“Living life to the full with dementia”

A report from Overview & Scrutiny

Contents

Preface		**3**
Summary of Recommendations		**4**
1	**Background**	**6**
1.1	The Aim of the Inquiry	6
1.2	Evidence Gathering	6
1.3	The Dementia Strategy	7
1.4	Commissioning Dementia Services in Birmingham	7
1.5	Role of the City Council	8
2	**Introduction**	**8**
2.1	What is Dementia?	8
2.2	Types of Dementia	9
2.3	National Strategies	9
2.4	Facts and Figures	10
2.6	Local Demographics	10
2.7	Financial Position	10
3	**Public Awareness and Health Promotion**	**12**
3.1	Tackling the Stigma	12
3.2	Building Dementia-Friendly Communities	12
3.3	Working with Schools	13
3.4	Dementia Friends and Dementia-Friendly Communities	14
3.5	Birmingham Dementia Action Alliance	15
3.6	Promoting Healthy Lifestyles	16
4	**Recognition, Assessment and Diagnosis**	**17**
4.1	Diagnosis the Gateway to Support	17
4.2	West Midlands Police	18
4.3	The Prison Service - HMP Birmingham	19
4.4	West Midlands Fire Service	20
4.5	Memory Assessment Service	20
4.6	Anti-dementia Medication	21
4.7	Dementia Adviser/ Support Service	21

5	**Living Well with Dementia**	**22**
5.1	Primary Health Care Services	22
5.2	Fire Safety	22
5.3	Day Services	23
5.4	Dementia/Activity Cafes	24
5.5	Singing for the Brain	25
5.6	Growing Older with Learning Disabilities and Dementia (GOLDD)	25
6	**Accommodation Options**	**26**
6.1	Independent Living	26
6.2	Care Homes	27
7	**Support for Carers**	**27**
7.1	Carers Assessments	28
7.2	Respite	28
7.3	Admiral Nurses	29
7.4	Training and Education	29
7.5	Dementia Information and Support for Carers (DISC)	30
7.6	Bereavement	31
8	**Acute Hospital Care**	**31**
8.1	Hospital care	31
8.2	Heart of England NHS Foundation Trust	32
8.3	Birmingham City Hospital	32
9	**Conclusion**	**33**
Appendix A:	**Types of Dementia**	**34**
Appendix B:	**Contributors**	**38**

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Preface

By Councillor Susan Barnett

Chair of the Health and Social Care Overview & Scrutiny Committee

I would like to thank members of the Health and Social Care Overview & Scrutiny Committee together with health partners and organisations from across the city who have given their time and effort to contribute to this Inquiry.

In May 2014, a 3-year joint Dementia Strategy for Birmingham and Solihull was launched. Based on the experiences of people living with dementia and carers, it essentially provides an infrastructure for commissioning services to meet the needs of those people and make a difference to their wellbeing.

In Birmingham, it is estimated that there are 14,000 people living with dementia and this figure is set to rise by 18% to around 16,000 by 2021. There is a drive, both nationally and locally, to increase the number of people who receive a timely diagnosis of dementia as this is seen as the gateway to receiving support, but it is essential that services are available to meet their expectations.

The focus of the inquiry was to find out what work was being carried out city-wide by those organisations who are involved in the Dementia Strategy to gain a better understanding of whether the current services, and those planned for the future, are providing the platform for people with dementia to live a full and active life.

The committee was pleased to learn about ongoing work to raise awareness of dementia as well as the various activities being delivered by third sector organisations, and welcomed their suggestions for further enhancements.

As the number of people with dementia increases, it is almost inevitable that, at some time in our lives, each of us will know of someone with dementia or someone who is caring for a person with dementia. We owe it to ourselves to be equipped with the knowledge and understanding to provide services and facilities attributed to a dementia-friendly city and it is hoped that the recommendations in this report will go some way to achieving that.

Councillor Susan Barnett

Summary of Recommendations

	Recommendation	Responsibility	Completion Date
R01	That the City Council should appoint a Lead Member for Dementia with specific responsibility to ensure high-quality dementia services.	Cabinet Member, Health & Wellbeing	February 2015
R02	That the impact on dementia care and support is considered in relation to all major actions, commissioning and decommissioning intentions arising from the emerging Better Care Fund arrangements.	Cabinet Member, Health & Wellbeing as Chair of Health and Wellbeing Board	November 2016
R03	That the Cabinet Member for Children and Family Services writes to all Birmingham secondary schools to request that they consider including dementia awareness (using the available Dementia Resource Suite for Schools) as part of the PSHE (Personal, Social & Health Education) curriculum for Year 9 students.	Cabinet Member, Children and Family Services	November 2015
RO4	That dementia awareness information is disseminated to all City Council Members and made available to all staff.	Cabinet Member, Health & Wellbeing	November 2015
R05	That the City Council works towards making Birmingham a dementia-friendly city beginning at District level.	Cabinet Member, Health & Wellbeing with District Chairs	November 2015
R06	That Birmingham Community Healthcare NHS Trust develops a process to identify people, using their community services, who may have dementia.	Birmingham Community Healthcare NHS Trust	November 2015
R07	That Commissioners explore with Birmingham and Solihull Mental Health Foundation Trust and primary care, the possibility of adopting a shared protocol for prescribing anti-dementia medication as part of locally based integrated care services that support vulnerable people, including those with dementia, in the community.	Birmingham and Solihull Mental Health NHS Foundation Trust CCG Commissioners	November 2015

R08	That West Midlands Fire Service should receive referrals for fire safety checks via:- a) The City Council as fire risk will form part of a care assessment. b) GPs who identify vulnerable or high risk patients	Cabinet Member, Health & Wellbeing Chairs of CCGs.	November 2015
R09	That the Alzheimer's Society continues to develop its work with multi-cultural communities and faith groups and updates the Health and Social Care O&S Committee on progress.	Alzheimer's Society	November 2015
R10	That an integrated commissioning pathway model should be developed for those people with a dual diagnosis of a learning disability and dementia.	Cabinet Member, Health & Wellbeing	November 2016
R11	That the ExtraCare Charitable Trust should explore with the Birmingham Clinical Commissioning Groups the feasibility of establishing a community nursing service for its schemes/villages across Birmingham and a "locksmith" service in the community.	The Extracare Charitable Trust Chairs of CCGs	November 2015
R12	That the feasibility of developing alternative models of respite care other than bedded respite care, such as providing domiciliary care for people with dementia, be explored.	Cabinet Member, Health & Wellbeing with Chairs of CCGs	November 2016
R13	That the model of support used by Dementia Information and Support for Carers (DISC) is highlighted as best practice and is considered for replication in other locations across the city.	Cabinet Member, Health & Wellbeing Chairs of CCGs	November 2015
R14	That an assessment of progress against the recommendations made in this report be presented to the Health and Social Care O&S Committee.	Cabinet Member, Health & Wellbeing	November 2015

1 Background

1.1 The Aim of the Inquiry

1.1.1 In May 2014, a 3-year joint Dementia Strategy for Birmingham and Solihull was published. It was developed around 5 themes that describe the dementia pathway of someone who has dementia and their carer and was based upon the experiences of people with dementia and carers, in Birmingham and Solihull, who have accessed dementia services.

1.1.2 This report is also broadly based around those 5 themes:

- Reducing stigma, promoting healthy lifestyles and dementia-friendly communities;
- What is being done to enhance early recognition and identification of the condition;
- How to ensure there is early diagnosis and access to advice and support;
- How we improve the quality of support to individuals and their carers;
- How we improve the quality of care in care homes and the acute hospitals.

1.1.3 The key question for this inquiry was:-

> What is being done in Birmingham to improve the support to people diagnosed with dementia and their carers?

1.1.4 The inquiry has focussed on the work being carried out by the City Council, health partners and organisations city-wide involved in the Strategy to gain a better understanding of whether current and future planned activities will improve the experience of people with dementia accessing dementia services and enable them to live a full and active life.

1.1.5 The aim was to produce a set of recommendations that will support the implementation of key actions set out in the Dementia Strategy and highlight issues which need addressing in order to deliver those actions between now and 2017.

1.2 Evidence Gathering

1.2.1 Health partners and organisations from across the city were invited to provide written evidence to the Committee. In addition, there were two public meetings where representatives of service users and carers were invited to join committee members to discuss a number of key lines of enquiry. Committee Members also visited Swanshurst School and, at the time of writing, had scheduled a visit to the Dementia Café at the Ann Marie Howes Care Centre.

