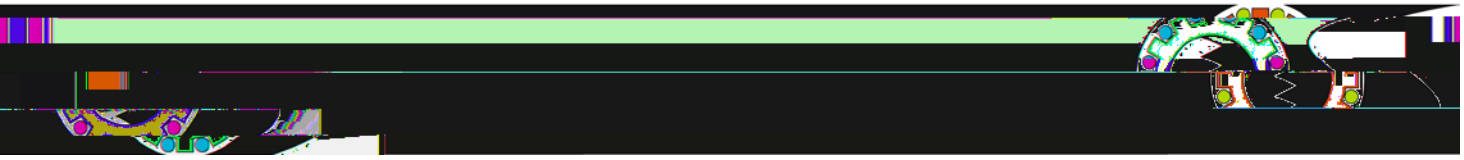
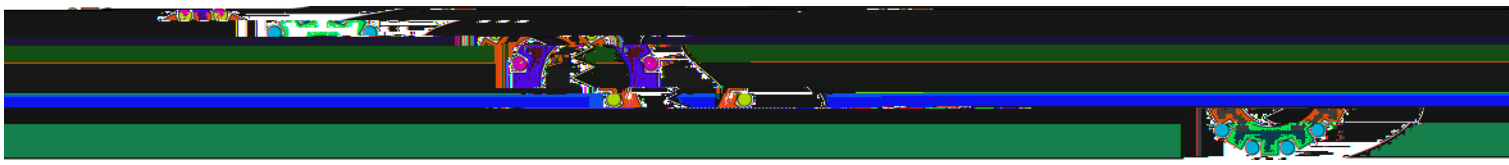


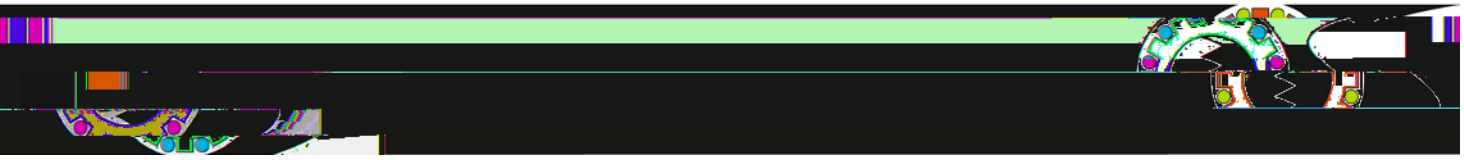
By Councillor Susan Bar nett

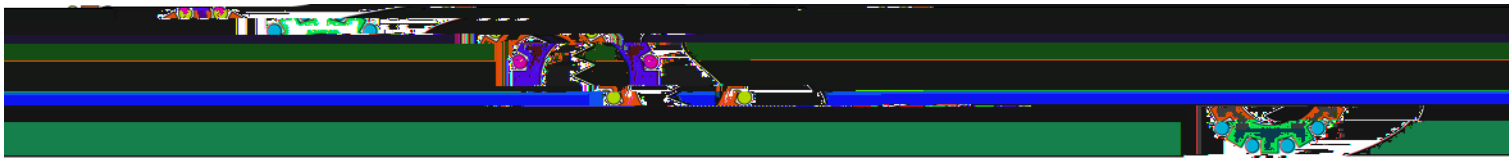
Chair of the Health and Social Care Overview & Scrutiny Committee

I would like to thank members of the Health and Social Care Overview & Scrutiny Committee together with



	That the City Council should appoint a Lead Member for Dementia with specific responsibility to ensure high-quality dementia services.	Cabinet Member,	





