Derby City Dementia Strategy

2011-2012

Easy Read Version
Foreword

Dementia is one of the biggest health and social care challenges of the present day. In Derby, the numbers of people with dementia is expected to grow by 58% by 2025. Derby City Council and NHS Derby have joined together to develop a strategy which sets out plans for improving services for people with dementia in Derby. The strategy is informed by national guidance on dementia care as well as local information specific to Derby.
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1. Introduction

1.1 What is dementia?
Dementia may be caused by a number of illnesses that affect the brain. Dementia typically leads to memory loss, inability to do everyday things, difficulty in communication, confusion, frustration, as well as personality and behaviour changes. People with dementia may also develop behavioural and psychological symptoms such as depression, aggression and wandering.

There's no single test that can identify dementia, although a range of blood tests and sophisticated brain scans can help and are important in ruling out reversible causes. Diagnosis is made by an assessment of symptoms and the use of brief questionnaires that test ability to remember facts, or draw simple diagrams.

Most types of dementia progress slowly. People may live with the condition for ten years or more, requiring increasing levels of support as they become less independent. By carefully planning the person's environment, and giving structure to their day with supportive activities, it may be possible to reduce the impact of the symptoms.

1.2. Dementia in Derby
In Derby City there are 3,243 people predicted to have dementia. By 2020 the number of older people (people aged over 65) in Derby is expected to rise by 19%. As there is a positive relationship between the number of older people and the number of people with dementia, Derby can expect to see approximately 4,122 people with dementia by 2015.

Derby has a large Asian population made up of Indian and Pakistani people. There is also a significant African Caribbean population.
These people are more likely to live in the wards of Arboretum and Normanton. People of Southern Asian descent are more likely to suffer from diabetes and cardiovascular disease which can lead to vascular dementia.

Many people with dementia do not have formal diagnosis and are therefore not included on registers held by their GP. In Derby it is thought that only 30% of people who have dementia will have a diagnosis. There are many reasons why people do not receive a diagnosis including unwillingness to come forward to the GP, lack of dedicated memory assessment clinics to diagnose people and poor data collection.

1.3 What is the purpose of this strategy?
In 2009 Living Well with Dementia: A National Dementia Strategy was published by the Department of Health. Living Well with Dementia is the first ever national strategy for dementia in England and Wales. The Derby City Emerging Dementia Strategy is the local response to the objectives in the national document.

This Strategy has been developed by NHS Derby City and Derby City Council with support from other stakeholders, local people and carers. It outlines what the priorities for improvement are and how those improvements will be made. It will also state who is responsible for delivering on the improvements. This is the Easy Read version of the Derby City Emerging Dementia Strategy, a full version of the strategy can be obtained by using the contact details in S.6.
The National Dementia Strategy identifies 17 objectives. Many of these objectives have been identified in the Derby City Dementia Strategy priority action areas. S.3 provides more information on each of these areas.

1.4 Dementia Quality Outcomes
In October 2010 the Department of Health published a revised implementation plan for 'Living Well with Dementia - A National Dementia Strategy’. Nine statements have been developed which aim to capture what people with dementia should expect in terms of their health and social care.

The statements are:

I was diagnosed early

I am treated with dignity and respect

I understand, so I make good decisions and provide for future decision making

I can expect a good death

I am confident my end of life wishes will be respected

I can enjoy life, I feel part of a community and I'm inspired to give something back

I know what I can do to help myself and who else can help me

Those around me and looking after me are well supported

I get the treatment and support which are best for my dementia, and my life
These statements have formed part of the Derby City Dementia Strategy and can be found included in the commissioning plan at S.4

1.5 Who has been involved in developing these plans?
Throughout 2009 and up to March 2010 events and workshops were held to involve people in Derby who have an interest in Dementia. Attendees included people with dementia and their carers, health and social care staff who support people with dementia and people involved in planning dementia services.

In February 2010 a series of events identified the top five priorities as:

- Workforce learning and development of staff
- Integrated dementia team /care coordination
- Respite within the home and in residential care settings
- Memory assessment service to diagnose people with dementia
- Joint 5th: Continence services; out of hours home care; seamless community networking.

It was also agreed that special attention should be paid to the specific needs of Asian and African-Caribbean people who mainly live in the electoral wards of Arboretum and Normanton.

These priorities have formed the basis of this strategy. More detail about how they will be turned into action can be found in s. 3 and s.4
2.0 Developing the Derby City Dementia Strategy

This strategy has been developed following a review of all of the work undertaken on dementia up to March 2010.

- A review of national and local policy has been completed
- Local people, carers, service providers and commissioners have been involved in setting priorities for action
- A review of best practice dementia care from other parts of the East Midlands and the country
- A review and mapping of the current financial spending on older adults
- A review and mapping of the current services for older adults

The different reviews and stakeholder events that took place resulted in the following conclusions about current services:

- **There is a lack of investment in community based care.** We know that 90% of Derby City Council Adult Social Care funding is spent on residential and nursing care. 9% of the budget is spent on community services such as home care, day care and assistive technology and only 1% on respite services. NHS Derby City also spend the majority of their budget on institutional care rather than community services.

- **Memory assessment services are underdeveloped.** Services are currently provided by GPs and Older Adults Community Mental Health Teams. At the moment there isn’t a dedicated memory assessment service which can make the process of getting a diagnosis of dementia more confusing.

- **Under diagnosed and under treated condition.** In Derby roughly only 1/3rd of people with dementia receive a diagnosis.
Without a diagnosis many people never receive the support and treatment they need.

