



THE YORK MENTAL HEALTH PARTNERSHIP
AND MODERNISATION BOARD

Implementing the National Dementia Strategy in York

A Report by the Board's Dementia
Working Group

July 2011_(v2)

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SECTION 1: EXECUTIVE SUMMARY

This is a report by York's multi-disciplinary Working Group on Dementia. The Group became a standing working group of the York Mental Health Partnership and Modernisation Board in 2010, and was tasked with recommending how the National Dementia Strategy (NDS) "Living well with Dementia" 2009 should be implemented in York.

The Group consulted York-based statutory, voluntary and independent service providers (including managers and staff from City of York Council (CYC) and independent care homes) and other organisations which work with older people.

The group considered each of the 17 objectives in the Strategy and identified the dementia services and dementia-related activities in York, identifying where local provision fell below the requirements of the NDS. From this, recommendations have been made against each objective and suggested priorities for future action.

The report outlines services that were already in place, and new developments that have been stimulated as the Group undertook the mapping exercises. The report highlights the progress that is being made by many of the organisations involved in providing care and that improving dementia care is not only about big commissioning decisions - the introduction of many small improvements across a wide range of activities can together make a significant difference to those receiving care.

It identifies further work needed as priority actions (for commissioning and administrative action) within three bandings:

Priority one actions include:

- Commissioning a Psychiatric Liaison Service at York Hospital.
- Providing a specialist in-reach service for care homes in order to reduce hospital admissions.
- Identifying investment opportunities to increase the support available to carers including carers' breaks.
- Providing an annual report on the monitoring of dementia services by CYC.

Priority two actions include:

- Ensuring that intermediate care services are open to people with dementia.
- Making better use of support networks by reviewing the local Voluntary and Community Sector (VCS) services including dementia support groups and learning networks, using learning from national demonstrator sites.

Priority three actions include:

- Supporting York and Selby Alzheimer’s Society in its work to raise awareness of dementia and funding the Society periodically to arrange local activities in support of national campaigns.
- Providing education for GPs on dementia to include dealing with patients at the various stages of dementia and the importance of effective signposting to appropriate services.
- Issuing guidance to care homes on avoiding the inappropriate use of antipsychotic medication.

The report calls for a detailed action plan which addresses the major gaps in our service provision and looks to the PCT and CYC to work with the two new health organisations in York – the new commissioning consortium and Leeds Mental Health Partnerships NHS Foundation Trust to develop a plan which establishes the desired outcomes for particular activities and identifies targets, lead responsibilities and costs.

The Working Group was not charged with looking at how York could (and should) prepare to deal with the big expansion in the numbers of people likely to need dementia care in the future, but identifies this as a key challenge.

Finally, the report concludes on the importance of empowering service users and carers to play a leading part in shaping and developing services, and highlights a new project, commissioned by the Joseph Rowntree Foundation, to enlist the help of people with dementia in identifying the factors that determine whether York is, or can become, a dementia-friendly city. The project called “Dementia Without Walls” aims to raise the aspirations of people with dementia and their carers, as well as those of providers and commissioners, about what services in York could become.

INTRODUCTION

The Working Group was originally set up by the PCT's Local Implementation Team but in early 2010 became a standing working group of the York Mental Health Partnership and Modernisation Board. The Group was tasked with recommending how the National Dementia Strategy (NDS) "Living well with Dementia" 2009 should be implemented in York. When the NDS was launched, it was expected that implementation would be spread over a five year period.

The NDS focuses on the following areas: the awareness of dementia both by members of the public and by professionals working with older people; the need for earlier specialist diagnosis and intervention through memory services; and higher quality health and social care for people with dementia. It makes a convincing case for improvements in all these areas. and this point was reinforced by the Audit Commission which said that, nationally, dementia care did not represent value for money.

No money was ring-fenced for implementing the Strategy and it was clear from the start that improvements in care would either have to be made by doing things differently within existing budgets or funded from efficiency savings or other reductions in the budgets of CYC, the PCT and other commissioners. The latter will be extremely difficult at a time when all budgets are under considerable pressure. However, as our work progressed, we found that a significant number of improvements could be made at little cost, for example, better training for staff involved in delivering care, adopting good practice from elsewhere and through better leadership in care homes and hospitals.

The profound negative effect of the illness on those with dementia and their families is brought out very clearly in the NDS and need not be rehearsed here. The high costs of treating dementia both now and in the future are also acknowledged.

Having assembled a multi-disciplinary team with appropriate experience (the members are listed on page 26), we approached our task as follows:

- First, we looked at the numbers of people with dementia in York and the predictions over the next 20 years. Details are at page 25.
- Next, we considered each of the 17 objectives in the Strategy and identified the dementia services and dementia-related activities in York.
- We then identified against each objective where local provision fell below the requirements of the NDS. We made recommendations against each objective and suggested priorities. Details are set out in Section 2.
- Our recommendation for an action plan for York which includes both commissioning and administrative action is at Section 3 (page 19).

This is a time of enormous change in local health and social care arrangements. Changes include: the transfer of community and mental health services to Leeds Mental Health Partnerships NHS Foundation Trust; the setting up of the new Vale of

York Commissioning Consortium; new organisations such as The Health and Wellbeing Board and HealthWatch; the transfer of public health functions to CYC; and the wider use of personalised budgets. With no ring-fenced money and so many changes in hand, this is clearly not an easy time to recommend a detailed and costed plan for implementing the NDS in York. We have not produced such a plan but we have made considerable progress towards doing so and details are set out in Sections 2 and 3. We believe that some of the changes set out above will provide opportunities to improve dementia care and this is something that needs monitoring in the coming months.

