AGENDA ITEM:

DEMENTIA AD HOC SCRUTINY PANEL

13 AUGUST 2009

DRAFT FINAL REPORT

BACKGROUND

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"Its an inevitable part of ageing"

"There's nothing you can do about it"

- 1. The two statements above are often heard in everyday life when people talk about Dementia. Both are widely believed to be true and both are wrong.
- In considering the topic of Dementia, the Panel has spoken to a wide range of people, representing different agencies and at times representing different viewpoints on what is needed to address the coming pressures that Dementia will bring.
- 3. Before this paper documents the evidence it has gathered, or possible approaches to dealing with the questions posed by Dementia and its rising prevalence, it sets out the data it has considered regarding the huge challenges that Dementia will pose in the coming years. Secondly, there is the financial and social cost that Dementia will pose for future generations.
- 4. The topic of Dementia has never had a higher national profile than the one it currently enjoys and this is the case for a number of reasons. The Government has undoubtedly given the topic a much greater political profile. By publishing the first ever National Dementia Strategy¹, the government has increased the level of discussion around a topic that was not spoken about enough and was not considered to be as big a problem as it is.
- 5. Quite apart from the moral act of raising the profile of Dementia and how society tackles it, there is also a financial necessity to do so. The preamble of the

¹ Please see

http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH_0 83362

National Dementia Strategy and *Paying the Price*², a recent report by the *Kings Fund*, highlights the staggering financial cost of Dementia to the UK economy. The total cost of Dementia care in 2007 for England was estimated at £14.8 billion, with a projected rise to £34.8 billion by 2026, which represents a rise of 125%. In 2007 it was estimated that 582,827 people in England had Dementia. By 2026, it is projected that this will rise to 937,636, which equates to a 61% increase.

- 6. It is also undoubtedly a bigger issue in the public consciousness, partly due to a number of high profile public figures who have publicised their personal experiences. This has undoubtedly done Dementia a great service, in raising the profile of a condition, which is going to require a bigger and bigger proportion of health and social care budgets.
- 7. In addition, there is a regional dimension to Dementia and it has been afforded a greater regional profile in considering the development of local services. The document *Our Vision, Our Future Our North East NHS*³ highlights Dementia as crucial to tackle and as a pressing concern.

8. Terms of Reference

- 8.1 To establish the prevalence and associated present and future cost of Dementia in Middlesbrough
- 8.2 To establish what the prevailing national policy is in relation to Dementia services and how it is being implemented in Middlesbrough
- 8.3 To investigate local Dementia services and establish the extent to which they are consistent with national standards
- 8.4 To investigate the level of support provided to the carers of those with Dementia
- 8.5 To establish the relevant patient pathways for people having been diagnosed with Dementia, including those diagnosed with young onset Dementia.
- 8.6 To establish the level of interagency working when dealing with people with Dementia
- 8.7 To investigate how the local health and social care economy will look to develop Dementia services in the next three to five years.

Membership

Cllr J Brunton (Chair), Cllr J McPartland (Vice Chair), Cllr B Dunne, Cllr D Davison, Cllr E Lancaster, Cllr E Dryden, Cllr F McIntyre, Cllr G Clark, Cllr H Pearson, Cllr H Rehman, Cllr J Cole, Cllr M Whatley, Cllr P Purvis, Cllr P Rogers, Cllr S Carter.

² <u>http://www.kingsfund.org.uk/research/publications/paying_the_price.html</u> Paul McCrone, Sujith Dhanasiri, Anita Patel, Martin Knapp, Simon Lawton-SmithISBN: 978 1 85717 571 4

³ http://www.northeast.nhs.uk/vision/future/

INTRODUCTION

9. The term 'Dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions⁴. Dementia results in increasing levels of disability and dependence for those with the condition and as can be seen in this paper, the impact of Dementia is strongly associated with expected demographic changes. There are over 100 different types of Dementia. Some of the more common causes are outlined below.

Alzheimer's disease

10. This is the most common cause of Dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.

Vascular Dementia

11. If the oxygen supply to the brain fails, brain cells may die. The symptoms of vascular Dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes, which may not have a physical impact.

Dementia with Lewy bodies

12. This form of Dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue.

Fronto-temporal Dementia

13. In fronto-temporal Dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory.

Korsakoff's syndrome

14. Korsakoff's syndrome is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a Dementia, people with the condition experience loss of short term memory and associated physical symptons.

Creutzfeldt-Jakob disease

15. Prions are infectious agents that attack the central nervous system and then invade the brain, causing Dementia. The best-known prion disease is Creutzfeldt-Jakob disease, or CJD.

AIDS-related cognitive impairment

16. People with AIDS sometimes develop cognitive impairment, particularly in the later stages of their illness.

⁴ Please see

http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200131&documentID=106

Mild cognitive impairment

17. Mild cognitive impairment (MCI) is a relatively recent term, used to describe people who have some problems with their memory but do not actually have Dementia.

Rarer causes of Dementia

- 18. There are many other rarer causes of Dementia, including progressive supranuclear palsy and Binswanger's disease. People with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease can also be at an increased risk of developing Dementia.
- 19. There is no cure for Dementia. Drug treatments, however, do have the potential to slow the progression of Alzheimer's Disease but doneepezil, galantamine and rivastigmine are only recommended by NICE for those with moderate severity rather than those in the early stages of the disease. Most care for Dementia takes the form of social care and support, residential care and informal care from family members.
- 20. When one consults the figures and looks at future estimates for the prevalence of Dementia in the population, the first question that most people would ask is something along the lines of "Why is it going to increase so much?".
- 21. The first and perhaps most significant reason for this is that people are living longer. As Dementia is predominately (but not exclusively) something that affects people over 65, it stands to reason that the longer someone lives over 65, the higher the odds are that they will develop Dementia. This, it could be said, is a natural consequence of the fact that we, as a species, are living longer and longer.
- 22. As medicine and living standards have improved, living to an old age is no longer the preserve of the highly privileged. It is therefore predictable that if more people are living to those ages, more people will develop Dementia.
- 23. Secondly, there is a question of diagnosis. Like most medical conditions, such as cancer or heart disease, as diagnostic technologies and techniques improve, it can appear that more people 'have' a condition, than have ever had, whereas in reality there are higher levels of diagnosis. There will be an element of this effect in the Dementia figures. Despite higher diagnosis rates, the Panel has heard that diagnosis of Dementia remains an issue of crucial importance where development is required. The Panel has considered this topic in great detail elsewhere in the report.
- 24. In considering the current cost implications of Dementia, and the predicted future cost implications of Dementia, it is useful to see where those cost pressures will be greatest. The following graph is a useful demonstration of where they lie.

EVIDENCE COLLECTED

Discussions with Regional Leads for Older People's Mental Health

- 25. The Panel met with the North East Director of Commissioning in Mental Health and Learning Disabilities and the Lead Commissioner in order to receive information about emerging national policy in relation to Dementia services. At the time of the Panel's meeting the publication of the National Dementia Strategy had been delayed but it was since publicised during the course of the review.
- 26. The Panel heard that in August 2007 a year long programme was launched by the Department of Health to develop a national Dementia strategy and implementation plan. The work would concentrate on 3 key themes
 - improve awareness of Dementia, among the general public and among health and social care professionals
 - ensure that the condition was diagnosed as early as possible to allow for early intervention
 - deliver a high quality of care and support for both those with Dementia and their carers.
- 27. There was a common misconception held by people that Dementia was just a natural consequence of getting old and that nothing could be done. However the Panel were informed that, in practice, there was a great deal that could be done to delay the onset and progression of the condition and to improve the quality of life of all patients and carers. Dementia is not a normal part of the ageing process and where there was an early diagnosis it could often lead to a better outcome. The strategy was to be designed in order to address the needs of everyone with Dementia, regardless of the type of Dementia they had, their age, ethnic origin or social status.

Key Points

- 28. The Panel learnt about a number of key facts which are summarised as follows
 - Dementia is predominantly a disorder of later life, but at least 15,000 people under the age of 65 have the illness
 - People with Downs Syndrome are at much higher risk of developing Dementia⁵

⁵ About 20 per cent of people with a learning disability have Down's syndrome, and people with Down's syndrome are at particular risk of developing dementia. Figures from one study (Prasher 1995) suggest that the following percentages of people with Down's syndrome have dementia: 30-39 years 2%, 40-49 years 9.4%, 50-59 years 36.1%, 60-69 years 54.5%

Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. However, research has shown that amyloid protein found in these plaques and tangles is linked to a gene on chromosome 21. People with Down's syndrome have an extra copy of chromosome 21, which may explain their increased risk of developing Alzheimer's disease. Please see http://alzheimers.org.uk/factsheet/430

- > Over 570,000 people in England have Dementia
- The number of people with Dementia is projected to double in the next 30 years
- 29. The Dementia UK⁶ report estimates the cost of Dementia for the UK as a whole to be about £17billion per year, and projects that the number of people with Dementia will double to 1.4 million in the next 30 years and the associated costs set to treble to over £50 billion per year.
- 30. It is estimated that the cost of Dementia care exceeds that of cancer, heart disease and stroke combined.
- 31. Dementia has a devastating impact on those with the condition. It also has profound, negative effects on the family members who provide the majority of all care. Dementia is a terminal condition, but people can live with it for 7-12 years after diagnosis.
- 32. The National Audit Office has identified problems in the current systems of heath and social care for Dementia. Its report '*Improving Services and Support for People with Dementia*'⁷ estimates that approximately two-thirds of people with Dementia don't receive a formal diagnosis, or have contact with specialist services, at any time in their illness.
- 33. There is clear evidence that providing people with a diagnosis decreases their levels of depression and anxiety.
- 34. The Panel were informed that the strategy set out a series of recommendations to put people with Dementia and their carers at the heart of planning their lives, empowering people to make choices about their care.