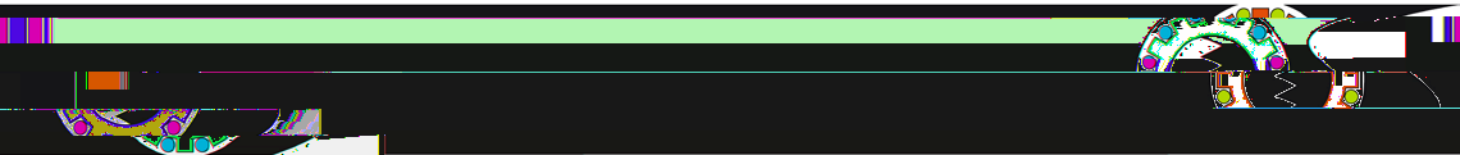
1.1.1 In May 2014, a 3-year joint Dementia Strategy for Birmingham and Solihull was published. It was developed around 5 themes that describe the dementia pathway of someone who has dementia and their carer and was based upon the experiences of people with dementia and carers, in Birmingham and Solihull,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

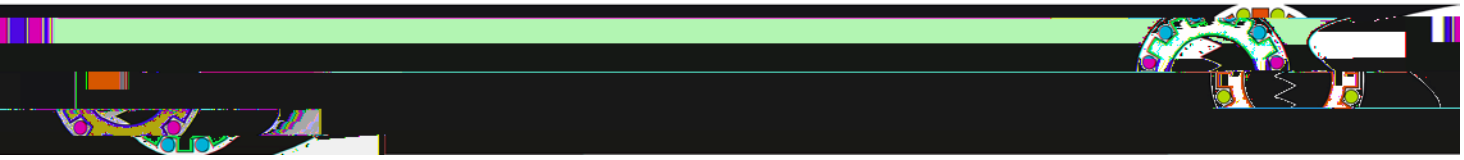
1.1.3 The key question for this inquiry was:-

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



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.

1.4.1 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 ( )1(f



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).

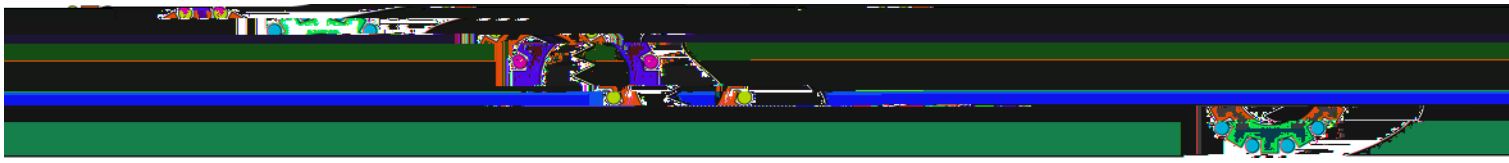
2.3.1 In February 2009, the Department of Health published 'Living Well with Dementia: A National Dementia Strategy' which provided a strategic framework that identified 17 key objectives for improving the quality of dementia services and promote greater understanding of the causes of dementia.

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



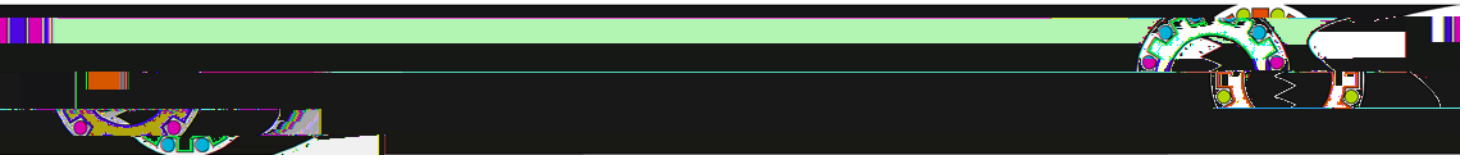
2.6.1 There are an estimated 14,000 people in Birmingham who have dementia and we know from

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 o f 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



3.3.1 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.

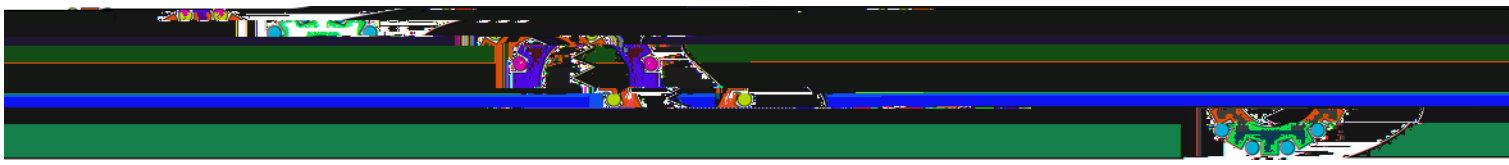
3.3.2 The topic formed part of the Personal, Social and Health Education (PSHE) programme of study and was delivered over three lessons. Year 9 students were chosen as the target group because of their maturity compared to Years 7 and 8, and the fact they would not be involved in external examinations.