In September 2010 the Department of Health (DH) published a paper “Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy”. This paper confirms that the Coalition Government intends to see the NDS implemented and it sets out four priority objectives: good quality early diagnosis and intervention for all, improved quality of care in general hospitals, living well with dementia in care homes and reduced use of antipsychotic medication. The paper states that “local organisations are expected to publish how they are delivering quality outcomes so that local people can hold them to account”. We believe that our Report could help meet this requirement.

In the course of our work we consulted York-based statutory, voluntary and independent service providers (including managers and staff from CYC and independent care homes) and other organisations which work with older people. Our members included a representative from LINKs and we have kept in touch with the York Health Overview and Scrutiny Committee. We intend to work closely with all these organisations as our work continues.

Since our work began there have been a number of new developments and initiatives. The PCT, which has the lead in dementia across the whole PCT area, has set up a North Yorkshire and York Dementia Network which is proving to be useful in undertaking work which is common to all localities and details are included at Section 3 on page 22. Nationally, a number of demonstrator sites have been set up in order to inform the local implementation of the NDS and details are on page 23.

We have covered a large number of subjects in preparing our report but a lack of money and resources have meant that there are many important issues that we have not tackled. We return to these issues in Section 4 (Further Work and Conclusions).

And finally, I am grateful to Working Group members for their time and contributions and to the many others who have helped in our work.

John Bettridge CBE
Chair

28th July 2011

SECTION 2: NOTES ON YORK'S DEMENTIA SERVICES AND THE GROUP'S COMMENTS AND RECOMMENDATIONS

The National Dementia Strategy (NDS) sets out key opportunities for transforming dementia care under the following four themes: raising awareness and understanding; early diagnosis and support; living well with dementia; and making the change. The Strategy contains 17 objectives, which are listed below.

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
RAISING AWARENESS AND UNDERSTANDING	
1 A public information campaign to improve public understanding about dementia	
<p>1a A national dementia awareness campaign on TV, radio and in the press took place in March 2010.</p> <p>The York branch of the Alzheimer's Society has a range of good material which it uses to raise general awareness about dementia.</p> <p>There have been no recent dementia awareness initiatives run by the Alzheimer's Society or the statutory services in York.</p>	<p>We recommend that the Alzheimer's Society is supported to continue its work to raise awareness locally. We recommend that the focus of this work should be on people who already have dementia, together with their carers and families. Priority 3</p> <p>The possibility of arranging local awareness initiatives to coincide with future national campaigns should be considered by CYC. Priority 3</p> <p>The Dementia Action Alliance has over 40 organisations committed to transforming the quality of life for people living with dementia in the UK and the millions of people who care for them. Members of the Alliance have signed up to a National Dementia Declaration and have published their own action plans setting out what each will do to secure these outcomes and improve the quality of life of people with dementia by 2014. The PCT has signed up to the Declaration and we recommend that CYC also signs. Priority 3</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
EARLY DIAGNOSIS AND SUPPORT	
2	<p>Good quality early diagnosis and intervention for all (all people with dementia to have access to a pathway of care that delivers a rapid and competent specialist assessment, an accurate diagnosis sensitively communicated to the person with dementia and their carers and care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area)</p>
2a	<p>The Strategy makes the case for commissioning a specific service for the early diagnosis of dementia and intervention. There is no such service in York – instead, this is undertaken by CMHTs and GPs. GPs have guidance on specialist assessments and early diagnosis of dementia and this is also available on the internet. Assessments take time to do properly and GPs do not always have the time to do them. GPs often identify cases and refer them to services.</p> <p>Setting up a specific service (as described opposite) is not a priority at present. Further discussion on this should await the completion of the transfer of services to the new provider. Setting up a new service would also need to be co-ordinated carefully with other improvements in dementia care in order to avoid raising expectations which could not be met. Priority 3</p>
2b	<p>CMHTs provide a specialist memory service but not through memory clinics. Assessments are sometimes made at a person's home. There are no dedicated dementia advisers or care navigators but some elements of this work are provided by CMHTs and some voluntary sector organisations such as Age UK and the Alzheimer's Society.</p> <p>Memory advisers play a very useful role in supporting patients and carers and they can provide information and advice and help "signpost" patients to further support. In June 2011 York Health Group (GP Commissioning) and the PCT jointly funded a memory adviser post in York / Selby which is being filled by the Alzheimer's Society. The service will be evaluated after a year.</p>
2c	<p>Feedback from carers suggests that some GPs could conduct consultations with patients experiencing the early symptoms of dementia more sensitively. Some carers felt that they should be more involved when assessments were being made. We also noted that some people find it difficult to accept a diagnosis of dementia.</p> <p>A new, local care pathway for dementia has been prepared and this will become part of the Map of Medicine. The "map" is a computer-based tool for clinicians and health professionals. It includes details of local statutory and voluntary sector services available at different stages of the care pathway.</p> <p>We recommend provision of education about dementia for GPs as part of their continuing professional development to include dealing with patients at the various stages of dementia and the importance of effective signposting to appropriate services. However, before this can be delivered, more work needs to be done to redefine appropriate pathways and guidance for GPs. Priority 3</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities	
EARLY DIAGNOSIS AND SUPPORT		
3	Good quality information for those diagnosed with dementia and their carers (providing people with dementia and their carers with good quality information on the illness and the services available, both at diagnosis and throughout their care)	
3a	No specific information packs are available but staff are able to put together appropriate packs from information they have on procedures for diagnosis, local dementia services, and care after diagnosis etc. The Alzheimer's Society has produced a local directory of services available. Feedback from carers suggests that patients do not always get the timely information they need.	We recommend that a review is carried out to determine if this system is satisfactory or if new information packs are required. Where national information material is used it is important that it is complemented by adequate local information. We note that the Hospital Dementia Strategy Group is also reviewing this topic. A good way of tackling this would be to ask people with dementia and their carers what they think – see page 20. Priority 3
4	Enabling easy access to care, support and advice following diagnosis (one of the strongest messages from people with dementia and carers in the consultation on the Strategy was that people want a single local named contact (a dementia adviser) to advise them about dementia and where they can get help)	
4a	York has no dementia advisers but members of the CMHTs carry out part of this function.	We support the idea of dementia advisers. We note that a number of national voluntary sector organisations provide a similar service. We also note that Bradford / Kirklees is one of the national demonstrator sites for dementia advisers; we intend to monitor the lessons from this and similar sites when they are available. Priority 3
4b	CMHTs are not integrated with social care staff as they are in many areas; this needs to be explored as part of the work on integrating health and social care.	
5	Development of structured peer support and learning networks (people with dementia and carers have said that they draw significant benefit from being able to meet other people with dementia and carers to share practical tips about how to live and cope with dementia. Some of these networks already exist across the country as dementia cafes or support groups. These networks will also enable people with dementia and their carers to take a more active role in the development and prioritisation of services)	
5a	In York, a number of dementia support groups and networks are provided by the voluntary sector and part-funded by the PCT and CYC. Providers include the Alzheimer's Society, Age UK, Our Celebration / Mind and the York Carers' Forum. These services, in various ways, offer practical and emotional support and help overcome problems of isolation.	We believe that support and learning networks have a very important role to play in helping people with dementia and their carers cope with the illness. They also play an important part in helping people with dementia take control of their own lives and care for themselves as much as possible. We recommend that a study is carried out jointly with the organisations providing these networks to: identify the different local models, evaluate their outcomes and report on their capacity to meet the need. Priority 2

