At an Extraordinary Meeting of the HEALTH AND WELL-BEING REVIEW COMMITTEE held in the CIVIC CENTRE, SUNDERLAND on WEDNESDAY, 15TH FEBRUARY, 2009 at 9.45 a.m.

Present:-

Councillor N. Wright in the Chair

Councillors Fletcher, Leadbitter, Old, Shattock and A. Wilson

Also Present:-

Sharon Lowes	-	Development Manager, Integrated Services, Health, Housing and Adult Services
Ann Dingwall	-	Care Manager, Health, Housing and Adult Services
Nigel Cummings	-	Review Co-ordinator
Dr. Cooper	-	Old Age Psychiatrist, NTW
Alison McDowell	-	Team Manager, Health, Housing and Adult Services
Ian Holliday	-	Lead Commissioner, Mental Health/Learning Disabilities – NHS South of Tyne and Wear.
Service User	-	Person with Dementia (accompanied by Sharon Morgan, Support Worker)
Dr. Henry Choi	-	GP, Southwick Medical Practice
Mr. Daniel Collerton	-	Consultant Clinical Psychologist NTW
Pauline Porteous	-	Carer
Ernie Thompson	-	Sunderland Alzheimer’s Society

Apologies for Absence

There were no apologies for absence.

Declarations of Interest

There were no Declarations of Interest.

2008/09 Policy Development Review: Dementia Care in Sunderland

The City Solicitor submitted a report (copy circulated) to support evidence gathering for this year's policy review 'Dementia Care in Sunderland' through an 'Expert Jury' approach.

(For copy report – see original minutes).

The Chairman welcomed everyone to the Committee and introduced Sharon Lowes, Development Manager, Health Housing and Adult Services and Ann Dingwall, Care Manager, Health Housing and Adult Services and advised that they would facilitate the flow of information and discussion by Members. Eight 'sectoral interests' had been invited to attend at various points throughout the day. The witnesses represented a full cross section of people and professionals who had direct experience or regularly addressed issues around service provision for dementia sufferers. The key questions set out in paragraph 2.6 of the report were shared with the witnesses and Chairman in advance of the meeting and formed the focus of their representations.

To provide context for the day, the Chairman welcomed Sharon Lowes, Facilitator, who gave an introduction setting the scene around the implications of the Dementia Strategy at a national and local level.

Ms. Lowes addressed the Committee and advised that nearly a decade ago the Forget Me Not Strategy set out an analysis of mental health services for older people in England and Wales. Key findings from an audit of services was that GPs needed more support to diagnose dementia early and that health and social care could improve the pathway to care for dementia.

In 2004 the service development guide 'Everybody's Business' was produced to inform local discussions on commissioning services and to assist health and social care practitioners in developing their understanding of how services could better meet the needs of older people with mental health problems.

Ms. Lowes advised that both documents were "should haves and not must dos" and reflected very similar aims.

Sunderland was ahead of the game in relation to some of the action points and guidance. Intermediate care at Farnborough Court was an integral part of service provision for people with dementia.

The new National Dementia Strategy again sets out to increase the awareness of dementia, ensure early diagnosis and intervention and radically improve the quality of care that people with the condition receive. Furthermore, the new Strategy gives clear timeframes at a local level for delivery dependent upon local circumstances and the level and development of services within each NHS and local authority area.

Following the recommendations drawn out by the Committee, Ms. Lowes asked Members to consider who they will be reported to. She advised that the Older People's Mental Health Group consisted of multi stakeholders and had a formal reporting mechanism. The Group would be responsible for monitoring the Local Implementation Plan. A benchmarking exercise had already been carried out by the Group around meeting the 17 objectives of the Strategy. With reference to the objectives, Ms. Lowes addressed them in turn.

It was imperative that public and professional awareness of dementia was raised. However, negative awareness of the disease could be a barrier to people and their carers seeking help. Ms. Lowes advised that an older people focus group revealed a widely-held perception that dementia was a symptom of old age and an inevitable consequence of getting old. This view could lead to a lack of urgency attached to diagnosing and addressing the disease.

