

Health and Well-Being Review Committee Policy Review 2008 – 2009

Dementia Care in Sunderland Draft Final Report

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1 Foreword from the Chairman of the Committee

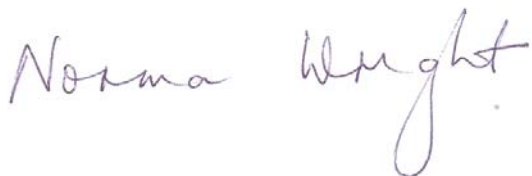
On behalf of the Health and Well-Being Review Committee I am delighted to publish this report. I would like to thank all those who participated in the process, for their time and effort and continued commitment to helping Sunderland continuously improve.

The Community Day was a hugely successful day and I was very interested to hear the views of all those who attended. We were able to gather a great deal of useful information from the day. I would also particularly like to thank our expert witnesses for the detailed evidence they gave to the Committee.

Dementia is not a sign of old age or that you are 'getting on a bit', dementia is a progressive disease of the brain. There are around 700,000 people in the UK with dementia and that figure is set to rise over the coming years as the baby boom population ages and people live longer. The launch of the first National Dementia Strategy in England highlights the importance of removing the stigma that surrounds dementia and improving and delivering better services for people with this disease.

In carrying out this review the Health and Wellbeing Review Committee have explored the key themes and issues that are presented in the National Dementia Strategy including around themes of raising awareness, reducing stigmas, early diagnosis and support. While there are no known cures for dementia it is important that Sunderland looks to address the many issues surrounding it and delivers services that help to provide the best quality of life for people with dementia in the City.

Conducting this piece of work has been very worthwhile and has engaged a large number of people. We have been able to look at the issues involved in depth and it has been wonderful to see such a high level of dedication and enthusiasm from everyone involved. If we continue to work together and develop even stronger partnerships, we will be able to make significant improvements to dementia services and care in Sunderland.



Councillor Norma Wright, Chair of the Health and Well-Being Review Committee



2 Executive Summary

2.1 At the start of the 2008/09 municipal year Members of the Health and Well-Being Review Committee agreed to review dementia services and the emerging National Dementia Strategy.

2.2 The title of the review was agreed as 'Dementia Care in Sunderland' and its objectives were agreed as:

2.2.1 To provide a national and local context to dementia and add to the Council's evidence base in this area.

2.2.2 To identify and highlight current service provision for dementia sufferers throughout Sunderland.

2.2.3 To look at the support mechanisms available for carers to assist in their caring role including young carers and hard to reach carers.

2.2.4 To consider the role of partner organisations and the public in the provision of dementia care services.

2.2.5 To assess Sunderland's dementia care provision against an emerging national strategy and the potential for a local strategy.

2.2.6 To make recommendations that help to signpost and improve dementia care services in the future.

2.3 The approach to this work included a range of research methods namely:

- Desktop research – review of relevant documentation including government documents such as the National Dementia Strategy 'Living Well with Dementia'
- Interviews – with key individuals both internally and externally
- Focus groups – with key individuals both internally and externally
- Presentations at committee
- A Community Day - large public event
- Expert Jury Event

2.4 The review made the following overall conclusions:

2.4.1 Dementia is a Growing Issue

People are living longer lives and as a result dementia cases are on the rise across the UK. The problem needs to be addressed and is a major social care issue that has seen the launch of a national dementia strategy to provide a framework across England to highlight and address dementia issues and care.

2.4.2 Stigma of Dementia

There is a stigma attached to dementia and this can often lead to fear and a reluctance to seek advice and help in the early stages of the disease. The new strategy and the promotion of celebrity cases of the disease are helping to remove much of the stigma and fear that surrounds dementia.

2.4.3 Raising Awareness and Understanding

Through raising awareness and understanding of dementia many of the stigmas can be removed. This is a key cornerstone of the new strategy and an area that needs development across the country. Although it has been recognised that the awareness of dementia has never been greater through mediums such as the dementia strategy, newspapers, TV programmes and celebrity cases it is an understanding of dementia which needs to be addressed. People need to understand the symptoms and that life does not end with a diagnosis of dementia. There is a need for national and local campaigns to debunk some of the misconceptions and challenge the prejudices that currently surround dementia.

2.4.4 Early Diagnosis

Throughout all the evidence gathering processes one of two major themes was constantly at the fore, early diagnosis was one of them. It is crucial to all that follows that a correct diagnosis of dementia is made as soon as is possible. All too often diagnosis is made at the point of crisis which leaves patients, carers and families with a very negative experience and poor outcomes. The strategy and all witnesses recognised the importance of people receiving early diagnosis to ensure that future pathways can be planned and the right services are provided to make possible positive outcomes for people with dementia and their families.

2.4.5 Training

The other major theme was training for all those associated with the dementia care pathway from GP's to home care support workers. It was felt throughout the policy review that further training in the detection of dementias and the signposting advice and guidance was crucially important to improve dementia care services in Sunderland. Everyone who is in the pathway of care was identified as needing suitable training to understand dementia and provide a better service through greater knowledge.

2.4.6 Peer Support

Peer support helps people with dementia come to terms with disease and lift the stigma and feelings of shame that can often be associated with dementia. Peer support groups can have a very positive effect on people and listening and learning from other people's experiences can provide great support to each other. Dementia cafes and support groups including the Alzheimer's Society and Carer Centre provide good networks for people with dementia and their families to receive support and help from their peers. It was also recognised that younger people with dementia also need that peer support and it can often be difficult for those people younger than 65 to relate to older people with dementia due to lack of common interests. There is often little in the way of support mechanisms for younger people with dementia and it was highlighted as important not to forget this group of people.

2.4.7 Importance of Empowerment

With early diagnosis comes the opportunity for empowerment, the ability to plan a future and enhance the quality of life. An early diagnosis allows people and their families to come to terms with the dementia at much earlier point and allow those

with a dementia to plan their own futures and make the choices they want to make for their own enhancement of life and their families.

2.4.8 Pathways of Care

Pathways of care need to be clear and concise and easily accessible by those diagnosed with a dementia. It has been recognised throughout the review process that it will be vital to ensure that once diagnosis is made that patients are provided with a clear pathway to services, treatments and information that will assist them and their families on the journey ahead.

2.4.9 Seamless Services

It is evident from the research undertaken that there are many organisations both statutory and voluntary who are involved in the dementia pathway of care. It is a key to improved services that there is a whole city joined up approach to the development of services and it is important for service users that there is a seamless quality to their service provision.

2.4.10 Third Sector

The importance of the third sector cannot be ignored in the development of dementia services. Service provision is not the remit of one organisation and through the development of working relationships and practices with other organisations a more cohesive whole city approach could be achieved. Many people often look to support group or community networks including Age Concern, The Alzheimer' Society or the carer centre rather than statutory bodies as they can feel less intimidating and provide a solid support for people with dementia and other illnesses.

2.4.11 Funding the Strategy

The national dementia strategy is supported by funding of £150million which sounds a lot but when divided across the whole of England will not amount to very much. It will be important for commissioners and service providers to ensure that resources are well used and provide good value for money to meet the demands and expectations that have been raised as a result of the National Dementia Strategy.

2.5 The following recommendations are made as a result:

Recommendation 1: To clarify the prevalence and incidence of dementia in Sunderland by initially utilising information that has already been collated by the PCT and Local Authority. This will also provide a means of examining the levels of under diagnosis of dementia, which currently exist in Sunderland.

