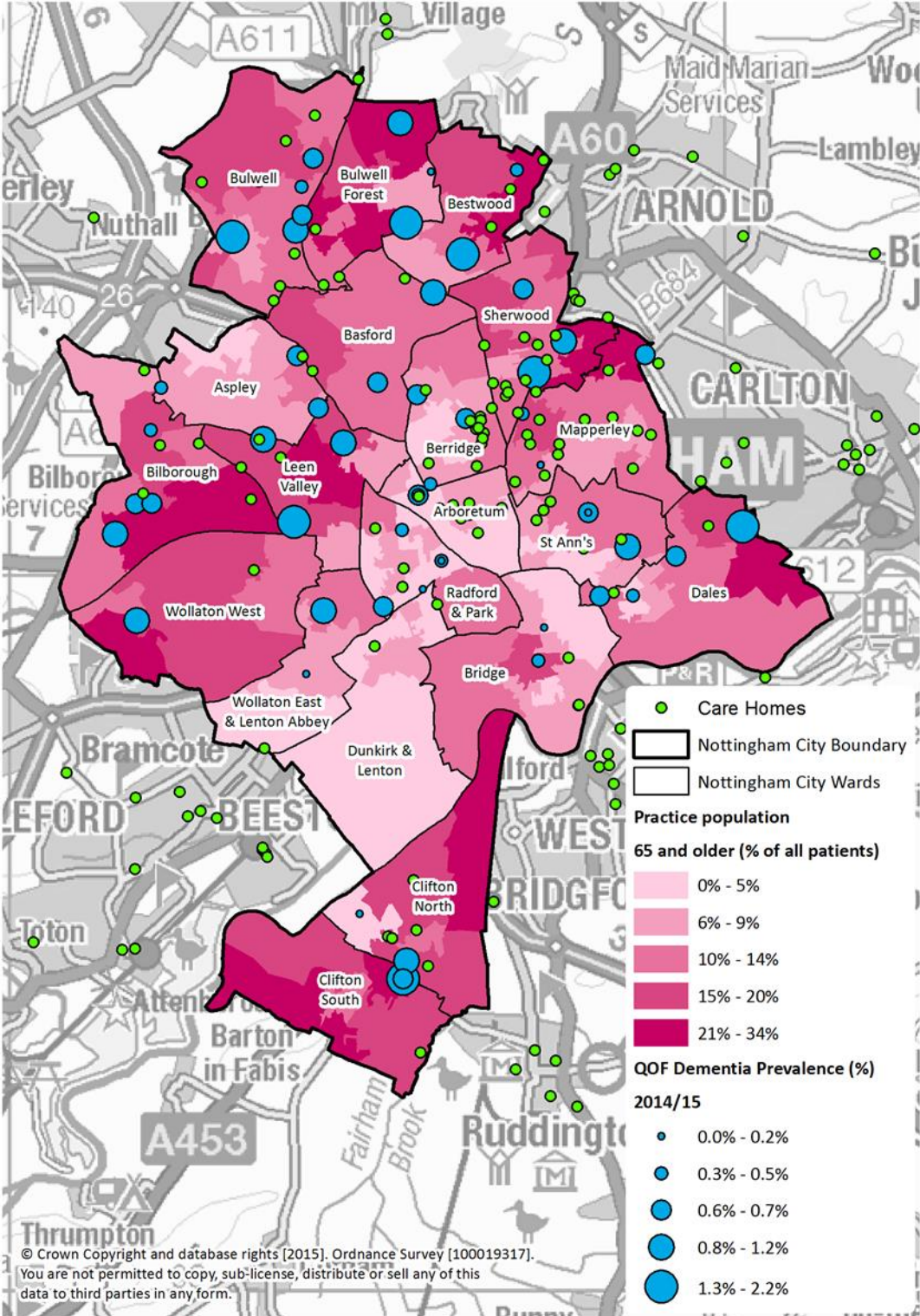
The number of people aged over 65 living with dementia in Nottingham is predicted to rise from 2914 in 2015 to 3096 in 2021¹. This represents a 6% increase over 6 years (13).

Data indicates that Nottingham City CCG's estimated prevalence for people over 65 with dementia is 2471 with an actual dementia diagnosis rate of 85.8% which exceeds the expected national level of diagnosis 66.2%. Nonetheless there is an estimated gap

¹ These figures as based on national estimates

of 393 people (including citizens under 65 years) who may benefit from access to support by way of a dementia diagnosis (15).

Figure 2: Map showing proportion of people aged 65 and over in Nottingham City, with QOF prevalence of dementia by practice and location of care homes.



Prevalence of dementia across the cities Care Delivery Groups (CDGs) varies from 0.96%, in CDG 1 covering Bulwell and Bulwell Forest in the north, to 0.27% in CDG 7 which covers Wollaton East & Lenton Abbey and Wollaton West.

The largest numbers of people with dementia live in CDG 3 which accounts for 19% of all diagnosed dementia patients. CDG 3 covers Aspley, Bilborough and Leen Valley and has a dementia prevalence of 0.76%.

In Nottingham City, 71% of the population is white; the most prominent BME group is Asian (13.1%) followed by Black (7.3%) and mixed/multiple ethnic group (6.6%). However, in the older population (65+), only 9.6% belong to a BME group (4.2% Asian, 4.6% Black and 0.6% Mixed/multiple) (16). Assuming a similar prevalence of dementia in these groups, we would expect to find around 200 citizens from Asian or Black backgrounds with a dementia diagnosis.

Whilst the number of older citizens in Nottingham is lower than the England average the number is predicted to increase. As the number of older citizens increases the number of citizens with dementia will also increase.

3.3 Dementia and ethnicity

Research suggests that as the proportion of older people from BME groups in the UK increases steadily the numbers with dementia, depression, and other mental health problems will increase (17). This will require services to develop to meet the needs of older people from diverse BME communities. For example, work to ensure that staff from 'communities of interest' are represented in the workforce and that language barriers are minimized through the use of interpreters.

Evidence suggests that many people do not approach dementia support or care services due to a lack of information around dementia in BME communities despite them being at a higher risk (18). An understanding of cultural and ethnic issues in dementia is important in diverse populations such as Nottingham. National evidence suggests that citizens from some BME communities are less likely to come forward for a dementia diagnosis and less likely to receive support from statutory services.