1.3 The Dementia Strategy

1.3.1 The Strategy is essentially a commissioning infrastructure for the local authority and Clinical Commissioning Groups (CCGs) which can be used when planning services. It sets out what services are currently provided for people with dementia and their carers and changes needed to improve services in the future. It also illustrates the challenges that face both the local authority and health and social care generally in terms of the projected increase in the number of people diagnosed with dementia and the huge financial impact that brings with it. Therefore, it is imperative to ensure money spent on commissioning services for people with dementia and their carers does make a difference to their wellbeing.

1.4 Commissioning Dementia Services in Birmingham

1.4.1 NHS Clinical Commissioning Groups replaced Primary Care Trusts in 2013 and are now responsible for planning and commissioning the majority of health services across the country. In line with this, the commissioning lead for dementia services in Birmingham currently sits within the Joint Commissioning Team for Mental Health and Learning Disabilities. This team is hosted by Birmingham CrossCity CCG and works on behalf of three NHS Clinical Commissioning Groups and Birmingham City Council. The three CCGs are Birmingham CrossCity NHS CCG, Birmingham South Central NHS CCG and Sandwell and West Birmingham NHS CCG (in this context for services in West Birmingham only).

1.4.2 The term 'dementia services' describes a wide range of generic and specialist support that meets the needs of people with dementia and their carers in many settings including in their own homes, in hospitals, in sheltered and extra care housing, in residential and nursing homes and in hospices. Dementia is a long term condition with many people living at home in communities and neighbourhoods and using mainstream services. The commissioning of services currently reflects the range of need with services commissioned and procured in many different ways, not just by the Local Authority or Clinical Commissioning Groups. This means that a 'whole systems' approach is important and that commissioning plans are developed in an integrated way that supports the development of services that can provide co-ordinated care for people with dementia and their families and carers.

1.4.3 In Birmingham the proposed introduction of the Better Care Fund is intended to support the planning and commissioning of integrated health and social care services by sharing existing health and social care budgets. Commissioning will then be driven by new joint arrangements, which promote closer working and improve outcomes for patients and people with care and support needs.

1.5 Role of the City Council

1.5.1 The Strategy was written in such a way to enable both the CCGs and the local authority to take their own particular focus and stance on it. From the City Council perspective, it has three broad roles in this area:

- Joint commissioner of services – Together with the NHS large sums of money are invested in commissioning services which include residential care, day care and enablement services. There is also a lot of work commissioned from the third sector and the Dementia Café activity is a particularly good example of that kind of provision.
- Place shaping – Facilitating a whole range of public services e.g. leisure, transportation and housing, which are accessed by people with dementia and their carers and ensuring that all of those services reflect the needs of people with dementia.
- The third role is a broadly strategic one. It is about how the City Council can influence and effectively make use of relationships with its partners in health through advocacy, persuasion and negotiation.

2 Introduction

2.1 What is Dementia?

> "The word dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language, and sometimes, changes in mood or behaviour.
> Dementia isn't a natural part of ageing. It occurs when the brain is affected by a disease."[1]

2.1.1 The main risk factor for dementia is age. 1 in 14 people over 65 years of age will have dementia. 1 in 6 people over 80 years of age and 1 in 3 people over 95, so the risk increases significantly as you get into older age. But dementia also occurs in much younger adulthood and people have developed dementia in their 30s. People with learning disabilities may experience a higher risk of dementia and generally develop it at a younger age. This is particularly the case for people with Down's syndrome: one in three develop dementia in their 50s.

[1] The dementia guide published by the Alzheimer's Society.

2.2 Types of Dementia

2.2.1 There are many types of dementia but the most common are Alzheimer's disease and vascular dementia. Of those people with dementia in the UK, 62% have Alzheimer's disease and 17% vascular dementia. Others include mixed dementia (10%), dementia with Lewy bodies (4%), rarer causes of dementia (3%) and fronto-temporal dementia (2%). (Appendix A provides a brief description of each type of dementia).

2.3 National Strategies

2.3.1 In February 2009, the Department of Health published 'Living Well with Dementia: A National Dementia Strategy' which provided a strategic framework that identified 17 key objectives for improving the quality of dementia services and promote greater understanding of the causes of dementia.

2.3.2 In 2010, the All-Party Parliamentary Group (APPG) on Dementia published the report 'A misspent opportunity? Inquiry into the funding of the National Dementia Strategy' which made a number of recommendations to support the implementation of that strategy. As the National Dementia Strategy came to an end in March 2014, the APPG thought now was an appropriate time to assess progress made against their recommendations and published 'Building on the National Dementia Strategy: Change, progress and priorities' in July 2014. The report made further recommendations for central government, local authorities and CCGs. In particular, recognising the need for strong leadership and recommending that "Every CCG and local authority should appoint a Dementia Lead with specific responsibility to ensure high-quality dementia services." (R01).

2.3.3 The Prime Minister's Dementia Challenge was launched in March 2012. It set out to build on the progress already made through the National Dementia Strategy and focussed on three key areas:

- Driving improvements in health and care
- Creating dementia-friendly communities that understand how to help
- Better research

2.3.4 In order to take this forward, a champion group was set up for each of the key areas comprising members from health and social care, industry and the third sector. In May 2014, the groups published a report on the progress made in improving dementia care since the launch of the dementia challenge which will end next year.[2]

[2] https://s3-eu-west-1.amazonaws.com/media.dh.gov.uk/network/353/files/2014/05/10092-2902335-TSO-Dementia-Letter-to-PM-ACCESSIBLE.pdf

2.4 Facts and Figures[3]

- 850,000 people live with dementia in the UK. If we don't take action this number is predicted to rise to over 2 million by 2051.
  - 2025: 1,142,677. This is more than the entire population of Birmingham.
  - 2051: 2,092,945. This is more than the entire population of Liverpool, Manchester and Birmingham together.
- Dementia costs the UK £26.3 billion a year. That's enough to pay the annual energy bill of every household in the country.
- Dementia costs over £30,000 per person with dementia each year.
- Two thirds (£17.4 bn) of the cost of dementia is picked up by people with dementia and their families.
- 1,340,000,000 hours were spent caring for people with dementia in 2013. That's more than 150,000 years.
- 43% of carers don't receive enough support.
- Services need to reflect the needs of individuals.
  - 1 out of 20 people living with dementia are under the age of 65.
  - 7 out of 10 people are living with another medical condition or disability as well as dementia.
- In the West Midlands, the number of people with dementia is 73,406.

2.5

2.6 Local Demographics

2.6.1 There are an estimated 14,000 people in Birmingham who have dementia and we know from statistical analysis that this is expected in increase by about 18% to approximately 16,000 by 2021. Compared to some areas of the country this is a very small increase. But the increase is significant in the over 85 age group which, predictably, have higher levels of need. Birmingham is often thought of as a 'young' city and a very diverse city in terms of its communities, but 93% of people over 85 years of age in Birmingham are classed as White/British or White/Irish. Therefore, in the very old group of people, where dementia is very high, we are dealing with a predominantly white section of the population. This will change as the younger population of Birmingham age. Movement of the population in and out of Birmingham will also impact on that figure.

2.7 Financial Position

2.7.1 The increased number of people living with dementia will not only be demanding for individuals, families, communities and public services, but also brings with it a significant financial challenge. Birmingham currently spends around £300 million per year on dementia related activity. If we look ahead to 2021, we expect that figure to rise to £350 million. Of this spend, only £3.5 million

[3] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2761

goes on the early assessment and early intervention activity (see Table 1) which provides opportunities to maximise peoples' independence and ability to make choices. Instead, the majority is spent on emergency hospital admissions, longer stays in hospital and care home provision which lead to poorer outcomes for people. Therefore, it will be necessary to look at how more of the £300 million spend can be prioritised towards services for early intervention.

2.7.2 At present, we do not have a pooled (shared) budget for commissioning dementia services. Whilst, nominally, dementia sits within the joint commissioning framework there is no designated budget although clinical services, such as memory assessment, are paid for through the mental health budget. As we move towards the Better Care Fund integration approach of pooling health and social care resources this would provide an opportune time to propose a way forward by pooling resources into a single budget. (R02)

2.7.3 **Table 1 – Examples of actual expenditure on commissioned community services**

Service	**£**
Memory Assessment Service	1,000,000
Dementia Advisor Service	100,000
Rare Dementias Service	927,308
Memory / Activity Cafes	22,764
Dementia Cafes	66,667
Carer Support (DISC)	127,690
Dementia Support Workers/ Service	150,000
Admiral Nurse Service	132,171

3 Public Awareness and Health Promotion

3.1 Tackling the Stigma

3.1.1 It is widely recognised that one of the biggest challenges we face as a society is in reducing the stigma and dispelling the myths associated with dementia. There is a need to raise awareness and understanding of dementia in order to confront some of those preconceptions that exist. A person with dementia is, stereotypically, portrayed as "old, sitting in a chair and unable to communicate" when, in fact, in the early to middle stages of dementia this could not be further from the truth.