National Policy Agenda

- 35. The nature of Dementia meant that the development of a policy and services for people with Dementia and their families also needed to be put into the wider policy context. Including policies initiatives and guidance such as
 - > 'Our NHS, Our Future'
 - Putting People First A shared vision and commitment to the transformation of adult social care
 - > The current public debate on the future of the care and support systems
 - > The National Institute for Health and Clinical Excellence (NICE)
 - The Carers' Strategy

⁶ http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2

⁷ http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx

> The National End of Life Care Strategy

Issues for commissioners and service providers

- 36. In order to deliver the strategy it means that there were going to be big challenges to commissioners. Specifically, as to how they would commission services that could meet the growing need. Decisions would of course depend on local analysis and prioritisation including a consideration of how best to use existing resources. Dementia care was seen as an issue for both the health and the social care systems as a whole, rather than simply the responsibility of a specialist older people's mental health service.
- 37. It was noted that innovation and the redesigning of services would be needed in order to achieve the transformational change required to ensure that all those people with Dementia would receive a high quality diagnosis and care.

The Dementia Strategy

38. The strategy's vision included a number of areas beginning with improving both professionals and the public's awareness of the condition and informing people that it isn't just a normal part of ageing and that an early diagnosis is best. There needed to be a simple referral process and rapid response, specialist memory assessments for all new cases and a single point of referral for diagnosis in each area. In terms of care once diagnosed, the strategy wanted to ensure that there would be a provision of high quality care and support for people with Dementia and their carers, be it in their homes, acute hospitals, or care homes.

North East Picture

39. The Our Vision, Our Future – The Darzi Next Stage Review Report identified that Dementia services in the north east were generally underdeveloped and would not meet the growing needs of the region's ageing population. The improvement and development of Dementia services should be an urgent priority.

Progress to Date

- 40. In order to facilitate the implementation of the strategy in the North East a group of members from local councils, GPs, patients and carers, trusts, third sector organisations, Strategic Health Authority (SHA), Department of Health and the regional commissioning team had been established which meets once a month. It was currently focused on mapping Dementia services in the North East in order to highlight good practice, areas for improvement and gaps in service.
- 41. The Panel was informed that less than half the people who had Dementia received a proper diagnosis and that for some they could be two or three years into their illness before a diagnosis was made.
- 42. Early recognition and diagnosis of Dementia was a priority for developing effective local services. It was recognised that joint working with service providers would develop robust and clearly understood pathways for identification, diagnosis and treatment of Dementia in all care settings. In addition to this it was also important to provide a programme of training for staff and accessible public

information. The Panel learnt that there was an indicative sum of £400,00 allocated for Middlesbrough for the next financial year from the SHA and NHS Middlesbrough, and that a significant amount of the sum would be used to invest in education and staff training.

- 43. In order to enhance early diagnosis and specialist assessment a single point of referral for diagnosis in each area needed to be commissioned. The strategy proposed open access memory clinics, which will not require a referral from a GP and that all new cases would receive a specialist memory assessment. It was important to ensure a correct diagnosis as there were different forms of Dementia, with Alzheimer's, Vascular and Lewy Bodies being the three most common and treatment for each type varied.
- 44. It was noted that it was going to be a challenge for commissioners to be able to meet the needs identified and prioritise using existing resources. The Lead Regional Commissioner was unable to provide specific information on the value of current services commissioned.

Evidence from NHS Middlesbrough & Middlesbrough Council's Department of Social Care

- 45. The publication of the National Service Framework for Mental Health in 1999 and for Older Adults in 2001 were instrumental in the development of higher quality care for these two major health areas. However, the Panel was informed that despite some major achievements there still remained significant challenges to the delivery of health and social services for older people with mental illness. In particular older adults with mental illness had not benefited from some of the developments seen for working age adults.
- 46. In JCUH in 2006/07 there were 20,000 admissions of over 65s of which 12,000 would be expected to have a common mental health problem. At the time of the review it was estimated that there were 1,671 people over 65 with Dementia in Middlesbrough and that there would be an estimated 239 people being diagnosed with Dementia each year. There were approximately 45 people who were aged under 65 with Dementia. It was also estimated that these figures would rise by about 20% in 20 years.

Current Expenditure

- 47. The Panel was interested to find out what the current NHS Middlesbrough and Middlesbrough Council spend was on Dementia services and what range of services that money provided. It was reported to the Panel that the exact amount of NHS Middlesbrough spending on Dementia services was difficult to quantify and that the figures that were available did not include a variety of costs such as prescribing of all medication in General Practice and support offered through non-specialist and mainstream NHS services. Therefore the Panel were asked to treat the figures provided only as a broad guide.
- 48. The main bulk of NHS Middlesbrough spending on mental health services for older people in Middlesbrough is focused on one major contract with TEWV NHS Trust.

49. TEWV's Service Spend – 2008/09

Service	Spend £	
In Patient Services	1,912,343	
Community Mental Health	1,280,501	
Young Onset Dementia	126,013	
Total	3,318,857	

Other expenditure

- 50. In addition to the Middlesbrough NHS Middlesbrough spend approximately £980,000 annually on supporting nursing home placements both locally and with out of area providers and £130,000 is spent on anti Dementia medication⁸ across the locality.
- 51. The local authority estimates the spend on Dementia services for 2008/09 as follows

Service	Estimated Out Turn £
OPMH Social Work Team ⁹	266,625
OPMH Nursing Care	699,100
OPMH Residential Care	2,147,400
OPMH Respite Care	37,800
OPMH Block Contract Willows/BUPA	67,300
OPMH Res Short Stay Placements	25,000
Hazeldene Day Centre	252,600
OPMH Day Care – Phoenix	10,000
OPMH – Alzheimers's	27,100
OPMH Direct Payments	130,500
Young Onset Dementia Team	15,000
Total OPMH	3,678,425

52. The impact on finance of the increasing demand for Dementia services was recognised within the Social Care commissioning strategy. Dementia was identified as a key priority and there were specific actions, which were designed to support the strategy. The Social Care commissioning strategy aimed to reduce the impact of Dementia on people's lives and recognised that Dementia had a devastating effect on patients, carers and their families. That would be addressed through the systematic implementation of the National Dementia Strategy.

Provision in Middlesbrough

53. The Older Persons' Mental Health Local Implementation team, which is led by the Head of Service for Mental Health & Learning Disabilities, was established in 2001 and is made up of representatives from Middlesbrough Adult Social Care, NHS Middlesbrough, TEWV Foundation Trust, the voluntary and independent

⁸ A detailed account of anti-Dementia drugs can be accessed at the following address <u>http://alzheimers.org.uk/factsheet/408</u>

⁹ OPMH stands for Older Peoples Mental Health

sectors and carers. This was in recognition that in order to improve the mental health capacity of generic older people's services and develop specialist mental health services for older people, there was a requirement for a higher profile and increased investment of time, people, joint planning and funding. There was also a recognition that a model of mental health services for older people needed to be developed with all stakeholders, jointly owned and documented in order to inform service development, commissioning and performance management. A good example of that kind of approach was the Woodside Community Mental Health Resource Centre that opened in 2003.¹⁰

- 54. A service plan for the development of the Mental Health Services for Older People was produced by the Local Implementation Team and had the following aims:
 - a clear and strategic direction for health and social services senior management
 - a resource for all stakeholders in their local partnership work in planning and developing service models
 - > an action plan for stakeholders to develop, deliver and invest in services
 - a basis for multi-agency ownership of the strategy and commitment to excellence in mental health services for older people
 - a platform to praise the profile of mental health issues in the community, through consultation involving users and carers
 - a link with other strategies, including Skills Development and Intermediate Care
 - a resource to achieve Local Delivery Plan requirements and priorities set out in the Social Services Delivery and Improvement Statement and to build on the TNEY Strategy for the Development of Mental Health Services for Older People.
- 55. The Department recognised, through evidence from reports such as *Forget Me Not*¹¹ and *Out of the Shadows*¹² that one of the biggest areas of concern for people was the delay in receiving a diagnosis.
- 56. The Social Care Department undertook to work with service providers to develop clear ways of identification, diagnosis and treatment of Dementia across all care settings and developing personalised packages of care. What was also important in delivering the strategy was increasing awareness amongst staff working in health and social care settings of the effects of Dementia and improving the recognition of its symptoms.
- 57. It was reported that the initiatives would be monitored through a range of measures and would have targets for the access to diagnosis, the development of personalised care plans and increased patient satisfaction.

Residential Care

¹¹ National Audit Office 2000

¹⁰ The Panel has subsequently heard a number of positive reports about the work being carried out at Woodside. The Panel actually enquired about the possibility of a visit to Woodside, but it was told such a visit would not be possible at the time.

¹² Alzheimer's Society 2008

- 58. It was reported that the residential bed occupancy for elderly Dementia service users was running at less than 90% for the past year and had reduced to 80% in the last month¹³. It was well known that Middlesbrough has an ageing population and that the demand for care home places for people suffering from Dementia would steadily increase. In order to deal with this issue Middlesbrough Council and the NHS Middlesbrough said that they would monitor changes in demand on a weekly basis and 'endeavour to commission' new services or altering existing services. Panel members questioned this commitment and were told that they would be working with independent advisors and residential homes in order to be able to provide places.
- 59. The Panel learnt that Middlesbrough was one of the top performing authorities in supporting people over 65 to live in their own home and that this would continue to be a priority when providing services for people with Dementia, including investment in technology and adaptations.