Recommendation 2: To undertake the development of a Reducing Stigma Campaign that includes a focus on the positive experiences of people with dementia.

Recommendation 3: To develop and promote a Raising Awareness Campaign that provides a coordinated approach involving all the major stakeholders.

Recommendation 4: That Sunderland City Council, if the opportunity arises, should apply to be a demonstrator site for the Dementia Advisor role as outlined in the National Dementia Strategy.

Recommendation 5: To review the current Public Health Strategy in order that messages within the strategy focusing on healthy lifestyles include links to the prevention of vascular dementia.

Recommendation 6: To develop a coordinated stakeholder service directory that is available to the general public that provides advice and information on dementia services through information that is already held on the Starting Point Database which, is currently in use in the city. . This process would allow for the review of the existing information that is available, taking into consideration the quality and accessibility of support throughout an individual's journey.

Recommendation 7: To review the current pathway of care identifying where changes need to be made in order that an early diagnosis and intervention can become a reality, including the referral into the pathway.

Recommendation 8: To review the role of the liaison service within City Hospitals to identify and address any capacity issues in service provision.

Recommendation 9: To ensure inclusiveness when implementing the local response to the National Dementia Strategy that consideration is given to young people and people with learning disabilities who have dementia.

Recommendation 10: To progress the workforce development strategy that exists in each sector (Local Authority, Public Health, and PCT) so that all dementia service providers offer good quality services to people with dementia.

Recommendation 11: To raise awareness of the Community Mental Health Team in Sunderland, including increasing the profile of the team and how potential service users can access the service.

Recommendation 12: To undertake a financial exercise on current spending levels for services that provide support for people with dementia and compare this to other Local Authorities and PCTs, with a view to informing best practice in both the current and future provision of services. .

Recommendation 13: To review existing support services to ensure they are fit for purpose against the vision set by the National Dementia Strategy identifying good practice and clear areas for improvement.

Recommendation 14: To recognise the importance of third sector potential in delivering good quality support to people with dementia through better engagement across the statutory and third sector.

Recommendation 15: To review and strengthen existing peer support mechanisms, which could be strengthened by the statutory sector working closer with the third sector.

Recommendation 16: That consideration is given to the possibility of a Dementia Champion within Sunderland City Council as outlined in the National Dementia Strategy.

Recommendation 17: That the Health and Wellbeing Review Committee receives regular reports on the local implementation plan.

Recommendation 18: That the Health and Wellbeing Review Committee provides a written response to the Department of Health on the National Dementia Strategy.

3 The Review Process & Scope

3.1 In undertaking a scrutiny review a number of stages are involved in the process and these stages are broadly defined as follows:

Stage 1 Scope	The initial stage of the review identifies the background, issues, potential outcomes and timetable for the review.
Stage 2 Investigate	The Committee gathers evidence using a variety of tools and techniques and arranges visits where appropriate.
Stage 3 Analyse	The key trends and issues are highlighted from the evidence gathered by the Committee.
Stage 4 Clarify	The Committee discusses and identifies the principal messages of the review from the work undertaken.
Stage 5 Recommend	The Committee formulates and agrees realistic recommendations.
Stage 6 Report	Draft and final reports are prepared based on the evidence, findings and recommendations.
Stage 7 Monitor	The Committee monitors recommendations on a regularly agreed basis.

3.2 Members agreed that the review would consider the following issues related to dementia and dementia care:

- What is the national and local picture in relation to dementia?
- How is dementia diagnosed?
- What services are available for sufferers?
- How are services accessed?
- What services/support is available to younger (pre-65) sufferers?
- What support is available for carers? How can outcomes be improved?
- What is the national dementia strategy?
- How will this help dementia care locally?
- Is there a need for a regional/local dementia strategy?
- How do the council and its partners work together?
- What are the current and emerging treatments?
- What are patient and carer experiences of services?
- Are services properly signposted for service users?

3.3 The title of the review was agreed as 'Dementia Care in Sunderland' and its objectives were agreed as:

1. To provide a national and local context to dementia and add to the Council's evidence base in this area.
2. To identify and highlight current service provision for dementia sufferers throughout Sunderland.

3. To look at the support mechanisms available for carers to assist in their caring role including young carers and hard to reach carers.
 4. To consider the role of partner organisations and the public in the provision of dementia care services.
 5. To assess Sunderland's dementia care provision against an emerging national strategy and the potential for a local strategy.
 6. To make recommendations that help to signpost and improve dementia care services in the future.
- 3.4 Members agreed that as the review progressed, they may feel that the review should narrow its focus further in order to ensure that robust findings and recommendations are produced.
- 3.5 Members agreed to look particularly at the new National Dementia Strategy and how this would help to improve and develop services as well as looking at the current state of dementia care in Sunderland.

4 Approach

4.1 The approach to this work included a range of research methods namely:

- Desktop research – review of relevant documentation including government documents such as the National Dementia Strategy ‘Living Well with Dementia.’
- Interviews – with key individuals both internally and externally
- Focus groups – with key individuals both internally and externally
- Presentations at committee
- A Community Day - large public event
- Expert Jury Event

4.2 All participants were assured that their individual comments would not be identified in the final report, ensuring that the fullest possible answers were given.

4.3 Time restrictions did not allow large scale surveys to be carried out for this research, therefore it should be noted that many of the statements made are based on qualitative research i.e. interviews and focus groups. As many people as possible were interviewed in an attempt to gain a cross section of views, however it is inevitable from this type of research that some of the statements made may not be representative of everyone’s views. All statements in this report are made based on information received from more than one source, unless it is clarified in the text that it is an individual view. Opinions held by a small number of people may or may not be representative of others’ views but are worthy of consideration nevertheless.

5 Findings and Conclusions

Findings relate to the main areas highlighted in the National Dementia Strategy. Following each set of findings are the conclusions drawn from the research and recommendations made as a result.

5.1 Dementia – The National and Local Picture

What is dementia?

- 5.1.1 Dementia is a term used to describe symptoms such as a decline in memory, communication skills, reasoning and a gradual loss of skills that are used on a day-to-day basis. These symptoms are caused by structural and chemical changes in the brain from physical diseases. Dementia is a progressive condition meaning that the symptoms become more severe over a period of time. Although dementia is most often associated with the ageing process it is worth noting that people under the age of 65 are diagnosed with forms of dementia.
- 5.1.2 There are no known cures for dementia. Research continues to develop new drugs and treatments and some have been developed that can temporarily lessen some of the symptoms of some forms of dementia. The National Institute of Health and Clinical Excellence (NICE) has ruled that such drugs (Donepezil, Rivastigmine and Galantamine) should only be used to treat Alzheimer's once it has progressed to a moderate stage.
- 5.1.3 There are many different forms of dementia caused by different diseases of the brain. The most common forms are:
- **Alzheimer's Disease** - changes the chemistry and structure of the brain which results in brain cells dying. A person's memory will deteriorate over time and they may eventually have difficulty with recognising familiar people, eating, swallowing and communication skills. Alzheimer's Disease has almost become a shorthand term to cover all forms of dementia. It accounts for 62% of the dementias in England.
 - **Vascular Dementia** – is as a result of difficulties with the supply of oxygen to the brain such as hypertension, strokes or circulation of blood to the brain. Vascular dementia progresses in a similar way to Alzheimer's Disease with progression more 'stepped' rather than gradual, usually as a result of a new stroke. Vascular dementias including mixed vascular with Alzheimer's dementias account for 30% of the dementias in England.
 - **Fronto-temporal Dementia** – is a rarer form of dementia that affects the front of the brain. This type of dementia often affects people under 65 and in the early stages memory loss is not prevalent but it is more likely to experience behaviour and personality changes. The later stages of the disease are very similar to Alzheimer's Disease. This accounts for 4% of the dementias in England.
 - **Lewy Bodies** – is caused by spherical protein deposits that develop inside nerve cells in the brain. This form of dementia has very similar symptoms to

those of Parkinson's Disease. This is a rare form and accounts for 2% of the dementias in England.