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
6 Improved community personal support services (two thirds of people with dementia live in their own homes either on their own or with a carer. The Strategy proposes the provision of an appropriate range of services to support people with dementia to remain more independent. It stresses the need for access to flexible and reliable services ranging from early intervention to specialist home care services)	
<p>6a Services provided, funded or part-funded by CYC and the PCT include the following:</p> <ul style="list-style-type: none"> • Three multi-disciplinary community mental health teams (CMHTs). • Specialist home care teams. • Primary care mental health workers (these work with people of all ages and deal mostly with common mental health issues). • Memory groups – these are not the same as the memory service described in paragraph 2b. These groups are less formal groups and are run by occupational therapists providing courses of about eight sessions offering strategies to cope with failing memory. • Peer support services – dementia cafes, day clubs, and support groups (see also serial 5a, page 9). <p>The York Vision for Older People sets out important outcomes and guidance for services funded by health and social care. The Dementia Network has carried out work into the availability of advocacy services for people with dementia. No advocacy services have been commissioned by the PCT or CYC in York. There have been discussions between the PCT and CYC on developing a generic advocacy service for all ages but these have been put on hold until there is more clarity on the role of HealthWatch</p>	<p>York has a wide range of community personal support services. However, we believe that the following are gaps (or deficiencies) in services which need to be addressed:</p> <ul style="list-style-type: none"> • There is considerable anecdotal evidence which suggest that there are insufficient places at supported day activities for people with dementia. Priority 2 • There is a specialist care service at weekends but this is only for people who are already known to the CMHTs. The service needs increased capacity in order to manage new referrals and prevent unnecessary hospital admissions. Priority 2 • We are concerned that the needs of people with early onset dementia are not being met. Younger people with early onset dementia are at present being treated by the older people's services. This means that it is often difficult to put together an appropriate package of care for people in this category. • The York / Selby Alzheimer's Society runs a support group for younger people with dementia; the outcomes of this group should be monitored. • The service for "more challenging" individuals has a men-only service. There is no women-only service. An equivalent women-only service is needed. All above Priority 3