Examples of Services available to Older People with Mental Health Problems in Middlesbrough

- 60. Examples presented to the Panel were as follows
 - Liaison Mental Health Services into Acute Hospitals nurse led, hospital based, which is planned to expand into a multidisciplinary team.
 - Older People's Mental Health Carers Forum group meets to provide support to carers
 - > Dementia Link Co-ordinator offering advice, support and information
 - Intermediate Care Services prevent unnecessary admission and promote early discharge
 - Specialist Mental Health Services Inpatient Care Older Adult Acute Assessment – functional assessment unit for older people
 - Integrated Community Mental Health Team based at Woodside Resource Centre and close to support services
 - Primary and Community Care including Day Services, Day Hospitals/Treatment Services, Home Care Services, Residential Care Homes
 - Special Group Services for young people with Dementia
 - Support Services Older Person's Group Phoenix Project activities run by volunteers and service users
 - Woodside Resource Centre providing Day and Respite Care Services alongside Nursing Home provision.

Investment in services

61. The Panel learnt that there had been an increase in the investment in services for people with Dementia in the last year. It had included the development of an older persons' mental health team to work in the care home sector. There were 3 specialist mental health nurses working across the Middlesbrough and Redcar & Cleveland areas that offered support, advice and education to staff working in the care home sector. The advice would be on all areas of mental health in older people and would focus particularly on Dementia and depression and help

¹³ At the time of the meeting

to raise awareness of the condition, again helping to ensure people got access to timely and appropriate treatment.

- 62. The Panel were also informed that there had been an investment to provide an additional 3 specialist mental health workers in the Acute Hospital Liaison service working into JCUH to offer advice, education and support in managing older people with mental health problems in an acute hospital setting. A memory clinic had been developed in Middlesbrough based at the Woodside Resource Centre. The clinic would undertake assessments of memory problems and undertake investigations to assist in the diagnosis of Dementia. Following diagnosis patients would be offered treatment where appropriate and advice and support to prepare people for the future.
- 63. Further developments that were planned included the extension of the Community Mental Health Team for older people, to provide a 7 day service that enabled access to specialist mental health services. This will support people in receiving a wider range of care and treatment in their own homes and reducing the reliance on hospital based services. There was also a planned increase in investment in the Acute Hospital Liaison Service for JCUH.
- 64. A service plan for the development of Mental Health Services for Older People had been produced for Middlesbrough by the Local Implementation Team. The commissioning priorities from the plan were being developed and the plan was reviewed and monitored on a regular basis.
- 65. To conclude, the NHS Middlesbrough and the Department of Social Care said that they would continue to work together closely and monitor the increases in demand for services, as well as projections of demand based on population data and plan and commission services to meet the needs of the people.
- 66. They would also improve services in line with the National Dementia Strategy, increasing awareness and access to services, increase screening, diagnosis and timely interventions to provide high quality treatment.

EVIDENCE FROM TEWV

- 67. Following the receipt of evidence from the local authority and NHS Middlesbrough regarding the amount of money spent and where it is spent on Dementia services, the Panel were keen to get the views of the specialist mental health trust serving the area, which is the TEWV NHS Trust.
- 68. Prior to the Panel meeting, a number of questions were sent to TEWV and they were initially answered in a paper submitted to the Panel¹⁴. The meeting then took the form of a debate about the points raised in that paper.
- 69. The first question asked what the current TEWV spend on Dementia services was for Middlesbrough and for how many people. The Panel heard that the disaggregation of the TEWV mental health contract by service and by locality had not been completed. In addition, the Panel heard that there has not been any

¹⁴ The paper can be found as part of the supporting papers to the Panel.

precise assessment of the spend on older people with Dementia and the spend on older people with age psychosis, with age related depression or anxiety.

- 70. Nonetheless, it was estimated that around £2million per annum, from the contract, is spent on services relating to Dementia in Middlesbrough. Over the course of a year, this typically provides inpatient care for 50 people. A further 400 patients will be assessed and treated in the community or in day care. The Panel also heard that TEWV would assume that acute hospital liaison nurses see around 100 people with Dementia. The Panel heard that clinical staff would express the view that they spend around two thirds of their time addressing issues pertaining to Dementia.
- 71. The Panel was rather troubled to hear that TEWV believes that it is only in contact with around a third of the 1600 people likely to have Dementia in Middlesbrough at the present time. The Panel was told, however, that this number is increased through the contacts with the social care staff that are part of the integrated team in Middlesbrough.
- 72. The Panel accepted that itemised costing and associated tariffs were harder to conceptualise and implement in Mental Health, as treatment is much less distinct that in physical health. Nonetheless, it expressed the opinion that the lack of intelligence about what is spent on Dementia services in Middlesbrough is concerning. This is something, the Panel heard, that is being worked on. The Panel also heard that whilst each intervention or episode could not be costed exactly, it is certainly clear that if there was a upturn in the number of Dementia sufferers accessing TEWV, (say significantly more than the estimated one third that access TEWV services now), the current funding from the NHS Middlesbrough would not be adequate. Whilst TEWV would endeavour to meet the demand in year, on a more strategic level such a greater call on expertise would not be sustainable without additional funding, which would be a matter for the NHS Middlesbrough to consider.
- 73. The Panel expressed an interest in ascertaining the types of services, provided by TEWV, that are available in Middlesbrough for people with Dementia. There are:
 - Inpatient assessment and treatment together with a continuing care for people wit challenging behaviour. One of these units focuses specifically on Dementia and the other on generic mental health problems. They are both provided on a south of Tees basis.
 - Community teams providing specialist, multi-disciplinary assessment and treatment including some support for people at the end of life. A team specialising in this patient group sees patients who are under 65 years, which has been in place since 1999.
 - Day services are provided at Woodside on two days for people who would otherwise need residential care.
 - Liaison services into the acute hospital and care homes by staff who assess, provide advice or input into the management of people with Dementia.

- 74. The Panel asked whether TEWV provides any services for Dementia carers in Middlesbrough. It was said that TEWV has an important role in identifying people with a caring role and offering assessments of their needs. TEWV would also provide advice and support as part of the care offered to patients and their relatives. If relatives require psychiatric support then TEWV staff can signpost to those services, including those TEWV provides.
- 75. It was confirmed that TEWV does not offer other services to carers, for example respite care or financial assistance, or help with benefits. The Panel heard that TEWV recognise how vital such services are, although they are not commissioned to provide such services and as a clinically focus organisation, are probably not the best placed to deliver those services.
- 76. Indeed, the view was expressed that whilst happy to assist in the provision of advice, if TEWV was to take a much more active role in this sort of service provision, without a NHS Middlesbrough commissioning mandate, it would actually be diverting funds away from expressly commissioned services. It was also asserted that there may be a distinct advantage in such advice and assistance services not being provided by the statutory sector. Third sector organisations are often much better at providing such services and people may feel more comfortable speaking to a 'non NHS' service, especially if there are complaints or concerns over elements of the treatment or service provided. Fundamentally, it is NHS Middlesbrough and Middlesbrough Council's decision to commission such services and whom they commission them from.
- 77. The Panel was interested to hear TEWV's views as to whether there are presently any gaps in Dementia services and the patient journey that require attention. The Panel heard that, in the view of TEWV, there could be improvements made in the speed of referrals for assessment, diagnostic services and support available to people whom are newly diagnosed, particularly from the third sector.
- 78. The Panel heard that TEWV also feel that information available to patients and their carers could be improved, particularly in ensuring that information given is understood and that there is an opportunity to ask questions. It was also confirmed to the Panel that, in the view of TEWV, people with Dementia and their carers would benefit from more intensive support and availability of support through extended hours across the week.
- 79. It was also confirmed to the Panel that, in the view of TEWV, the availability of the acute liaison services is "a long way short of the ideal". The topic of liaison services for the acute setting is a theme that the Panel revisits later in this report. Nonetheless, the Panel was keen for TEWV to expand on its views in relation to acute liaison services.
- 80. The Panel heard that whilst acute liaison services have improved a great deal when compared to their historical performance, there is still along way to go, which is accepted by all in the local NHS. The Panel heard that there remains a pressing need to improve the level of care given to people with Dementia when dealing with their physical health needs. It was suggested by TEWV that a number of questions should be asked when considering the effectiveness of acute liaison services, such as:

- > What tools does an acute facility have to assess possible Dementia cases?
- How are staff on wards (such as surgical) trained in respect of dealing with Dementia?
- The nature of discharge procedures and how they pay any attention to people with Dementia?
- > What are the views of the STHFT on the liaison service?
- How good is the engagement with carers of those who come into an acute hospital with Dementia?
- 81. The Panel heard that it is quite common for nursing staff to not receive Dementia training per se, even in wards that will receive a high proportion of older people. This seemed quite bizarre to the Panel and was identified as something that the Panel would like to explore further.
- 82. It was said that the TEWV representative would have concerns over the standard of care for those with Dementia in JCUH, in terms of the totality of their needs being met. TEWV advised the Panel that there are also concerns over some GPs in the handling of people with possible Dementia.
- 83. The Panel also heard that TEWV would be interested in hearing how the acute hospital environment has worked towards the implementation of *Who Cares Wins*¹⁵.
- 84. *Who Cares Wins* is a document published by the Royal College of Psychiatrists and it focuses upon improving the outcomes for older people admitted to the general hospital.
- 85. The Panel's attention was particularly caught by the following excerpt from Who Cares Wins:

"The number of older people, those aged 65 or older, will rise by 59% from 2000 to 2031, with an even greater increase of 79% in the "older old", those aged 80 years and over.