3.1.2 Members were told that stigma amongst black and minority ethnic communities is greater because some South Asian languages do not have a word for dementia. There may also be cultural reasons whereby the family will care for the person with dementia rather than seek support to prevent members of the community from finding out.

3.1.3 The Alzheimer's Society emphasised the importance of making connections with community and faith leaders because, particularly for first generation and older people, they may well be the first point of call for assistance. They are currently doing this through links with the Chaplaincy at University Hospital Birmingham. There are approximately 60 part time Chaplains representing all faiths who are connected to congregations across the city. (R09)

3.1.4 The Alzheimer's Society has developed some resources for ethnic minority communities. For example, they have produced fact sheets and DVDs in different languages to help those communities understand the condition and address this stigma. Alzheimer's Society also run 4 Activity Groups each month for South Asian people at 2 specialised sheltered housing schemes in Sparkbrook and Hall Green.

3.1.5 In order to tackle the stigma we need to create a dementia-friendly city where all generations and communities have access to information and advice and the knowledge to be able to talk openly about dementia. So, what is being done city-wide to tackle the stigma and raise awareness?

3.2 Building Dementia-Friendly Communities

> "A dementia-friendly community is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives."[4]

[4] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2282

3.3 Working with Schools

3.3.1 One example of raising awareness was that of Swanshurst School in South Birmingham which has taken part in a national project called Dementia4Schools. The school became involved in the project in July 2012 when the Lead Teacher was asked to join a steering committee to look into the region's response to the Prime Minister's Dementia Challenge. Swanshurst was one of twenty two schools from across the country to participate in the pilot project and the only school in Birmingham to take part.

3.3.2 The topic formed part of the Personal, Social and Health Education (PSHE) programme of study and was delivered over three lessons. Year 9 students were chosen as the target group because of their maturity compared to Years 7 and 8, and the fact they would not be involved in external examinations.

3.3.3 The aim of the project was to educate young people to understand dementia, allay any fears and provide an opportunity for them to interact with people with dementia. The Alzheimer's Society believes that educating children and young people about dementia is essential to creating dementia-friendly communities.

3.3.4 Some committee members took the opportunity to visit Swanshurst School and met with the Lead Teacher, Douglas Smith, and a group of pupils who had previously taken part in the lessons. It was evident that the work had made a lasting impression as the students were very knowledgeable and enthusiastic especially so when talking about the third lesson where they met people with dementia, carers and professionals who support people with dementia. Mr Smith stated that "This was the most important lesson because, despite how often you tell pupils something, it is by direct contact that they will understand the messages we hope to convey. The main point for me is the pupils responded to the person and not the label of their illness."

3.3.5 The students felt that dementia awareness lessons should be rolled out not just across schools but also to other adults so that awareness of dementia is more broadly spread and people know what services might be in place, and what kind of things to ask for if a loved one does receive a diagnosis. (R03)

3.3.6 Following on from the success of the Dementia4Schools pilot project a Dementia Resource Suite for Schools[5] has been developed based on tools and resources developed by pupils and teachers who took part in the project. The Suite can be used to support teachers to develop their own dementia awareness lessons and activities.

[5] http://www.hscpartnership.org.uk/policy-and-consultancy/our-current-projects/intergenerational-and-schools-project/dementia-for-schools-resource-suite/?preview=true

Case Study: Swanshurst School – Dementia4Schools Project

Three lesson plans (1 hour in duration) where developed which covered the following topics:-

- Understanding dementia
- Helping those living with dementia
- Meeting a person with dementia

The objectives were as follows:-

- Understanding dementia
  - To raise awareness of dementia
  - To develop knowledge and understanding about the types of dementia and its causes
  - To understand how the chances of getting dementia can be lessened e.g. living healthily
- Helping those living with dementia
  - Appreciate the experiences and difficulties of being a carer
  - Recognise the support available for a carer
  - Know the purpose of assistive technology and how it can support health problems
- Meeting a person with dementia
  - To be able to empathise with those with dementia and their carers
  - To appreciate that a diagnosis of dementia is not the end of the battle
  - To know how carers are supported and what can be done to help those with dementia and the support available for a carer

The lessons plans are simple to follow and can be easily adopted by other schools.

3.3.7 Members were told about another example of a good relationship and strong links between Lordswood School and the ExtraCare Hagley Road Retirement Village. Here the schoolchildren have been getting involved by producing a media CD for the village. They also went along to the launch of the facility and did some street dance which involved some of the residents. It then emerged that some of the students wanted to get involved in ballroom dancing so the residents offered to teach them.

3.4 Dementia Friends and Dementia-Friendly Communities

3.4.1 Dementia-Friendly Communities and the Dementia Friends Programme are important contributors in developing understanding and awareness, therefore reducing the stigma of dementia. The Dementia-Friendly Communities programme focuses on improving inclusion and quality of life for people living with dementia. In these communities, people will be aware of and understand more about dementia; people with dementia and their carers will be encouraged to seek help and

support; and people with dementia will feel included in their community, be more independent and have more choice and control over their lives. One way of developing dementia-friendly communities is to encourage people to become dementia friends.

3.4.2 The Dementia Friends programme is based on the provision of awareness raising sessions by volunteer Dementia Friends Champions. To become a Dementia Friends Champion, a person must attend a one day course which is delivered by the Alzheimer's Society. They are then encouraged to present one hour dementia awareness/Dementia Friends sessions both to their communities and in the workplace. Dementia awareness sessions are also available via the internet.

3.4.3 Members were told that part of the responsibility for all the organisations signed up to the Strategy is to encourage staff to sign up as Dementia Friends. Not just staff who work with older people but all staff. The Alzheimer's Society is running a national initiative to create a network of one million Dementia Friends across England by 2015. The number of people who have signed up to be Dementia Friends currently stands at 466,935[6].

3.4.4 All of the organisations that provided evidence to the committee had training programmes in place and many were also encouraging staff to undertake the Dementia Friends Programme. Other teaching methods also being used included e-learning packages and an accredited course at the University of Worcester.

3.4.5 The West Midlands Fire Service holds Dementia Friends training in its community fire stations and regularly encourages health partners and third sector organisations to go along and use the sessions to share information with the fire crews. In Birmingham there are plans to try and get a Dementia Champion in each one of the 15 stations city-wide.

3.4.6 Members also heard that the Alzheimer's Society, nationally, is working with the Local Government Association to produce some guidance for elected Members around what they need to know about dementia and some of the issues they may face particularly around councillor surgeries. Therefore, this provides a big opportunity for the City Council to support their members to learn more about that.

3.4.7 Dr Nicola Bradbury, Birmingham and Solihull Mental Health Foundation Trust, said that "all organisations should introduce a mandatory dementia awareness training alongside health and safety and fire training, to ensure you begin to build a base of people who have a basic understanding of dementia and then become, hopefully, more sensitive to dealing with people with dementia." (R04)

3.5 Birmingham Dementia Action Alliance

3.5.1 The City Council is in the process of joining the Birmingham Dementia Action Alliance. To become a member, organisations must sign up to the National Dementia Declaration and submit a short

[6] As at 21st October 2014. For current figure see https://www.dementiafriends.org.uk/

action plan setting out how they will work towards delivering the outcomes outlined in their declaration.

3.5.2 The City Council's draft plan outlines their commitment to making the city a place that is more friendly and accessible to people with dementia. To reflect dementia issues in all strategic planning activity. To provide dementia awareness training. To reflect an awareness of carer specific needs with regards to relatives or others with dementia in HR policies. Also, to encourage and influence partner organisations to sign up to the Dementia Action Alliance.

3.5.3 This is an opportunity for Birmingham to become a dementia-friendly city. It will not happen overnight. It is a gradual process and will take a number of years. It was recognised that making a city the size of Birmingham dementia-friendly is a huge task but there are structures in place at District level and it might be easier if we begin by creating dementia-friendly Districts. (R05)

3.6 Promoting Healthy Lifestyles

> "I think we are sleepwalking into a disaster with our unhealthy lifestyles. So many of us just take our health for granted and are just walking into a vascular disaster."
>
> Dr Andrew Coward
> Chair, Birmingham South Central CCG

3.6.1 A 5 year delay in the onset of dementia can result in a 49% reduction in projected dementia prevalence and reduce death directly attributable to dementia by 30%.[7] This is an extremely important statistic given that some dementias may be preventable or onset could be delayed if a healthy lifestyle is adopted.