- **Korsakoff's Syndrome** – is a brain disorder associated with heavy alcohol consumption over a prolonged period of time. Although Korsakoff's syndrome is not strictly speaking a dementia, people with the condition experience loss of short-term memory.

5.1.4 Participants at the Community Day Event heard from a number of speakers about dementia and one of the common messages to emerge from all the speakers was that dementia is not simply a sign of growing old but is a disease that has a devastating impact on the person their immediate family, relatives and friends.

Dementia: Facts and Figures – The National Perspective

5.1.5 In 1952, when Queen Elizabeth II came to the throne, she sent 273 birthday telegrams to centenarians. This figure is now over 3,000 per year. People are living longer and from research conducted in 1999 it was estimated that 18% (10.7 million people) of the total UK population was over pensionable age and this is expected to rise to 11.9 million in 2011 and 12.2 million by 2021.

5.1.6 There are currently around 700,000 people in the UK with some form of dementia, roughly 1 person in every 88, and over 15,000 of these people are aged under 65 years. By 2010 there will be approximately 840,000 people with dementia in the UK and this is expected to rise to over 1.5 million by 2050.

5.1.7 The total number of people with dementia in the world was 11 million in 1980, 18 million in 2000 and is estimated to be 34 million in 2025.

5.1.8 The rises in dementia cases in the UK are largely due to the ageing population but conditions including high cholesterol and blood pressure, and lack of exercise are also contributory factors that can increase the risk of dementia.

5.1.9 The total cost of dementia in the UK is currently £17 billion per annum with a projected increase over the next 30 years to £51 billion per annum. Experts agree that the issues surrounding dementia care is the challenge of the 21st century for health and social care. The government also recognises the importance, so much so that it has recently published the first National Dementia Strategy to address the problem and set out a way of improving care.

Dementia: Facts and Figures – The Local Perspective

5.1.10 There is currently no register of Sunderland residents with dementia or how under-diagnosed dementia is at a local level. However research estimates that in 2005, of the 45,600 people living in Sunderland over the age of 65 approximately 2963 people will have some form of dementia. More people will suffer as the population ages and research conducted by Sheffield Hallam University projects an increase in dementia in Sunderland from 2963 cases in 2005 to 4433 in 2025.

5.1.11 The Sunderland population aged 65 and over is estimated to increase by a third by 2025 with the total population of the city set to decrease by around 2%. Also of note is the change in the structure of the population aged over 65 as over the next 20 years the over 85 age group is set to double from 4,100 to 8,000. It is worth highlighting that it is this group where the frequency of dementia is highest.

- 5.1.12 This was also highlighted at the Community Day Event where participants were informed that over the next 15 years the over 65 age group was set to rise by 30% to 59,500 and older people with functional dependencies would rise by 28% to 22,400 of the Sunderland population.
- 5.1.13 The launch of the National Dementia Strategy is important for the whole country and participants at the Community Day Event recognised the importance of the document but appreciated that there was still a long road ahead in terms of shaping services in Sunderland. The National Dementia Strategy was acknowledged as a measure for developing services in Sunderland but local development would be dependent on key organisations including Sunderland council, Sunderland TPCT, City Hospitals Sunderland and Northumberland Tyne and Wear Trust working with other key stakeholders including the Alzheimer's Society.

Conclusions

- 5.1.14 Dementia is an illness and it has a deep impact on people who are diagnosed with dementia and their families. Dementia is progressive and results in a decline in everyday functions, memory, and reasoning and can also lead to depression, psychosis, wandering and aggression. Dementia is a terminal illness that has no known cure but with an early diagnosis people can still have a quality of life and live for many years after diagnosis.
- 5.1.15 The UK's population is ageing and current estimates indicate that by 2051 dementia will affect the lives of around 1 in 3 people either as a patient, a carer or a relative. The cost of care for late-onset dementia is an average £25,472 per year and the bulk of these costs are met by people with dementia and their families. The figures make for a stark realisation that dementia is a huge challenge for health and social care services across the country. The total true cost and spending on dementia services across Sunderland is unknown and therefore makes it difficult to ascertain if dementia services are under-resourced.
- 5.1.16 In Sunderland the estimated changes to the size of the population and make-up of the City have a number of implications on the demand for dementia services. An ageing population signifies that there will be an increase in the number of people with some form of dementia in the City unless the age-specific prevalence happens to change. This will also see the largest increases in the oldest section of the population and therefore a greater percentage of people with dementia who are living alone or with an ageing partner who will find it difficult to be the principal carer. The general change in Sunderland's demographic due to lower birth rates and movement of people of working age out of the locality will also mean there are less younger family members to provide a level of care.

Recommendations

Recommendation 1: To clarify the prevalence and incidence of dementia in Sunderland by initially utilising information that has already been collated by the PCT and Local Authority. This will also provide a means of examining the levels of under diagnosis of dementia, which currently exist in Sunderland.

5.2 Raising Awareness and Understanding

The Stigma of Dementia

- 5.2.1 A survey conducted by the Alzheimer's Society indicates that the stigma that surrounds dementia can make life much harder for patients. The survey carried out with more than 4,000 members of the general public found that around half of those surveyed felt the associated stigma was a serious problem for people with dementia.
- 5.2.2 Participants at the Community Day felt that a stigma existed around dementia and that more public awareness raising of the illness would prove useful, particularly around how to recognise the early signs or symptoms of dementia. This could be done through various forms of media including television adverts. The stigma did not bother all people who were affected by the disease and participants felt they were offered help and support. Luncheon clubs were seen as useful, as they enabled dementia sufferers and their families to share their experiences and lift the stigma and myths surrounding the disease. Many participants recognised that tackling the stigma was a high priority.
- 5.2.3 At the expert jury day it was acknowledged that the stigma of dementia is a massive issue which needs to be addressed to reduce anxiety and promote better understanding of dementia with the general public. There is a lot of ignorance around dementia and much of the publicity associated with it concentrates on the negative experiences. Witnesses suggested that there needed to be a shift of emphasis to the positive experiences of living with dementia. While no one was suggesting that having a dementia was a good experience it was highlighted that people can have a good quality of life for many years with the disease and this positive aspect needed to be promoted.
- 5.2.4 It was emphasised that any stigmas or misconceptions around dementia needed to be challenged through professional organisations and even by health professionals in their day to day routine. Only by challenging current views through information, real-life experiences and myth busting can people's opinions on dementia be changed.