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
7	Implementing the carers' strategy for people with dementia (family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the carers' strategy are available. Carers have a right to an assessment of their needs and also to support – this will include good quality personalised breaks. Action should be taken to strengthen support for children in caring roles ensuring that their particular needs as children, are protected)
7a	<p>There is a national carers' strategy and also a carers' strategy which has been agreed by the PCT and CYC. Carers (including those caring for people with dementia) have been involved in developing this strategy.</p> <p>The strategy correctly emphasises the importance of short breaks for people with dementia and their carers. We see this as a high priority area and it is one which will increasingly be influenced by "personalisation".</p>
7b	<p>Our Celebration/Mind provides a specialist counselling service for carers.</p> <p>Our comments/recommendations are as follows:</p>
7c	<p>Carers' grant funding is used to support short breaks for carers including a home sitting service.</p> <p>1. The York Carers' Strategy Group currently reviews its progress in implementing the Strategy quarterly. The Group has been tasked with setting up a clear framework for the provision of breaks which links to self directed support and "personalisation". Once this has been done the cost of meeting any shortfall should be identified. Priority 1</p>
7d	<p>There is no new ring-fenced money for carers' breaks and feedback from carers suggests that the demand for carers' breaks is not being met.</p> <p>2. The Carers' Strategy is currently being "refreshed" in the light of new national guidelines and local consultations by LINKs and the Health Overview and Scrutiny Committee.</p>
7e	<p>Although some care homes provide good information, anecdotal evidence suggests that people paying for their own care often find it difficult to get appropriate information.</p> <p>3. We note that the need to support young carers and protect them from inappropriate caring is included in the priorities set out in the York Strategy for Carers 2009-2011. The Carers' Centre has been working with young carers – this work has included: the development of a Young Carers' Forum; production of an awareness raising DVD; and work with schools.</p> <p>4. Better information needs to be provided for people funding their own care. Priority 3</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
8	<p>Improved quality of care for people with dementia in general hospitals (identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and commissioning of specialist liaison older people's mental health teams to work in general hospitals. The impact of these proposals will be to: make hospital environments more dementia-friendly, ensure that dementia is identified and managed alongside other conditions, provide better care and allow quicker and more effective discharge from hospital into the community with less recourse to long-term care)</p>
8a	<p>Dr Sandeep Kesavan is the dementia lead at York Hospital.</p>
8b	<p>There is not an agreed care pathway for people with dementia in the hospital.</p>
8c	<p>The hospital does not have a specialist liaison older people's mental health team. Setting up a Psychiatric Liaison service at York Hospital was a key recommendation of the Health Scrutiny Committee Report on dementia care in 2008.</p>
8d	<p>Feedback from carers suggests that clinicians and nursing staff often exclude carers at critical stages, including when patients are assessed.</p> <p>The Dementia Network has a workstream on improving care for people with dementia in General Hospitals. This has identified 4 main areas for improvement: staff training; care pathway policies and procedures; support for carers; and use of antipsychotic medication.</p>
<p>1. A Hospital Dementia Strategy Group has been set up to oversee and monitor improvements in dementia care. The Group is working on an end of life care pathway – a draft has been prepared. The pathway will recognise the importance of the role and needs of carers.</p> <p>2. It has been decided (May 2011) to commission a Psychiatric Liaison Service.</p> <p>3. The hospital has participated in the National Audit of Dementia which looked at clinical and organisational issues at the Hospital. A report was published in 2011 and a follow up action plan is now being prepared.</p> <p>4. The hospital has carried out some dementia awareness raising training. A dementia nurse has been identified on each elderly ward. This person will take the lead on dementia-related training (see also Objective 13 on page 16).</p> <p>5. We note that action is in hand to ensure that people admitted to hospital for reasons other than dementia but who subsequently show symptoms of the illness, are identified and referred appropriately. We strongly support this</p> <p>6. The PCT has included the following in its guidance on Admissions and Discharges: the requirement for staff training in dementia; actively including carers in the care and treatment of people with dementia (with the consent of the cared for person); and providing advice and support for carers in their caring role after discharge.</p>	