In relation to the objective of early diagnosis, a range of screening and diagnostic tools were available to GPs, however, specialist knowledge was needed to make the best of them and not all GPs used these tools. If there was voluntary sector involvement, it was important that an individual's GP was on board.

Good quality information for people with dementia and their carers that was easily accessible was essential at diagnosis and throughout care. An information pack could be developed to explain how to approach services and what to expect from ongoing care and support.

In relation to the creation of a role of National Dementia Advisor, who would signpost and facilitate appropriate care support and advise, Ms. Lowes advised that as this was a new role there will be an initial need for the development and generation of demonstrator projects to pilot and evaluate models of service provision prior to implementation. It was hoped Sunderland could be involved in the pilot.

Objective 5 related to peer support. Health and Social Care Commissioners would need to consider how to support the development of local peer support networks for people with dementia and their carers.

Objective 7, related to implementing the Carers' Strategy for people with dementia and places greater recognition on family carers as the most important resource available for people with dementia. Sunderland must ensure that the provisions of the Carers Strategy are delivered.

Referring to Objective 8, improving the quality of care for people with dementia in general hospitals, Ms. Lowes advised that this was a capacity issue. There needed to be more specialist liaison posts to work in general hospitals.

Improved intermediate care for people with dementia is outlined in Objective 9. This was about ensuring that the right package of care and resources was available to meet a dementia sufferer's need.

Objective 10 involves housing related support concerning the needs of people with dementia and carers when looking at the development of housing options, assistive technology and Telecare. The Telecare service in Sunderland works well as a support to carers. Ms. Lowes advised that Extra Care Housing would be an accommodation option but would have to be a particular model.

The 11th Objective – living well with dementia in care homes, related to the need to manage quality of care with specialist in-reach services through community mental health teams.

End of life care was a PCT issue and would focus on better end of life care for people across settings.

Objective 13, an informed and effective workforce for people with dementia was about ensuring all health and social care staff had the necessary skills to provide the best quality of care within the roles and settings where they work.

A joint commissioning strategy sets out the purpose of developing systems to identify the needs of people with dementia and how best to meet these needs. The PCT and local authority would need to refresh their approach to coherent joint services.

Objectives 15, 16 and 17 focused in the main on national targets and supporting people at a local level.

Ms. Lowes concluded by stating that these objectives could be borne in mind when considering key issues throughout the day.

The Chairman welcomed Dr. Cooper, Old Age Psychiatrist, NTW, to the Committee and invited him to respond to the three questions posed from a provider perspective.

Dr. Cooper stated that an important part of the Dementia Strategy was the focus on awareness raising and reduction of stigma. He stated that parallels could be drawn between dementia now and cancer in the 1950's when patients were commonly not told the diagnosis for fear of stress.

Memory assessment services were currently piecemeal, but if properly developed would offer a responsive service to aid the early identification of dementia and include a full range of services. Memory assessment services that worked well would ensure an integrated approach.

Early diagnosis and intervention had many benefits, including quicker access to support, benefit of treatment and planning for the future. Dr. Cooper commented on the challenging task for clinicians of distinguishing patients with the early signs of dementia from the 'worried well'. However, Dr. Cooper advised that often dementia may not be diagnosed or acknowledged until a patient is admitted to hospital for an acute physical illness. Sufferers and carers may well be aware that something is wrong but up until they hit crisis point have 'managed' the condition.

Dr. Cooper advised that dementia was often associated with Alzheimer's; however, there are many other causes of dementia or cognitive impairment that can be stabilised. It is important that all dementias were recognised.

Other benefits of early intervention include the opportunity for sufferers and families to plan their future medical care and finances.