Raising Awareness

- 5.2.5 Participants at the community day and expert jury events all agreed that the recently launched National Dementia Strategy will help to promote and raise awareness of dementia in the public domain. The strategy was welcomed by many of the witnesses interviewed during the committee's investigations and was seen as a positive step forward in raising awareness.
- 5.2.6 Looking at the projected figures for the prevalence of dementia across the country it can be argued that awareness will be raised by the nature of the increased frequency of cases of the disease that will be seen in the UK.
- 5.2.7 It was argued that there was room for both national and local campaigns on awareness raising and that both would be important and support each other. The National Dementia Strategy had given the high profile launch and this has been further supported by media figures such as Sir Terry Pratchett and John Sutchet sharing their own very personal experiences with the general public. At the expert

jury day it was acknowledged that leaflets and posters were good communication tools but that nothing really substituted that personal experience which people can really relate to.

- 5.2.8 It was recognised that health professionals need to be aware of what services were available for people with dementia and be able to direct people to the services that can best provide information, support and help. Services needed to be linked up and provide a more cohesive and comprehensive service for users. There is good advice and information available to the public but in most cases it needs to have better signposting. This is a very complicated area and there is a danger that if there are any gaps in service signposting that some people may fall through if health and social care do not have a coordinated working relationship. Peer support was also identified as an important awareness raising mechanism as through organisations including the Alzheimer's Society and the Carer's Centre people can share experiences with each other.
- 5.2.9 Information was helpful and important to people but it needed to be more easily accessible and in plain English. Information was not easily found and sometimes added to the confusion surrounding dementia a more joined up approach was identified by experts and participants alike as beneficial.
- 5.2.10 It was suggested that dementia awareness should be provided to schools as a way of developing an early education into the issues surrounding the disease and also can highlight the prevention measures through healthy diets, drug and alcohol use and help to instigate healthier lifestyles for young people into adult life. Even film clips like the Featherhead presentation (a short film made by The Alzheimer's Society that provides a window on the experiences of people with dementia and the people closest to them, it is about relationships, memories, feelings and emotions) shown at the community day event can highlight the issues of dementia and provide an introduction to the understanding of what dementia is and its effect on people and those closest to them. The Featherhead feature was well received at the community day and attendees felt the presentation was powerful, poignant and informative.

Understanding Dementia

- 5.2.11 At the community day event it was highlighted that there is a huge misconception that nothing can be done for people with dementia or those looking after them and this viewed is held by both the public and professionals alike. In fact many attendees noted that at the community event they had learned a lot about dementia and the services and support mechanisms that were available and found the day hugely informative.
- 5.2.12 The role of a dementia advisor was discussed at the expert jury day and many of the witnesses saw this as a vitally important role. To have a specialist in dementia who could train and provide advice and help people along the pathway was identified as being of potentially enormous benefit.
- 5.2.13 In developing an understanding of dementia there is a strong preventative message that also needs to be put across to people. While the reasons for people developing dementias are still unclear there are strong medical arguments to support a healthy diet and lifestyle are a good prevention against many vascular dementias. It is important that the public understand that what is good for the heart is good for the

head and again linking this with education through schools through adult life is important.

5.2.14 In raising awareness and understanding of dementia can help people to overcome the fear associated with the disease and act early rather than ignore some of the potential symptoms. People need to understand that while there is no known cure many of the conditions are treatable to allow a good quality of life.

5.2.15 With information and services often disjointed and confusion about what people may want or need to access it was suggested at the expert jury day that a service directory could be developed for dementia. This could help to signpost people to the right organisations or services to seek out help or advice. It was also suggested that the directory could be a colour coded to make it more visual for people with dementia.

Conclusions

5.2.16 Stigmas, ignorance and general poor understanding of dementia with the general public and many professionals alike is something which needs to be addressed. Lifting the stigma and taking away the myths around dementia could help to make people feel more comfortable talking openly about dementia and coming to terms with the possibilities of dementia and actually seeking help. The stigma of dementia leaves people feeling socially embarrassed because people notice the changes in their manner or behaviour and therefore people stop doing the things they like to do and this impacts on the quality of life. People need more practical help and instruction on how to continue to live life.

5.2.17 Dementia awareness has improved over the last 20 years and it is as good as it has ever been as it is seen on television in newspapers and on the radio. Celebrity figures are also coming out and sharing their own experiences with the public creating a powerful media message about dementia. The National Dementia Strategy has also been launched by the government to tackle this growing issue and Alzheimers has almost become a generic word in common usage for all types of dementia. What is evident from the research is that the information available needs to be more coordinated and joined up to avoid confusion and that information should be much more easily accessible to the general public. It is also now much more about understanding dementia and its effects on people and those closest to them.

5.2.18 It is as important to develop an understanding around dementia as it is to raise awareness of the disease. It is important that levels of understanding are developed and these are not just restricted to health organisations but should also include major employers and schools. Any awareness campaigns should also look at the preventative aspects to vascular dementia and promote healthy lifestyles from an early age and outline the increased risks of dementia from alcohol or drug abuse.

Recommendations

Recommendation 2: To undertake the development of a Reducing Stigma Campaign that includes a focus on the positive experiences of people with dementia.

Recommendation 3: To develop and promote a Raising Awareness Campaign that provides a coordinated approach involving all the major stakeholders.

Recommendation 4: That Sunderland City Council, if the opportunity arises, should apply to be a demonstrator site for the Dementia Advisor role as outlined in the National Dementia Strategy.

Recommendation 5: To review the current Public Health Strategy in order that messages within the strategy focusing on healthy lifestyles include links to the prevention of vascular dementia.

Recommendation 6: To develop a coordinated stakeholder service directory that is available to the general public that provides advice and information on dementia services through information that is already held on the Starting Point Database which, is currently in use in the city. . This process would allow for the review of the existing information that is available, taking into consideration the quality and accessibility of support throughout an individual's journey.

5.3 Early Diagnosis and Support

Early Diagnosis and Intervention

- 5.3.1 One of the recurring themes throughout the community day was the importance of early and/or improved diagnosis of dementia. A number of speakers related to attendees the significance of an early dementia diagnosis in improving access to services and treatments as well as assisting people, their families and carers in coming to terms with and adapting to the changing circumstances. It was also highlighted that only around a third of people with dementia receive any specialist health care assessment or diagnosis and it is often late in the illness, too late to enable choice and at a time of crisis. This issue was also a common theme during the subsequent group discussions.
- 5.3.2 General Practitioners (GP's) were recognised as the gatekeepers to dementia services. It was highlighted that GP's today have a greater understanding of dementia but it was felt by expert witnesses and community day attendees that more training and guidance was still required to improve the diagnosis of dementias. Although it was noted that GP's often do have the knowledge regarding the disease they can fail to put this into practice. Witnesses at the expert jury day reported that GP's were not aware of all the services available to dementia patients and this needed to be made clearer in order that better guidance and information could be given. It was also acknowledged that it can often be extremely difficult to recognise the signs of dementia as it can be masked by other symptoms and it was suggested that GP's needed to have more flexibility and support in prescribing dementia drugs to patients and in promoting the potential benefits of these drugs for people with dementia. The screening of patients for dementia was also discussed and it was highlighted that GP's sometimes can fail to screen patients and use other methods including appearance and conversation for the determination of dementia.
- 5.3.3 Early diagnosis was also recognised as important for patients, carers and family members alike. The value of an early diagnosis is evident in the enhancement of the quality of life and can allow for long-term planning and an empowered role for

people with dementia and their families to plan for the latter stages of the disease. The early diagnosis can allow families to grow and develop together along the journey. It was reported that often diagnosis are made at the wrong time and at a time of crisis which can result in the wrong outcomes for people.