3.6.2 A proportion of dementias are called 'vascular'. There are a number of conditions which can cause or increase damage to the vascular system including high blood pressure, heart problems, high cholesterol and diabetes. High levels of obesity and persistent physical inactivity need to be tackled to prevent more people developing these conditions and increasing their risk of vascular dementia. The increased presence of some of these risk factors for vascular dementia has meant that it is thought to be more common among Asian and Black Caribbean people than in the white population.

3.6.3 Members were also told that Korsakoff's syndrome is being seen more often. Korsakoff's syndrome is a brain disorder usually associated with heavy alcohol consumption over a long period. Whilst not a dementia, people with the syndrome do display many of the common symptoms of dementia. People with a long history of alcohol misuse may develop what is known as 'alcohol related dementia', or 'alcoholic dementia' the symptoms of which are broader and more

[7] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341

numerous than those of Korsakoff's syndrome, and are similar to those of Alzheimer's disease. In addition excessive drinking is a risk factor for other, more common, forms of dementia including vascular dementia and Alzheimer's disease. There are about 144,000 adults in Birmingham who have a significant drink problem. Due to relaxed attitudes towards alcohol now, more issues around alcohol and people experiencing dementia are expected to be seen in future generations.

3.6.4 All dementias are progressive and, at the present time, incurable but there is evidence that the risk of developing some dementias may be reduced by adopting a healthy lifestyle i.e. 5 portions of fruit/vegetables a day; regular exercise; not smoking; not drinking too much; and having enough sleep. Therefore, more needs to be done to send out clear messages to people in early adulthood that it is not just the heart that can be helped by adopting healthy lifestyles but also it can reduce the risk of developing dementia later on.

4 Recognition, Assessment and Diagnosis

4.1 Diagnosis the Gateway to Support

4.1.1 The Government has set a target to increase dementia diagnosis rates in England to 67% by March 2015. Recently published figures show that the number of patients with a recorded diagnosis has increased from 213,000 (40%) in 2006/7 to 344,000 (61%) in 2013/14. It has been acknowledged that this rise could be due to an aging population or partly due to increased case finding and improved recording of diagnosis.[8] Since 2006, the Quality Outcomes Framework (QOF) has required GPs to keep a register of people with a diagnosis of dementia among their practice list.

4.1.2 In Birmingham, diagnosis rates vary across the three Clinical Commissioning Groups (CCGs) ranging from 46% to 67% and between practices within CCGs. The higher rate was achieved by Birmingham South and Central CCG. All three Birmingham CCGs are working closely with surgeries that have low diagnosis rates to identify any anomalies in data collection and any other issues that are affecting the numbers with a diagnosis.

4.1.3 Members were told that, in the past, some GPs had been reluctant to diagnose a patient with dementia because they felt there was no point of investigating and identifying dementia when it is incurable. This position is now changing. In Birmingham, there has been a lot of work to assure GPs and primary care staff of the worth of a diagnosis as a gateway to support. GPs have been given information about the services that are available for people with dementia so that it may take away some of the negativity that may be associated with a diagnosis.

[8] Quarterly Outcomes Framework (QOF) Recorded Dementia Diagnosis, Provisional 2013/14 Data. Published by the Health and Social Care Information Centre, 30th July 2014.

4.1.4 Some other initiatives include commissioning NHS Health Checks to include dementia[9] and a GP Directly Enhanced Service for dementia which rewards GP practices for identifying patients known to be at risk of dementia and encouraging them to have an assessment.

4.1.5 Birmingham Community Healthcare Trust stated that, in terms of inpatient services in Community Hospitals, all patients go through a screening process and if there is a possibility of dementia, which had previously been undiagnosed, the course of action is a referral back through primary care to the GP. Very occasionally, a consultant, either a psychiatrist or geriatrician may make a diagnosis but, generally, it goes back to the GP for onward referral to Memory Assessment Services as appropriate. At the moment, there is no similar process for the patients they work with in the community. (R06)

4.1.6 The Department of Health introduced a Commissioning for Quality and Innovation (CQUIN) payment to incentivise NHS Trusts to screen for dementia in patients aged over 75 who are admitted to hospital in an emergency. Therefore, routine screening in acute and community hospitals is also contributing to improving diagnosis rates.

4.1.7 Members were also told about the Rapid-Assessment, Interface and Discharge (RAID) service that operates in the acute hospitals across Birmingham. This is a specialist multidisciplinary mental health service that works with people over the age of 16 who have a mental disorder or mental health care needs, including dementia. The service aims to ensure that these patients are able to access the services they need to either manage their condition away from the acute hospital or, if that is not possible, to ensure their mental health needs are managed during their hospital stay.

4.2 West Midlands Police

4.2.1 West Midlands Police are committed to improving the way they deal with vulnerable people. They are currently in the process of attempting to understand the demand that is driven through dementia. The recording of data within the police currently does not provide this in an easily accessible format. The force does not routinely collate data or information relating to a person's medical diagnosis but is committed to improving both data integrity and how the workforce deal with understanding and identifying dementia through a programme of work that commenced in September 2014 and which includes signing up to the Dementia Action Alliance and ongoing training to improve officers' knowledge and identification of vulnerability.

4.2.2 One of the challenges highlighted was how officers deal with a person with dementia who is detained in custody and the importance of health screening to obtain any information that may be of relevance to support the individual through the process. In other areas across the force there are two Custody Liaison and Diversion pilot schemes which have dedicated mental health specialists working to screen individuals and Birmingham is currently working on a bid for a similar

[9] The NHS Health Check programme invites everyone (every 5 years) between the ages of 40-74 to have a check to assess their risk of heart disease, stroke, kidney disease and diabetes.

project. It was also noted that all persons in custody who are deemed to be vulnerable should have access to an appropriate adult during the process.

4.2.3 A project called 'Street Triage' has also been piloted across Birmingham and Solihull. This involves a Paramedic, a Mental Health Nurse and a Police Officer to respond to persons with a mental health crisis. In the first six months, 1245 interventions have taken place both on the street and within individual's homes. This service provides front line staff with ready access to support and pathways which creates a holistic partnership methodology rather than a pure criminal justice approach.

4.2.4 In future, every Local Policing Unit will have a nominated lead for dementia. This will normally be the Crime and Vulnerability Officer, who will be tasked to link into local networks to engage with communities.

4.3 The Prison Service – HMP Birmingham

4.3.1 The healthcare provision at HMP Birmingham is provided in partnership between Birmingham and Solihull Mental Health Foundation Trust and Birmingham Community Healthcare Trust. In relation to dementia, the prison does not have a significant number of patients but given the aging prison population this is likely to change. When cases are identified referral is made to the Trust's Older Adult Services for assessment, advice and care planning.

4.3.2 One area identified for improvement is around training and awareness of dementia for healthcare staff and officers who work on the wing for older adults. Members heard that the Alzheimer's Society had previously provided some awareness sessions with staff and were hoping to develop this further.

4.3.3 Another issue was around the appropriate placement of prisoners with dementia when it impacts on their lives and ability to cope. The prison no longer has social work input which is a gap in terms of issues like this and how services related to dementia may be accessed if required. Members suggested that secure residential accommodation might be a more appropriate alternative for prisoners with dementia.

4.3.4 The Care Act 2014 sets out the responsibilities for care and support for adult prisoners and people residing in approved premises. Where it appears to the local authority that adults in prison or approved premises may have needs for care and support, the Authority will be under a duty to assess their needs; and may be under a duty to meet those needs.[10]

[10] The Care Act 2014, Report to Cabinet from the Strategic Director for People, 15 September 2014.

4.4 West Midlands Fire Service

4.4.1 The Fire Service makes referrals to key partners about any issues concerning vulnerable people they may come across whilst undertaking their duties. In response to a suggestion that a single telephone number for referrals from partners might be useful, Members were told about some ongoing work with Digital Birmingham to use an electronic hub. Initially, it is to be trialled in two City Council Letting Suites, to refer vulnerable people to various partners. This is still in the early stages and there have been difficulties with getting partner computer systems to interface with each other.

4.4.2 The Committee was advised that it would assist the West Midlands Fire Service if fire safety was considered in the first instance as part of any care package and if the Service was able to engage with GPs more proactively to appraise them of fire risks so that these could be considered early when dealing with vulnerable individuals.