There is a lack of understanding and high stigmatization of dementia amongst BME groups. Not only is there an absence of any equivalent term for dementia in many BME languages but also there is culturally an element of 'shame' associated with BME elders becoming 'forgetful' or 'going crazy' and not being able to maintain their dignity as a 'normal part of the ageing process'. In addition to this there is a sense of pride that prevents BME communities from asking for help with looking after their elders and concerns around services not being culturally specific and therefore able to uphold their values (19). Cognitive therapy needs to be trans-cultural and services need to be able to deliver culturally specific services supported with information for families and Carers'.

Local intelligence suggests that whilst the proportion of BME citizens accessing dementia services has increased over the last 3-4 years further action is needed. In addition to BME groups being less likely health and social care services, personal budgets are underutilised. The Alzheimer's Society provides a wide of leaflets many of which are translated into a variety of languages. Wide availability of these leaflets would support BME citizens at the point of diagnosis.

Educating service provider staff on the needs of older people from BME communities is also important, as is making information available in relevant languages and building on

Carers' and citizens experiences. The authors conclude that such person-centred care is beneficial to all service users.

Local intelligence suggests that there has been a considerable increase in the number of admissions of citizens with dementia from BME communities into secondary care as a result of awareness raising and education amongst BME communities and care workers. However, there are a number of complex factors that hinder early recognition and presentation and these differ within different BME communities.

Referrals for assessment of older people from some BME communities where older citizens have not accessed formal education and have little English can present particular challenges. A vignette of such a citizen can be found in appendix 1.

4. Risk and prevention

The greatest risk factor for dementia is age, although an increasing number of adults of working age are diagnosed with dementia each year.

There do not appear to be guaranteed ways of preventing dementia as risk factors are complex but adopting a healthy lifestyle incorporating the factors listed below can help lower the risk of developing dementia (20):

- Stopping smoking;
- Maintaining a healthy weight;
- Being active;
- Avoiding excessive consumption of alcohol;
- Maintaining healthy blood pressure;
- Keeping stress in check;
- Leading a “brain-healthy” lifestyle including mental stimulation and
- Sleeping well

5. Diagnosis and early intervention

Early diagnosis of dementia enables individuals to plan their care, access appropriate services and reduces the risk of crisis necessitating admission to a care home.

NHS Health Checks now include information on the signs and symptoms of dementia for participants aged 65 years and over provided information on local memory services.

5.1 Memory assessment services

Memory assessment services offer early diagnosis for people experiencing memory problems and/or where dementia is thought to be a likely diagnosis. Citizens access the service via GP referral. The memory assessment team is nurse-led who work closely with doctors and other healthcare professionals.

5.2 Pharmaceutical options

There are no drug treatments that can cure Alzheimer's disease or any other common type of dementia. However, medicines have been developed for Alzheimer's disease that can temporarily alleviate symptoms, or slow down their progression, in some people (1). There are two types of medication used to treat Alzheimer's disease: acetylcholinesterase inhibitors (often shortened to just 'cholinesterase inhibitors') and NMDA receptor antagonists.

In the past, people with dementia have frequently been prescribed antipsychotic drugs as a first resort and it has been estimated that around two thirds of these prescriptions are inappropriate. Reducing the use of antipsychotic drugs for people with dementia is a national priority in England (1).

In 2012/13 local commissioners agreed a quality incentive (known as CQUIN) with Nottinghamshire Healthcare Foundation Trust (NHFT) to reduce the inappropriate prescribing of anti-psychotic medication for patients with a diagnosis of dementia in line with the requirements of the national Dementia Strategy. This was achieved by reviewing all inpatients with a diagnosis of dementia that were prescribed anti-psychotic medication. Any patient that was identified as no longer requiring anti-psychotic medication was offered alternative treatment where appropriate. NHFT reviewed 100% of patients as required by CQUIN. This practice became part of routine care and patients continue to be reviewed to ensure they do not continue to be given inappropriate prescriptions.

Drug treatment for Alzheimer's disease is important, but the benefits are small, and drugs should only be one part of a person's overall care. Non-drug treatments, activities and support are just as important in helping someone to live well with Alzheimer's disease.

6. Community support and intervention

Supported by appropriate, joined up local health and care services and supported by a good network of family and community, it is possible for people with dementia to live independently in their own homes, sometimes until the end of their lives.

6.1 Community based support

Social isolation and loneliness is reported by many people with dementia (21) and it is important to recognize the importance of social interactions for people living with dementia. Existing social networks and local services help the individual to remain socially active if they wish to.

In Nottingham the activities available include:

- Libraries, which provide *Books on Prescription* specifically for dementia
- Reminiscence groups through the museums
- Memory cafes
- *Bestfoot Forward* who support guided walking groups

- *Singing for the Brain*
- Dementia friendly swimming at Harvey Hadden Stadium
- Self-help groups
- Befriending services
- *'Imagine'* project that uses the arts to enrich the lives of older care home residents particularly those with dementia
- Notts County FC - Early Onset Dementia Multi-sports project at Portland Centre in the Meadows.

The concept of becoming dementia friendly is spreading throughout communities and organisations nationally. Creating dementia friendly communities is part of a social movement to help people live well with dementia. *Age Friendly Nottingham* has a Dementia Working Group which will focus on Nottingham becoming a more dementia friendly community and support the council to achieve dementia friendly status.

'Dementia Friends' is an Alzheimer's Society initiative that aims to give people across England a greater understanding of dementia, and identify small actions that can make a real difference to people living with the condition. In Nottingham, the number of Dementia Friends continues to grow but to achieve dementia friendly status more Dementia Champions will need to be recruited.

As the workforce ages and the number of people retiring at a later age increases, the number of people living with dementia and their Carers' who continue to work is set to rise. This has implications for employers, who are beginning to recognise that dementia is becoming an increasing issue for their organisations and their staff. Services are offered by employer groups and the NHFT to support people to remain in work.

6.2 Personalization, day services and support within the home

All citizens with dementia who require long-term support to remain in their home now receive a *Personal Budget* to meet their social care outcomes. This allows citizens and their families and Carers' to have choice and control over how their needs are met. For example, they can choose to use commissioned services, direct payments, internal services or a combination of the above.