- 5.3.4 The role of GP's was also raised during discussions and if in fact GP's were the right people to offer an early diagnosis. However it was acknowledged that GP's were most commonly the first point of contact and a lot of work was required to develop the role of the GP in the dementia pathway. GP's were referred to as the 'gatekeepers' to dementia services, through the current referral system, it was raised by witnesses that people are often reluctant to go to their GP as people don't volunteer for an early diagnosis of dementia and people may also bring negative perceptions through their own experiences with parents or relatives. It is important that assessment services are positive and as unthreatening as possible and provide a message of hope. The possibilities of future development of the referral pathways were also highlighted with discussions around opening the referral pathway to other health professionals and third sector organisations as well as the potential of self-referral. It was also expressed at the community day that social workers and psychiatrists could be based in local surgeries to help speed up current referral processes.
- 5.3.5 It was also highlighted that acute hospitals e.g. City Hospitals Sunderland also had a part to play in diagnosis and intervention as it is in hospital where dementia symptoms can first come to light. In Sunderland a liaison service has commenced at City Hospitals Sunderland through a liaison nurse who links into the Community Mental Health Team (CMHT) and other assessment pathways. Due to capacity issues the liaison nurse concentrates primarily on care of elderly wards and can only identify elderly people on these wards who may have a dementia illness.
- 5.3.6 On balance it was recognised that it was very positive to receive an early diagnosis if it was done well and could lead to harm prevention, the enablement of choice, long terms savings, planned interventions and better outcomes for patients and carers. It was recognised that most people want to continue living at home and in familiar surroundings when diagnosed with dementia and early diagnosis can lead to support provisions and care at home which can reduce the need for institutionalisation.
- 5.3.7 Also in considering dementia diagnosis and interventions witnesses expressed the importance of also looking at young people with dementia and people with learning disabilities who may also have a dementia to ensure they too had access to good quality services which were tailored for their needs. It was identified at the community day event that younger people do get dementia and have different needs to older people.
- 5.3.8 It was highlighted that an important task is to develop good quality information for those people with dementia and their carers regarding local services that are available and what to expect from them, beginning at diagnosis and throughout the course of care.

Support

- 5.3.9 Peer support was identified throughout the review process as an important mechanism for people with dementia and their carers to access practical and emotional support. The Alzheimer's Society and Carer's Centre in Sunderland

provide invaluable support to people with dementia and their carers and it is important that the statutory sector continues to work and develop its relationship with the third sector to improve this peer support.

- 5.3.10 It was evident throughout the community day and expert witness day that training was important not just for GP's as previously mentioned but for all support staff who provide services for people with dementia. It is crucial that care staff understand and are trained to provide levels of support that enhance the quality of life of those living at home and their family members. Dementia can have a very negative effect on people and it is important that services provided are seamless in delivery to create that positive outcome.
- 5.3.11 The Community Mental Health Team in Sunderland work extremely well and provide good advice as well as helping people and families come to terms with the issues surrounding dementia. Currently the team consists of 2 social workers and an early onset dementia social worker which was identified as an imbalance which needed to gain some parity. Through the evidence gathered, it would appear that the CMHT were also not well advertised to GP's again reinforcing the need to develop knowledge around interventions and support mechanisms available and also a need to raise the profile of the CMHT. Support services were also identified as needing to be more responsive to allow more individual control over planning of a persons own care.
- 5.3.12 The concept of a Dementia Advisor, as detailed in the Dementia Strategy, was also discussed by many of the witnesses and this was felt to be an important step forward for people with dementia. To have someone who could guide and support a person and their family throughout the journey and also ensure a clear pathway through services and treatment would be a very positive move forward. The development of this post will be piloted in several cities across the country and following evaluation, will be rolled out to every locality. At present, it is unknown whether Sunderland can bid to be part of the pilot as a process is, as yet, unknown.

Conclusions

- 5.3.13 Early diagnosis, intervention and support are all crucial in ensuring positive outcomes for people with dementia their carers and families. One of the key challenges emerging from the National Dementia Strategy is to ensure that a system can be put in place whereby people with dementia and their carers have an accessible source of advice and signposting into appropriate assessment and treatments throughout the course of their illness. It is vital that the pathway to care services and information is one of clarity. Any new service developments need to acknowledge the whole care pathway from accessing to leaving the service.
- 5.3.14 Being diagnosed with dementia is a major life changing event but with well made and well delivered diagnosis people can adjust and plan their own future care needs and prepare with their families for the future. It is important that people where possible can be empowered to be able to future plan for their own individual needs and requirements. With this in mind it is important that support services are responsive and able to adapt to individual needs and provide the level of support requested.
- 5.3.15 There is not a single outcome that fits everyone and it is important that this is recognised and that people are presented with the best possible outcomes. Assessment services need to be more accessible and perhaps this can be done in

the home rather than a clinic which is more comfortable and puts people more at ease with the situation.

5.3.16 It is important that recognition is given to the support services available to people with dementia and the value of peer support should never be underestimated for the powerful experience it is. Statutory sector organisations need to look at developing stronger links with third sector organisations and ensuring that health professionals are fully aware of what support is available on the ground for people with dementia.

5.3.17 Further training so that health professionals and all those involved in social care understands the journey that people take with dementia is also important as is the consistency of care throughout this journey. The notion of Dementia Advisors will help and provide greater support for patients and families and help to ease the burden of care and help to access the correct support to enhance quality of life.

Recommendations

Recommendation 7: To review the current pathway of care identifying where changes need to be made in order that an early diagnosis and intervention can become a reality, including the referral into the pathway.

Recommendation 8: To review the role of the liaison service within City Hospitals to identify and address any capacity issues in service provision.

Recommendation 9: To ensure inclusiveness when implementing the local response to the National Dementia Strategy that consideration is given to young people and people with learning disabilities who have dementia.

Recommendation 10: To progress the workforce development strategy that exists in each sector (Local Authority, Public Health, and PCT) so that all dementia service providers offer good quality services to people with dementia.

Recommendation 11: To raise awareness of the Community Mental Health Team in Sunderland, including increasing the profile of the team and how potential service users can access the service.

5.4 Living with Dementia - Sunderland

Living with Dementia – National Picture

5.4.1 The National Dementia Strategy indicates that currently two-thirds of all people with dementia live in their homes in the community. The stages that these people are at with the disease will vary greatly and as discussed earlier the right support is crucial to these people and their families. Apart from the care of family members the most important service is that provided by home care services. Current national practices of task over outcome, failure to develop relationships due to time constraints and consistency of work are all huge issues for people with dementia.

5.4.2 The National Dementia Strategy also highlights that emerging research indicates that there are benefits to people with dementia and their carers from specialist

dementia home care as opposed to standard home care services including reduced stress, risk of crises for carers and extended capacity for independent living.

