Wirral Primary Care Trust

Dementia Care Pathway

Benchmarking Exercise

with

The National Dementia Strategy

Contents

The National Dementia Strategy/Wirral Dementia Pathway

Benchmarking Exercise

Executive Summary

The government has made dementia a national priority and this has been marked by the publication of the first National Dementia Strategy in February 2009.

Three key areas for improvements are

- Improved Awareness
- Earlier diagnosis and intervention
- Higher quality of care

The Strategy identifies 17 objectives, which when implemented, should result in significant improvements in the quality of services for people with dementia.

The Wirral Primary Care Trust commissioned the Dementia Care Pathway, which began in November 2007. The key findings and recommendations of this work were categorised under seven headings

- Prevention and Promotion
- Early intervention
- Assessment and follow up
- Support at home
- Hospital care
- Long term care
- Palliative care

The Wirral Dementia Pathway work, which fed into the further work undertaken by CSED (Care Services Efficiency Division of the Department of Health) was completed at the end of 2008.

Some of the gaps identified within the National Strategy include new services for which Demonstrator Sites will be used to pilot services for effective evaluation. One is the proposed 'Dementia Adviser' as outlined in Objective 4 of the National Strategy, best commissioned from the Third Sector, but could be located within the Early Diagnosis and Intervention Service (described as the Memory Service in the Wirral Pathway).

There are several similarities between this proposal and the current service, the Carers Outreach Project in Wirral. This role fulfils several of the areas raised for support 'throughout the journey' in the National Strategy. The major gap is that the Wirral project was funded to support carers of people with dementia, not people with dementia who live alone and have no carer or family. In fact, the Wirral Pathway identified the lack of support for people with dementia who do not have carers.

Whilst the Wirral Pathway is a smaller less detailed document, it identifies locally the majority of issues and gaps raised in the Strategy, within Objectives

1 – 14. Objectives 15 – 17 cover performance monitoring, research and the implementation of the Strategy).

The recommendations for the creation of a Central team would address most of the objectives, in particular 2,3,4,6, 8, and 9.
The evident gaps in the Wirral Pathway are:

- It is less specific about who will carry out diagnosis. The pathway only addresses GP training.
- Care in Hospital – less detail, main emphasis on the discharge process and no real mention of a care pathway from admission. No specific mention of a dementia clinician or specialist liaison
- Care homes – medication issues not addressed. No mention of a dementia lead in each home or specialist in-reach services

It is encouraging to see that the local work is in much agreement with the National Strategy, recognising gaps in services and the recommendations to address the gaps.

The Strategy recognises that each area will have to meet local needs in developing the services and that the pace of implementation will inevitably vary, depending on local circumstances and the level and development of services within each NHS and Local Authority area.

Sue Newnes
March 2009

The National Dementia Strategy

The government has made dementia a national priority and this has been marked by the publication of the first National Dementia Strategy in February 2009.

The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas:

- Improved awareness
- Earlier diagnosis and intervention
- Higher quality of care

The Strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services for people with dementia and should promote a greater understanding of the causes and consequences of dementia.

Earlier work undertaken:-

Wirral Dementia Care Pathway

This pathway was commissioned in November 2007 by Wirral Primary Care Trust to enable informed commissioning of services for people with dementia in Wirral.

The process for this pathway began with a series of small workshops and interviews with stakeholders from primary/secondary health, Social Services, the Third Sector and various other agencies. Carers and people with dementia were also involved in the process. These events reviewed current services, identified gaps and emerging issues. After two events mapping the 'ideal pathway' the key findings and recommendations were categorised under the following headings:

- Prevention and Promotion
- Early intervention
- Assessment and follow up
- Support at home
- Hospital care
- Long term care
- Palliative care

This work fed into a project undertaken by CSED (Care Services Efficiency Delivery, from the Department of Health. As a result of this work, a System Dynamics model was developed as a tool for commissioning of future services.

This report will examine the 17 objectives of the National Dementia Strategy compared to the findings and recommendations of the Wirral Pathway as a benchmark for commissioning.

There is no expectation that all areas will necessarily be able to implement the Strategy within five years, depending on local circumstances and the level and development of services within each NHS and local authority area.

A large amount of work has already been carried out in Wirral and there is a desire to implement positive changes in line with the local pathway recommendations and the National Strategy.

National Dementia Strategy/Wirral Pathway

Objectives/Recommendations

National Dementia Strategy - The Vision for services for dementia:

- Encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- Make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed; and
- Enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

Objective 1: Improving public and professional awareness and understanding of dementia

How this can be delivered:

- Developing and delivering a general public information campaign,
- Inclusion of a strong prevention message that 'what's good for your heart is good for your head'.
- Specific complementary local campaigns.
- Targeted campaigns for other specific groups (eg utilities, public-facing service employees, schools and cultural and religious organisations)

The case for change within the Dementia Strategy states that 'the stigma of dementia creates a background where both the public and non-specialist professionals find it hard to talk about dementia, and seek to avoid addressing the possibility of an individual being affected'. Also, 'there is a false view that there is little or nothing that can be done to assist people with dementia and their carers'.