Numerous tests have been developed for identification of dementia, including the Mini Mental State Examination (MMSE) which was developed by psychiatrists and is regarded as the gold standard test for dementia. The test consists of 30 questions and out of 30, a score of 22 or lower should be treated as a sign of significant memory impairment.

Dr. Cooper referred to the NICE (National Institute of Clinical Excellence) guidelines on the use of anti-dementia drugs in the NHS. NICE proposed to limit treatment to the moderate stages of the disease. Although the proposals were based on cost-benefit reasons, Dr. Cooper advised that the costs of untreated illness was even greater and withholding drugs would not encourage the early recognition and assessment of those with mild to moderate dementia who could be excluded from treatment.

The direct benefits of medication for many people could not be disputed; however, there were other valuable treatments and therapies that could be offered to sufferers and carers to target feelings of social inadequacy and embarrassment that could sometimes occur.

Regarding dementia awareness raising, Dr. Cooper stated that a number of high profile television programmes (involving Terry Pratchett, Norman Wisdom and the wife of former newsreader John Suchet) had highlighted the condition. Dr. Cooper commented that dementia awareness would increasingly begin to come out of the shadows as more and more people were likely to suffer from the condition with the increasingly ageing population. However, it must be borne in mind that awareness raising does not eradicate the fear.

Dr. Cooper advised that medical professionals naturally approached dementia from a biochemical perspective and there could be a tendency to retreat into medically categorising a person. The balance needs to be brought down on the other side and concern needs to be attached to personhood – putting oneself in an individual’s position in order to target the way you help them and making the necessary adjustments to a sufferer’s environment. Key to this was effective training to carers and care homes in strategies to help.

Dr. Cooper advised that good day care proved to have a huge impact on patient morale and carer burden. Further support could be given to the voluntary sector to provide such services.

The development of signposting people through the system was essential and one which would be proactive in identifying and responding to information needs. Mr. Cooper advised that in his opinion in order to provide the best support and information to people with dementia, their carers and families there needed to be individual face to face contact as appropriate.

Dr. Cooper commented on his experience of dementia services in Sunderland. He stated that he experienced first hand on a daily basis the phenomenal feelings of love carers and families showed for dementia sufferers.

Dr. Cooper advised the Committee of the different types of dementia people suffer from and the different symptoms they would experience. This could also lead to problems for people to access services that are tailored to their specific needs.

There was an increasing move to release resources into a community setting and where possible look after people in their own homes. However, it was important to recognise that for some individuals hospitalisation was the safest and most appropriate action. However, people should not remain in inpatient facilities longer than necessary.

Upon being questioned by the Chairman, Dr. Cooper stated that links with Sunderland GPs was good and in the main they used a single point of access. There could be problems in relation to bureaucratic barriers in which GPs could have a tendency to refer an individual patient to a specific consultant instead of referring to the “team”.

Councillor Shattock referred to Dr. Cooper’s warning that practitioners may become “overwhelmed by the rising tide” and sought clarification on why this was happening. Dr. Cooper advised that as life expectancy increased so would incidences of dementia, placing further pressure on resources. Currently dementia services were under resourced to meet the targets of the Government’s Strategy.

Following Dr. Cooper’s attendance, the facilitator and Members drew out key issues from the responses to the questions. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed Alison McDowell, Team Manager, Health, Housing and Adult Services, and invited her to respond to the questions from a staff member perspective.

In response to the first question, Ms. McDowell stated that awareness raising was imperative to the early diagnosis of dementia. People would not seek help if they were unaware of the symptoms of dementia. There must be a challenge to the myth that dementia was merely a part of getting old. If symptoms were diagnosed early, intervention could be more effectively planned.

Long term planning and the use of advance directives would enable people to plan ahead when their health deteriorates.

Referring to the second question, Ms. McDowell stated that staff in Health, Housing and Adult Services had a very pivotal role to play in raising awareness of dementia in their day to day jobs. For staff to do this they needed to be properly trained. Mandatory training for staff should be person centred and experiential. Working in partnership with the Carer’s Centre and Alzheimer’s Society would ensure this could be successful.