The number of Direct Payments being used by eligible citizens is increasing with 30% of citizens now choosing to meet their Social Care outcomes through this method.

Nottingham City Council commissions the *Care at Home Framework* and a range of older person's day care and day opportunities. There are seven providers on the homecare framework with four lead providers who are contracted to deliver the majority of care in four separate zones across the city. In addition, there are a number of 'spot contracted' providers who are able to deliver care when framework providers cannot pick up the required capacity.

On the *Day Care/Day Opportunities Framework* five of these services; Radford Care Group, Sybil Levin Centre (Age UK), Yolanta House, Time Out Care Services (Tuntum) and Seely Hirst House, are able to cater to the needs of and provide activities for,

people with varying stages of dementia. Radford Care Group also provides specific sessions for Carers' of those with dementia.

Internal services are able to deliver care to citizens with dementia include Jack Dawe (homecare), The Willows Resource Centre and Albany House (Day Care) and the BME centres, Pakistan Centre, Indian Community Centre and Marcus Garvey Centre (Day Care) .

6.2.1 Training

Training staff on dementia is crucial to ensuring citizens with dementia and Carers receive the right support. Many social care staff have completed some or all modules of dementia care training including Introduction to Dementia, Dementia Care Level 1 and Dementia Care Level 2. The induction programme for new staff includes an hour's introduction to dementia.

Specialist dementia training including Dementia Awareness, Reminiscing with Museum Objects, Dementia, MUST (Malnutrition Universal Screening Tool) and supporting staff with challenging behavior has been provided for relevant staff.

In addition, approximately 10-12 care workers will be undertaking QCF Health and Social Care Diplomas from January onwards and will take the Dementia pathway for the Level 2 or 3 Awards.

The training and development team are currently putting together resources on a range of topics, including dementia, for teams to use for in-house activities such as team meetings. The resources are in the form of "tool-kit talks" with activities and information and links to relevant e-learning, web sites etc.

Care at Home Framework providers are also required to train their workforce to be able to deliver care to citizens with dementia.

6.3 Personal Health Budgets

The CCG currently have 11 citizens with dementia who have a fully-funded, personal health budget. There are more citizens with packages which are jointly funded by the CCG and NCC. These personal health budgets (PHB) are managed by NCC. A further three people who have Working Age Dementia have a PHB for their dementia as part of the Personal Health Budgets pilot.

The majority of the PHB spend relates to the employment of personal assistants but also includes support with laundry and respite care. One service user resides in a care home Monday to Friday and uses their PHB to go home at the weekend which requires a support package.

Some citizens have used their PHB for gym membership and to access chair based exercise. All these citizens identified that they would improve their health and wellbeing through regular exercise.

6.4 The role of GPs

GPs are usually the first port of call to supporting someone to get an assessment for suspected dementia. Once a person has a diagnosis they offer a range of support to a person with dementia, including:

- General advice on ways of preventing illness and promoting health
- Medical advice and treatment
- Referrals to specialist help and other services

The local lead suggests that the role of the GP in dementia care is changing from *'little can be done'* to *"how I can further improve better quality health care for my patient, their Carer and families?"*

Most GPs recognise the importance of early diagnosis and consider the options of drug therapies and yet non-drug therapies are showing evidence of improving effectiveness. This included cognitive stimulation therapy as well as better information provided by charities such as the Alzheimer's Society. Staying well messages are also important and GPs have a role in reducing cardiovascular risks in citizens with Alzheimer's as part of *'a better bodies and better minds'* strategy.

GPs can also discuss with citizens, families and Carers' that at some stage patients will lose capacity to make decisions about their care and advance care documents like 'statements of wishes and preferences', 'living will' and 'Power of Attorney' are valuable instruments.

The needs of Carers' are paramount and GPs are well placed to consider the health of Carers'. For example, looking out for stress or depression and supporting planned respite care when needed.

7. Treatment, support and local service provision

7.1 Working age dementia service

The Working Age Dementia service was commissioned to ensure that younger people with dementia have access to an age-appropriate service in accordance with the *East Midlands Next Stage Review: A Picture of Health (22)* and the *National Dementia Strategy (1)*.

The service provides specialist diagnosis for younger people with suspected dementia. There is a single point of access via the Consultant (lead for the service), in community settings familiar to the patient. In more complex cases, the team will be supported by a specialist neurology service including MRI scans and spectroscopy. The service assesses the patient's level of functioning and risk, at home, in the community and at work. The person and their family are immediately given information and support.

Each patient is managed by a care coordinator within their local Community Mental Health Team, who will:

- Manage and care coordinate all referrals to their team, of people below the age of 65 years with actual or suspected dementia ensuring all individuals and Carers' have a named person to reduce fragmentation.
- Provide input into the memory assessment service for their area when a younger person with dementia is attending to provide specialist knowledge and information from the outset.
- Complete a functional assessment (assessment of activities of daily living) for every younger person with dementia referred to their team, who wishes to. Providing advice and the implementation of strategies to maintain skills, roles, ability, and reduce risks from the outset. This may also include assessment for assistive technology.
- Devise care plans with the individuals to ensure activities chosen are graded at the right level for individuals to succeed and maintain health and well-being.

The service will work with the allocated worker from NCC and also work closely with palliative care specialists if the person is near to the end of life.

One of the key aspects of the service is to offer consultation to clinicians from other services including mental health, learning disabilities, alcohol and substance misuse, where dementia is a secondary diagnosis. Service users and their families will remain known to the team whilst their needs remain specialist. When clients reach 65 years their needs will be discussed following multi-disciplinary assessment and discussion with clients and Carers'/families and if they no longer require specialist care they will be transferred to their local Community Mental Health Team for Older People.

7.2 Community Mental Health Teams (CMHTs) for Older People

CMHTs provide care management and general emotional support, as well as specific and other modes of therapy that will help with recovery for people with cognitive impairment or a functional mental illness. Wherever possible, the CMHT help to discharge service users back to the care of their GP once a stable period of recovery is achieved. The service is available for those over 18 who have a mental health issue caused by disease affecting the brain or dementia treatment groups.