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
9	Improved intermediate care for people with dementia (intermediate care which is accessible to people with dementia and which meets their needs)
9a	<p>DH is developing new guidance on intermediate care for people with dementia to make clear that intermediate care services should be accessible for people with dementia. Providing better access to appropriate intermediate care (e.g. rehabilitation services) will ensure that people with dementia would be more likely to remain in their own homes for longer. In York, there is an agreement that intermediate care services will be open to people with dementia.</p> <p>Setting up a Psychiatric Liaison Service at York Hospital (see 8b above), will help people with dementia who are discharged from hospital access intermediate care services. We note the agreement that intermediate care services will be open to people with dementia. We recommend that use of these services by people with dementia be monitored. Priority 1</p>
10	Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers (the needs of people with dementia and their carers should be included in the development of housing options, assisted technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services)
10a	<p>The Strategy suggests tackling this in three ways:</p> <ol style="list-style-type: none"> 1. Monitoring the development of models of housing, including extra care housing, to meet the needs of the people with dementia and their carers. This is done in York. 2. Staff working in housing-related services to develop the skills needed to provide the best quality care. In York, home care staff (who also provide support in Extra Care Housing) are only trained in basic dementia awareness. There is no specific training for generalist housing support workers. 3. A watching brief over the emerging evidence based on assistive technology and telecare to support the needs of people with dementia and their carers. CYC does this. <p>York has 4 Council run extra care schemes and 2 run by social landlords. Supporting People contracts for housing-related support in extra care housing require 10% to be available to people with dementia – these include mild and moderate cases and (where it is safe to do so) those with severe needs.</p> <p>The requirement to improve levels of training of staff in housing-related services should be included in the work on training recommended under Objective 13 (see page 16).</p> <p>CYC is to conduct a review of its elderly persons homes; the consultation period for this is July – October 2011. The Working Group plans to contribute to this. Priority 2</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
11	Living well with dementia in care homes (improved quality of care for people with dementia in care homes through the development of explicit leadership for dementia care within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health times and through inspection regimes)
11a	The Strategy suggests this can be delivered by the following actions:
11b	Appointment of a senior staff member to take the lead for quality improvement in dementia care in the care home. In York this happens where a home is registered to provide dementia care. In other homes this is not always the case.
11c	The commissioning of specialist in-reach services from older people's CMHTs to work in care homes. Also the commissioning of other in-reach services e.g. primary care and dentistry. In York there is no dedicated specialist in-reach service for homes but where a resident is an active patient of the CMHT, support will be provided. Some care homes provide the other in-reach services described above.
11d	Readily available guidance for care home staff on best practice in dementia care. In York there is no agreed standard guidance on this but most homes have prepared their own material.
11e	Only appropriate use of antipsychotic medication for people with dementia. More work is needed on this in York.
11f	Contracting for quality of care in care homes. In York, the importance of this is understood and CYC has introduced a new monitoring system which will help inform commissioning decisions.
<p>A big gap in service provision is the lack of a specialist in-reach service for care homes (see 11c opposite). In our view, a good in-reach service could reduce emergency admissions to hospital and is a high commissioning priority.</p> <p>Priority 1</p> <p>A particular concern for some of our members was the question of inappropriate use of antipsychotic medication for people with dementia. Our recommendations on this are in Section 3 (page 20). Priority 2</p> <p>As a Working Group we are keen to stress the importance of good leadership, staff training and person-centred care all of which contribute to the creation of a stimulating environment in a care home. We note that CYC give these issues a high priority in their contracting decisions.</p> <p>In our discussions with care home managers and staff we were struck by the readiness to share good practice and consider new ideas. Our meetings have been useful in this respect and we have compiled a list of "good practice" ideas that is being shared. An example of this is that maintaining a daily activity sheet for each client can show that people have enough to do and, where it is appropriate, help with administrative tasks around the care home. We believe that CYC's inspections and liaison visits are also proving useful in sharing good practice in care homes.</p> <p>We recommend that in all care homes run or used by CYC:</p> <ol style="list-style-type: none"> Written guidance is readily available for staff on best practice in dementia care. There is clear guidance to all care homes on the need to avoid the inappropriate use of antipsychotic medication. Breaches of safeguarding standards in care homes are monitored together with the action taken to prevent further breaches – a,b,c, above – Priority 2. 	

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
LIVING WELL WITH DEMENTIA	
12	Improved end of life care (people with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the DH End of Life Care (EoL) Strategy. Local work on the EoL Care Strategy to consider dementia)
12a	<p>The Strategy recognises that end of life care for people with dementia is often limited. It emphasises that the principles and priorities outlined in the DH End of Life Strategy and also best practice in mental capacity and palliative care need to apply to care for people with dementia.</p>
12b	<p>The NDS recommends that local EoL Care pathways are consistent with the Gold Standard Framework identified in the DH EoL Care Strategy.</p>
12c	<p>In York, there is an EoL Care Locality Group (run jointly with Selby), which follows the PCT's EoL Strategy. An end of life pathway exists but it is a general pathway and does not address the particular needs of people with dementia.</p>
12d	<p>York has a Palliative Care Team and good pain relief and nursing support in community units for the elderly</p> <p>In May 2011 the role, terms of reference (TOR), membership, and priorities of the York / Selby Locality EoL Care Locality Group were reviewed. As indicated opposite (12c), the Group deals with all EoL issues regardless of age or illness – it is not feasible to have a separate care pathway for each illness. The locality group plans to engage with the new Vale of York Commissioning Consortium and will identify local priorities. The Group reports to the PCT EoL Care Strategy Group, (but the locality groups will be reporting to the various commissioning consortia once the TOR have been revised). Our Working Group plans to keep abreast of the work of the Locality Group through its Chair.</p> <p>We believe that the following requirements of the NDS are not yet being addressed:</p> <ul style="list-style-type: none"> a. That people with dementia and their carers should be involved in planning EoL care (i.e. services and pathways). b. That the special EoL needs of people with dementia will be met. c. That EoL care pathways are consistent with the Gold Standard Framework (see 12b opposite). <p>Priority 2</p> <p>We note that the training of care staff involved in delivering EoL for people with dementia in all care settings is particularly important – see also Objective 13 on page 16.</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE	
13	An informed and effective workforce for people with dementia (all health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia)
13a	<p>People with dementia and their carers need to be supported and cared for by a trained workforce with the right knowledge skills and understanding of dementia to offer the best quality care and support. The need for improved training is a priority that runs across all the NDS themes.</p>
13b	<p>The NDS calls for the Department of Health to work with representatives of all bodies involved in professional and vocational training in order to reach agreement on the core competencies required in dementia care.</p>
13c	<p>Locally, we identified a number of effective training schemes but the approach to training has been somewhat piecemeal.</p> <p>In York a Workforce Development Unit was set up in April 2010 and is preparing an Adult Social Care Training and Development Strategy; the work on dementia training in York will form part of this Strategy.</p> <p>The Dementia Network has a workstream on Workforce Development which has:</p> <ul style="list-style-type: none"> • evaluated a number of E-learning schemes, the results of which have been encouraging; • developed dementia competencies for staff; • begun preparing a Dementia Workforce Development Action Plan. York is participating in this work which is drawing on the results of the work at national level (see opposite). <p>Deciding who needs training and to what level is a complex matter bearing in mind the large number of organisations and agencies involved; setting standards and arranging monitoring systems to ensure that training is carried out are also important.</p> <p>However, once this work is complete, commissioners will be able to specify the training required by staff of service providers and also the dementia training required by other staff whose work involves dealing with older people.</p> <p>There is a need to monitor all the above.</p> <p>Priority 3</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE	
14	A joint commissioning strategy for dementia (local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers and how to best meet these needs. These should be informed by World Class Commissioning guidance)
14a	<p>The NDS emphasises the importance of joint local planning on dementia to improve access to quality dementia services. This is particularly important given the complexity of the dementia pathway and the need of a wide range staff in many services that need to understand dementia.</p> <p>A draft overarching dementia strategy has been prepared by the PCT and this is expected to be agreed by NYCC, and CYC shortly.</p> <p>The draft strategy (see opposite) is due to be signed off by all parties by the Autumn 2011.</p> <p>As part of its work, the Working Group has consulted local statutory, voluntary and independent sector organisations which work with older people. It has informed the York Health Overview and Scrutiny Committee of its progress and has kept in touch with York LINK through its representative on the Group.</p> <p>The CYC Transition Board is preparing new arrangements for commissioning and these will include dementia care. The new structures will include the new local commissioning consortium and new boards and organisations such as York's Health & Wellbeing Board. The transfer of mental health services to Leeds Partnerships NHS Foundation Trust by November 2011 is another important development which will affect local planning.</p>
15	Improved assessment and regulation of health and social care services and of how systems are working for people with dementia and their carers (inspection regimes for care homes and other services that will ensure better quality of dementia care)
15a	<p>We noted that the Care Quality Commission, which is responsible for inspecting care homes, is changing its current ratings system following reports of a lack of confidence in the system. We also note that the Dementia Network has a workstream which is working on a revised set of standards for care homes.</p> <p>We believe that this objective is particularly important, bearing in mind that at least two thirds of people in care homes have dementia. See also our comments on Objective 11, page 14.</p> <p>CYC has introduced additional quality monitoring for residential homes and other services for which it is responsible and this includes input from service users and carers. We welcome this initiative and recommend that this scheme is kept under review - see also Objective 11 on page 14. Priority 1</p>