Since many illnesses become more common with increasing age, this demographic change has considerable implications for healthcare. An ageing population brings with it a disproportionate increase in common conditions such as degenerative disorders, stroke, cancer, and Dementia.

Older people currently consume approximately 40% of healthcare resources in England and Wales and the position is similar in other parts of the British Isles. Older People occupy two thirds of general hospital beds so that, in a typical general hospital of 500 beds, at any time some 330 beds will be occupied by older people, and approximately 5000 older people will be admitted to this hospital each year. It is

¹⁵ Who cares wins, Improving the outcome for older people admitted to the general hospital: Guidelines for the development of liaison mental health services for older people. Report of a working group for the faculty of old age psychiatry, royal college of psychiatrists, © 2005 The Royal College of Psychiatrists.

estimated that of those 330 beds occupied by older people that around 102 will have Dementia.

- 86. The Panel revisits the ethos of *Who Cares Wins* later in this paper, particularly when discussing in detail the role of acute liaison services. As an initial observation, however, the Panel was particularly interested in the following recommendations from Who Cares Wins, which it pursues later in this paper.
- 87. **Commissioners** Need to ensure that all acute hospital trusts have clear plans to meet the mental health needs of older people. This will require the provision of specialist liaison mental health services, attention to skill mix and improved training for general hospital staff.
- 88. **Acute Hospital Trusts** Need to work with mental health services to improve understanding and the routine assessment of the mental health needs for older people admitted to general hospitals.
- 89. The Panel asked TEWV about its view on the recently published National Dementia Strategy and particularly how the strategy will influence the design and provision of TEWV Dementia services. The Panel was told that TEWV welcomed the Strategy and that TEWV aspires to play its part in the delivery of the seventeen key priorities. TEWV's own strategic plans anticipated the content of the strategy and TEWV, the Panel heard, is particularly keen to develop memory clinics, which can be an integral part of early diagnosis and support. The Panel also heard that TEWV is keen to improve the level and quality of care provided in people's homes and extend the hours available into the weekend.
- 90. It was said that TEWV has identified a need to be sufficiently flexible, to work with other organisations who will need to respond to the requirements of the Strategy and to ensure that all parts of the system work well together. The Panel also heard that ensuring that all parts of the system work well is a task for which commissioners are ultimately responsible. It was also important to note that the implementation of the strategy by the Department of Health will ultimately be through the SHA and NHS Middlesbrough, rather than service providers.
- 91. As a final question, the Panel was interested in hearing how TEWV, as Foundation Trust, would like to develop the services it provides in the next 3 to 5 years. The Panel heard that the following actions are important areas where work should be undertaken.
 - The provision of community services seven days a week and developing the ability/capacity to responds to crises with an increased level of support.
 - Improving access to psychological therapies
 - Increasing the availability of physiotherapy within the core community team

- The introduction of speech & language therapists, with nutritionists and physical care practitioners, into the teams in Middlesbrough.¹⁶
- Participate in joint information systems linked to PARIS¹⁷
- It was also said that TEWV would like to be able to demonstrate the high quality nature of its services in much more explicit terms than it is currently able to do.
- 92. It was also noted that a huge improvement in accommodation for mental health services was on track to be delivered when the new Roseberry Park opens on the site of St Luke's in 2010.
- 93. TEWV also added that as previously touched upon, acute liaison services are presently not fit for purpose and require significant development.
- 94. It was noted, however, that TEWV could only set about delivering these developments in service if they are supported by commissioners, such as NHS Middlesbrough and Middlesbrough Council.
- Those around the table discussed the nature of relationships between service 95. providers and commissioners further. It was noted that the nature of mental health contracting would be going through a huge change in the next few years, in an attempt to bring it more in line with the tariff system, now a fixture in areas of physical health services. At present, the Panel heard that mental health commissioning and the nature of contracting lagged behind developments in physical health. At present, the Panel has heard that NHS Middlesbrough designate a quantity of money for mental health services under a block basis, rather than at cost per case basis. As such, NHS Middlesbrough does not know, other than indicative amounts, how the money is spent. It was acknowledged that in the last 10 years, a huge amount of money has been invested into mental health services, which has gone along way to addressing the criticism of mental health services being treated as the 'Cinderella Service'. Nonetheless, it was noted that the service couldn't account for that money's impact in the same way as physical health services can and this is largely down to the tariff system in operation in physical health services.
- 96. The question was posed as to whether it would be in TEWV interests to become more explicit in costings and therefore let NHS Middlesbrough know what they receive for their investment. Whilst it was accepted that this could be a view held by people, TEWV is committed to working with commissioners to improve financial analysis to demonstrate where money is spent. Nonetheless, the Panel was told that it should be accepted that mental health interventions were more difficult to quantify and to cost, by their very nature, than say, a hip replacement. The Panel heard that a good indicator of effectiveness of service is the number of bed days a given case takes up and this may be a useful starting point.

¹⁶ The Panel heard that such posts are in place elsewhere in the TEWV area of responsibility and they have had a positive impact on the delivery of, and people's experience of mental health services. The Panel was told that replicating that success in Middlesbrough was a key aim of TEWV.

¹⁷ PARIS is a NHS records system

- 97. It was noted that aside from being a national policy priority to better quantify mental health spending (which is presently being worked upon by the Department of Health), it was said that it is also a financial necessity. All available evidence indicates that the onset of the global economic downturn, and particularly its impact on the public finances, means that future financial settlements for public services will be the tightest they have been for a significant period of time. This will also come at a time when, if all demographic analysis and predictions are to be believed, the cases of Dementia will rise substantially. The Panel acknowledged therefore that understanding what mental health funding is presently buying becomes so much more essential than it was in the previous years of record funding increases.
- 98. It was acknowledged that it must be NHS Middlesbrough that seeks to drive this, and lead on the look and feel of Dementia services in the future. The point was made that whilst it remains a TEWV policy to meet demand when it is called for, over the medium to long term there would have to be a number of significant decisions to be made about funding for Dementia services and how Dementia services are structured. It was certainly felt that if the system is to continue to deal with Dementia as it currently does (which no-one the Panel has spoken to accepts is the ideal), the predicted rise in likely cases would necessitate a significant rise in funding, which may not be financially possible. As a result, it was said that the systems needs, as a priority, to reconsider how it focuses on Dementia, how it approaches the topic and how it deals with it when it is present. In short, the predicted rising demand can probably not be met to the necessary standard, if current practices are maintained.
- 99. It was said that TEWV is willing and able to play its full part in that work, although it is essential that the Commissioners lead the debate, map out the service models that it would seek to commission and service providers, such as TEWV, to provide.
- 100. The Panel heard that key challenge in delivering that vision, aside from the poor state of public finances, would be to deliver a modern and sufficiently skilled workforce. In addition, the Panel heard that there is a debate about whether the system should address Dementia (and other mental health problems) by creating more beds (and therefore more inpatients) or more community based facilities.

Evidence from South Tees Hospital NHS Foundation Trust (STHFT)

- 101. When one considers the topic of Dementia as a mental health problem, it is understandable that attention turns to the quality of services provided by General Practice and specialist mental health services. Nonetheless, the Panel has been told by a number of people that in any assessment of local Dementia services, how acute hospitals cope with those with Dementia is of critical importance.
- 102. With this in mind, the Panel thought it important to speak with the STHFT about how Dementia is approached within JCUH. This was done at a Panel meeting on 26 March 2009, which heard from a number of senior staff, clinical and managerial on the STHFT's approach to Dementia.

- 103. The Panel heard that historically, physicians have been quite poor at recognising and understanding matters of mental health. Whilst the system is now better than it was, it is by no means perfect. This is illustrated by the assertion the Panel heard that not everyone entering JCUH, who may require a mental health assessment will get one.
- 104. The Panel heard that whether a patient receives a mental health assessment or not, will largely depend on their behaviour and condition when they are being assessed. If their behaviour indicates that there may be a mental health problem, a recognised mini mental state examination tool is conducted, which is cognitive in nature.
- 105. Following an assessment, should there be an indication of poor mental health, the STHFT has a tool known as a G52 observation policy¹⁸. This is a function that is practically one to one nursing, whereby someone is assessed every 15 minutes or so, so a detailed picture of his or her behaviour can be built up over a 24-hour period. It would not be done as a matter of routine but it exists for when there is a call for it.
- 106. The Panel heard that a G52 policy observation could be kept up for a full month if there was a need and only withdrawn when a suitable facility or service was able to take them. Many people who are assisted by way of a G52 policy can be frail and at risk of falling or a danger to themselves or others, so the STHFT's duty of care to patients and staff dictates that such a course of action is taken.
- 107. The Panel was interested to hear about the ways in which the STHFT may learn that someone entering JCUH has Dementia. It was said that staff might learn about someone's Dementia from a GP's letter, from previous medical notes, or from the patient's relatives/carers. The Panel was told, however, that this is by

A member of staff is not required to remain with the patient at all times but the implications for staff resources should be considered. Any patient on close observation must not leave the ward without being escorted by a member of staff or other designated responsible person at the discretion of the nurse in charge.

¹⁸ The Panel has subsequently heard that **Level 0 - Normal** - Staff are expected to be aware of the whereabouts of all patients in their care.