7.3 Nottingham City Specialist Dementia Outreach Team

The service will ensure improved quality of care for people with dementia through specialist input into care homes in the City. The key aims are to:

- Increase standards of care in care homes
- Increase independence and choice for the person with dementia living in a care home

- Improve the mental health and wellbeing of care home residents
- Provide skilled, specialist staff to support adults with dementia and their Carers' in care homes
- Prevent avoidable deterioration of mental health
- Improve the skills and confidence of care home staff to care for adults with dementia, through providing advice, support and training as well as input to care planning
- Avoid unnecessary admission to hospital and support timely discharge when people are admitted
- Support timely hospital discharge
- Avoid unnecessary transfers of care e.g. transfer to alternative care homes.

The service takes referrals from MHSOP consultants in the Nottingham city area. Once the referral is accepted they provide mental healthcare support to people in care homes with dementia who are registered with a NHS Nottingham City GP (this will include some people in care homes situated in the County). On receipt of the referrals they will undertake a mental healthcare assessment of the service user and work alongside the home staff in planning care and developing individual treatment plans as defined by the healthcare assessment. The Dementia Outreach Team will also refer for equipment and support for physical rehabilitation needs where necessary.

One of the key aspects of the service is to provide comprehensive training for staff in care homes to help develop their skills, expertise and knowledge of dementia.

The service also case-manage, continuing healthcare clients with dementia who are in care homes. Case management will involve regular visits to the care home to ensure the patient's needs are being met and offer support to the care home in managing that patient and will include working in partnership with the NHS Nottingham City Continuing Care Team at the continuing care reviews (carried out after 3 months and then at least annually thereafter) with input to the completion of the assessment tools and resulting recommendation concerning eligibility for continuing healthcare.

7.4 Intensive Multi-disciplinary Assessment & Treatment Service for Functional Mental Health (Older people) and Dementia

The intensive multi-disciplinary assessment and treatment service provides a high quality and evidence based service to improve the lives of people with mental health problems and/or dementia. The service supports:

- Confirmation of diagnosis in more complex cases
- Educate and support service users, families and Carers' in the management of dementia, depression and anxiety
- Management of challenging behaviour e.g. to ensure people can continue attending other day services
- The service will provide some training and support to social and voluntary sector day care

The service is time-limited and usually provides support for a maximum of 8 weeks; it involves specialist assessment, active therapy and treatment. It delivers group-work,

one-to-one and outreach to other day services. The service links to primary care specifically where service users' have co-morbidity with other long-term conditions (in particular, case management/community matrons). Specific programmes are also provided if required to ensure access for e.g. BME groups, people with learning disability and dementia, younger people with dementia, people with challenging behavior and people with dementia and physical nursing needs. Normal operating hours are Monday to Friday, 9am – 5pm.

7.5 Admiral Nurses

The Admiral Nurse service was established in Nottingham in July 2014 with one full time registered RMN, in June 2015 another full time Admiral nurse (RMN/RGN) joined the team. Admiral Nurses are experienced, qualified nurse professionals who specialise in supporting those affected by dementia and their families and Carers.

The Admiral Nursing service provides a clinical assessment and framework to assess and support the needs of both the Carer and the person with dementia. The service provides a holistic and person-centred assessment which includes physical needs including medications, liaison with GPs, Psychiatrists and other professionals. The assessment includes mental health and wellbeing, assessment of social needs, Carers' stress, support and guidance and essential education tailored to the family's individual needs.

The team work from diagnosis right through the whole journey of dementia building strong therapeutic relationships. Admiral Nurses state that they:

“.....never discharge, our aim is to help families and patients live well with dementia and feel fully supported.”

Admiral Nursing is provided collaboratively with Dementia UK who provide continual professional education and supervision, in partnership with City Care, to enable the team to deliver the *Dementia Carers Coffee Clubs* alongside Admiral Nurse Clinics at every coffee club. Admiral Nurses offer guidance, support, education and training to all City Care staff.

In addition, Admiral Nurses established the first Dementia Link Clinicians forum. 22 teams from City Care took part in its inaugural meeting. The plan is to meet at least 4 times a year to offer education and training with the ultimate aim that teams become dementia focused; confident in providing a seamless service for both Carers and citizens.

Admiral Nurses currently work with over 200 families in Nottingham and have received positive feedback.

7.6 Secondary Mental Healthcare Service use

Figure 3 shows the proportion of patients receiving care from secondary mental healthcare services by need expressed as mental health care cluster. Mental Health Care Clusters are a way of grouping Service Users with similar needs and problem

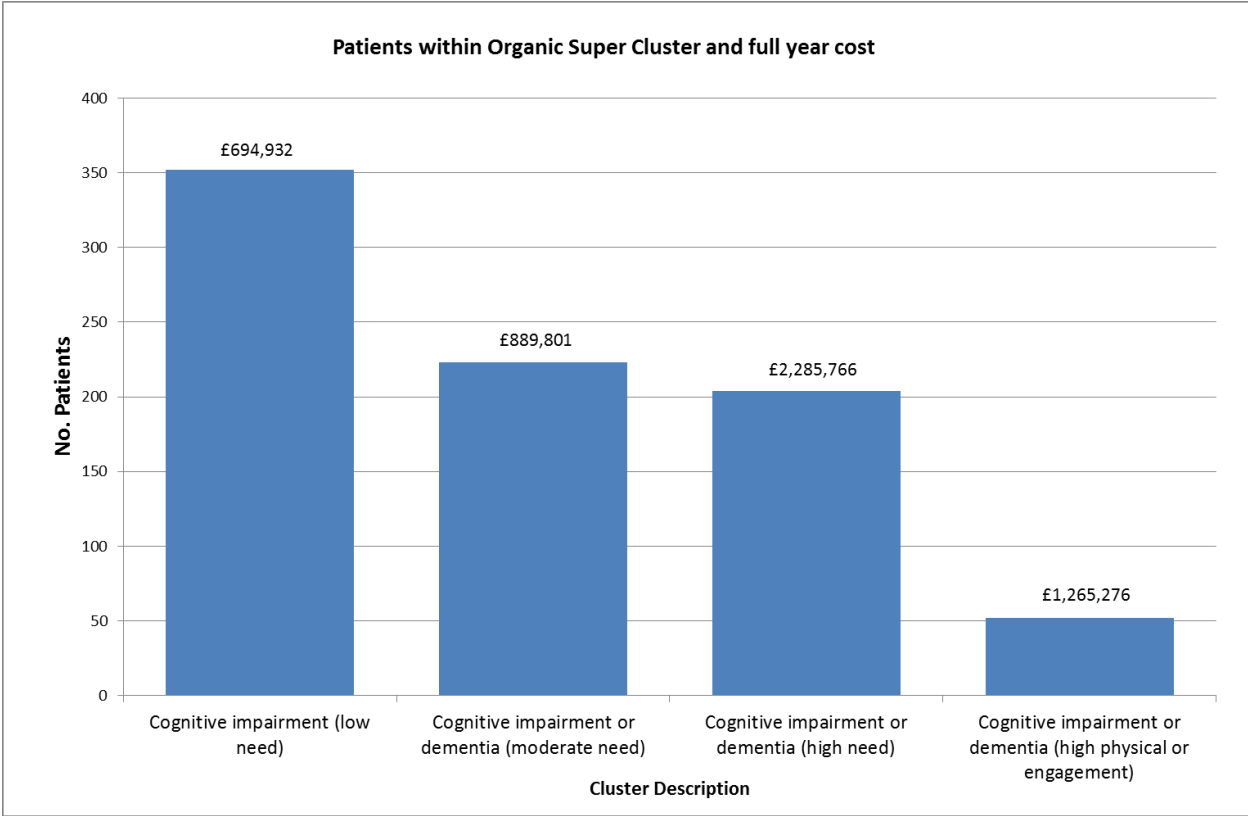
severities. Using Care Clusters is one way of gathering information that helps standardise what care the NHS offers to service users with similar problems. More information on care clusters can be found in appendix 2.