Ms. McDowell commented on her experience of dementia services in Sunderland and informed the Committee that since joining the Authority in 1997 she had seen vast improvements to dementia services during that time. These improvements included the Dementia Rehabilitation Service, Extra Care Housing and the integrated model for day services. Individual care planning was essential and services needed to be continually looked at and reviewed. The range of services to support people did exist in Sunderland; however, it was important to understand how they should be moulded for the greatest outcome.

Ms. McDowell advised that greater understanding of young people with dementia was still in its infancy.

From a practitioner perspective a whole person approach needed to ensure services were flexible enough to help at all stages of a person’s dementia.

It should not be ignored that dementia can have a frightening and negative impact on suffers and carers and support such as therapeutic therapies should be pursued with the individual.

Ms. McDowell acknowledged that there was a parity of resources in relation to dementia compared to other life threatening diseases and people with dementia for too long had been forced to simply accept ‘good’ resources.

In response to a question from Councillor Leadbitter regarding the Community Mental Health Team, Ms. McDowell advised that there were two Older People Social Workers and two Mental Health Social Workers. As many of the issues they dealt with were cross cutting, they needed to work closely alongside each other.

Councillor Shattock referred to care packages and questioned how rigorously they were monitored. Ms. McDowell advised that within the first 4 weeks of a package of care being implemented, monitoring was stringent. Following the 4 weeks, monitoring was carried out an annual basis; however, if there were any emerging issues these would be promptly investigated.

The Directorate needed to work alongside the independent sector. Ms. McDowell advised that she would like to see care reviews that focused on positive outcomes for the individual rather than timescale targets, ensuring people were happy with their care.

In response to a question from Councillor Wilson regarding day services, Ms. McDowell stated that day care should be about positive choices for the individual.

Following the questions to Ms. McDowell, the facilitator and Members drew out key issues from the responses. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed Ian Holliday, Lead Commissioner, Mental Health/Learning Disabilities, NHS South of Tyne and Wear and invited him to respond to the questions from a commissioning perspective.

Mr. Holliday addressed the key questions outlined in the Committee's report, highlighting the current evidence that dementia was greatly under-diagnosed. It is estimated that only ⅓ of sufferers were given a formal diagnosis for dementia. This needed to be looked at and tested at a local level. Mr. Holliday advised that diagnosis also tended to be made at the wrong time – at the point of crisis, which could produce the wrong outcomes for individuals. The value of early diagnosis was immense. It would enhance quality of life, prevent unnecessary admission to care homes and hospital and enable professionals to engage, at an early stage, with families and carers. Support to carers was imperative.

Mr. Holliday referred to the role of the GP in the care pathway. They were often the first point of contact, thus it was essential they had the correct training to diagnose dementia. The newly defined service must have a focus for referral. The initial referral process needed to be wider than GPs and include voluntary organisations and other partners.

Mr. Holliday stated that there needed to be flexibility in assessments in which people could be seen in their own homes as opposed to clinics.

It was still unclear what the role of the new dementia advisor would be within the terms of the strategy. However it was anticipated that the role would be similar to that already carried out in the third sector.

With regard to current information, Mr. Holliday stated that commissioners needed to work with colleagues in public health to make the national strategy a very local campaign. The strong prevention message currently playing out in the media needed to be followed through and delivered. Mr. Holliday reminded the Committee that 50% of dementia was due to vascular deterioration (smoking, diet etc.). The notion that nothing could be done needed to be challenged and the prevention message should be widely disseminated.

Local initiatives in awareness raising could target major employers within the City. Generational awareness would mean changing attitudes at an early age within schools.