Level one – Close Observation - Requires that the patients' location, clinical condition or therapy should be checked at regular intervals, e.g. 15 - 30 minutes, and the outcome of these checks documented. The exact intervals between assessments and what the assessment should consist of should be decided at initial risk assessment and documented.

Level Two – Constant Observation – For patients who are at immediate risk of harming themselves or others, due to their clinical condition or behaviour. Constant observation requires that a member of staff remains with the patient at all times and should not under any circumstances leave the patient alone and will not undertake any other duties whilst constant observation is being undertaken.

It is the responsibility of the Nurse in charge to ensure staff allocated to perform this task is competent and capable to undertake the task. The nurse in charge must also ensure that there is sufficient rotation of staff so that staff undertaking this level of observation can be relieved after no longer than 1 hour. A member of staff is required to remain with the patient at all times and the implications for staff resources must be considered. The majority of patients will not require an increased level of observation outlined in this policy i.e. the patient will be at level 0 and will therefore not require the level of nursing observation to be documented

no means a robust system, is somewhat 'hit and miss' and can quite often fall short of providing appropriate levels of information for members of staff.

- 108. The Panel heard that finding out about the mental health condition of a patient is potentially a lot easier when someone is attending JCUH for elective care, which allows time for information to be provided by, or on behalf of, the patient.
- 109. Conversely, when someone enters the hospital through an unplanned, urgent or emergency route, such as Acute Assessment or Accident and Emergency, it is much more difficult to obtain intelligence about their mental state and wider mental health. It was confirmed to the Panel that in such instances, relatives and/or carers are of vital importance in the provision of information about a patient. If there is no one to accompany the patient, it can make it extremely difficult for the hospital staff to build up a good picture of a patient's situation, although a full assessment of the individual would be done. It was also mentioned that Middlesbrough Council's Department of Social Care would be contacted to see if a person was known to them. Nonetheless, it was confirmed to the Panel that the hospital does rely a great deal on the knowledge and assistance of third parties and without it; it can be very difficult to know whether an admitted patient has Dementia.
- 110. Having acknowledged that such problems exist, the Panel was interested to hear about what the STHFT was doing to combat them.
- 111. The Panel heard that the STHFT has offered Dementia awareness training to nursing and admission staff from 2006 and it has introduced a Mental Health NVQ. The STHFT also receives support from the University of Teesside to deliver mental health awareness training sessions and some medical staff are required to consistently update their skills, which can cover mental health awareness.
- 112. It was said that historically, the STHFT has relied on consultation with mental health professionals when it was felt to be appropriate. Over the last three years, JCUH has had access to liaison psychiatric nurses, which was felt to be a huge improvement.
- 113. The Panel heard, however, that the older person's community liaison psychiatry service is significantly over stretched and demand for the service far exceeds the service's capacity. The Panel was told that whilst JCUH has two liaison psychiatric nurses to call upon, a more appropriate number, given the demands, would be five. It was said that regular meetings take place with TEWV to secure more capacity, although they have not yielded any fruit as yet. The Panel also heard that trips have been taken to Carlisle and Gateshead to see other liaison psychiatric teams 'in action' to inform development at JCUH. In the last two years, an in reach older person's liaison service has been developed, but suffers from a low capacity. As a minimum, the Panel heard, an older person's psychiatry liaison service should be able to provide an assessment service, provide educational support to staff and patients needs and identify appropriate discharge arrangements. It is clear to the Panel, on the strength of the evidence received, that this is not available as a matter of course for all those who need it in JCUH.

- 114. The Panel heard that there is already in place a psychiatric liaison service for working age adults and JCUH would like to develop a similar function, where a speciality existed in older people's mental health. The Panel was also told that JCUH would actually aspire to have a half time psychiatrist to call upon, but it all depended on whether funding could be secured.
- 115. The Panel was also asked to consider the importance of and appropriate capacity of an older people's liaison psychiatric service, given the size of JCUH. The Panel was reminded that JCUH was a very large tertiary hospital, with a great deal of complex specialities and it was the view of those present that it should have an appropriately staffed and fully functioning older person's psychiatry liaison service. It was confirmed that over recent years, medical staff felt that the psychiatric liaison service had not offered particularly good support when called upon, although this is because it is significantly over stretched and not able to meet demand.
- 116. It was said, however, that it is not simply a matter of securing appropriate funding, as filling the posts can also be quite difficult. Firstly, older people's specialities are not particularly attractive for young medics choosing which field they would like to specialise in. Secondly, Middlesbrough is in a difficult position geographically, as it sits between two large training centres in Newcastle and Leeds and young medics quite often elect to stay and work where they have trained. JCUH, therefore, has to compete against this which makes it extremely difficult at times to attract appropriately qualified staff, who due to their role and high level of autonomy, require a good level of experience.
- 117. The Panel was particularly interested in the acute liaison psychiatry service, which is currently provided at JCUH. It was confirmed that, medical and surgical staff were not necessarily trained to identify Dementia-like symptoms in people they are treating, so it may often go undiagnosed. The Panel was told that there will often be occasions where people who are displaying symptoms of Dementia, and will specifically not be referred to a psychiatric liaison team, due to the knowledge that they will probably not be seen, given the lack of capacity currently available at JCUH. The Panel found this concerning. Given the evidence received, the Panel felt that the only impression it could draw was that psychiatric liaison services at JCUH are simply 'fire-fighting' and not in a position to offer a proactive service to all of the medical specialities which will require their assistance. This also means that a significant number of people are probably heading back into the community following treatment, who have Dementia and it is not being diagnosed.
 - 118. The Panel was concerned to hear about this and enquired as to the reasons for it. Whilst the Panel heard that there was not one single and readily available reason, although there was a very strong argument to support additional investment to increase capacity at in psychiatric liaison services. On this point, the Panel discussed it further at its meeting on 27 April 2009.
 - 119. The Panel made an enquiry as to whether the STHFT is satisfied with the way it deal with patients with Dementia. In short, the answer is "no" and this was largely due to STHFT dissatisfaction with the capacity of the current psychiatric liaison service. Nonetheless, the Panel was also told that there are a number of areas of activity, which the STHFT also needs to work on. They are:

- > The need to continually monitor care and implement new guidance
- To continue to work in partnership with mental health and social care colleagues
- To further develop the pathway for patients with mental health needs for elective and emergency care
- To finish a project currently being undertaken to identify the number of patients with Dementia who are accessing Acute Hospital services
- To develop a working group led by Clinical Matrons in the Elderly to include service users, health and social care representatives
- > To support the delivery of the National Dementia Strategy
- 120. The Panel discussed further the current project mentioned above. It was said that the STHFT is working to ascertain how many people 'come through the doors' at JCUH with Dementia. For example, the Panel heard that in January 2009, 138 people came into the hospital who had Dementia and best estimates would indicate that there are around 100 cases per month of undiagnosed Dementia entering JCUH. The Panel heard that, whilst JCUH is conscious that Dementia can affect a wide range of ages, most people it deals with who have Dementia are in their eighties.
- 121. The Panel was told that the research project currently underway would shed much more light on the topic of Dementia in JCUH and provide significantly more intelligence than is currently available, on those accessing JCUH with undiagnosed Dementia. It was said that there was a consensus (and a concern) amongst front line staff at JCUH that a significant number of patients access JCUH with undiagnosed Dementia and only ever receive attention for their physical complaints. It was hoped that by conducting such a detailed piece of work, a greater understanding of the needs of JCUH's community could be arrived at and it may strengthen the argument for greater resources in the psychiatric liaison services.
- 122. It was explained that without an adequate psychiatric liaison service, the service to those with Dementia will always be less than the ideal, as physicians have competing priorities.
- 123. The example was given of a respiratory surgeon, dealing with a patient who has suspected cancer. National policy dictates that there are extremely tight deadlines for various stages of dealing with a probable cancer patient. The natural implication of this is that any evidence of Dementia will not be treated as a priority. Whilst this is not ideal, the Panel accepted that such a scenario is predictable and it is also entirely understandable that a respiratory surgeon will focus on this. To expect them to treat (or even be sufficiently qualified to do so) the suspected Dementia as a priority is unrealistic. It is precisely this gap that a properly resourced and sufficiently qualified psychiatric liaison team would be able to fill.

- 124. It was said to the Panel that the relationship with partners could improve, which in turn would assist in making services for those with Dementia more integrated. It was also highlighted that if someone was suspected of having Dementia whilst in JCUH, that was probably not definitive. The Panel heard that it would always be prudent to reassess someone in the community, when they are away from what can be a fairly stressful experience in a large acute hospital. Nonetheless, if identified in JCUH someone would be highlighted to local services and they would stand a better chance of receiving the help they are entitled to.
 - 125. Another point to bear in mind, in the view of those speaking with the Panel is that the physical health outcomes for those with Dementia are worse than those people who do not have Dementia.
 - 126. On a final note, aside from policy, implementing strategies and strategic partnerships, there are a number of practical steps that can be taken. The Panel heard that JCUH has recently taken delivery of 62 beds, which are very well designed and play a substantial part in keeping patients with Dementia much safer.