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.

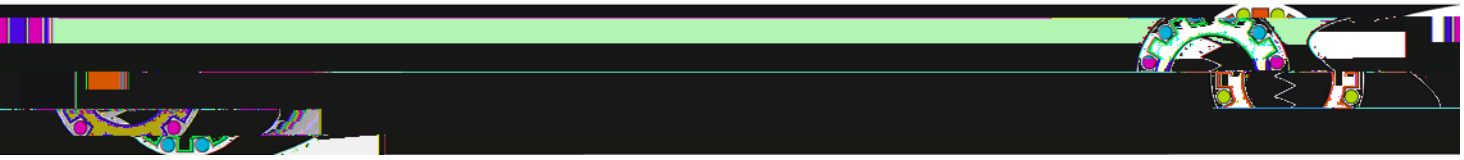
3.3.4 Some committee members took the opportunity to visit Swanshurst School and met with the Lead Teacher, Douglas Smith, and a group of pupils who had previously taken part in the lessons. It was evident that the work had made a lasting impression as the students were very knowledgeable and enthusiastic 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."

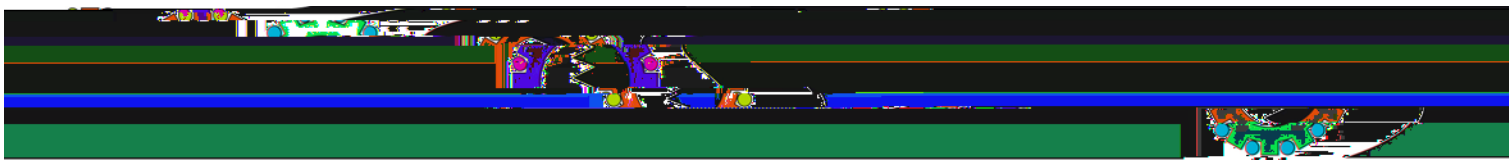
3.3.5 The students felt that dementia awareness lessons should be rolled out not just across schools but also to other adults so that awareness of dementia is more broadly spread and people know what services might be in place, and what kind of things to ask for if a loved one does receive a diagnosis.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



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

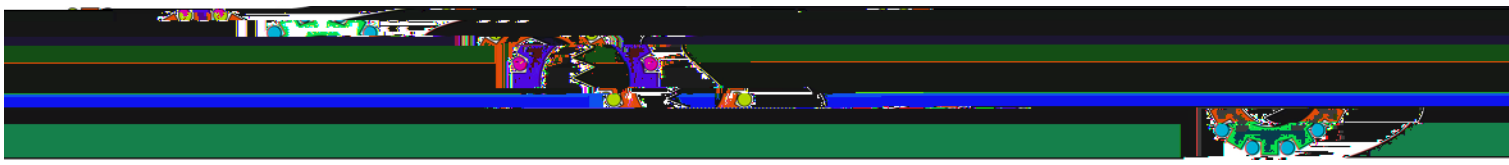




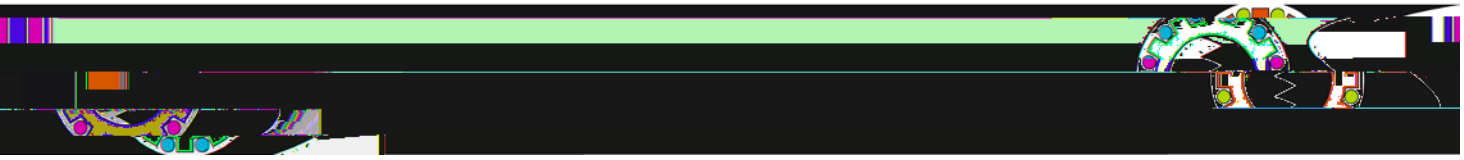
action plan setting out how they will work towards delivering the outcomes outlined in their declaration.