Wirral Pathway

This objective is in line with the key findings **1 Prevention and Promotion** The sections cover much of objective 1, with the addition of high risk factors and a help/advice line for carers or those worried about their memory.

The Pathway recommendations **8 Prevention and Promotion** encompass the objectives and include elements from the local perspective.

The work locally in Wirral of the development of a Carers Outreach Project pro-actively reaching out to support carers of newly diagnosed people, and

contacting professionals. Awareness raising by agencies such as the Alzheimer's Society have gone a long way to addressing these issues.

GAP – Locally, The Carer Outreach Project needs to include people with dementia who live alone.

This can be addressed by expanding the reaches of the workers to include anyone not covered by the current service.

Objective 2: Good-quality early diagnosis and intervention for all

How this can be delivered:

- The commissioning of good-quality service, available locally, for early diagnosis and intervention in dementia, which has the capacity to assess all new cases occurring in that area.

Also stated within the National Strategy, the Department of Health would publish details of the clinical and economic case for investing in services for early identification and intervention in dementia which PCT's should consider when planning local services. The detailed cost-effectiveness analysis for such services was published as Appendix 4 Department's dementia website at **www.dh.gov.uk/dementia**, and also in revised form advocated by the National Audit Office e (NAO) in their Value for Money Report can both increase the quality of care and save hundreds of millions of pounds of expenditure over a 10 year period.

The evidence also points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes.

Wirral Pathway

2 Early Intervention – the local key findings agree with the National objectives in this section, including the value of early diagnosis and intervention, the need for a central point of information and support and NICE guidelines that everyone should see a specialist for diagnosis (NDS states a clinician with specialist skills)

9 Early Intervention the Carer Outreach/Support workers are key to support people at point of diagnosis and to delay or prevent the need for admission to hospital or care homes.

The local pathway and the National Strategy agree that the present Old Age Psychiatric services focus on the severe and complex end of the spectrum, leaving early diagnosis and intervention largely unaddressed. The pathway recommendations9.2; 9.3; 9.4 addresses this issue at a local level.

The Pathway was less specific about who will carry out diagnosis of dementia and in particular mild dementia where the diagnosis is more complex. The National Strategy states a 'clinician with specialist skills'; and the Wirral Pathway calls for enhanced awareness training for GP's. The Pathway also includes identifying of dementia champions across the system.

Objective 3: Good quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good quality information on the illness and on the services available both at diagnosis and throughout the course of their care.

How this can be delivered:

- A review of existing relevant information sets
- Development and distribution of good quality information sets on dementia and services available and throughout the course of care
- Local tailoring of the service information to make clear local service provision

Wirral Pathway

This was addressed in key findings 1.7 and also in recommendations 8.1 linking in to Third sector such as Alzheimer's Society, Age Concern for information and 8.7 accessing a range of information and the proposed Central Team as a focal point

Objective 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.

How this can be delivered:

- This is a new role, development and generation of demonstrator sites, and piloting and evaluation of models of service provision prior to implementation
- A local dementia adviser service to provide a point of contact for all those with dementia and their carers, who can provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support.
- Contact with a dementia adviser to be made following diagnosis
- The dementia adviser not to duplicate existing 'hands-on' case management or care

This role has come from one of the most clear and consistent messages from the consultations with carers and people with dementia for someone they can approach for help and advice at any stage of the illness – 'someone to be with us on the journey'

Wirral Pathway

This role and service guidance is very much in line with our present Carer Outreach Project (GAP – being people with dementia who live alone) The pathway recommendations for a Central Team as a resource and support at all stages addresses these issues locally. May be a need to look at roles locally, to utilise the best points to suit the needs in Wirral.

Objective 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.

Peer support such as carer support groups, dementia cafes can address some of the issues of sharing and talking to others.

Wirral Pathway

This issue was not specifically addressed in the pathway, but mention of the 'Caring at Home' courses (education and support for carers) was included.

However, recent funding from the PCT Third Sector Innovation fund to the Alzheimer's Society for the employment of Dementia Outreach Workers has begun to address this, with the creation of drop in dementia cafes for people with dementia and their carers, and the plans for skills groups for people with dementia. The Wirral branch are also planning focus groups of carers and people with dementia to 'have their say' on service provision locally.

The Strategy will carry out evaluation to determine current activity and models of good practice.