4.5 Memory Assessment Service

4.5.1 The Birmingham and Solihull Mental Health Foundation Trust has recently introduced a single point of referral for all mental health referrals. Therefore, all referrals to the Memory Assessment Service (MAS) now go to a central team who do an initial triage and ensure people are offered the right services. This has removed the need for the referrer to identify the correct pathway and has led to an increased referral rate to the MAS.

4.5.2 Although the emphasis, both nationally and locally, is on an increase to diagnosis rates, it must be understood that a person also has the right not to know. Therefore, before proceeding with an assessment and diagnosis, every person is offered pre-assessment counselling. This gives them the opportunity to talk about the advantages and disadvantages of participating in a diagnostic assessment.

4.5.3 The MAS has seen an increasing number of people who have been told that they have Mild Cognitive Impairment (MCI) which means they do have changes in their thinking and it is often memory and sometimes language but there is no evidence that they have a progressive deteriorating condition. A proportion of people with MCI will go on to develop dementia but it is unclear, at that stage, which people. Therefore, a self-monitoring system has been set up so this group of people can check for any deterioration in their day-to-day functioning and can be fast-tracked back into the service.

4.5.4 The mental health service also referred to the challenge that different languages can present and how they are currently working with South Asian communities to deliver interventions and psycho-social groups in people's first language. They accepted that working with an interpreter was always going to be second best but there were very few tools or resources to access people's cognitive functioning that are validated in the person's first language.

4.5.5 Members were told that the target to increase the number of people who get a diagnosis in the city to 67% will prove a real challenge to the service. The number of referrals into the MAS is increasing and within the service there is work underway to ensure that resources are maximised while maintaining quality and ensuring people get their diagnosis in a timely way.

4.6 Anti-dementia Medication

4.6.1 In Birmingham, following a diagnosis of dementia some people (mainly those with Alzheimer's disease) will be able to receive what are informally called 'anti-dementia' drugs which may improve the quality of their life and slow the progress of the disease. These will be prescribed by a Community Mental Health Team to which they will be referred. There is work underway to explore the possibility of moving this into primary care services for most people, as support for people with dementia in primary care is developed. This would be in line with what happens in some other parts of the country, where there is a shared protocol with primary care. (R07)

4.7 Dementia Adviser/ Support Service

4.7.1 The Alzheimer's Society is commissioned to provide Dementia Adviser and Dementia Support Services. The Dementia Adviser team for Birmingham consists of 3 Dementia Advisers who provide advice and support for people who are diagnosed with dementia and 6 Dementia Support Workers who provide longer term case management and crisis support across the city. Following a diagnosis of dementia people are signposted to Dementia Advisers by the MAS. The focus of their work is predominantly on the person living with dementia to ensure they have an understanding of what dementia is and what services are available in the community, whilst also making sure they link in with other services. A diagnosis of dementia does not mean that people have any understanding of, or previous experience of, the whole range of support and welfare systems and benefits that may be available to them. So part of the role of these support services is to start giving people that information. Dementia Advisers predominantly work with people living with dementia and Dementia Support Workers work with both people with dementia and carers on a one-to-one basis to provide support and signposting to other services or, if necessary, the service will refer people to other services, such as statutory services like health and social care. These services work with people from the moment they are diagnosed, and their families, throughout their journey with dementia.

4.7.2 The Alzheimer's Society did highlight that there are capacity issues within the existing Dementia Adviser and Dementia Support services, and that as the rate of people receiving a formal diagnosis increases it is essential that there are adequate services to support them. However services are struggling to do this currently. In addition, there also needs to be a range of services to offer "choice" to meet the differing needs of the multi-cultural society of Birmingham.

4.7.3 Also indicated was the difficulty around sustainability. Contracts in the third sector are often just for 1-2 years which can make planning, recruitment and retention of staff problematic. It can take a while for a service to get established and then all too quickly the funding comes to an end.

5 Living Well with Dementia

5.1 Primary Health Care Services

5.1.1 Members were keen to pursue how primary care services are being delivered to people who are developing or showing signs of dementia. In particular, opticians, audiologists and dentists because sensory loss and pain, if unaddressed, may also lead to challenging behaviour at an earlier stage than might otherwise be the case.

5.1.2 There was an acknowledgement of the key role of the GP in supporting people with dementia to live well as they may be the one constant in the life of the person with dementia or their carer and their link to a range of other primary and secondary care services.

5.1.3 ExtraCare Housing employ a Wellbeing Adviser in each of their villages who will ensure that all of those primary care services are either provided on site or available nearby. They enable individuals to access those services after identifying concerns or issues through a Wellbeing Assessment. The Wellbeing Advisers are very proactive in getting opticians and dentists to provide services within the village for residents. This is especially helpful for residents who have more advanced dementia because they do not have to go out to a strange place and meet unfamiliar people.

5.1.4 Unfortunately, the inquiry received little evidence on the topic of wider healthcare services from Birmingham Community Healthcare but they did recognise that certainly as part of the pathway it was an area that needed to be addressed.

5.1.5 The Alzheimer's Society suggested that primary care services should be encouraged to sign up to the Dementia Action Alliance, and should focus on:

- Dementia training for clinicians appropriate to role
- Awareness training for support staff, such as receptionists, who need to be aware about potential patients with dementia and how to support them
- Review their premises to ensure they are a 'dementia-friendly environment', particularly around clear signage.

5.2 Fire Safety

5.2.1 Members were told that the highest number of fire deaths recorded in England was 1,096 in 1979. Through the 1980s and 90s there was a general downward trend. In 2003, the Government pump

primed all Fire Services across the country to introduce free Home Fire Safety Checks and fit smoke alarms. By 2012-13 the number of fire fatalities in England was down to 271. In 2013, there were 40 fatal and serious injuries in the West Midlands. Of those, 15% (6) had a known diagnosis of dementia and 35% (14) were in receipt of a care package. Therefore, the number of fatalities in the West Midlands is quite small but the number of people dying with a diagnosis of dementia is significant.

5.2.2 The West Midlands Fire Service has signed up to the Dementia Action Alliance and produced an Action Plan that sets out a number of objectives for increasing fire safety in the homes of vulnerable people. One of their main aims is to identify vulnerable people for home safety assessments at the earliest opportunity. Ideally, this would mean upon diagnosis.

5.2.3 One example was about a piece of work with GP surgeries in Solihull to identify vulnerable or high risk patients e.g. smokers and signposting them through for a referral to the Fire Service. This is something that the Fire Service is keen to do in Birmingham. There is also ongoing engagement with the Memory Assessment Service and hospital teams to gain referrals.

5.2.4 Another suggestion is that fire safety must be considered as part of the whole care package. The fire risk assessment would form part of the care package and bespoke interventions can be put in place at the earliest opportunity. This might not only be assistive technology e.g. linked smoke alarms but also fire retardant equipment. (R08)

5.3 Day Services

5.3.1 Age Concern Birmingham run six centres across the city. Three are specialist dementia service centres but people with dementia may attend any of the six centres, usually through choice because of geographical location, or in order to maintain someone who is developing dementia in an environment they know. At the moment, all the services at the centres are up to full capacity and there is a waiting list. In the short term, people are signposted to other services that are considered suitable to meet their needs. The services are funded and subsidised and people pay a daily fee to attend. Attendance at the centre is offered on a session basis. So if somebody only attends for a morning, that gives the opportunity for that place to be filled in the afternoon. It is possible to accommodate around 22 people at each session with 3 staff on duty and a Manager who works across 3 different centres.

5.3.2 The activities and sessions are varied. There are still a lot of people who want to play bingo and board games but there are also more people accessing the service who are experiencing dementia at a younger age and they want completely different activities. Therefore, activities are constantly being reviewed and developed to ensure that they are stimulating and meeting the needs of the clients.

5.3.3 One activity they were particularly keen on developing was outreach work in the community. Helping people to get out and about in the community and providing one-to-one support to give

them the confidence to be able to carry out routine tasks. This would be based on a befriending service model.

5.3.4 Age Concern Birmingham echoed the sentiments of the Alzheimer's Society in stating that one of the huge barriers is that funding is usually only offered on a 12 month contract which is a real concern in terms of retaining staff. Staff retention in dementia services is so important in order to continue to offer a quality service.

5.4 Dementia/Activity Cafes

5.4.1 The City Council commissions, through the Third Sector Prospectus, Activity Groups and Dementia Cafes for Birmingham. There are 5 Dementia Cafes each month in locations across Birmingham serving up to 100 people per month. Although there are also other informal arrangements which provide activities for people with dementia, access to services is a problem. Neither activity nor dementia cafes are actually cafes in the normal sense of the word, but places where people with dementia and carers can meet other people and enjoy activities together. One of the things that was established many years ago is that a diagnosis of dementia often, unfortunately, brings with it isolation. People shut themselves away or their social circle reduces. Additionally people find it difficult to find out about local activities they might join if they or their partner has dementia.