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)



4.1.4 Some other initiatives include commissioning NHS Health Checks to include dementia[9] and a GP Directly Enhanced Service for dem



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.

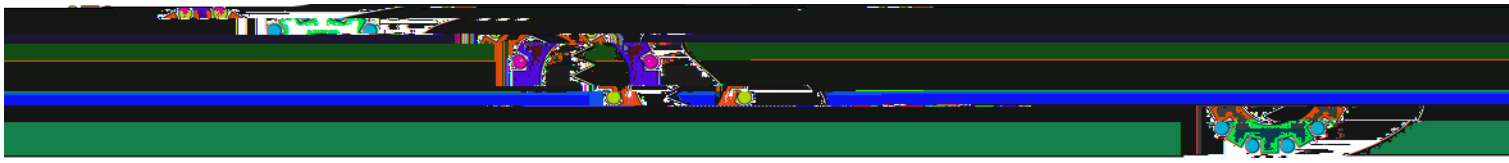
4.2.4 In future, every Local Policing Unit will have a nominated lead for dementia. This will normally be the Crime and Vulnerability Officer, who will be tasked to link into local networks to engage with communities.

4.3.1 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.

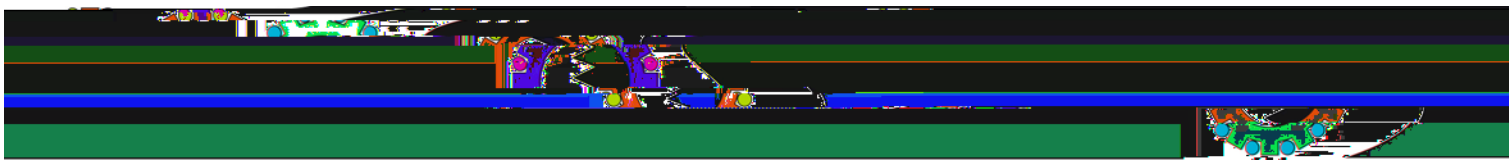
4.3.2 One area identified for improvement is around training and awareness of dementia for healthcare staff and officers who work on the wing for older adults. Members heard that the Alzheimer's Society had previously provided some awareness sessions with staff and were hoping to develop this further.

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



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

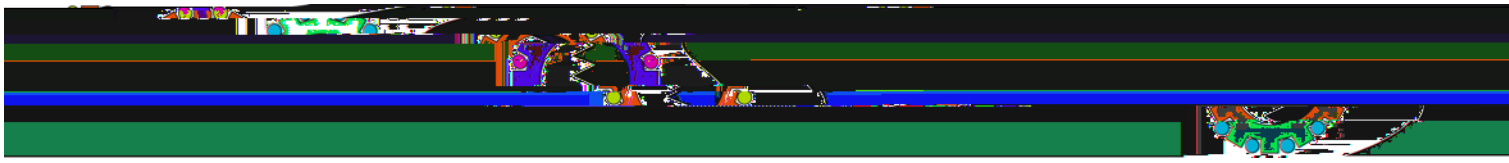


4.7.3 Also indicated was the difficulty around sustainability. Contracts in the third sector are often just for 1-2 years which can make planning, recruitment and retention of staff problematic. It can take a while for a service to get established and then all too quickly the funding comes to an end.