A Roundtable Debate on the future of Dementia Services in Middlesbrough

127. Up to this point, the Panel has gathered a great deal of factual information and had heard a great deal of opinions expressed about the treatment of Dementia in Middlesbrough, from a wider variety of sources. The purpose of this meeting was to present the key themes the Panel had heard so far and debate with those around the table a way forward in addressing the issues raised. The issues outlined as key to the debate are detailed at the footnote below¹⁹. The

- b) It is estimated that around two thirds of people with Dementia do not receive a formal diagnosis. Do GPs feel as though they have sufficient training to discharge their responsibilities in making appropriate referrals to mental health specialists? If not, what training could be delivered and how?
- c) The Panel has heard the view expressed that the Tees, Esk and Wear Valleys Trust is not the appropriate organisation to provide the softer elements of support such as advice services? So who should deliver such services?
- d) Is the current level of funding for local Dementia services fit for purpose, particularly when one considers the universally predicted rise in incidence of Dementia?
- e) The Panel has heard a great deal about the importance of early intervention in Dementia and has heard that there is probably around 1600 people with Dementia in Middlesbrough. According to evidence already received, it would indicate that a significant proportion of those people will be presently 'undiagnosed'. Should the local health and social care economy be trying to locate these people? And if so, how?
- f) In previous reviews of the Health Scrutiny Panel and Social Care Scrutiny Panel, it has been said that Middlesbrough is somewhat 'over-catered for' in the field of residential and nursing home places. How does Middlesbrough fare in the provision of facilities that specialise in services for people with Dementia? Is there capacity for current demand? Is there sufficient capacity to cope with the likely rise in demand?

¹⁷a) The Panel has heard there is insufficient psychiatric capacity at JCUH, which means that some people's mental health needs are not being met when in JCUH. Is this is an issue of insufficient resources, or could existing resources be used better?

debate started by addressing point (a) and the Panel worked its way through the themes outlined in footnote 17.

- 128. The Panel heard from the NHS Middlesbrough that in relation to how Dementia is addressed in the acute hospital setting, there are improvements required both in the level of investment and how the capacity within the psychiatric liaison service is utilised. The Panel heard that the NHS Middlesbrough's intention to commission more capacity is evidenced by the commitments made in the NHS Middlesbrough's recently published commissioning strategy.
- 129. It was mentioned that JCUH is an enormous hospital and serves a very large population. Efforts have been made to appoint to two additional posts, although recruiting the correct level of expertise is very difficult. In addition, there has been a piece of work undertaken to assess how psychiatric liaison services are configured and utilised.
- 130. The Panel heard that it has been accepted that adult (in mental health terms this means from 18 to 64 years) mental health services in JCUH were well evolved and had the benefit of a well resourced team and were providing a good service. The Panel heard that the same could not be said of older peoples' mental health services. It was said that there has been some progress on the delivery of a full team for older people's mental health, although it remains a work in progress. It was said that it was important to remember that a team dedicated to older peoples' mental health based at JCUH would have a responsibility across such fields as depression and delirium and not just Dementia. To put the matter in perspective, the Panel told that the best available intelligence indicates that around 55% of older people (over 65 years). admitted into JCUH already have a mental health problem, or develop a mental health disorder, during their hospital admission. It should be noted that this could manifest itself as co-morbidity, although the prevalence in older people is estimated at around 53% for depression, 35% for Dementia and 61% for delirium. The importance of skilled liaison staff was emphasised as often Dementia and depression can display similar symptoms.
- 131. It was confirmed to the Panel that the finance to meet the cost of the new team for older peoples' mental health is already in place. A number of new staff are expected to be in place by the Autumn, although it could not be guaranteed that the team will be up to full strength by Autumn 2009.
- 132. The Panel wanted to explore the role of General Practice in addressing Dementia in Middlesbrough. It was said that, by definition, GPs were generalists and could not be expected to have detailed knowledge of all areas of medical complaints. It was also explained that in most General Practices, people with Dementia formed a fairly small percentage of the case mix.

g) How do we move towards a scenario where support services are proactively offered to all diagnosed patients and carers at the point of diagnosis? This would mean a greater level of service interaction than probably exists now, but it would take the onus off the patient and family to seek the support they need.

- 133. It was said that whilst it is difficult to have a detailed knowledge of every problem which patients may bring up, one of the key skills of a GP was to identify when they do not have all the answers to something and require specialist assistance. This skill is absolutely critical when considering the topic of Dementia and how GPs relate to it.
- 134. The Panel made enquiries about the topic of GP training and development with a specific reference to Dementia awareness. The Panel heard that there are plenty of training opportunities for GPs to develop their skills and knowledge on an area of practice, such as Dementia. It was said, however, that at times it is difficult for GPs to stay 'on top' of all they need to know, across many aspects of physical and mental health, and maintain the day to day activity of being a GP.
- 135. It was accepted that historically, GPs' professional development and how it has been gone about was rather variable, with a high degree of autonomy afforded to GPs. It was confirmed that this largely remains the case to this day, although GPs will be increasingly 'reminded' of developmental issues in their learning cycles. Further, it is anticipated that from 2012 GPs will require validation every five years to continue their practice, which is felt to be an improvement. At present, GPs maintain their licence until they have done something 'wrong' and are taken through any relevant due process.
- 136. Whilst the Panel was pleased to hear of the coming 5 yearly validation process, it remained concerned around Dementia training for General Practice. The Panel's overriding concern was that (according to the best intelligence) Middlesbrough will have more and more people who develop Dementia. The impression that the Panel has is that if General Practice does not want to avail itself of training and development opportunities around Dementia, then it simply does not have to, so long as they evidence some year on year development. In that sense, the Panel remains uncomfortable about the level of self-governance over GPs training.
- 137. As a counter to the above view, it was put forward that GPs cannot become particularly knowledgeable in all fields of medicine that they will encounter, which the Panel accepts. Nonetheless, the Panel does not see why a practice, or a cluster of practices working together through the Practice Based Commissioning Framework, cannot develop a resource of local expertise in General Practice about Dementia, which could be shared and would lead to better and more informed referral behaviour. The Panel also feels that such a model could be applied to other areas of practice. Whilst the Panel accepts that the evidence on a useful Dementia screening tool is somewhat sketchy, there appears no reason as to why some GPs cannot develop further expertise in Dementia to increase the chances of identification and appropriate referrals for those who have developed Dementia.
- 138. To build on this point, the Panel heard that it is precisely because two thirds of people with Dementia never receive a formal diagnosis that early diagnosis remains a major priority and also a major challenge in Middlesbrough. The Panel has heard nothing to date to convince it that the local health and social care system is, as yet, making any inroads on ensuring that those two thirds of people who have historically never received a diagnosis are doing so now. The

Panel heard that General Practice would be keen to explore the possibility of a local enhanced service, aimed specifically at Dementia.

- 139. In previous meetings, and particularly at the Panel's consultative event at MIMA on 6 April, the Panel had heard the view expressed that GPs can be a barrier to people with suspected Dementia, or their concerned relatives/friends, receiving the expert intervention they require. By example, a scenario of symptoms being assessed as depression, with an associated prescription of anti-depressants, has been quoted to the Panel Members on a number of occasions.
- 140. The Panel heard that General Practice would very much hope it is not perceived as a barrier to people receiving the expert help they receive and it should be noted that General Practice is sometimes under pressure to not 'over-refer' to specialists. Nonetheless, it was said that General Practice would welcome a system, which delivered an improved referral process for those requiring such assistance. Still, it was accepted that General Practice may be able to receive assistance from mental health primary care teams. It was said that historically mental health services have not engaged with General Practice particularly well, although there were indications that this was changing locally, with a way to go still.
- 141. The Panel heard that according to some research done recently, 85% of GPs understand the role of Mental Health Trusts, know how to access the system effectively and understand the referrals process. It was noted that there are a myriad of different referral processes, to different agencies which makes it extremely difficult for GPs. Nonetheless, the idea that 15% of GPs, therefore, not being entirely clear on the role of Mental Health Trusts and how to engage their services is somewhat worrying. This is especially so for the proportion of the population whose GP is among that 15%.
- 142. A related point that concerned the Panel was that in most other areas of public services, performance and quality related data is readily available for the public's perusal. It was noted that such data is not available for General Practice.
- 143. The Panel was also interested to hear about the role of residential and nursing homes in assisting people with Dementia. From the perspective of JCUH, it was often said that when someone is admitted into JCUH from a nursing or residential home, the ward does not necessarily know all it needs to know about the patient, for instance, whether an individual has Dementia. It was felt that such relationships should be improved as a matter of priority, especially when one considers wards that will specialise in older people's health.
- 144. In relation to residential and nursing homes, the Panel heard that the NHS Middlesbrough had funded a team to work with nursing and residential homes. It was said that this team could provide a great deal of assistance in developing skills in residential and nursing homes, to assist staff to become more proactive in their approach to Dementia. The Panel heard that GPs felt that their links with the primary care mental health team could also be improved.
- 145. Members were also interested to discuss support services for those with Dementia and their carers, often called 'softer services' such as advice and

guidance. There was a consensus around the table that TEWV, as a specialist Mental Health Trust, should not be the provider of such advice services. It was said that this is not necessarily an area where TEWV has particular expertise and in addition, it is not what TEWV is commissioned to provide.