Living with Dementia in Sunderland

- 5.4.3 At the expert jury day the view was expressed that sometimes there is a danger of being overwhelmed by the rising levels of dementia but offset against this is the first hand experience of the phenomenal acts of love shown by carers and families. It was reported that there have been large scale improvements in services over the last 10-12 years and Sunderland has been at the forefront of some dementia services. It was recognised that services needed to be moulded around people and that a whole person approach through personalisation was a major challenge for the city and would require a joint approach with partners. It was recognised that the patient pathway needs to be consistent and seamless and there appeared to be a lack of joint planning and joint commissioning around the dementia pathway.
- 5.4.4 It was identified that there were a full range of services in Sunderland and that through Northumberland Tyne and Wear Trust (NTW) a number of services were commissioned including specialist memory assessment services, specialist community mental health services including management of challenging behaviour, acute assessment, challenging behaviour and ongoing care in-patient services. The staffing to run these services consisted of 5 old age psychiatrists; 37 community psychiatric nurses; 130 registered mental nurses; 6 occupational therapists; 6 physiotherapists; 3 clinical psychologists; 5 pharmacist; 4 administrative & reception staff. It was acknowledged that Cherry Knowle was no longer a suitable environment for in-patient services and attendees at the community day event believed that Cherry Knowle had a stigma attached to it. It was acknowledged that the inpatient facilities currently at Cherry Knowle were to be addressed.
- 5.4.5 While the New Dementia Strategy has funding of £150million attached when divided out between all the councils in England will not result in a great deal of extra funding and it will still require local authorities, health organisations and commissioners to look at service redesign to allow better use of resources. It is also difficult to determine the current spend on dementia services in Sunderland and therefore difficult to ascertain if the city is under-resourced at present in terms of dementia funding. Witnesses spoke of dementia as a rapidly growing problem and that resources needed to be utilised cleverly. Funding for third sector organisations was also discussed at it was reported that good support was received from the Local Authority but other potential funding streams were difficult to access.
- 5.4.6 Over the next 15 years in Sunderland over 65's will rise by 30%, older people with functional dependencies will rise by 28% and people with dementia will rise by 33%. Sunderland City Council's Health Housing and Adult Services Directorate is looking through its strategy to develop and improve a variety of support services which will enhance the lives of those people with dementia and support many of the themes and drivers outlined in the National Dementia Strategy. These include;
- Universal Services developed to meet the needs of individuals and communities
 - Information and advice provided locally
 - Greater self access with more choice & control
 - Providing opportunities for fulfilment & focus on prevention
 - Person centred plans, services, and budgets
 - Every citizen having access to good quality accommodation of choice

- Investment and efficiency will meet the demands and deliver better outcomes.

To turn this vision into a reality Sunderland has developed a 15 year Strategic Commissioning Plan as well as a 3 year delivery plan for adult social care in Sunderland. The 15 year plan outlines the vision for adult social care in Sunderland and the delivery plan identifies the priorities over the next 3 years and starts to develop and put into practice the transformational changes needed to achieve the aims established in the vision document.

5.4.7 The major themes to delivering the vision of adult social care were outlined at the Community Day Event and were as follows:

- Choice & Control (empowerment)
(advice / person centred / individual budgets)
- Independent Living (in the place of choice)
(decent homes / extra care / home improvement / telecare)
- Equal Access for all (to universal services)
(sports / leisure / cultural / learning / employment)
- Health & Well Being - Preventing Dependence
(early support & opportunities)
- More effective & intelligent use of resources
(commissioning / workforce / efficiencies / evidence based).

5.4.8 Attendees at the community day event acknowledged the good work already being done in Sunderland but emphasised the importance of building on the services already provided. There was discussion around the need to implement support networks and bring everyone together and to have greater consultation with the people actually using the services. It was also highlighted how important it was to bring people together to work and achieve the goals of the National Dementia Strategy including in the community and that a clear structure was important.

5.4.9 The City of Sunderland already has good provision for dementia patients including specialist home care teams and specialist day care provision, intermediate care at Farnborough Court that includes dementia care rehabilitation for people who require physical and/or mental health rehabilitation opportunities, The Alzheimer's Society, The Carer Centre and a Telecare service. Some of this provision has built up over time and much of it continues to be developed but there is also room for improvement. The use of technology is also moving to the forefront with the Sunderland Telecare service, which is operated by the Community and Cultural Services Directorate, and offers a range of equipment that can be fitted into homes that can help with safety and security. This includes highly trained staff that provides a rapid response to problems or concerns and a 24 hour monitoring centre that can respond to needs and ensures help can be there as quickly as possible. Sunderland also has day opportunities for people with dementia that offer social stimulation for patients and relief for carers and the Carer Strategy is also being taken forward in Sunderland.

Conclusions

5.4.10 Improving dementia services in Sunderland is very much dependent on the key players who include the Lead Commissioners within the Local Authority and Sunderland TPCT working together with NTW and key third sector organisations to work together and deliver much of what is highlighted in the dementia strategy and

work collaboratively to deliver improvements and service developments for the people of Sunderland.

- 5.4.11 It is important that services are seamless for people and that they are well signposted to ensure people with dementia are accessing the levels of care and support that they need to ensure a good quality of life. Sunderland already has many services and support networks for people including Sunderland Telecare, reablement and rehabilitation services, sheltered housing and home support services. The majority of services are designed to allow people with illnesses such as dementia to remain in their own homes for as long as possible and increase their quality of life. The visions and strategies put in place by Sunderland Council and the Health, Housing and Adult Services also aim to develop and improve services to provide people in Sunderland with a greater range of planning for their own care through choice and empowerment.
- 5.4.12 Services and organisations were still recognised as being disjointed and the pathway to care often unclear. It is important that as stated previously the pathway to care is clear and concise and that all the services and providers are working together to ensure that the care pathways are easily accessible and provide the support and care required as well as complementing each other. Commissioning will be vital in ensuring the pathway is a clear one and that the journey taken by each person although very different will result in the right outcomes for that person.
- 5.4.13 Improved dementia care in Sunderland and the implementation of new developments and services will require funding and it is already difficult to ascertain the true spending costs on dementia services currently in Sunderland so it will be important to look at a financial mapping exercise across the city to truly understand the costs involved and if the city is currently under-resourced in terms of spend on dementia care.
- 5.4.14 There is also an increasing and developing role for third sector organisations within the city and it important that organisations like The Alzheimer's Society, Age Concern and the Carer Centre are involved in joint working with statutory organisations and health professionals. It should not be underestimated the amount of community based work these organisations carry out and it often the case that people find such organisations far more easily accessible than statutory and professional bodies.

Recommendations

Recommendation 12: To undertake a financial exercise on current spending levels for services that provide support for people with dementia and compare this to other Local Authorities and PCTs, with a view to informing best practice in both the current and future provision of services. .

Recommendation 13: To review existing support services to ensure they are fit for purpose against the vision set by the National Dementia Strategy identifying good practice and clear areas for improvement.

Recommendation 14: To recognise the importance of third sector potential in delivering good quality support to people with dementia through better engagement across the statutory and third sector.

Recommendation 15: To review and strengthen existing peer support mechanisms, which could be strengthened by the statutory sector working closer with the third sector.