In terms of existing resources, Mr. Holliday advised that a full range of services existed, both in-patient and community within the City. The issue from his standpoint was the quality of in-patient resources. The care at Cherry Knowle was excellent but the environment was not good. To address future resources there first needed to be a thorough understanding of what was currently in existence, with a comprehensive mapping exercise. The PCT had recognised dementia as a priority and extra money had been put into future financial planning with an extra £800,000 over the next three years. As part of this future planning service a redesign using current resources more effectively would be carried out. Mr. Holliday referred to the national funding of the dementia strategy of £150 million and advised that it was not easy to pin point how this money would be utilised. The Chairman advised that the allocation of the £150M would be a question the Committee would be asking in its response to the national strategy.

Following the questioning of Mr. Holliday, the facilitator and Members of the Committee drew out the key issues from the responses. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed a dementia sufferer and her support worker to the Committee and invited her to respond to the questions from a service user perspective.

The service user informed the Committee that it was important that professionals were honest and explained to people that they have dementia and the possible implications. She recalled that her own GP had not been particularly helpful when she had initially presented her symptoms to them.

When asked how awareness of dementia could be raised, the service user suggested that ignorance of the disease needed to be combated. People believed dementia was a symptom of old age and that people under 50 did not get the disease.

The service user expounded the importance of writing dementia literature in plain English and ensuring its availability was widespread.

The service user informed the Committee of her own experience at the Grange and subsequently Glenholme day centre. Her experiences of both facilities had been mixed but she did highlight the importance of tailoring support to meet individual need.

The service user stated that she enjoyed going to the Alzheimer’s groups and was able to make her own decision about whether she wanted to go or not.

The Committee were informed by the service user that she had had a number of different carers coming in to her home. Often she did not know "who was coming from one day to the next" and she described this experience as confusing and horrendous with no continuity.

Upon questioning by the Chairman, the service user stated that the one thing she would change about the services she received would be continuity of care. Moreover, while she did have a care plan, if a change of carer was necessary this should be clearly communicated in the most appropriate method.

Following the service user's attendance, the facilitator and Members of the Committee drew out the key issues from the responses. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed Dr. Henry Choi, General Practitioner, to the Committee and invited him to respond to the questions from a GP perspective.

Dr. Choi advised that he had been a GP since 1990 and as such his experience of dementia was limited to practice based.

Dr. Choi highlighted the importance of the family in prompting an individual to present early with symptoms. Greater understanding of the condition was vital, and more specifically the different types of dementia.

Dr. Choi advised that better training for GPs was essential. Many practitioners had the knowledge but the key was putting it into practice. However, Dr. Choi informed the Committee that the symptoms of early dementia were not easy to diagnose and could be masked by other symptoms.

In Sunderland, for individuals under 65 diagnosed with dementia, it was very difficult to refer them to an assessment clinic. Although the Crisis Prevention Team was in operation, not all professionals utilised their services.

Dr. Choi stated that the pathway for services wasn't smooth.

The prevention message was not widespread.

Dr. Choi stated that there needed to be more contact and understanding between agencies with a Dementia 'Champion' co-ordinating information and available services.

Dr. Choi felt that dementia services in Sunderland were responsive with a turnaround time of approximately 2 weeks.

Dr. Choi's practice did visit residential homes to carry out an annual mental health diagnosis of patients. He advocated the importance of being able to see people in their own environment.

Dr. Choi felt that the PCT website should have a template guide of the types of checks a GP should cover to assist in diagnosis.

Dr. Choi advised that his surgery in Sunderland had a learning event every month which was protected time to look in depth at specific clinical conditions. Dr. Cooper had attended previously and spoke on dementia. If GPs could be encouraged to engage in these types of events this could help with their knowledge and understanding.

Following the questioning, the facilitator and Members drew out the key issues from the responses.

The Chairman welcomed Mr. Daniel Collerton, Consultant Clinical Psychologist (NTW) to the meeting and invited him to respond to the questions from a service provider perspective.