Objective 6. Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

How this can be delivered:

- Implement 'Putting People First' personalisation changes for people with dementia, utilising the Transforming Social Care Grant
- Establish an evidence base for effective specialist services to support people with dementia at home
- Commissioners to implement best practice models thereafter

Wirral Pathway

This section was covered in both key findings 4 and recommendations 11. Inclusion of flexible approaches to support, transport issues, housing, leisure and exploring alternative creative respite options, 11.2 – 11.8 address these issues with support from a Central Team
The GAP again here is supporting people with dementia who live alone, which was acknowledged in the Pathway process.

The Strategy vision for this service provision (Appendix 1) lists what would need to be provided, most of which has been included in Pathway recommendations.

Carers – the most valuable resource for people with dementia

Objective 7: Implementing the Carers' Strategy for people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia

How this can be delivered:

- Ensuring that the needs of carers of people with dementia are included as the strategy is implemented
- Promoting the development of breaks that benefit people with dementia as well as their carers

Wirral Pathway

This was again covered by recommendations, in particular 11.4 and 11.5 also 11.6 which covers ongoing support. Both the Pathway and Strategy clearly highlight keeping people at home as long as possible, with the appropriate support services as needed.

Objective 8: 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 the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

How this can be delivered:

- Identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital.
- Development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician.
- The gathering and synthesis of existing data on the nature and impacts of specialist liaison older people's mental health teams to work in general hospitals.
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- Thereafter, the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

Wirral Pathway

The key findings **5 Hospital Care**, 5.1 Identified clinician was included. Support for carers and the need for other options that full time care need to be explored in the discharge planning. An extra here is the current and continuing dementia training offered to staff in the acute hospital.

The Pathway agrees with the strategy, with less detail in the pathway, and no specific mention of specialist liaison. The main GAP is no mention of an explicit care pathway for management and care of the person with dementia, led by the senior clinician. The Pathway focussed on the discharge process

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

Wirral Pathway

The pathway addresses this objective in key findings 4 and recommendations 11. The present outreach service in Wirral endeavours to prevent hospital admission and crisis, but the current GAPS in intermediate care provision cause great difficulties, and the lack of specialist intermediate services also hinder hospital discharge, which links in to objective 8.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.

Wirral Pathway

Recommendations 11.5 raises this point, the need to explore alternative creative respite options and to increase extra care housing. Wirral has already begun to address these issues with the development of Cherry Tree House in Moreton, and an Assistive Technology service currently supporting people with dementia and their carers.

Objective 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 teams, and through inspection regimes

How this can be delivered:

- Identification of a senior staff member within the care home to take the lead for quality improvement in the care of dementia in the care home
- Development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member
- Only appropriate use of anti-psychotic medication for people with dementia
- The commissioning of specialist in-reach services from older people's community mental health teams to work in care homes
- The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc.
- Readily available guidance for care home staff on best practice in dementia care

Wirral Pathway

Key findings 6.1 – 6.5 and recommendations 13.1 – 13.3 addressed issues locally. Development of training programmes and support from the Central Team goes partway to addressing the gaps in this section. Several of the issues raised were discussed during the pathway process and agreed with the findings of the strategy.

GAPS the medication issue, a dementia lead in each home, or specialist in-reach services were not raised in the local pathway

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

Wirral Pathway

Key findings 7.1 – 7.5 and recommendations 14.1 – 14.4 recognised the issues in this objective. Dementia has already been included in the End of Life work being carried out in Wirral. Issues of pain management were also raised.

Objective 13: An informed and effective workforce for people with dementia

Wirral Pathway

Dementia training features throughout the pathway for all levels of staff, from diagnosis, to ongoing support, home care and in care homes. Core

competencies could be developed to train staff who are not professionally qualified or registered.

Objective 14: A joint commissioning strategy for dementia

Wirral

The development of the dementia pathway which began in November 2007 saw the start of this work in Wirral. The further involvement of CSED and the pilot study of dementia and the creation of the Systems Dynamic modelling to enable informed commissioning of future services.

Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.

Objective 16: A clear picture of research evidence and needs.

Objective 17: Effective national and regional support for implementation of the strategy

These last three objectives were not specifically covered in the Wirral Dementia Pathway work.