5.4.2 Activity Cafes (previously called Memory Cafes) are aimed at people in the earlier stages of dementia and are just for people living with dementia. As a rough rule of thumb, two of the criteria for attending those are that the person has a diagnosis of dementia and they do not require the provision of transport and can make their own way there. The purpose of those groups is so people living with dementia can get 'peer' support from each other. Speakers come in to talk about various subjects. But the whole purpose of those groups is that they are actually organised and run by people living with dementia themselves. There are members of staff there to orchestrate things and to ensure that the environment is safe but what is done in those environments is led by the people living with dementia who attend them.

5.4.3 Dementia Cafes are aimed at people later in their dementia and provide a place where they, their family and their carers (if they have one) can meet on a regular basis, socialise and make friendships and receive information. The Dementia Cafes run activities which are fun that can involve singing, artwork or music as well as external presentations about things which may not be directly about dementia but are of interest to attendees. For instance, the Fire Service are invited once a year to give a talk on fire safety in the home because they identify that in terms of fire hazards, the fire service consider people living with dementia and households that have people living with dementia in them, to be particularly risky. The welfare benefits agencies are also invited, once a year, to talk about any changes in benefits. In addition, a Dementia Support Worker is always present to offer one-to-one support and advice.

5.4.4 Members were told that the Activity and Dementia Cafes are more likely to be held in community centres and church buildings rather than a Café. In Birmingham, there are 3 in Birmingham's

Specialist Care Centres as well as 1 in a church hall and 1 in Waterloo Housing sheltered housing scheme. It was suggested that perhaps other locations could be considered e.g. a library. Members were informed that both the Birmingham Museum and Art Gallery and the Library of Birmingham were both interested in getting involved with some work around dementia.

5.4.5 The Alzheimer's Society works closely with community organisations to ensure that activities are culturally appropriate to meet the needs of each customer group. (R09)

5.5 Singing for the Brain

5.5.1 Singing for the brain is essentially using music and singing to get people socialising and using and maintaining the best of the abilities they have. It is not only a fun and enjoyable activity for both people with dementia and their carers but stimulates the brain into remembering music and songs.

5.5.2 These activities are held twice a month in 2 of the specialist care centres.

5.6 Growing Older with Learning Disabilities and Dementia (GOLDD)

5.6.1 The name Growing Older with Learning Disabilities and Dementia (GOLDD) is used in Birmingham to refer to both a sub group of the Learning Disability Partnership Board and day care provision for people with learning disabilities, mental health and dementia.

5.6.2 The sub group was set up about 10 years ago. It was tasked with looking at how the needs of older people with learning disabilities and people with learning disabilities and early onset dementia could be best met across Birmingham and, in particular, looking at routes of communication, information, so that service users and carers could make effective choices, but also better partnership working with all the agencies that were involved with peoples care.

5.6.3 GOLDD day care provides day care options for individuals with learning disabilities and dementia. The day care environments that they are offered fit with where people are at in terms of both their age and needs of somebody with learning disabilities and dementia, as their needs may be very different from those of older adults with dementia.

5.6.4 Within Birmingham Community Healthcare there is an adult learning disability healthcare team and with them GOLDD is developing a care pathway from point of recognition of dementia through to end of life that ensures that there is a prompt assessment and diagnosis and identification of support and care planning that is needed for adults with learning disabilities and their carers.

5.6.5 Birmingham Community Healthcare also links in with other agencies e.g. Midlands Mencap who provide family carer support because if the person who has a learning disability also has elderly parents they may need a different level of support so it is about bringing in agencies in an appropriate way. As a community service, initiatives and interventions can be delivered within the home to enable individuals to continue living within that environment and it is usually as a result of

a significant deterioration in physical health that a person would be moved to more appropriate accommodation to support their care needs.

5.6.6 In response to an issue that was raised concerning the amount of support provided for people who have a dual diagnosis of dementia and a learning disability, Members were told that the biggest challenge for GOLDD was matching service provision to what individuals and carers need. The rate at which dementia progresses for somebody with a learning disability is much more rapid than it is in the general population. In the general population from the point of recognition of dementia, through referral, diagnosis to the end of life can take up to 20 years, however, in the learning disability population, particularly in those individuals with Down's syndrome, this could be a lot less. So what often happens is that the processes, whether they are financial or in terms of the care planning in particular, may not respond to the level of progression that the person is actually presenting with and this has caused a delay. (R10)

6 Accommodation Options

6.1 Independent Living

6.1.1 The ExtraCare Charitable Trust provides housing, care and support for older people, pioneering new ways of helping people live well in later life.[11]

6.1.2 ExtraCare villages (there are currently three in Birmingham - New Oscott, Hagley Road and Pannel Croft in Newtown - with a fourth due to open in 2015 in Bournville) are retirement communities offering residents a wide range of sociable facilities and looking after people who need care.

6.1.3 Members heard about the specific service which ExtraCare has developed through its Enriched Opportunities Programme (EOP), which began as a research project with the University of Bradford. This service is for residents experiencing dementia, using specialist team members – "locksmiths" – who unpick impairments and unlock a person's potential.

6.1.4 The role of the locksmith is to work with a resident to understand how that person experiences their dementia rather than trying to tackle the word dementia itself. It is a person centred approach. Focussing on the person rather than the condition. It is about trying to understand what the person is experiencing and being empathetic to that and putting interventions in place that can help someone to cope with their condition.

6.1.5 Individuals are supported for as long as possible with a range of on-site services, including a well-being service, alternative therapies to aid sleep and alarmed doors to alert staff if residents go "wandering".

[11] ExtraCare Contribution for Birmingham City Council Scrutiny inquiry – Dementia Services

6.1.6 The outcomes of the EOP research show that residents supported by a locksmith are 50% less likely to move out of ExtraCare into a care home and spend less time in hospital as an in-patient.[12]

6.1.7 ExtraCare told Members that this could be further enhanced through the provision of a community nursing service in people's homes and also the expansion of the locksmith service in the community and this is something they are keen to explore further with a view to these services being in Birmingham. Similar services have been introduced in other villages across the country and have been instrumental in preventing hospital admissions and enabling people to remain in their own homes instead of being moved into residential care. (R11)

6.2 Care Homes

6.2.1 Members were told that Birmingham and Solihull Mental Health Foundation Trust have recently launched a Care Home Liaison Service which will be working alongside primary care and community health services to try to support nursing and residential homes to manage older people with dementia (and other mental health issues) when their normal place of residence is in a care or nursing home.

6.2.2 The City Council recognises that there is a need to develop bed stock. Also, to up-skill care home workers to be able to support people whose dementia worsens rather than moving them on to another care home to meet those needs. There is ongoing training for care home workers to be able to deal with those more complex needs. There is also a need to make sure that care homes, through the framework agreement, have clear guidance in the contract about what the expectations are of them.

7 Support for Carers

"As John said, it has been a very informative two days, if not mind blowing to try and take all in. But as John hasn't explained, he actually was the one who went to his GP and had his dementia diagnosed. From there he went for some tests and had a brain scan and then we were referred to the Juniper Centre. John has taken part in lots of activities that have been offered to him but, obviously, as the City Council is short of money; a lot of them are folding, which is an awful pity, especially places like the Memory Clinics. John isn't a person that talks much but he certainly talks there. I don't go at all. I have 5 hours off. But he has learnt and mixed with lots of people in the same position. We go to 'Singing for the Brain' at Kenrick Care Centre who does offer an awful lot of information. My only thing I would like to say is, as a carer, I don't know of anything that tells me how to be a carer. It was just thrust on me and as far as I'm concerned I'm

[12] 2009 Bradford Dementia Group Report

John's wife and, therefore, I should care for him. But you need support and I get support through the other wives from the different cafes that John goes to. So that's one of the ways we support one another but I haven't been to any formal meetings for carers. But, as I say, we all battle on. We don't have a bad life. It's a bit restrictive at times but we get on don't we and it's John's attitude, as well, which has helped. He will do what he can and that's what we have to do."

Mrs Gill Collins, talking about how she and her husband, John, live with dementia

7.1 Carers Assessments

"… I don't know of anything that tells me how to be a carer".

7.1.1 The Care Act 2014 has introduced new legislation that requires a local authority to provide a carers assessment on needs that a carer may have for support and the sustainability of providing that support – whether currently or in the future. The assessment will take into consideration the day-to-day life outcomes that the carer wishes to achieve e.g. whether the carer is able or willing to carry on caring, whether they work or want to work and whether they want to study etc.