- 146. Further, there was a consensus that agencies such as *Alzheimer's Society* were ideally placed to provide these services and they have a track record of providing such services to a high standard.
- 147. The Panel was particularly interested in speaking about support services for people immediately following a diagnosis to provide advice and various forms of support. A parallel was drawn with acute hospitals whereby such charities as Macmillan have a presence on site, who are able to provide assistance to people who are diagnosed with cancer. The Panel was aware that something similar is not available in appropriate facilities for people diagnosed with Dementia (and/or their carers) and enquired as to whether it was possible. The Panel heard that the NHS Middlesbrough was keen to pursue such an approach and was quite similar to the role of Dementia Advisor, which is outlined in the National Dementia Strategy. This role could be proactive and seek out people requiring assistance. Such a role would not have competing clinical priorities and would be able to give people the support and guidance they require.
- 148. The Panel heard that one good way of increasing the number of people receiving diagnosis and coming forward with their concerns is to normalise Dementia as much as possible, by tackling the stigma around it. In addition, by publicising the importance of early diagnosis and early intervention, more can be done for people. A key challenge was mentioned in that presently, a Dementia diagnosis can often be perceived as a 'doomsday' scenario, although it is far from reality that it need be.
- 149. The importance of the *Alzheimer's Society* was also underlined, with the view expressed by TEWV that the Middlesbrough Council and Middlesbrough NHS Middlesbrough are presently not doing enough to support the *Alzheimer's Society*. It was felt that the *Alzheimer's Society*, if it is to provide the sort of support that people would like to see, requires assistance and investment in developing its own capacity.
- 150. The Panel heard that "significantly" more money would be put into the *Alzheimer's Society* in the next year, equating to at least 50% more funding from the local authority. Whilst extra funding is always supported, the 50% additional funding is only a significant sum if the original investment is significant. The Panel is far from convinced that existing funding to the *Alzheimer's Society* is significant, given the size of the task expected of the organisation²⁰.
- 151. In conclusion, the Panel heard that there are significant changes on the way, such as recent NICE guidance that indicates that anti-psychotic drugs should no longer be prescribed to people with Dementia. In addition, the role of the consultant psychiatrist is changing, which will create different challenges for the system.

²⁰ The Panel has subsequently learned that support for the Alzheimer's Society from the local authority was at 27,820 in 2008/9 and will be the same figure in 2009/10.

152. The Panel heard that the local health and social care economy needs to be fit for purpose when dealing with Dementia and its implications, and the evidence to date indicates it is not fit for purpose. The system cannot continue to operate as it has done and expect to get hugely different or improved outcomes. The system is in a better condition than it has been historically, but there remains a great deal of work to be done.

Notes of a meeting with the Alzheimer's Society

- 153. A number of Members of the Panel also met with the area manager for the *Alzheimer's Society* on 1 June 2009, to ensure that the views of such an important charity on local services were taken into account.
- 154. As a starting point, the Members were interested to hear from the local *Alzheimer's Society* about what were the strengths of local services for Dementia. The Panel heard that the Dementia Links service was a positive service. It was confirmed that this was an advisory service (very similar in nature to the Dementia Advisor espoused in the National Dementia Strategy²¹), housed by the *Alzheimer's Society*, but funded by Middlesbrough Council. Whilst a very positive service, the Panel learned that the post was made vacant in January 2009 (due to the postholder leaving) and had not been recruited to as of June 1 2009. The Panel was disappointed to hear this, as it meant that this service was not fully available in Middlesbrough for at least six months, as it was confirmed there is only one post.²²
 - 155. It was confirmed to the Panel that in the view of the *Alzheimer's Society*, one post was not sufficient to cope with the current demand in Middlesbrough for advice and assistance with Dementia. Given that current estimates indicate that two thirds of those with Dementia do not receive a formal diagnosis, if diagnosis figures are improved, the pressure on such a service will be all the more acute.
 - 156. It was said that the *Alzheimer's Society* runs a day club for people with Young Onset Dementia, which is funded by the NHS Middlesbrough. The Panel heard that it has 8 places and is provided one day a week. It engages in all sorts of activities, which are largely driven by the interests of those attending. Members heard that it provides a good positive activity for people and it allows people to meet others that are 'in the same boat'. It is also a valuable source of respite for those with caring responsibilities. It was noted that in Middlesbrough they are around 40 people with Young Onset Dementia, so there is an obvious discrepancy with the number of places available. It was confirmed to the Panel that the reason for this is one of funding.
 - 157. In other positive elements of service in Middlesbrough, it was mentioned that anyone is welcome to call the *Alzheimer's Society* for advice and assistance

²¹ This provides a great deal of advice about aspects of the Dementia journey and signposting to various support services. Such advice could range with assistance in applying for benefits, advising of carer services and putting people in touch with residential or nursing homes and even providing lists of law firms capable of assisting with such matters as power of attorney. It was confirmed that it is a service available during office hours.

²² The Panel has subsequently heard that following the postholder's resignation, there was a decision made that the post would be left vacant until the National Dementia Strategy was published and its ramifications could be fully assessed.

whenever it is felt required. This could apply to people with undiagnosed as well as diagnosed Dementia.

- 158. Members were also pleased to hear that the *Alzheimer's Society* has a workforce development post, which is as a result of a contract with Middlesbrough Council. This post can provide a wide range of training and development courses around Dementia awareness/knowledge for members of staff. It was felt that this post is particularly important in a climate where Dementia figures where predicted to rise. This is especially so given that the *Alzheimer's Society* reports that a substantial amount of feedback is received from its networks about a lack of understanding, knowledge or expertise about Dementia exists in Middlesbrough's nursing and residential homes and their workforce.
- 159. The Panel was told that the *Alzheimer's Society* hears many positive reports of the Woodside Memory Clinic for those who have been referred to it following a diagnosis. The Panel would point out, however that receiving a timely diagnosis of Dementia in Middlesbrough (or anywhere else in the country) is by no means as easy as it sounds and is something that does not happen for two thirds of people with Dementia.
- 160. It was also said that some residential and nursing homes in Middlesbrough are particularly good, with a local BUPA service receiving a lot of positive feedback. Nonetheless, it was explained that the vast majority of care home staff are actually low paid, whilst doing a very taxing and difficult job. Should the status of the occupation be raised, it is likely that more talented people would be attracted to it.
- 161. The Panel was interested in hearing from the *Alzheimer's Society*, about what it hears about how Dementia is handled in JCUH. It was said that the vast majority of what the *Alzheimer's Society* hears about JCUH is, unfortunately, not particularly positive.
- 162. The Panel was told that it would seem that the presence of Dementia in patients is often missed and they can be sent back into the community having had their physical health needs met, but not their mental health needs. The Panel noted that this was probably not unique to JCUH, as it seems to be a common problem in most acute hospitals. In this respect, the Panel heard that training for staff at such a facility is of paramount importance and there remains a pressing need for all relevant medical staff to receive adequate and appropriate training. It was said that some had been delivered to junior grade doctors, which had been well received.
 - 163. The Panel was interested to hear the views of the *Alzheimer's Society* regarding the role of General Practice. It was said that there is undeniably something wrong with a system whereby only one third of sufferers of any condition receive an accurate diagnosis. It was said that General Practice was not the problem per se, although the variance within General Practice was a cause for concern and particularly the differentials in making sound referrals. It was said that there was a perception that people can sometimes 'get stuck' at the General Practice level and can feel as though they are being 'fobbed off'. The

Panel felt that this highlighted a possible need for greater expertise at a General Practice level in regard of Dementia.

- 164. The Panel was interested to hear the views of the *Alzheimer's Society* about what developments in local service provision would be particularly welcome in the next three to five years.
- 165. It was felt that services for Carers could be improved, despite the services that are currently available. There is lots of anecdotal evidence to indicate that carers continue to feel isolated.
- 166. It was also said that there should be advisory services available for people at the locations, where they may receive a Dementia diagnosis. It was said that a similar thing happens in hospitals where cancer is diagnosed and people can access an advisory and support service, typically provided by the voluntary sector, even before they leave the premises. It was felt that there was no reason as to why this could not be done for Dementia, if the organisational will was present. The Panel heard that in Stockton, such services were available at a memory clinic every Friday, but it would appear they are not available at the Middlesbrough Memory clinic.

Memory Cafes

- 167. Memory Cafes were also mentioned as a very positive example of what could be done.
- 168. A number of Councils across the Country have established informal gatherings for people with Dementia or memory loss, their families and friends and they are called Memory Cafes. The aim is to provide a safe, welcoming environment for people who may need emotional support and information and also the chance to talk to people about their situation. Some examples include presentations by professionals or local organisations, live music, refreshments etc.
- 169. Many cafes have websites, offering the opportunity for those who are interested to find out more information. Examples of memory clinics can be found in Cornwall, Bristol, Wolverhampton, Hampshire and Sutton.

CONCLUSIONS

- 169. The Panel has received a substantial amount of evidence to indicate that once a diagnosis is achieved, the range of services available to the people of Middlesbrough is good, with the Woodside clinic being mentioned to the Panel on a number of occasions as an excellent service. It is clear to the Panel, therefore, that there are a number of excellent facilities and services available in Middlesbrough, the development of which has been led by the Council's Department of Social Care and NHS Middlesbrough. Nonetheless, it has been brought into sharp focus for the Panel that for whatever reason, a substantial number of people with Dementia have difficultly in accessing such specialist services.
- 170. On the basis of the evidence considered, the Panel is confident that all local agencies accept that there is a lot of work to be done in Dementia services and are keen to play, and are playing, their part. The Panel has also heard the unanimous

view that if services for Dementia continue to be delivered 'as they always have been', services will not be able to meet the future demands placed upon them. Such unanimous recognition of the pressing need for change encourages the Panel and such a consensus is the first step to implementing the necessary wide-ranging improvements.