5.1.1 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



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

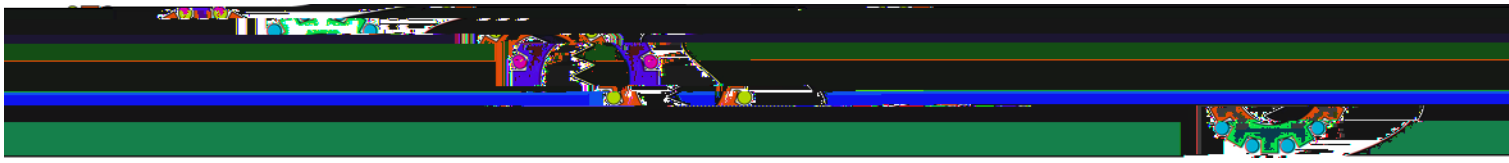
5.3.4 Age Concern Birmingham echoed the sentiments of the Alzheimer's Society in stating that one of the huge barriers is that funding is usually only offered on a 12 month contract which is a real concern in terms of retaining staff. Staff retention in dementia services is so important in order to continue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

5.4.1 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



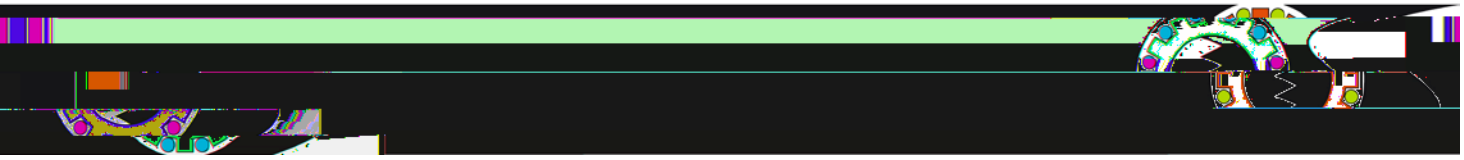
a significant deterioration in physical health that a person would be moved to more appropriate accommodation to support their care needs.

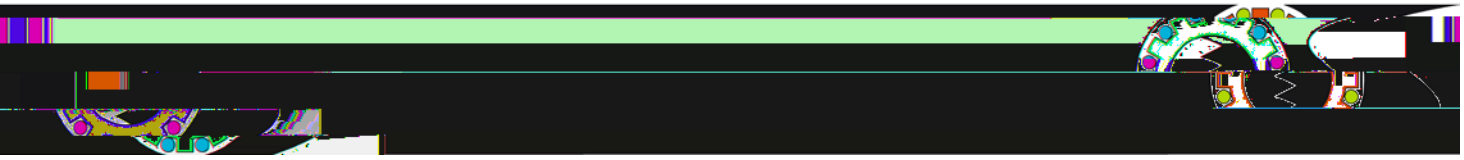
5.6.6 In response to an issue that was raised concerning the amount of support provided for people who have a dual diagnosis of dementia and a learning disability, Members were told that the biggest challenge for GOLDD was matching service provision to what individuals and carers need. The rate at which 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)

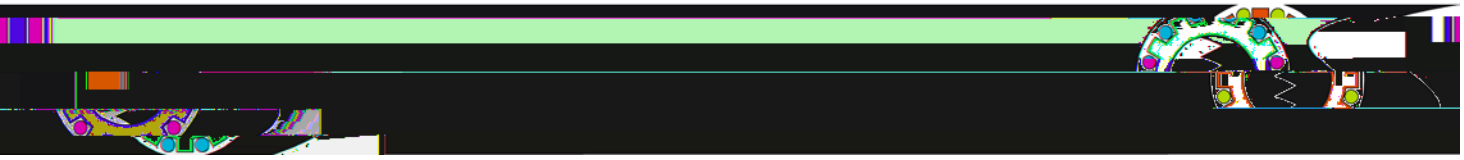
6.1.1 The ExtraCare Charitable Trust provides housing, care and support for older people, pioneering new ways of helping people live well in later life.[11]

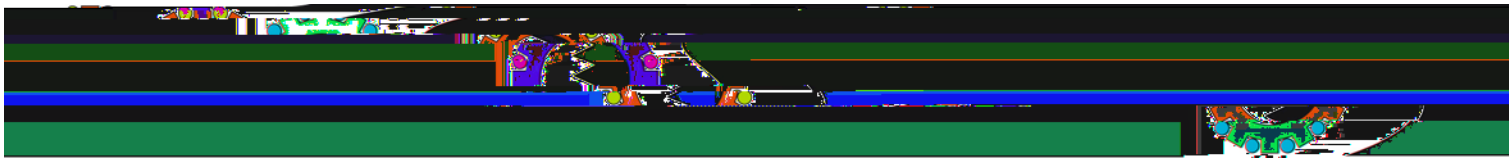
6.1.2 ExtraCare villages (there are currently three in Birmingham - New Oscott, Hagley Road and Pannel Croft in Newtown - with a fourth due to open in 2015 in Bournville) are retirement communities offering residents a wide range of sociable facilities and looking after people who need care.