The clusters referenced in figure 2 are:

- Cluster 18, cognitive impairment, low need;
- Cluster 19, cognitive impairment or dementia, moderate need;
- Cluster 20, cognitive impairment or dementia, high need and
- Cluster 21, cognitive impairment or dementia high physical need or engagement².

Figure 3 shows that the majority of citizens cared for by secondary mental healthcare services in Nottingham have cognitive impairment (low level of need). This is unsurprising as there are more citizens in the city with cognitive impairment and/or dementia than there are with more complex needs. Figure 3 also highlights that the higher the need, the greater the cost of care.

Figure 3: A snapshot of the number of patients receiving care from secondary mental healthcare services by need (Q2, 2015/16)³



² No longer able to engage which impacts on social functioning, ability to self-care, awareness etc.

³ Please note these are full year costs

8. Crisis support and care

8.1 Mental Health Intensive Recovery (MHIR)

The service provides short term intensive support to allow people with a mental health problem (including dementia) to remain at home who would otherwise be at risk of being admitted to hospital or other care settings. Often these people are acutely ill mentally or presenting with behaviours that challenge. Carers' are often in acute distress and struggling to continue caring.

Visits from support workers can be up to four times a day by two staff to promote independent living and provide tailored mental health treatments and interventions. The service is multidisciplinary in nature and is delivered by nurses, occupational therapists, physiotherapists, assistant practitioners and support workers.

The service supports people with a functional mental illness and people of any age with a diagnosis of dementia. The service is currently seeing 30-35 patients per month with an average of 14 contacts per patient.

9. Hospital/in-patient support

In 2012 NHFT, in agreement with CCGs, commissioned a bed utilisation review by an independent organisation, Mental Health Strategies. The review showed a significant number (54%) of dementia admissions to NHFT wards were to support breakdowns in care at home, rather than evidence based clinical need for admission. Furthermore, length of stay in dementia assessment beds was extended by up to 60% due to lack of alternative and more clinically appropriate provision within the community.

Once admitted, alternative levels of care, i.e. step down provision, was often cautiously introduced (56%). The review also identified that in 25% of cases there is a lack of clinically appropriate provision within the community which inappropriately impacted on lengths of stay for these patients.

The review by Mental Health Strategies examined older people's mental health services across Nottinghamshire against national averages. This showed:

- The Nottinghamshire Healthcare Foundation NHS Trust had a higher number of older adult acute beds and bed days per population.
- The older adult acute admission rate is proportionally higher.
- There were longer lengths of stay for older people in acute beds.

In October 2014, following a public consultation and supported by commissioners, NHFT presented proposals to Overview and Scrutiny to close two older adult wards on the City Hospital site, designate an existing ward as a Dementia Intensive Care Unit (DICU) and increase community services to support people to remain in their own environment.

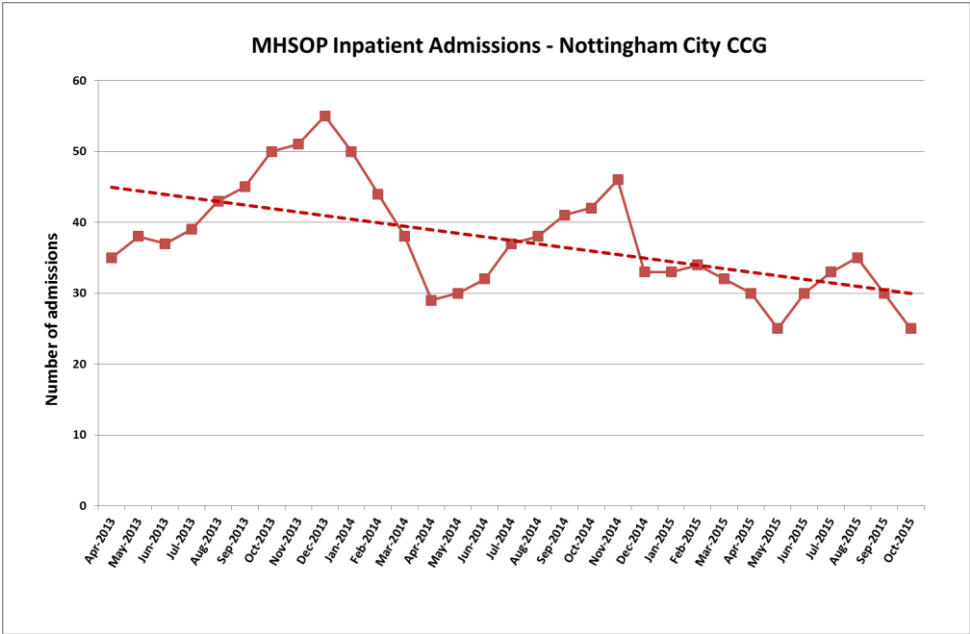
An Equality Impact Assessment (EIA) was undertaken to ensure that the bed closures would not discriminate against people who share one or more of the protected

characteristics defined in the Equality Act (2010). The EIA noted no positive or negative impacts for the majority of these groups whilst noting that an increase in community care provision could have a positive impact on Carers'. The EIA highlighted that the EMPACT review had identified that 54% of admission days could have been prevented with better Carer support and/or respite. Community services are known to help prevent Carer breakdown that results in an admission.