Initial findings on dementia services and related activities in York	Recent progress and the Group's comments, recommendations and priorities
MAKING THE CHANGE	
16	<p>Dementia Research. A clear picture of research evidence and needs (DH has committed to work with the Medical Research Council and research funders across the public, private and voluntary sectors to develop a plan for the future of dementia research in the UK)</p>
	<p>We have noted the national programme of research into the assessment, treatment and care of people with dementia.</p>
17	<p>Effective national and regional support for implementation of the Strategy (appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good quality information to be available on the development of dementia services including information from evaluations and demonstrator sites)</p>
	<p>The evaluations from the national demonstrator sites will be particularly important. We expect to get these and examples of good practice in dementia care from across the Region through the Dementia Network.</p>

SECTION 3: RECOMMENDATIONS FOR A YORK ACTION PLAN

Part a: Action by Commissioners. We have set out below the key commissioning issues we have identified.

Serial	Sec 2 Table	Action	Notes
1	8c	Commission a Psychiatric Liaison Service at York Hospital. Priority 1	A decision has been made to proceed with this but funding has not yet been agreed
2	11	Provide a specialist in-reach service for care homes in order to reduce avoidable hospital admissions. Priority 1	
3	7	A recent CYC review of carers' breaks along with contract monitoring and anecdotal evidence, suggests that support for carers (including carers' breaks) does not meet demand. Priority 1	Once the Carers' Strategy Group has completed its review (see page 11) the cost of meeting any shortfall should be identified.
4	9A	PCT and CYC to ensure that intermediate care services are open to people with dementia. Priority 2	This is included in the "Levels of Care Project" signed up to by the PCT, the Vale of York Commissioning Consortium, CYC and York Foundation Trust
5	2	Commission an early assessment and diagnosis service. Priority 3	Consideration of this should await the transfer of mental health services to Leeds Partnerships NHS Foundation Trust. Setting up a new service would need to be co-ordinated carefully with other improvements in dementia care (see page 8).
6	1a	Provide funding support to the York and Selby Alzheimer's Society in their work to raise awareness of dementia. Priority 3	This funding should be sufficient to enable the Society to arrange local activities in support of national campaigns.
7	2	Provide education for GPs on dementia as part of their continuing professional development. This should include dealing with patients at the various stages of dementia and signposting to appropriate services. Priority 3	Before this can be delivered more work needs to be done to redefine appropriate pathways and guidance for GPs.

Part b: action (other than commissioning) by service providers, the PCT (including acute trusts), CYC and the VCS. Some of the serials may require commissioning action in due course.