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 osfor reside ilope



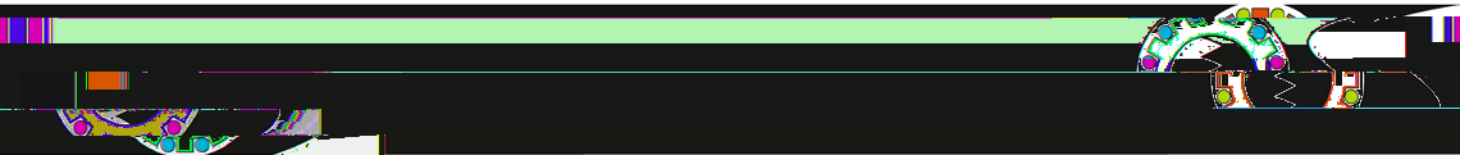


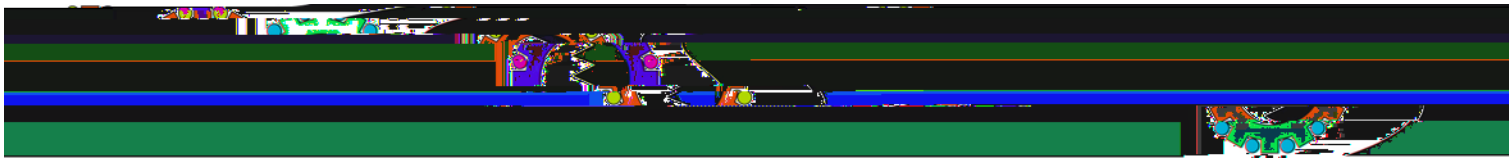




8.2.1 Members were told in evidence from Heart of England NHS Foundation Trust (HEFT) that in treating specific conditions the Trust recognised that they needed to have the capacity and competencies to cater for those patients who also have dementia. Members were advised that the Trust had improved in 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



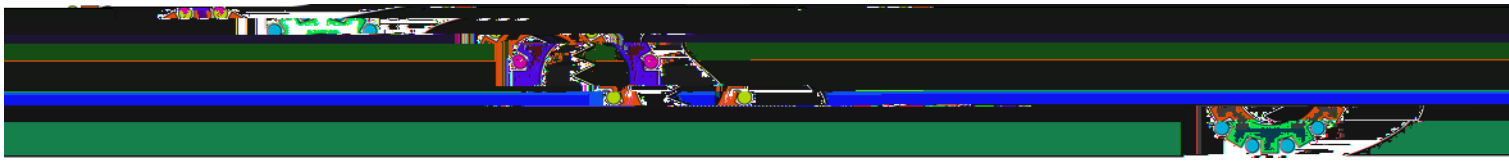


Alzheimer's disease

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.

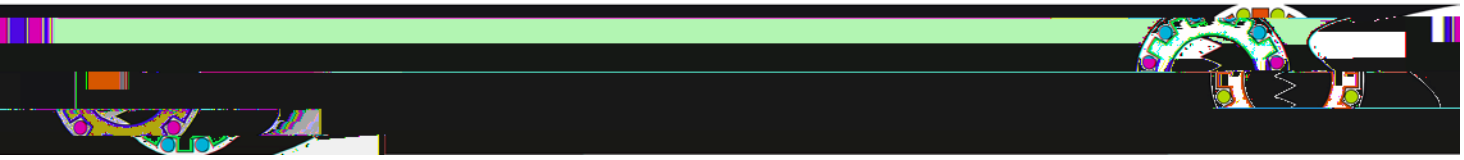
There is



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 dise