Following the closure of the Daybrook wards both Silver Birch Ward (based at Highbury Hospital) and Amber Ward (Millbrook Unit, Mansfield) have been identified as enhanced wards. The wards provide multidisciplinary dementia assessment and interventions for people who present with different types of cognitive impairment and behaviours that challenge.

Figure 4 shows that between January and October 2015, Silver Birch ward beds, which are more likely to be used by City residents, experienced between 82% to 96% occupancy. Overall, the number of bed days used by Nottingham City CCG has declined slowly as people move to more community based services.

Figure 4: Mental Health Services for Older People (MHSOP) inpatient admissions (2013-15)



9.1 Enhanced Dementia Wards

The referral pathway into Silver Birch Ward (Highbury Hospital) and Amber Wards (Millbrook Unit, Mansfield) is for the most complex patients with a wide range of health, social and behavioural needs. Patients who traditionally may have been admitted to inpatient care are now assessed and treated by the enhanced community services identified in the community services model (MHIR).

The Silver Birch model works to a 12 week assessment and treatment pathway. This includes assessment and treatment of patients using a multidisciplinary approach to identify patients' physical and psychological needs to ensure that individuals are placed within the least restrictive environment on discharge. This approach includes the use of standardised clinical assessment materials, access to psychology, occupational therapy, physiotherapy and speech and language therapy, and a structured and individualised activities programme. Regular case formulation sessions are held on the ward to discuss clinical cases and reflect on best practice. The wards have enhanced staffing levels which ensure the optimum intervention and shorter length of stay for the patients.

9.2 Rapid Response Liaison Psychiatry

The Rapid Response Liaison Psychiatry Service (RRLP) at NUH commenced in November 2012 following the commissioning of a pilot based on the Birmingham RAID model (Rapid, Assessment, Interface and Discharge). RRLP is a service made up of three highly specialist clinical streams; adult mental health, older people's mental health and a substance misuse and alcohol service. The service focuses on meeting the mental health needs of people who are being treated for physical health problems or symptoms within acute hospital settings.

The aim of the Older People's Team is to provide a rapid response service for people of any age with dementia, patients over the age of 65 who are experiencing mental health problems and patients with a physical health problem which may present as a mental health difficulty i.e. delirium. The service is provided to people who are inpatients within acute hospital settings. The service also provides formal and informal packages of training and education for acute care colleagues; this provision aims to improve the patient experience and enable staff to be confident in their approach to older adults with mental health problems during their hospital stay. The service is provided by a multi-disciplinary team of medical staff, psychiatric nurses and occupational therapists.

The MHSOP RRLP teams work in partnership with acute hospital colleagues, crisis response services, primary and secondary care, mental health teams/MHIR, social care and the voluntary sector. It operates 7 days a week from 9am-5pm and has the capacity to do urgent, same day assessments.

One of the central aims of the service is to avoid unnecessary delay once a person is medically fit for discharge from hospital. The team liaises with the discharge teams within the hospitals and makes direct onward referrals to community based services for example Mental Health Intensive Recovery Team, Community Mental Health Teams or reablement services. Patients and their families are encouraged to input into the care plan and engage with support from third sector providers/community groups that will be available to them post-discharge.

Work currently being undertaken: a review of the service is currently being undertaken. Right Here Right Now (2015) states liaison models need to be tailored to meet the needs of their patients and to respond to ED presentation times. The paper states presentation of dementia is most likely seen between 15:00–22:59. Analysis of data from April 2014-August 2015 shows that in Nottingham of the 525 admissions (patients aged 70 plus) 236 of these equating to 44% took place out of the older adults working

team operating hours. This local data supports the need to remodel the service to ensure the model operating matches patient flow.

9.3 Ward B47

Ward B47 is a 28-bed ward, acute medical ward for those with dementia and/or mental health problems staffed by three registered mental health nurses, a specialist mental health occupational therapist and an activities coordinator who work alongside staff providing physical healthcare. The multidisciplinary team includes an occupational therapist with experience in discharge planning.

The ward was set up in January 2010 as part of a collaborative research project between Nottingham University Hospitals NHS Trust and the University of Nottingham, which was funded by the National Institute of Health Research and the Department of Health. B47 has received a national health and social care award for mental health and wellbeing.

9.4 Quality

Four Quality Visits have been undertaken over the last 12 months to Dementia services commissioned by Nottingham City Clinical Commissioning Group:

- Working Age Dementia Service
- Nottingham City Dementia Outreach Team
- Dementia Intensive Care Unit. All of which are provided through Nottinghamshire Healthcare NHS Foundation Trust, and
- The Memory Café, a Dementia Support service provided by the Alzheimer's Society.

Quality Visits provide an opportunity to get a greater sense of what it feels like to receive or deliver care in different services. The focus of visits is based on the three strands of Quality Governance; Patient Safety, Patient Experience and Clinical Effectiveness. Visits are usually announced and last around 1.5 hours with a representative from both the CCG's Quality Governance and Commissioning Team.

The Quality Visits overall were deemed positive with no immediate concerns raised. Assurance was gained that staff were up to date with relevant training with close monitoring in place. Evidence of patient's experience being captured and reviewed including support for Carers' and families was noted. During the visit to the Working Age Dementia Service based at Highbury Hospital it was noted that a number of informal complaints had been received regarding waiting times for the service. Commissioners are in the process of working with the Trust to look at options of how the service can be reconfigured in order for these waits to be reduced.

10. Care home provision

Research suggests that 75% of care home residents have cognitive impairment, including dementia (23). Gordon states:

'The prevalence of cognitive impairment was considerably higher than previously reported in UK care homes-75% of residents had an MMSE =22, compared with a 50% dementia prevalence reported in 2004. This may represent an increasing tendency for care homes to be used predominantly for the growing number of people with dementia rather than physical disability alone.'