Mr. Collerton informed the Committee that NTW had formed a focus group for people with dementia. The Group had revealed that individuals wanted and expected very different outcomes from services. Some people wanted to know what would happen at every step of their treatment and have a definite name for their illness. Other people wanted as little to do with health services as possible. This reluctance on behalf of some individuals to acknowledge that they had a problem and approach a professional highlighted the need to make assessment services as friendly and approachable as possible with messages of hope. People needed to be aware that early diagnosis could give them the best possible chance of a good outcome.

Mr. Collerton advised that of all the people he saw with dementia, approximately half were in the early stages of the disease. If services were more accessible, more people would be willing to come forward. However he warned there would always be a group of people who do not want to visit a health professional and a balance needed to be struck between a patient's rights to autonomy with the need to give a patient the best possible medical outcome.

Mr. Collerton stated that early diagnosis for dementia was not 100% reliable as there could be uncertainties as to what type of dementia an individual was suffering from. Any pathway system would have to work with that uncertainty in a positive way.

Mr. Collerton informed the Committee that dementia awareness had improved immeasurably over recent years, particularly with regard to Alzheimer's. However, the consultant advised that while the awareness of dementia as a concept and terminology had increased, an understanding of what it meant for sufferers was lagging behind, awareness needed to be developed along the same lines as cancer. A realistic and personal experience from sufferers and carers was the best way to change attitudes.

In relation to signposting, Mr. Collerton stated that the various agencies involved with dementia care needed to work together. If there was a hole in the service then dementia sufferers were the most likely to fall into it.

Mr. Collerton stated that Sunderland had evidence of good and bad practice in relation to dementia services. The system does not work consistently around the needs of the individual. Health and social care needed to integrate to provide a seamless service. There was a great enthusiasm in Sunderland to strengthen and provide more cohesive services. Historically, the demands of working age adults have taken precedence over older people's mental health facilities.

In response to a question from the Chairman, Mr. Collerton stated that there were mechanisms in place to share good practice. There was a strong local network of psychologists who meet regularly and share best practice.

Following the questioning, the facilitator and Members drew out key issues from the responses. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed Pauline Porteous, Carer, to the meeting and invited her to respond to the questions from a carer's perspective.

Mrs Porteous gave a very honest depiction account of her personal experiences as carer to her husband who had suffered from dementia.

Mrs. Porteous stated that she felt GPs and District Nurses needed to be given dementia awareness training. When appropriate GPs should be able to prescribe dementia drugs.

Mrs. Porteous felt that education programmes in school would not only help to combat the stigma and fear that existed around dementia but would also raise awareness around making healthy lifestyle choices. A short awareness raising film shown in schools and cinemas could be a very effective means of communication.

In relation to signposting, information was not easy to find and when it was the messages could be confusing. Mrs. Porteous showed the Committee an example of a colour coded directory she had designed which she believed would act as an easy aid to signpost the user to the relevant area. The directory would have a breakdown of services and who would provide them.

Mrs Porteous informed the Committee that it was imperative a dementia sufferer's other health issues were not ignored. Continuity of care was also important; people should always be treated as individuals and should be able to trust the individual or team responsible for their care.

Home care services needed to be available for end of life situation.

Carers as advocates need to be party to excellent communication. It should never be forgotten that carers were vulnerable too.

Following the questioning, the facilitator and Members drew out key issues from the responses. A full list of the key issues identified by the Committee can be found at the end of these minutes.

The Chairman welcomed Ernie Thompson, Alzheimer's Society to the meeting and invited him to respond to the questions from a voluntary and community sector provider perspective.

Mr Thompson addressed the key questions outlined in the Committee's report and agreed that memory clinics were necessary as a medium to long term answer to addressing quality of care for people. However there needed to be the availability for people to self refer.

As gatekeepers, some GP's were excellent while others were not so good. Referral patterns needed to be adequately monitored in order to gain an insight into diagnosis and intervention.

A Carer's Strategy was being developed which it was hoped would help to support carers. People with dementia and their carers benefit significantly from being able to talk to other people living with dementia and their carers to exchange practical advice and emotional support. Structured peer support networks needed to be developed and supported.