7.1.2 When the assessment is complete the local authority must decide whether the carer's needs are eligible for support. The Act also puts in place a national eligibility threshold for carers. Whether the carers needs meet the criteria or not they must still be provided with a written record of advice on what could be done to reduce, prevent and meet needs.

7.1.3 The local authority must then carry out a financial assessment to decide if the carer can afford to pay. If a carer has eligible needs but also has the means to pay then the local authority can charge for the provision of services.

7.1.4 Where the local authority has a duty to meet a carer's needs they must prepare a support plan which sets out how those needs will be met. As part of the support plan, a carer should also receive a statement which sets out the amount the local authority will pay and the amount the carer will pay (if any) to meet those needs. This is called a personal budget. The carer can then request that the personal budget is taken in the form of a direct payment which will give them control over how their support is provided.

7.2 Respite

7.2.1 Respite care is short-term care used as a temporary alternative to a person's usual care arrangements. Caring for someone can be the most rewarding and satisfying thing a person can do. It can also be very tiring and lead to social isolation. Access to respite care and short breaks is imperative for a carer's own health and well-being.

7.2.2 The My Care in Birmingham website (www.mycareinbirmingham.org.uk) provides the major tool by which people in the city can access information about respite and short breaks provision. Carers who meet the eligibility criteria for a personal budget may use that to purchase respite care.

7.2.3 Members heard that there is a huge challenge around providing adequate respite care and support for carers. It was suggested that there needs to be some work with regards to developing a market for care homes to provide respite care. The aim should be to make it possible to have beds that can be provided either in an emergency or for planned respite care. There is also a need to look at not being bound to a model of respite care that is based on bedded services. A lot of carers find that having the use of Activity Cafes or other services during the day, where they know their loved ones are looked after and they can have some time to themselves is crucial to their own wellbeing. Another option is developing models around domiciliary care whereby people can be looked after in their own home. (R12)

7.3 Admiral Nurses

7.3.1 Admiral Nurses are mental health nurses specialising in dementia. They primarily focus on supporting carers and families of those affected by dementia with a particular focus on those with complex needs, providing emotional and psychological support through periods of transition.

7.3.2 Referrals to the Admiral Nurse Service are made through the community mental health service by a number of different professionals such as Psychiatrist, Psychologist, Community Mental Health Nurse senior practitioner or Occupational Therapist. The carer needs to be in agreement with the referral and be supporting a person with dementia or likely to receive a diagnosis at the time of referral. Carers can also contact the service themselves.

7.3.3 Admiral Nurses offer time limited interventions and support to carers along their journey. After discharge, carers are given information on sources of support and can re-contact the Admiral Nurse Service if necessary.

7.3.4 There are currently 2 Admiral Nurses for the whole of Birmingham and Members questioned whether there were any plans to increase capacity within the service. They were told that Admiral Nurses are part of the solution. They are within the pathway that people should have access to, but a nursing role might not necessarily be appropriate for everyone. It was more about developing a range of support to meet peoples' needs, including the needs of carers.

7.4 Training and Education

7.4.1 During evidence gathering, one area that was specifically identified for further consideration was that of training, support and education for carers. It is widely recognised that a person very often takes on the role of a carer without ever receiving any prior training or information and can find themselves 'muddling through'. (R13)

7.4.2 The City Council commissions carers services through fixed term contracts and the tender has recently been awarded to the Forward Carers consortium. The consortium holds the overall contract for the delivery of carers support services and sub-contracts out a range of required services to members. Carers can access information and advice through the Carers Hub. The services currently available are:-

- Information and advice
- Signposting or referral to support services
- Access to training
- Emergency respite support
- Day opportunities
- Access to short breaks for disabled children
- Referral and access to support for young carers
- Carer support groups
- E-news services

7.4.3 The Carers Emergency Response Service (CERS) is also run by the consortium. This is a free backup service to help carers to plan for possible emergencies and to assure carers that the person they care for is given support in case of an emergency. The service operates 24 hours a day, 7 days a week and can provide support for up to 48 hours (72 hours on Bank Holidays) after which, if necessary, long term care can be arranged. Carers must be registered with the service to receive support.

7.4.4 They also offer two free training courses on *Moving & Handling of People* and *Moving, Handling and Hoisting People*.

7.4.5 The Growing Older with Learning Disabilities and Dementia service informed the inquiry that they had rolled out an e-learning training programme, predominantly for organisations in Birmingham but also for parents, which provides information about people who have a learning disability and early onset dementia.

7.4.6 The Alzheimer's Society indicated that they run Carer Education Programmes across the country but this service is not, at present, commissioned in Birmingham.

7.5 Dementia Information and Support for Carers (DISC)

7.5.1 DISC was established in 2003 and funded through the City Council and the NHS. The service supports carers of people living with dementia who reside within the old Heart of Birmingham PCT catchment area (mainly west Birmingham). It provides a person centred and holistic approach to support for the carer from point of diagnosis to the end of their 'journey'. Some of the services provided include:

- One to one support from a Specialist Dementia Adviser
- Coping strategies and stress management
- Training in the home e.g. moving and handling, falls prevention and first aid
- Respite care services
- Support programmes and activities

7.5.2 A carer's role may change if they suffer bereavement or the person they care for moves into residential or nursing care. The DISC model enables these carers to continue receiving support in order to continue with existing social networks and thus effectively maintain their health and well-being. (R13)

7.6 Bereavement

7.6.1 The sensitive subject of bereavement was raised when receiving evidence from Birmingham Community Healthcare. A member said that there was a perception from carers that support stops when the person with dementia dies and many felt somewhat exposed and may not necessarily know who to contact. The inquiry was informed that the Carer Support Team would offer one appointment after someone with dementia had died and after that would signpost a carer to other agencies. It was not possible to support people for longer because of a capacity issue i.e. the team consists of 3 people. They acknowledged that the process does not end for somebody when a loved one has died and it needed to be a little longer. Therefore, they would investigate the possibility of linking the Carer Support Team with the Admiral Nurses to see if there was a way of making a referral to them, but this may only be feasible if there is an increase in the number of Admiral Nurses.

7.6.2 It was also suggested that rather than signpost carers to other agencies it would be more beneficial for the Carer Support Team to make a direct referral to the agency and ask them to contact the carer.

8 Acute Hospital Care

8.1 Hospital care

There will always be occasions where people with dementia will need to be admitted to an acute hospital either in a planned way or as an emergency admission. But there is evidence that the hospital environment can increase the person's confusion and impact on their physical and mental health in adverse ways. Hospitals locally are looking at ways they can improve their care of people with dementia.

8.2 Heart of England NHS Foundation Trust

8.2.1 Members were told in evidence from Heart of England NHS Foundation Trust (HEFT) that in treating specific conditions the Trust recognised that they needed to have the capacity and competencies to cater for those patients who also have dementia. Members were advised that the Trust had improved in terms of reducing the number of times a patient was likely to be moved from one hospital ward to another but it was acknowledged that in some cases there was poor communication in relation to moves/discharges of dementia patients and that sometimes a telephone conversation could help to smooth the process as opposed to placing too much reliance on electronic methods of communication.

8.2.2 The unfortunate incidences reported in the recent Care Quality Commission inspection report of Good Hope Hospital where beds of patients with dementia were moved into the corridors overnight to enable staff to observe them were referred to. The Trust acknowledged that this sacrificed the dignity of service users for safety reasons and had occurred due to staff shortages but Members were assured that this no longer happens.

8.2.3 It was reported that most hospital wards have a Dementia Champion and that the number of staff who had received training is increasing, with priority for dementia training being given to A&E units.

8.3 Birmingham City Hospital

8.3.1 The evidence from Birmingham City Hospital (BCH) reiterated the point previously made by HEFT that it is inappropriate for patients to be admitted to hospital just with dementia and that patients with dementia are best kept away from a hospital environment unless admission is the best way for them to receive treatment. Members were told that on average every ward has between 2-4 patients with dementia at any single time.

8.3.2 BCH recognised the importance of working with social services and social care agencies to prevent hospital admissions. They have Dementia Champions working in the A&E department, where they use a checklist to assess patients and some areas of the A&E department are dementia-friendly. Members were told that once patients with dementia are admitted, there are often delays and problems getting patients discharged from hospital which not infrequently results in delayed transfers of care.

8.3.3 It was acknowledged that there is a need to work and to interact better and build better relationships with the families of patients with dementia to ensure that staff have all the information available that they need to deal with the patient in the most appropriate way.