By contrast, 62% of the respondents had dementia diagnoses. The report author states that care was taken to ensure that the care homes sampled reflected the local prevalence of dementia care offer.

10.1 Care Home Vanguard, the Dementia Outreach Service

Nottingham City's Care Homes Vanguard, one of six national Care Home Vanguard sites selected by NHS England, is an ambitious programme of work aimed at raising quality, strengthening services and delivering positive experiences of care across the care homes sector. 53 homes across and bordering on the city, delivering older people care to an increasingly complex resident cohort, are within project scope. These homes provide 1881 beds, of which 1169 are residential and 712 nursing beds, though this proportion changes. We know that an increasing proportion of residents are experiencing cognitive impairment; a 2013 study by the University of Nottingham found a 75% prevalence of cognitive impairment in the resident population.

One element of Vanguard work will look to strengthen the specialist services offer to care home residents. This will include review and expansion of the existing Dementia Outreach Team. Recent engagement work carried out by Age Concern within city care homes found that specialist services were highly valued by residents, relatives and staff, but that residents in particular felt services could work in a more joined up way. This is an aim supported by Vanguard and is particularly important for residents with dementia.

This need for integrated services will be addressed in a number of ways within the programme and will be supported by:

- Better IT and information sharing
- Clearer pathways and a single point of contact
- Better support and oversight for the workforce within care homes, with lower turnover and less use of agency staff.
- A MDT approach for residents to facilitate better service integration and wrap around care for residents.

To take this work forward the CCG is recruiting to a set of task and finish groups, which will include mental health commissioners, to ensure a focus on residents with dementia.

11. Research

Research in dementia is often subdivided into cause, cure and care:

- Cause is neurobiology including genetics and basic science
- Cure is about halting or reversing the disease process
- Care about supporting people and their families when the condition is already manifest.

Most media attention is on cure although risk and/or prevention stories such as '*...champagne helps prevent dementia*' are also popular.

Research in Nottingham includes cause, cure and care. It is a centre for molecular genetics, neuroimaging and other biological research. Nottingham also participates in drug trials many of which are large multi-centre trials. Professor Denning's research, through the Institute of Mental Health, focuses on 'care' including dementia and technology, dementia and the arts, services for people with dementia and dementia and employment

12. Costs

It is challenging to estimate spend on dementia services in Nottingham. For example, some services, such as mental health services, are not 'coded' in a way that differentiates between citizens with dementia and those with other mental health problems affecting older people. In addition, spend on physical health services for citizens with dementia are not captured when only mental health services are considered.

Social Care data systems do not allow estimation of spend on dementia as dementia is not captured as a standalone category.

13. Carers'

The needs of Carers' have been identified in the Care Act (24) through the introduction of wider Carers' assessments. Many Carers' for a person with dementia report not being provided with information and advice on basic practical issues and experience higher levels of stress and depression compared to other caring roles (25).

The complexity in navigating support is compounded by many people with dementia may have up to six other health conditions. The Alzheimer's Society in Nottingham provides information sessions for Carers' but also offer a short six week 'CRISP' (Carer Information and Support Programme) sessions. These sessions provide an opportunity for Carers' to talk in a friendly and confidential environment about their experiences of caring and the impact it is having on them.

Nottingham City Council commissions the Carers' Federation to deliver the Carers' Hub; an information, advice and support service for Carers' including those caring for someone with dementia. In addition, Carers' of those with early stages of dementia,

who are not yet eligible for care services, are able to access pre-eligibility day-time respite via assessment by the Carers' Federation.

The Council, in conjunction with the Carers' Federation, has implemented the universal Carers' Support Plan. The first part of the document includes useful information and advice for Carers' about what support is available for them locally. The second part is a contingency plan that sets out the specific needs of the person they care for, including medication, contact numbers, communication needs and likes and dislikes. The contingency plan is identified by a sticker on the fridge which alerts care staff as to where in the house the contingency plan is stored should an emergency occur.

In addition, the voluntary, community and faith sectors play an invaluable role in supporting Carers'. Initiatives in Nottingham include peer support groups for Carers' of people with dementia and memory cafes where Carers' can go to a separate room nearby to learn from each other's experiences and offer mutual support.

14. Next steps

Nottingham City currently exceeds the national target of 67% for diagnosis rates. However, awareness of dementia and support for people from BME communities and other minority groups requires further work. Dementia in BME communities is layered with complexities and differences within and between communities and requires in depth work to understand this in its entirety in order to inform policy and service design.

Others areas for development include:

- Increased post-diagnosis support for all citizens targeted to those that are less likely to access support such as those from BME communities
- Ensuring all citizens are aware of local services that support people with dementia and their Carers'
- Better alignment between mental and physical health services
- Improving the quality of acute hospital care for people with dementia and/or delirium
- Improving quality in care homes including through the Care Homes Vanguard;
- Increased awareness of the needs of people with dementia in primary and acute care.

In addition, services will need to adapt to meet the needs of citizens with a learning disability who develop dementia and to respond to dementia associated with the increasing levels of alcohol dependency in Nottingham.

Public health should continue to monitor evidence of effectiveness of preventative services which seek to reduce dementia prevalence through the promotion of healthier lifestyles.

15. Additional information

The main causes of dementia are well described at:

<http://www.nhs.uk/conditions/dementia-guide/pages/causes-of-dementia.aspx>

The Alzheimer's Society provides information on dementia for citizens, their families and carers and professionals. It can be accessed at:

<https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120>

16. Contributors

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Appendix 1 – Case Studies

Shanaz

Shahnaz is probably about 78 years old. She lives with her youngest son, Ali, and his family. The immediate family includes Ali and his wife and their two sons, one of whom is married with a 2-year old child, Shahnaz's great-granddaughter. Ali is a taxi driver and works irregular hours. The little girl has a congenital heart problem.