Serial	Sec 2 Table	Action	Notes
1	11a and 15	CYC has an updated monitoring scheme for its care homes and other homes which it helps fund. CYC undertakes to keep this scheme under review – this should also include breaches of safeguarding standards. Priority 1	CYC has agreed to provide a report annually in October on this and on its dementia services and arrangements in general.
2	5	Review local VCS dementia support groups and learning networks. Priority 2	We recommend asking people with dementia and their carers for their views. This may be something that the “Dementia Without Walls” project would wish to address (see page 24).
3	3	Review the information packs on dementia which are currently in use to determine if the material is satisfactory. Priority 3	As above
4	6a	Review the availability of places at supported day services to determine if these meet the need Priority 2	See notes at serials 2 and 3 above
5	6a	Increase the capacity of the specialist care service to provide cover at week ends to manage new referrals and prevent unnecessary hospital admissions Priority 2	
6	11	Issue guidance to care homes run or used by CYC on best practice in dementia care. Priority 2	The Dementia Network has a workstream looking at similar issues
7	11	Issue guidance to care homes either run by or used by CYC on avoiding the inappropriate use of antipsychotic medication. Priority 2	This is a matter common to all localities It is being addressed by the Dementia Network in Autumn 2011. We also note that the PCT is co-ordinating an audit on this in 2011.
8	12	End of Life (EoL) care. People with dementia and their carers should be involved in planning services and pathways. Action is required to ensure that the special EoL needs of people with dementia are met. EoL pathways should be consistent with the Gold Standard Framework as recommended by the NDS. Priority 2	The Working Group plans to keep in touch with the work of the EoL Care Locality Group through its Chair. The Dementia Network intends to provide feedback from the PCT EoL Care Strategy Group.

9	12a	The dementia care pathway needs to make it clear that people with dementia have the same access to services as everyone else covered by the End of Life Strategy. The pathway should also provide guidance about “advanced decisions” and preferred future treatment. Priority 3	As in serial 8 above
10	4a	Dementia advisers - monitor the results of the national demonstrator sites. Priority 3	The Working Group expects to work with the Dementia Network on this.
11	6a	Anecdotal evidence suggests that the needs of people with early onset dementia are not being met. This should be examined further. Priority 3	The Working Group to discuss this with the PCT and the new service provider.
12	6a	Monitor the Alzheimer’s Society local support group for younger people with dementia to determine if this approach could be used more widely. Priority 3	Action by the Working Group.
13	6a	Provide a women-only service for more challenging individuals. Priority 3	At present there is a men-only service. A women-only service is under consideration by the PCT.
14	7	Better information needs to be provided for those funding their own care. Priority 3	The Dementia Network is working on this topic.
15	13	The work of the York Workforce Development Unit and the other measures described on page 14 which are designed to ensure an informed and effective workforce, need to be monitored. Priority 3	To be included in CYC’s annual report (see serial 1 above). This should include progress in improving the training of staff that come into contact with people with dementia across a wide range of care settings.
16	1	CYC should consider signing up to the National Dementia Declaration. Priority 3	
17	10a	CYC’s is to review its elderly persons homes – the consultation period is July – October 2011. Priority 2	The Working Group to advise the Partnership Board on the line to take – bearing in mind the implications for people with dementia.

Part c: The North Yorkshire and York Dementia Network Workstreams. The Network has set up a number of workstreams which are looking at particular areas of work identified in the NDS. These are areas where common approaches could apply to localities throughout the PCT area.

Serial	Sec 2 Table	Action	Notes – additional measures being taken in York to meet local priorities
12	4	Workforce Training The network has set up a group to work on this and recommend standards of training and learning for staff who deliver dementia care. Lead is Jan Cleary of NYCC	York's Workforce Development Unit is participating in this workstream and is preparing a Social Care Training and Development Strategy which will include dementia training
13	6	Personal Support/Advocacy The network has a workstream on personal support and advocacy provision.	In York, CYC and the PCT are reviewing these topics. The lead for York is Catherine McGovern.
14	8	Dementia Care in General Hospitals Dignity and older people's champions have been identified in each Acute Trust. Ongoing work includes: staff training, discharge policy, liaison services and advice on prescribing anti-psychotic medication. Lead is Judith Knapton.	
15	11	Living Well with Dementia in Care Homes This workstream is led by Jacki Tonkin. The Group intends to circulate an information pack shortly with the results of its work including: what people expect from care homes, information in lay language for care home staff and residents, information for self-funders and details of Care Quality Commission inspections.	The Working Group has established useful contacts with managers and front line staff from local care homes (see page 14).
16	12	Improved End of Life Care Feedback from the End of Life Strategy Group will be provided to the Network. Subjects under review include: resuscitation, "advanced decisions" and the use of "do not resuscitate forms"	
17		Involvement of people with dementia and their carers The Alzheimer's Society has a number of service user groups which have become sub-groups of the Network. These groups will provide feedback on services and plans. Lead is Jill Quinn (Alzheimer's Society).	In York, we expect to learn from the Dementia Without Walls project about engaging with people with dementia and their carers and how they can be empowered to play a leading part in shaping and delivering services.

Part d: The National Demonstrator Site Programme. About 40 sites have been set up – 20 have been funded for each of the following themes. The funding covers two years and the programmes will be completed in 2011.

Serial	Sec 2 Table	Action	Notes
17	4	Enabling easy access to care, support and advice following diagnosis.	A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.
18	5	Development of structured peer support and learning networks.	The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

SECTION 4: FURTHER WORK AND CONCLUSIONS

Our remit has been to recommend how the NDS should be implemented in York. Our work so far has prompted a number of service providers to make improvements in dementia care. We have identified in this Report the progress which is being made by the PCT, CYC, the Vale of York Commissioning Consortium and statutory, voluntary and independent sector care providers. We believe that improving dementia care is not only about big commissioning decisions but also about making many small improvements across a wide range of activities which, together, can make a significant difference to those receiving care.