5.5 Delivering a National Strategy

Delivery of a national strategy

- 5.5.1 The National Dementia Strategy addresses issues around dementia and care and this strategy needs to compliment other policy drives and services developments that are current and ongoing within local government and the NHS. The strategy itself acknowledges this fact and identifies the links with and need to aide delivery of key initiatives including Putting People First, the Next Stage Review (NSR), the Carers' Strategy and End of Life Care Strategy.
- 5.5.2 PCT's and local authorities will be expected to demonstrate continued progress towards meeting the key objectives contained within the strategy and while priorities for improvement are left to local determination the key messages from the strategy and investigations carried out by the review committee are to prioritise the early diagnosis and intervention of dementia, training & development and the quality of care received. The state of existing services will need to be taken into account along with financial issues and readiness for change. At the expert jury day it was reported that the Sunderland TPCT were giving the strategy and dementia care a high priority which is important.
- 5.5.3 Attendees at the community day event realised the importance and significance of a national dementia strategy but appreciated there was still a long way to go in terms of shaping services in Sunderland. It was also identified by attendees that there was a danger that what the strategy provides could be different from what service users want. While the strategy is a national approach it was felt important by attendees to have a degree of flexibility to allow for local authorities and partners to implement the strategy for maximum benefit to the locality. Attendees also felt it was important that as the strategy principles were developed across the country examples of good practice should be identified and shared with other areas.
- 5.5.4 In delivering a national dementia strategy in Sunderland the question was raised as to who would be ultimately responsible for the overview of the strategy in ensuring that all the stakeholders and providers were on track. It was suggested that there could be a role for a high profile champion to do this. Greater clarity around the funding issue to implement a strategy was also raised and attendees were particularly interested in how the strategy would be funded in Sunderland? Attendees also wondered how ready Sunderland was to implement the strategy?
- 5.5.5 Sunderland City Council has a number of key documents which will help to support and implement many of the themes and priorities highlighted in the new dementia strategy, these include the 15 Year Strategic Commissioning Plan, Sunderland Strategy, Health, Housing and Adults Directorate 3 Year Implementation Plans and Local Area Agreements. It will be important for any implementation that it is agreed in partnership with local authorities, NHS and other key stakeholders. Attendees at the community day felt it was important for Sunderland to strive towards their strategic plans and visions and make it a reality and more importantly look at individual areas of the strategy and set key priorities that need to be achieved.

Conclusions

- 5.5.6 The National Dementia Strategy is key document in the pursuit of improved care and services for people with dementia. The strategy provides a framework from which to move forward and develop services to meet the growing issues around care for people with dementia. The strategy provides the guidance but it will be up to local stakeholders to move forward with the priorities and shape their own services and develop new and better models of care.
- 5.5.7 The strategy has an in-built flexibility to it which was recognised by many people as important to allow regions and localities to develop the themes and priorities which they themselves judge to be the most important. Vital to the success of any implementation of a strategy is that it suits the service users and it is important that service users are consulted to ensure that this is something that they want and can see real benefits in. It is also crucial that implementation is a joint-approach from the major stakeholders to provide quality services and gain the best use of resources that are available. While the notion of a dementia strategy champion is interesting what is crucial is that there are mechanisms in place to illustrate how well Sunderland is performing in implementing the key components of the strategy in the city.
- 5.5.8 From April 2009 the Care Quality Commission (CQC) will come into force to promote and protect the health, safety and welfare of people using health and social care services. The CQC will have a very important role in raising standards for people with dementia who receive support from health and social care services among others. The CQC will help to provide through its work an understanding of the experiences of people living with dementia and their carers and will assist in assessing the progress and effectiveness of the dementia strategy.

Recommendations

Recommendation 16: That consideration is given to the possibility of a Dementia Champion within Sunderland City Council as outlined in the National Dementia Strategy.

Recommendation 17: That the Health and Wellbeing Review Committee receives regular reports on the local implementation plan.

Recommendation 18: That the Health and Wellbeing Review Committee provides a written response to the Department of Health on the National Dementia Strategy.

6 Summary of Conclusions

Conclusions were listed after each section of findings however, key themes have arisen which are summarised below.

6.1 Dementia is a Growing Issue

People are living longer lives and as a result dementia cases are on the rise across the UK. The problem needs to be addressed and is a major social care issue that has seen the launch of a national dementia strategy to provide a framework across England to highlight and address dementia issues and care.

6.2 Stigma of Dementia

There is a stigma attached to dementia and this can often lead to fear and a reluctance to seek advice and help in the early stages of the disease. The new strategy and the promotion of celebrity cases of the disease are helping to remove much of the stigma and fear that surrounds dementia.

6.3 Raising Awareness and Understanding

Through raising awareness and understanding of dementia many of the stigmas can be removed. This is a key cornerstone of the new strategy and an area that needs development across the country. Although it has been recognised that the awareness of dementia has never been greater through mediums such as the dementia strategy, newspapers, TV programmes and celebrity cases it is an understanding of dementia which needs to be addressed. People need to understand the symptoms and that life does not end with a diagnosis of dementia. There is a need for national and local campaigns to debunk some of the misconceptions and challenge the prejudices that currently surround dementia.

6.4 Early Diagnosis

Throughout all the evidence gathering processes one of two major themes was constantly at the fore, early diagnosis was one of them. It is crucial to all the follows that a correct diagnosis of dementia is made as soon as is possible. All too often diagnosis is made at the point of crisis which leaves patients, carers and families with a very negative experience and poor outcomes. The strategy and all witnesses recognised the importance of people receiving early diagnosis to ensure that future pathways can be planned and the right services are provided to make possible positive outcomes for people with dementia and their families.

6.5 Training

The other major theme was training for all those associated with the dementia care pathway from GP's to home care support workers. It was felt throughout the policy review that further training in the detection of dementias and the signposting advice and guidance was crucially important to improve dementia care services in Sunderland. Everyone who is in the pathway of care was identified as needing suitable training to understand dementia and provide a better service through greater knowledge.

6.6 Peer Support

Peer support helps people with dementia come to terms with disease and lift the stigma and feelings of shame that can often be associated with dementia. Peer support groups can have a very positive effect on people and listening and learning from other people's experiences can provide great support to each other. Dementia cafes and support groups including the Alzheimer's Society and Carer Centre provide good networks for people with dementia and their families to receive support and help from their peers. It was also recognised that younger people with dementia also need that peer support and it can often be difficult for those people younger than 65 to relate to older people with dementia due to lack of common interests. There is often little in the way of support mechanisms for younger people with dementia and it was highlighted as important not to forget this group of people.

6.7 Importance of Empowerment

With early diagnosis comes the opportunity for empowerment, the ability to plan a future and enhance the quality of life. An early diagnosis allows people and their families to come to terms with the dementia at much earlier point and allow those with a dementia to plan their own futures and make the choices they want to make for their own enhancement of life and their families.

6.8 Pathways of Care

Pathways of care need to be clear and concise and easily accessible by those diagnosed with a dementia. It has been recognised throughout the review process that it will be vital to ensure that once diagnosis is made that patients are provided with a clear pathway to services, treatments and information that will assist them and their families on the journey ahead.

6.9 Seamless Services

It is evident from the research undertaken that there are many organisations both statutory and voluntary who are involved in the dementia pathway of care. It is a key to improved services that there is a whole city joined up approach to the development of services and it is important for service users that there is a seamless quality to their service provision.

6.10 Third Sector

The importance of the third sector cannot be ignored in the development of dementia services. Service provision is not the remit of one organisation and through the development of working relationships and practices with other organisations a more cohesive whole city approach could be achieved. Many people often look to support group or community networks including Age Concern, The Alzheimer's Society or the carer centre rather than statutory bodies as they can feel less intimidating and provide a solid support for people with dementia and other illnesses.