Mr Thompson felt that the NICE (National Institute Clinical Excellence) recommendation that all Alzheimer's drugs should no longer be used in the treatment of mild to moderate Alzheimer's disease was a retrograde step and a disincentive to GP's in relation to understanding dementia. Although diagnosis could be a long process this should not stop there being active intervention in the process. The voluntary sector had a vital role to play in ensuring the personal needs and preferences of individuals were met.

If early diagnosis was not achieved this could lead to crisis intervention which was costly both financially and emotionally. General hospitals have a vital role to play in being able to diagnose possible dementia in a patient who may have been admitted for other reasons. There was 1 liaison nurse at City Hospitals and Mr. Thompson felt that more were needed to fulfill demand.

Making contact with 'hidden carers' would allow them to have their needs assessed as they too could feel vulnerable and isolated. Signposting was inadequate particularly around low level support.

Mr Thompson advised that the care pathway needed to be agreed by all, it needed to be seamless, person centred, supportive and followed through. Information sharing was starting to happen between partners. They needed to back this up by also listening to the needs and wants of patients and carers.

Mr Thompson warned of the trend that CSCI had highlighted of providing better quality services but to fewer people. As the current baseline figure spent on dementia in Sunderland was unknown it begged the question how future spend could be mapped and if it was adequate.

The last witness having left the meeting, Members had a closing discussion, taking into account the evidence they had heard throughout the day.

The Chairman having thanked Members and Officers for their attendance and the facilitators, Ms. Lowes and Ms. Dingwall for their expertise, it was:-

1. RESOLVED that:-

(i) the information contained in the presentations and brought out during the discussion be received and noted;

(ii) Comments be included in the draft report of the Policy Review

(Signed) N. WRIGHT,
Chairman.

Key Issues Identified by the Committee:

- Fear and ignorance of the disease are barriers to people and unpaid carers approaching their GP about suspected dementia. GP's attitudes could also hamper diagnosis – the role of the GP as the early detector needs to be developed. Sufferers needed to be supported to accept their diagnosis

- Message of hope rather than hopelessness

- Referral pathways need to be reviewed – home based assessment for psychiatrists should be supported

- Inclusion of strong prevention message 'what's good for your heart is good for your head'

- Need a unified approach to memory services across the locality. Support services needed to be responsive

- The importance of future planning, advance directives

- Improving peer support for sufferers on all levels of their journey, working with the third sector to actively develop local services. Need to value peoples personal experiences

- A wide range of screening and diagnostic tools were in use by GP's, psychiatrists and others. However specialist knowledge amongst GPs appeared to be very limited

- Problems with the quality of home care for people with dementia including lack of staff continuity.

- Proactively challenge the misconception that dementia is caused simply by old age.

- Significant diagnosis gap – there needs to be a recognition of all dementias. People with early onset dementia and learning disabilities should not be forgotten.

- Coordination of good quality information was essential

- Lack of understanding around care placements and the process involved

- Resource issue – there do not appear to be adequate to meet future demand and the recommendations of the National Strategy

- For the service user her diagnosis was poorly communicated

- There needs to be person centred training for paid/unpaid carers

- To avoid distressing people with dementia, continuity and consistency of care was important arising from good co-ordination. This could be improved in Sunderland

- Role of Community Mental Health Team

- There needed to be practical help in terms of day opportunities and social stimulation

- PCT's in conjunction with GP's should benchmark their performance in diagnosing dementia against expected prevalence which could be used to set local targets for improvement

- Need to gain an understanding of the local situation regarding all resources across the city in order to understand where new monies are needed

- Information needs to be provided in a way that benefits the individual

- Look at role of CMHT and the apparent difficulties in referring into them

- Education starting at an early age in schools perhaps via the media of a short film

- Common sense approach to caring for the individual

- Consistency – same supportive team throughout journey