9 Conclusion

9.1.1 The inquiry was set up to look at what was being done city-wide to support people with dementia and their carers. Members have heard about the good work being carried out by Dementia Advisers and Support Workers, carers' services and activities like the Dementia Cafes and Day Services, but there simply aren't enough.

9.1.2 There also needs to be equitable access to services across the city. Traditionally, commissioning has been quite fragmented. Different organisations commissioning different things. This has led to a patchwork approach across the city whereby there are different services you can access depending on your postcode. Therefore, a more consistent approach needs to be taken city-wide.

9.1.3 There are currently an estimated 14,000 people living with dementia in Birmingham and if all of those people requested a service it would be impossible. As the number of people diagnosed increases so does their expectation of services that are available to support them. The City needs to meet those expectations in a sustainable and financially viable way. There is no additional money to do this. Consequently, the funding for dementia services needs to be pooled into a single budget and reprioritised towards early intervention services to increase their capacity in order to meet demand and to reduce unnecessary and costly hospital and residential care episodes for people with dementia.

Appendix A: Types of Dementia[13]

Alzheimer's disease

Inside the brain

Abnormal material called 'plaques' and 'tangles' builds up in the brain. This disrupts how nerve cells work and communicate with each other, and the affected nerve cells eventually die.

There is also a shortage of some important chemicals in the brain when someone has Alzheimer's disease. Reduced levels of these chemical mean messages don't travel around the brain as well as they should.

Early symptoms

Alzheimer's disease usually begins gradually with mild memory loss. This is because the first changes in the brain are often in the part that controls memory and learning. A person with Alzheimer's disease might forget people's names or where they have put things. They might also have problems with language, such as finding the right word for something.

Other early symptoms include feeling confused or finding it hard to follow what is being said. Some everyday activities might seem challenging, for example, someone might get muddled checking change at the shops. Some people also become more withdrawn and experience mood swings.

Vascular dementia

Inside the brain

The word 'vascular' relates to blood vessels. Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain (called subcortical vascular dementia).

Strokes happen when a blood clot blocks the flow of blood to part of the brain, or when a blood vessel bursts in the brain. Vascular dementia sometimes follows a large stroke. More often though, it comes after a number of small strokes (called multi-infarct dementia).

[13] The dementia guide published by the Alzheimer's Society.

Subcortical vascular dementia – when there is poor blood flow to the deep parts of the brain – is often due to narrowing of the arteries supplying the brain.

Early symptoms

If someone has had a large stroke, symptoms of vascular dementia can begin suddenly. Symptoms can then remain stable or even get a little bit better over time in the early stages. If the person has another stroke, these symptoms might get worse again.

If someone has a series of small strokes, their symptoms may remain stable for a while and then get worse in stages (rather than have a gradual decline). With subcortical vascular dementia, symptoms may get worse gradually or in stages.

The symptoms of vascular dementia will depend on which part of the brain has been damaged. Some people might have physical weakness on one side due to a stroke. Other changes include difficulty thinking quickly or concentrating and there might be short periods when they get very confused. Some people might also become depressed or anxious. Memory loss isn't always a common early symptom.

Mixed dementia

It's possible for someone to have more than one form of dementia – called mixed dementia. The most common combination is Alzheimer's disease with vascular dementia. It's also possible to have a combination of Alzheimer's disease and dementia with Lewy bodies.

Dementia with Lewy bodies

Inside the brain

This form of dementia gets its name from tiny abnormal structures called Lewy bodies that develop inside brain cells. Similar to the plaques and tangles of Alzheimer's disease, these structures disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die.

Lewy bodies are also found in people with Parkinson's disease. One third of people who have Parkinson's disease eventually develop dementia (called Parkinson's disease dementia).

Early symptoms

People who have dementia with Lewy bodies might find it hard to remain alert and have difficulties planning ahead, reasoning and solving problems. These symptoms typically vary a lot from one day to the next.

People might have problems with how they see things. For example, it might be hard to judge distances or they might mistake one object for another. Many people see things that aren't really there (visual hallucinations). Disturbed sleep patterns are also common.

However, if someone has dementia with Lewy bodies, their memory will often be affected less than someone with Alzheimer's disease.

Many people with dementia with Lewy bodies also develop symptoms like those in Parkinson's disease, including shaking (especially in the hands), stiffness and difficulty moving around.

Frontotemporal dementia

Inside the brain

The term frontotemporal dementia covers a range of conditions. It was originally called Pick's disease and this term is sometimes still used. Frontotemporal dementia mostly affects people in their 40s, 50s and 60s (younger than most people who get Alzheimer's disease or vascular dementia). It's caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills.

In most cases, abnormal proteins collect within brain cells in these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

Early symptoms

There are three different forms of frontotemporal dementia – behavioural variant, semantic dementia and progressive non-fluent aphasia.

With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. The person might seem withdrawn or not to care as much about other people. They might make socially inappropriate remarks. They may also become obsessive or impulsive, for example developing fads for unusual foods.

When someone has semantic dementia their speech is usually fluent but they lose the meaning or understanding of some words. Language is also affected in progressive non-fluent aphasia. Speech is often slow and requires a lot of effort.

People in the early stages of frontotemporal dementia often don't experience day-to-day memory loss.

Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are rare, and together account for only about 5% of all people with dementia. However, they are more common in younger people with dementia.

These diseases include:

- Corticobasal degeneration.
- Creutzfeldt-Jakob disease.
- HIV-related cognitive impairment.

- Huntington's disease.
- Alcohol-related brain damage and Korsakoff's syndrome.
- Multiple sclerosis.
- Niermann-Pick disease type C.
- Normal pressure hydrocephalus.
- Progressive supranuclear palsy.

Appendix B: Contributors

The Committee would like to thank all those who have taken the time to contribute to this inquiry.

Witnesses	
Presenter	**Organisation**
Angela Bradford	Commissioning and Healthy Lifestyle Director, ExtraCare Charitable Trust
Becky Smith	Director of Operations, Age Concern Birmingham
Clive Robinson	Community Risk Reduction Officer, West Midlands Fire Service
Cllr John Cotton	Cabinet Member for Health and Wellbeing
Derek Tobin	Head of Healthcare, HMP Birmingham
Douglas Smith	Teacher, Swanshurst School
Dr Andrew Coward	Chair, Birmingham South Central Clinical Commissioning Group
Dr Liz England	Clinical Lead for West Birmingham, Sandwell and West Birmingham Clinical Commissioning Group
Dr Martin Sandler	Consultant Physician and Clinical Director for Elderly Care, Heart of Birmingham NHS Foundation Trust
Dr Nicola Bradbury	Clinical Director, Birmingham and Solihull Mental Health NHS Foundation Trust
Dr Patrick Brooke	Chief Officer, Solihull Clinical Commissioning Group
Dr Paul Turner	Mental Health GP Lead, Birmingham South Central Clinical Commissioning Group
Frances Clarke	Associate Director of Nursing, Birmingham Community Healthcare NHS Trust
Helen Jenkinson	Group Director of Nursing for Medicine and Emergency Care, Birmingham City Hospital
Janice Connolly	Operations Manager, Alzheimer's Society
Jeevan Jones	Dementia Action Alliance Coordinator – West Midlands, Alzheimer's Society
John Short	Chief Executive Officer, Birmingham and Solihull Mental Health NHS Foundation Trust
Mary Latter	Joint Commissioning Mental Health Manager (Dementia), Joint Commissioning Team, NHS
Melanie Cleary	Clinical Team Leader, Rapid Response Mental Health and RA Lead, Birmingham Community Healthcare NHS Trust
Michael Spellman	Locksmith, ExtraCare Charitable Trust
Mr Emerson Jones	Carer for his wife
Mr John Collins	A gentleman who has dementia.
Mrs Gill Collins	Carer for her husband.
Mrs Jill Jukes	Carer for her daughter.
Sean Russell	Chief Inspector, Mental Health Lead for West Midlands Police
Shirley Hall	Lead for Dementia Service, ExtraCare Charitable Trust
Steve Hayward	Services Manager, Alzheimer's Society
Sue Brookin	Partnership Manager (Birmingham), West Midlands Fire Service
Sunny Kalsy	Interim Head of Psychology Services and Chair of GOLDD (Growing Older with Learning Disabilities and Dementia), Birmingham Community Healthcare NHS Trust
Tariq Somra	Service Manager, D.I.S.C. (Dementia Information and Support for Carers)

Member Visits
Organisation
Dementia Café at Ann Marie Howes Care Centre - scheduled
Swanshurst School