- 171. The Panel is still, even after a number of discussions on the topic and consideration of a great deal of written material, far from convinced that established patient pathways exist for people with Dementia. The Panel would like to see strategies established which outline what a patient and their carer(s) can expect from the first time they visit General Practice with concerns and the sorts of steps they will be taken through and the sorts of support they will be offered. Whilst anecdotal in part, a lot of what the Panel has heard would indicate that it is a genuine struggle for patients and carers to navigate the system and access the support they require. This should not be the case. Related to this, the Panel is particularly concerned about those people of less assertive dispositions who will not want to push the system and thereby 'give up' at the first hurdle. The Panel is concerned that all too often such people are disappearing from the system and fending for themselves, until the Dementia is extremely advanced.
- 172. On the basis of the evidence that the Panel has received, older people's acute psychiatry liaison services at James Cook University Hospital do not have anything like the capacity required to deal with the workload they are expected to meet. The Panel is particularly concerned to hear that clinicians at JCUH sometimes do not refer people to the acute liaison psychiatry service due to a feeling that they will not be seen, despite concerns for their mental health. The Panel feels that this highlights the lack of capacity perfectly. The Panel has not been able to entirely establish whether this is symptomatic of a lack of resources or a case of resources not being used in the most effective manner, although the Panel suspects that there is an element of both involved. Nonetheless, the Panel is absolutely clear that the current level of service, with its current level of capacity, is not acceptable. Of great concern to the Panel is that a significant number of patients with Dementia, will be entering and exiting JCUH, and missing the opportunity to have their needs highlighted.
- 173. The Panel has heard that two thirds of people with Dementia will never receive a formal diagnosis. The Panel sees this as very worrying and in need of urgent attention. Without a formal diagnosis from an appropriately qualified professional, people with Dementia are not able to access the specialist assistance they are entitled to and require. When a situation exists where two thirds of sufferers of a condition do not receive a formal diagnosis, the Panel does not feel able to conclude that the condition is appropriately addressed in the local population.
- 174. Related to the topic of increasing the numbers of accurate referrals and diagnoses would be the importance of making early diagnoses as there is a substantial body of evidence to indicate that there are a number of things that can be done to delay the advancement of Dementia.
- 175. On the basis of the evidence received, the Panel is left with the view that there is a lack of capacity within General Practice, in relation to how the symptoms of Dementia are potentially identified and appropriate referrals are made. The Panel

has heard the view expressed on a number of occasions that some parts of General Practice are seen as a barrier to those seeking help for suspected Dementia. The Panel acknowledges the many pressures placed on General Practice and accepts that not all General Practitioners can be experts in all aspects of physical and mental health. Nonetheless, the Panel has heard the view expressed more than once that General Practice is perceived by some to be a barrier in seeking a referral to appropriate mental health services. With that in mind, the Panel can see nothing to stop the Practice Based Commissioning model, other than a lack of will, being employed to develop a further level of Dementia expertise in General Practice that all of Middlesbrough's General Practice could engage with when felt necessary. This would ultimately be concerned with ensuring that there are more appropriate referrals to specialist services for those suffering from Dementia.

- 176. The Panel has spent a great deal of time considering what happens to those people who receive a diagnosis, immediately after the diagnosis. The Panel has heard that there is a lack of support for patients and carers of those diagnosed with Dementia, especially with low level Dementia. The Panel has heard that a lot of information is made available, although there is very little support for people to be guided by someone and there is a sense that people are required to interpret the information for themselves. The Panel contrasts this with when one considers the experience of those newly diagnosed with cancer, who can access advice and guidance from specialist services before they even leave the medical facility premises where they receive the diagnosis. On the basis of the evidence that the Panel has received, the same can not be said of those receiving a diagnosis of Dementia, especially at a low level. It appears that there are more services for those with advanced Dementia.
- 177. The Panel has learnt that the local health and social care economy looks towards the *Alzheimer's Society*, quite rightly, to provide a lot of the support services that could be available to patients and carers, due to the Society's expertise and experience. The Panel feels this is correct, although would like to highlight the fact that there appears to be a lack of capacity in the local *Alzheimer's Society* to deliver such services across Middlesbrough to the desired standard. The local health and social care economy is therefore left in the curious position of accepting that the statutory sector shouldn't and perhaps isn't able to offer 'softer' support services to patients and carers, but with a local voluntary sector that does not currently have the capacity to meet anticipated demand. In addition, the Panel does not feel that the support structures currently in place are sufficiently assertive, or have a sufficiently high profile to assist most people in need for such support.
- 178. The Panel would also like to highlight the role of carers for those with Dementia. As is the case in many other areas of poor mental health, carers are shouldering a great deal of the strain for those people with Dementia. Whilst the Panel is aware of a number of services available to Carers, the Panel would encourage the local health and social care economy to seek and develop services for carers, and crucially, the profile of such services. Particularly, the Panel feels that thought should be given to how out of hours services Dementia support could be developed and what campaigns could be organised to reduce Dementia's stigma and thereby normalise the condition to some extent.
- 179. The Panel would also like to raise the topic of Dementia Cafés and the possibility of their use in Middlesbrough. The Panel has heard about the concept of a Dementia

Café and has completed some research about where and how they are used. The Panel feels that this is something that could be explored in Middlesbrough, at very little financial cost and is something that could greatly assist those with Dementia and those caring for those with Dementia. Overview & Scrutiny at Middlesbrough Council would be happy to assist in the development and introduction of such a service in any way it can.

Recommendations

- 180. The Older Peoples' Inreach Acute Liaison Psychiatry Service at JCUH, operated by TEWV, should be developed to the extent where it has the capacity to deal with the likely calls on its time, which is far from the case at the moment. The Panel sees this as a shared responsibility amongst the local health and social care economy and feels this should be treated as urgent.
- 181. That the Middlesbrough Practice Based Commissioning Cluster scopes and invests in a specialised Dementia services for use across General Practice in Middlesbrough. Such a resource would ensure that there is the necessary expertise and capacity in General Practice to increase the amount of accurate and appropriate referrals for those with suspected Dementia. The Panel recognises that neither the PBC Cluster or NHS Middlesbrough can implement such a service in isolation. NHS Middlesbrough has a responsibility to support the PBC framework as much as it can in delivering such a vision. General Practice has a responsibility to actively engage in the debate, as the current picture of a one third diagnosis rate for Dementia must be challenged.
- 182. That NHS Middlesbrough and Middlesbrough Council further develops Dementia Advice services. Such services should be located, or at least heavily advertised, in places where people will typically receive diagnosis of Dementia.
- 183. That NHS Middlesbrough and Middlesbrough Council invests, as a priority, in an appropriate number of Dementia Advisor Posts as envisaged in the National Dementia Strategy. To fill the position of this sort that is currently vacant would be an excellent start. These posts should be proactive, contact people who are newly diagnosed and guide the patient and their carers through all stages of the journey, paying specific attention to the 'softer' services that people rely upon so much.
- 184. The Panel recommends that NHS MIddlesbrough and Middlesbrough Council develop and open a Dementia Café for the use of patients and carers. Such a facility could be operated in established premises, to keep down capital costs. It would provide patients and carers with an opportunity to meet with people going through similar experiences and would allow patients and carers the opportunity to speak with professionals in a relaxed, informal and 'normal' environment.
- 185. NHS Middlesbrough and Middlesbrough Council should consider in detail whether the local *Alzheimer's Society* and associated third sector organisations, currently have the capacity and appropriate funds, to deliver the sorts of 'softer services' that are envisaged as being developed and that are the speciality of the sector. The Panel would like to hear the outcome of that exercise.

- 186. The Panel recommends that the local health and social care economy investigate methods to increase awareness of the condition and thereby challenge the perception that it is a 'normal' part of ageing. In so doing, it is hoped that the stigma could also be challenged. Whilst anecdotal, the Panel feels that the stigma associated with Dementia probably prevents some people accessing the services they need.
- 187. The Panel is aware of the advancements made recently in services for Carers, particularly out of the Life Store. The Panel would urge the local health and social care economy to keep the needs of Dementia Carers at the forefront of its thinking when developing Dementia services.
- 188. The Panel recommends that staff on wards at JCUH which deal with a high proportion of older people should continue to receive training on how to recognise poor mental health symptoms amongst older patients. Such training, however, is intrinsically linked to the urgent work required in ensuring that the older people's acute liaison psychiatry service has the capacity to deal with referrals when they are received.

COUNCILLOR JAN BRUNTON CHAIR, DEMENTIA AD HOC SCRUTINY PANEL

BACKGROUND PAPERS

- 189. The following background papers were used in the compilation of this report
- National Dementia Strategy Please see http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDe mentiaStrategy/DH_083362
- Paying the Price Kings Fund Please see <u>http://www.kingsfund.org.uk/research/publications/paying_the_price.html</u> Paul McCrone, Sujith Dhanasiri, Anita Patel, Martin Knapp, Simon Lawton-SmithISBN: 978 1 85717 571 4
- Who cares wins, Improving the outcome for older people admitted to the general hospital: Guidelines for the development of liaison mental health services for older people., © 2005 The Royal College of Psychiatrists.
- Dementia UK Report 2007 Please see http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2
- Improving Services and Support for People with Dementia' http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx
- Forget Me Not National Audit Office 2000
- Out of the Shadows
 Alzheimer's Society 2008

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Glossary of Abbreviations

NHS Middlesbrough - The new name for Middlesbrough PCT

JCUH – James Cook University Hospital

SHA – North East Strategic Health Authority

TEWV – Tees Esk and Wear Valleys NHS Trust (Mental Health & Learning Disabilities)

STHFT – South Tees Hospitals Foundation Trust (The Acute Trust responsible for managing JCUH)

OPMH – Older People's Mental Health

TNEY – Tees & North East Yorkshire NHS Trust (former Mental Health Trust for the Tees region which was merged with County Durham Priority Services Trust to form TEWV)