6.11 Funding the Strategy

The national dementia strategy is supported by funding of £150million which sounds a lot but when divided across the whole of England will not amount to very much. It will be important for commissioners and service providers to ensure that resources

are well used and provide good value for money to meet the demands and expectations that have been raised as a result of the National Dementia Strategy.

7 Recommendations

Recommendation 1: To clarify the prevalence and incidence of dementia in Sunderland by initially utilising information that has already been collated by the PCT and Local Authority. This will also provide a means of examining the levels of under diagnosis of dementia, which currently exist in Sunderland.

Recommendation 2: To undertake the development of a Reducing Stigma Campaign that includes a focus on the positive experiences of people with dementia.

Recommendation 3: To develop and promote a Raising Awareness Campaign that provides a coordinated approach involving all the major stakeholders.

Recommendation 4: That Sunderland City Council, if the opportunity arises, should apply to be a demonstrator site for the Dementia Advisor role as outlined in the National Dementia Strategy.

Recommendation 5: To review the current Public Health Strategy in order that messages within the strategy focusing on healthy lifestyles include links to the prevention of vascular dementia.

Recommendation 6: To develop a coordinated stakeholder service directory that is available to the general public that provides advice and information on dementia services through information that is already held on the Starting Point Database which, is currently in use in the city. . This process would allow for the review of the existing information that is available, taking into consideration the quality and accessibility of support throughout an individual's journey.

Recommendation 7: To review the current pathway of care identifying where changes need to be made in order that an early diagnosis and intervention can become a reality, including the referral into the pathway.

Recommendation 8: To review the role of the liaison service within City Hospitals to identify and address any capacity issues in service provision.

Recommendation 9: To ensure inclusiveness when implementing the local response to the National Dementia Strategy that consideration is given to young people and people with learning disabilities who have dementia.

Recommendation 10: To progress the workforce development strategy that exists in each sector (Local Authority, Public Health, and PCT) so that all dementia service providers offer good quality services to people with dementia.

Recommendation 11: To raise awareness of the Community Mental Health Team in Sunderland, including increasing the profile of the team and how potential service users can access the service.

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Recommendation 17: That the Health and Wellbeing Review Committee receives regular reports on the local implementation plan.

Recommendation 18: That the Health and Wellbeing Review Committee provides a written response to the Department of Health on the National Dementia Strategy.

8 Monitoring

- 8.1 The Health and Wellbeing Review Committee in preparing this report recognises that to achieve many of these recommendations will take a multi-organisational approach and it is hoped that the key stakeholders will assist the Health, Housing and Adult Services in developing and achieving these recommendations. It is to this end that the Older People's Mental Health Strategy Group will play a vital role in coordination, implementation and monitoring of the recommendations. The group has representatives from Sunderland City Council (who chair the group), NTW, Sunderland TPCT, City Hospitals, Third Sector, Carers and people with dementia.
- 8.2 The Health and Well-Being Review Committee will receive quarterly reports from the Health, Housing and Adult Services Directorate and the Older People's Mental Health Strategy Group about progress made on the implementation of the recommendations in this report. These presentations should be facilitated by the Review Co-ordinator.

9 Bibliography

9.1 The following documents have been circulated to Members as background information useful for this review:

- Department of Health (DoH), 2009. Living well with dementia: A National Dementia Strategy. Department of Health. Crown Copyright.
- Older People's Mental Health Group 2007. Dementia in Sunderland: A Health Needs Assessment.
- Sheffield Hallam University 2008. Healthy Ageing in the City of Sunderland. Independent report for Sunderland Partnership.
- Alzheimer's Society 2007. Dementia UK: A report into the prevalence and cost of dementia.
- Kingshill Research Centre 2002. Before diagnosis of dementia is established.
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Appendix 1 – Research Undertaken

- Interviews with the following were carried out
 - Sharon Lowes – Strategic Commissioning Manager - HHAS
 - Ann Dingwall – Strategic Commissioning Officer - HHAS
 - Norman Taylor – Deputy Head of Adult Services - HHAS
 - Stephanie Downey – Team Manager – Services for Older People
 - Alison McDowell – Team Manager – Services for Older People

- Individual interviews with the following Sunderland City Council staff were carried out:
 - Sharon Carr -
 - Jean Hamilton -

- Interviews with the following external providers:
 - Ernie Thompson – The Alzheimer’s Society
 - Sheelagh Dilworth – The Alzheimer’s Society

- A visit was undertaken to look at the work of the Community Mental Health Team with Margaret Trethowan and Alison Scott.

- A Community Day held on 5th February 2009, invited views from the public, service users, carers and provider organisations. Approximately 130 delegates took part in the event. Key Speakers for the event included:
 - Professor Sube Banerjee – Co-author of the National Dementia Strategy
 - Neil Revely – Director of Health, Housing and Adult Services
 - Pauline Porteous – a carer
 - Dr Wendy Kaiser – Divisional Manager Older Peoples Services – NTW
 - Ian Holliday – Lead Commissioner Mental Health Services
 - Caroline Burden – Regional Manager The Alzheimer’s Society

- An expert Jury Event on 18th February 2009, where final evidence was presented to members of the committee by:
 - Sharon Lowes – Head of Performance and Development (Adults), HHAS (who gave an introduction to the event and facilitated along with Ann Dingwall)
 - Dr Andrew Cooper – Old Age Psychiatrist - NTW
 - Alison McDowell – Team Manager, HHAS
 - Ian Holliday – Lead Commissioner Mental Health Services
 - Dr Henry Choi – General Practitioner
 - Service User
 - Mr Daniel Collerton – Consultant Clinical Psychologist, NTW
 - Pauline Porteous - Carer
 - Ernie Thompson – Alzheimer’s Society and carer

Appendix 2 – Community Day

The Community Day was held at the Stadium of Light on 5th February 2009. Below was the itinerary for the day.

	Buffet lunch	12:00-12:45	(45 mins)
1	Cllr Norma Wright, Chair of HWB Review Committee Welcome	12:45-12:50	(5 mins)
2	DVD Presentation – Featherhead A short DVD made by the Alzheimer’s Society	12:50-13:00	(10 mins)
3	Professor Sube Banerjee, Co-Author of the National Dementia Strategy The national picture and a look at the development of the National Dementia Strategy	13:00-13:30	(30 mins)
4	Neil Revely, Director of Health, Housing and Adult Services Sunderland City Council The Local Authority perspective	13:30-14:00	(30 mins)
5	Pauline Porteous A personal perspective	14:00– 14:20	(20 mins)
	Coffee break	14:20-14:40	(20 mins)
6	Ian Holliday – The commissioning perspective Dr Wendy Kaiser – Service provider perspective	14:50-15:20	(30 mins)
7	Caroline Burdon – The Alzheimer’s Society A voluntary and community sector provider perspective	15:10-15:30	(20 mins)
8	Group discussion Questions for group discussion: 1. Based on the presentations you have heard, how important will the National Dementia Strategy be in shaping services in Sunderland? 2. What will be the key issues to the National Dementia Strategy in providing future dementia services in Sunderland?		
9	Cllr Norma Wright, Chair of HWB Committee Questions and close	16:30-16:45	(15 mins)

The day generated much discussion about the issue of dementia.