In this Report we have set out our recommendations for an action plan for York. Ideally a detailed action plan is needed which sets out how the gaps in local services and other shortcomings in dementia-related activities are to be addressed. The plan should list the desired quality outcomes for particular activities and identify targets, lead responsibilities and costs. A local plan on these lines can only be made by commissioners from the PCT, CYC, and the new commissioning consortium, working together with the new provider of services. We believe that making a detailed plan will have to wait until the new provider of services and the new commissioning consortium have settled into their new roles and the changes being considered by the Transition Board have been put in place.

Because our task has been to recommend how the NDS should be implemented in York, our work has been directed at short and medium term improvements. We have not addressed how York could (and should) prepare to deal with the big expansion in the numbers of people likely to need dementia care in the future – a problem which Paul Burstow MP, Minister for Care Services has described nationally as “the greatest health and social crisis of the century”. Another big problem which needs to be addressed is how people with dementia and their carers can be empowered to play a leading part in shaping and developing services. We know this should be done but, if it is to be done thoroughly, it will need considerable resources.

With these last two points in mind, we believe that The Joseph Rowntree Foundation’s (JRF) York dementia project (Dementia Without Walls) which began last month is an exciting development for everyone working to improve dementia care in the City. In writing recently about the project, John Kennedy (Director of Care Services JRF Housing Trust) explained that “the aim of the project is to enlist the help of people with dementia in identifying the factors that determine whether York is, or can become, a dementia-friendly city and, in drawing from their engagement, make recommendations about how barriers to achieving this can be overcome. The project aims to raise the aspirations of people with dementia and their carers, as well as those of providers and commissioners, about what services in York could become by identifying practical exemplars locally, nationally and internationally. This project has been commissioned by JRF as a key part of our new programme Dementia and Society <http://www.jrf.org.uk/work/workarea/dementia-and-society>

ANNEX A: DEMENTIA PREDICTIONS – YORK

People in York aged 65 and over predicted to have dementia by age band (65-69, 70-74, 75-79, 80-84 and 85 and over) projected to 2030.

Dementia – All People	2009	2015	2020	2025	2030
People aged 65-69 predicted to have dementia	105	138	123	132	149
People aged 70-74 predicted to have dementia	212	224	284	257	276
People aged 75-79 predicted to have dementia	382	417	433	561	508
People aged 80-84 predicted to have dementia	603	647	714	761	986
People aged 85 and over predicted to have dementia	1002	1282	1481	1750	2045
Total people 65 and over predicted to have dementia	2304	2708	3035	3461	3964

Source: Institute of Public Care 2008

ANNEX B: MEMBERS OF THE WORKING GROUP

John Bettridge	Carer and Chair
Sheila Barry	Service User and Carer
Sue Beckett	Directorate Manager Elderly Medicine, York Hospital
John Burgess	Chair Voluntary Sector Mental Health Forum and Trustee of Our Celebration / Mind and OCAY
Judith Knapton	Head of Commissioning (Adult and Community Services) NHS NY&Y
Dr Kate Langridge	GP and dementia lead for York Health Group (GP practice-based commissioning); this Group has since been disbanded
Veronica Mackley	Service Manager for the Elderly – Bootham Park Hospital
Catherine McGovern	Commissioning Manager – Commissioning and Partnerships CYC
Dr Lance Middleton	Consultant Psychiatrist
Gill Myers	Support Services Manager York and Selby Alzheimer's Society
Dr Cath Snape	GP, Vice Chair Vale of York Commissioning Consortium and lead for mental health
Katie Smith	York Carers' Forum
Robin McIlroy	York LINKs

We have also been grateful for advice from a number of specialists from the statutory services and from managers and frontline staff from local care homes. The latter group has included: Keren Wilson Chief Executive Independent Care Group; Janice MacDonald Operations Manager for Barchester based at Mulberry Court; Elaine Pollard Manager Morrel House (CYC); Val Sutton Group Manager Adult Services at CYC with responsibility for Elderly Persons' Homes and Learning Disabilities Day Services; and Karen Cox Head of Unit, Dementia Care, South Park Care Home

ANNEX C: SOME OF THE RELEVANT POLICY DOCUMENTS AND PAPERS WE HAVE CONSULTED

1. Living well with Dementia – National Dementia Strategy 2009
2. Department of Health (DH) – Quality outcomes of people with dementia: building on the work of the National Dementia Strategy, September 2010
3. DH Mental Health Strategy – No health without mental health, February 2011
4. North Yorkshire & York End of Life and Palliative Care Commissioning Strategy 2008-2011, September 2008
5. North Yorkshire & York Mental Health Commissioning Strategy, 2010-2015
6. A Review of Services for People with Dementia, the case for Change Across Yorkshire and Humber – Yorkshire and Humber Improvement Partnership (undated)
7. Inspiring Innovation in Dementia – Regional Directory for Yorkshire and the Humber 2010
8. North Yorkshire & York Dementia Strategy (third draft)
9. Improving Dementia Services in England – an Interim Report – National Audit Office, January 2010
10. Dementia Review (Accessing Secondary Care) – Report of the CYC Health Scrutiny Committee, November 2008
11. York Strategy for Carers 2009-2011
12. The Vision of Older People’s Health and Well Being in York 2010-2015, May 2010