Shahnaz has been getting muddled and forgetful for some years. In some ways this does not matter too much as her daughter-in-law is at home and runs the household. However, there have also been some changes in her behaviour. She often wakes up in the night and is terrified as she doesn't know where she is. This makes her start shouting and wakes the whole household. She doesn't like to wash or change her clothes and the family find it difficult to help her as she just shouts at them or lashes out if they try to get her in the bathroom. She is suspicious and often won't eat meals with the family, as a result of which she has lost a lot of weight. She has high blood pressure and diabetes but discarded tablets are found all over the house so clearly she doesn't take her medication. She mumbles to herself or to what appear to be hallucinations of people. Her speech is indistinct. Most of the time she does nothing but sometimes will rifle through the rubbish bins. Her grandson's wife is scared of Shahnaz who once pulled her hair very badly.

Shahnaz is originally from Kashmir. She had no schooling and never learned to read or write. At 14, she married her first cousin from the same village. He moved to England to work on the railways and 10 years later she joined him. She was a competent housewife but never learned to speak English. Her husband died 10 years ago and she has found it hard since then. She has four other children, all living locally.

The family want to look after Shahnaz at home but they are struggling. Nobody is getting enough sleep and they all worry about what if things get worse.

Graham – A Case study of someone with Pick's Disease taken from the Alzheimer's Society website

Graham's view - This is our story of a journey and beyond. My name is Graham and my wife is Debbie. My problems all started when I walked into a lamppost while being nosey. It felt like my head was bleeding, but all I got was a lump the size of an egg.

Over Christmas 2005 I became ill with a virus. I felt so terrible I could not get out of bed. I went to our brilliant GP and explained how my head was feeling - like my skull was shrinking and my brain was swelling. The GP sent me to a specialist, who arranged an MRI scan. It showed shrinkage in the frontal and temporal lobes of my brain. I was admitted to a neurological unit for four days of tests.

I was diagnosed with frontotemporal lobe degeneration (Pick's disease). Debs and I just looked at each other. Debs asked what the prognosis was. The neurologist told us that there was no cure, nor any drugs to slow down the disease. I had between two and ten years if I was lucky. It was a surreal feeling. I just went numb. Within seconds I was no

longer the breadwinner. But it was also a relief because at long last we knew what was wrong.

Debs has been an absolute rock. She got a second job to help pay the bills until we settled down and tried to get ourselves straight. We have three children between us. My older daughter, who is 23, does not wish to know anything about the disease; my son, 21, knows more than me and I have to stop him talking about it sometimes; and the younger daughter, 20, is in denial.

Through our local Alzheimer's Society in Brighton we discovered the Towner Club for younger people with dementia. I go every Friday, and it is wonderful because when I come out at the end of the day, I feel like I have achieved something. It keeps me stimulated. Before I went to the club, I was invited to another club for older people by my social worker. I am only 50. If I'd have wanted to sit and stare at four walls I would have stayed at home. It was not stimulating for anyone and people had no input in what they did.

I suggested doing some voluntary work for the club to introduce activities and have been taken up on the idea. I want to fight for our rights as human beings and offer people choice in what they would like, not just accept what others want us to do for an easier life.

For me this is the tip of an iceberg. We should be able to have our choice and say what we would like and not be told what to do. During Alzheimer's Awareness Week, I was asked to speak at a conference about early onset dementia in front of consultants and social workers. I typed out a speech but tore it up when I arrived and spoke from the heart. Since then, I have been asked to do more talks, which I am grateful for.

One of the symptoms of the disease is that you no longer feel emotions. I was told to surrender my driving licence after 25 years of being a delivery driver. I thought it would be like cutting my arm off, but surprisingly I don't miss it. After 25 years of working non-stop, I now have time to slow down, to look at the things around me. I no longer just see front doors. When Debbie is driving, I often see something to the right of me, and I throw my arm across her line of sight and ask, 'Did you see that?' I also have time to spend with my grandson, Kyle, and he makes me feel so good.

There are days when all I can do is just go off to bed. I also have days when I suffer with a lot of pain, and feel I'm not going to wake up. But the best medication we have found is to make sure we laugh every day.

Debbie's view - When Graham was diagnosed, Debbie took all her holiday as sick leave so they could come to terms with their situation.

She said, 'We were told that Graham had Pick's disease, that there was no cure, and to go and look on the internet. I was also asked if I wanted to take him home! 'It was a shock, but I knew it must have been something to do with his brain as he was behaving very differently.'

Through the internet, Debbie found the Pick's Disease Support Group, the Alzheimer's Society and the Towner Club. She said, 'Graham tries so hard to conform but it exhausts him. At the Towner Club he doesn't have to be on his guard.'

She says they still haven't come to terms with what's happened.

'We have a totally different relationship now. I've always been the dappy one in our family and now as well as watching Graham I have to take responsibility for all the finances.

'It can be hard as he doesn't feel emotions now. I can be crying and he'll just pat me like a dog. He'll tell the whole pub he's dying, not realising people don't want to hear it.'

Debbie is determined to be there for Graham, and feels upset when social services suggest he goes away for respite. She said, 'He's given so much to my family and I over the years that I want the best for him.'

This story was first published in [Living with Dementia magazine](#), September 2007

Appendix 2

Care clusters are the basis of mental health payment systems. This means all service users who are accepted onto older aged adults mental health team caseloads will be allocated to an appropriate care cluster following initial assessment.

To allocate a Service User to a Care Cluster, a qualified Mental Health Care Practitioner uses their knowledge of the service user's problems and case history to rate the Mental Health Care Cluster Assessment Tool (MHCT). The cluster assessment provides evidence of service user's level of needs. The cluster assessment scores are used alongside cluster descriptions to choose a care cluster. There are 21 care clusters, 4 of these specifically relate to dementia:

Cluster 18 (low need): People who may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) who have some memory problems, or other low level cognitive impairment but who are still managing to cope reasonably well. Underlying reversible physical causes have been rule out.

Cluster 19 (moderate need): People who have problems with their memory, and or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self-neglect or harm to others and may be experiencing some anxiety or depression.

Cluster 20 (high need): People with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their Carers' or services. They may have high levels of anxiety or depression, psychotic symptoms or significant problems such as aggression or agitation. They may not be aware of their problems. They are likely to be at high risk of self-neglect or harm to others, and there may be a significant risk of their care arrangements breaking down.

Cluster 21 (high physical need): People with cognitive impairment or dementia who are having significant problems in looking after themselves, and whose physical condition is becoming increasingly frail. They may not be aware of their problems and there may be a significant risk of their care arrangements breaking down.

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