Comparisons – at a glance

National Dementia Strategy	Wirral Dementia Pathway	Comparisons	Gaps
Objective 1: Improving public and professional awareness & understanding of dementia	Prevention and Promotion Key findings 1.1 – 1.7 Recommendations 8.1 – 8.7	Much of objective 1 were covered in the sections, with addition of high risk elements and help/advice line	Locally services are still not including people with dementia who live alone (highlighted in pathway)
Objective 2: Good-quality early diagnosis and intervention for all	Early Intervention Key findings 2.1- 2.6 Recommendations 9.1 – 9.6	Agreement in the pathway with the local inclusion of a Central Point of information and Carer Outreach/support workers to prevent crisis/emergency hospital admissions. Also need for dementia champions	Pathway less specific about who will carry out diagnosis. Strategy states 'clinician with specialist skills', pathway calls for enhanced training of GP's.
Objective 3: Good quality information for those with diagnosed dementia and their carers	Prevention and Promotion Key findings 1.1 – 1.7 Recommendations 8.1 – 8.7	This was address also linking into third sector such as Alzheimer's Society, Age Concern information Central team as focal point	1.7 partly addresses for local tailoring of information to make clear local service provision
Objective 4: Enabling easy access to care, support and advice following diagnosis	Early Intervention 9.1; 9.2 Support at Home 11.2	Dementia Adviser role in line with our present Carer Outreach project	Carer Outreach Project does not include people with dementia who live alone – needs to be included
Objective 5: Development of structured peer support and learning networks	Not specifically addressed in pathway	Pathway mentions 'Caring at Home' courses which covers some education and support for carers Recently funded (PCT Third Sector Innovation) Dementia Outreach Workers establishing peer support networks, cafes, skills groups, focus groups	This section was not specifically covered in the pathway
Objective 6: Improved community personal support services	Support at Home Key findings 4.1 – 4.7 Recommendations 11.1 – 11.8	Pathway includes flexible approaches to support, transport, housing, leisure and exploring alternative creative respite options. Support from the Central Team	Supporting people with dementia who live alone, which is acknowledged in the Pathway
Objective 7: Implementing the Carers' Strategy for people with	Support at Home Recommendations 11.4; 11.5;	Both Pathway and Strategy clearly highlight keeping people at	Lack of appropriate services to offer support (acknowledged in

dementia	and 11.6	home as long as possible, with appropriate support services	pathway report)

Comparisons – at a glance cont'd

National Dementia Strategy	Wirral Dementia Pathway	Comparisons	Gaps
Objective 8: Improved quality of care for people with dementia in general hospitals	Hospital Care Key findings 5.1 – 5.9 Recommendations 12.1 – 12.5	Identified clinician was included, support for carers and need for options prior to discharge planning. Extra is the current and continuing dementia training to staff	Less detail in the pathway and no specific mention of specialist liaison. No mention of care management pathway led by specialist clinician
Objective 9: Improved intermediate care for people with dementia	Support at home Key findings 4.1 – 4.7 Recommendations 11.1 – 11.8	Carer Outreach project endeavours to prevent hospital admissions and crisis	Current lack of intermediate service provision causing great difficulties and lack of specialist intermediate services also hinder hospital discharge, linking into objective 8
Objective 10: Considering the potential for housing support, housing related services and telecare	Support at home Recommendation 11.5	Wirral has begun to address this with Cherry Tree House and the Assistive Technology service	
Objective 11: Living well with dementia in care homes	Long term care Key findings 6.1 – 6.5 Recommendations 13.1 – 13.3	Development of training programmes and support from the Central Team. Several issues raised in the pathway process and agreed with the findings of the strategy	Medication issues A dementia lead in each home Specialist in-reach services
Objective 12: Improved end of life care for people with dementia	Palliative care Key findings 7.1 – 7.5 Recommendations 14.1 - 14.4	Already included in End of Life planning presently being undertaken in Wirral. Issues of pain management also raised	Currently gaps, but work ongoing
Objective 13: An informed and effective workforce for people with dementia	Covered throughout the pathway	Training for all levels of staff	Monitoring of staff in order to assess value of training and use of knowledge in workplace. Ongoing support, home care and in care homes.
Objective 14: A joint	Pathway/CSED involvement	Began in November 2007. CSED	

commissioning strategy for dementia		involved in pilot study of dementia (in Wirral) and creation of Systems Dynamics modelling to enable informed commissioning	

Comparisons – at a glance cont'd (2)

National Dementia Strategy	Wirral Dementia Pathway	Comparisons	Gaps
Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers	This area was not specifically covered in the pathway work		
Objective 16: A clear picture of research evidence and needs	Not covered by the pathway		
Objective 17: Effective national and regional support for implementation of the strategy	Not covered by the pathway		

Appendix 1

From the National Dementia Strategy

Objective 6: Improved community personal support services

A comprehensive community personal support service would provide:

- Home care that is reliable, with staff who have basic training in dementia care
- Flexibility to respond to changing needs, not determined by rigid time slots that prevent staff from working alongside people rather than doing things for them
- Access to personalised social activity, short breaks and day services
- Access to peer support networks
- Access to expert patient and carer programmes
- Responsiveness to crisis services
- Access to supported housing that is inclusive of people with dementia
- Respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers
- Flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia
- Independent advocacy services
- Assistive technologies such as telecare