- **Not enough coordination between services.** Services providing dementia care should be better coordinated to stop unnecessary delays, missed opportunities and poor experience.

Solutions to these problems have been developed and identified as priority areas for action.

### 2.1 The emerging model of care

Diagram 1 (below) shows a suggested Dementia Model of Care. The model shows that the different dementia services need to be closely linked to other dementia services and mainstream services. The services should be able to work together to provide all of the care the person needs, this approach is often called 'person centred' care.

Diagram 1
3.0 Priority areas

The following areas have been identified as priorities for action.

3.1 Good quality early diagnosis and intervention for all
NHS Derby City is committed to commissioning Memory Assessment Services to increase the number of people who receive a formal diagnosis of dementia.

The main features of Memory Assessment Service are:
- Services will be run by dedicated specialist teams
- The service will be open access and based in community locations to make them as accessible as possible, linking with peer support services as much as possible
- After diagnosis the person with dementia and their carer will be offered the Living Well Programme which will provide information, education and other help straight after diagnosis
- The Memory Assessment Service will be responsible for ensuring that every person with dementia and their carer knows where to access information and support from, this will be achieved by linking with existing peer support and advice services

3.2 Easy access to peer support and advice
People with dementia reported that after diagnosis they often felt alone and unsure how to get the help and support they need. We are delivering peer support services as part of the Department of Health Peer Demonstrator Site. For more information on this project and what we have already achieved in this area please go to section 5 on page 21.

We are committed to ensuring that peer support and advice is an integral part of the dementia pathway. As people are diagnosed earlier by the memory assessment service they will be directed to
peer support and advice. In some cases this will be achieved by locating dementia cafes or advice services in the same place as the memory assessment service. The memory assessment and peer support service will work together closely to ensure people are passed seamlessly from one service to another.

3.3 An informed and effective workforce across all services
People with dementia and their carers should be able to expect services and support from staff who are knowledgeable about dementia and who have the right skills to do their job. In Derby organisations commissioning and providing dementia care will agree standards for the knowledge and skills which every worker providing care to a person with dementia should have.

Local work has shown that many organisations providing dementia care in Derby want to access a range of different training options. We are therefore making an e learning package for basic dementia training available. We have already had commitment from Derbyshire Health NHS Foundation Trust and Royal Derby Hospitals to pilot the programme in their organisations.

Carers and people with dementia told us that carers should be thought of as part of the dementia workforce. To respond to this we have commissioned the Alzheimer’s Society to deliver education and information programmes for carers of people with dementia. The first of these programmes will start in March 2011.

3.4 Good quality care for the physical health care needs of people with dementia
Current estimates suggest that up to a quarter of people in general hospital have dementia. Once in hospital people with dementia on average stay longer and often have poorer outcomes then people
who do not have dementia. In Derby we have taken the view that services in the community can find ways of caring better for the physical health needs of people with dementia to stop them going into hospital in the first place.

NHS Derby City is working with partners across the city on the Integrated Care Pathway Project. The project has the following aims:

- Improved liaison between specialist Mental Health staff and staff at the Royal Derby Hospital
- Better access to diagnostics for people with dementia
- Improved recording of dementia as a diagnosis when a person is in hospital

NHS Derby City has been awarded Innovation funding to pilot a Green Medicines and Communication Bag. The Bag contains the Alzheimer’s Society ‘This is Me’ document and contact information which the person with dementia and the carer will complete in advance. In an emergency situation the East Midlands Ambulance Service will locate the bag and if the person goes into hospital the Bag will be transported with them. The Green Medication and Communications Bag will be evaluated to see if the information contained in the bag helps medical professionals make better decisions about their care.

For more information on this project contact Derby City Patient Advice and Liaison Service on 0800 032 32 35 or email pals@derbycitypct.nhs.uk

3.5 Improved Personal Care for People with Dementia
Two-thirds of people with dementia live in their own homes. We believe services should be in place to support people to maintain their
skills and abilities. We have already commissioned a home respite service that will support carers and give people with dementia an opportunity for some social activity. You can read more about this service under section 5 on page 21.

Derby City Council provides a fast track assessment and installation of telecare equipment for people with dementia and their carers. The project has received funding as part of the NHS East Midlands Innovation Awards. Offering people with dementia telecare equipment can help maintain independence, reduce carer anxiety, increase dignity and control and avoid crisis. This project will be evaluated to determine success and recommend how people with dementia can access telecare as part of Derby City Council's wider telecare service.

3.6 Improved Care in Care Homes

NHS Derby City is working on a regional project to develop a quality schedule for people who are in nursing homes and are fully funded by continuing care. Similarly, Derby City Council is developing quality standards for residential care homes. Both schedules will include specific measures for staff training, assessment and care planning, dealing with behaviour that challenges and end of life care. All care homes will then be monitored against these standards to ensure they are delivering the required levels of quality.

NHS Derby City and Derby City Council are committed to work together with other partners to reduce the use of inappropriate anti psychotics for people with dementia. National and local evidence shows that people in Derby are often prescribed anti psychotics or kept on them for longer then necessary. In many cases better knowledge about dealing with challenging behaviour and non medical interventions can prevent a prescription of anti psychotics or support someone to come off them. We are joining forces with colleagues in Derbyshire County to work with a small number of care homes to pilot
specialist dementia input into the homes. The specialist input will focus on supporting care home staff to deal with challenging behaviour more effectively while monitoring if this has an impact on anti psychotics.
4.0 Commissioning Plans

Table 1 is an action plan which outlines the key short, medium and long term aspirations of the Derby City Older Peoples Commissioning Group. The action plan will be regularly reviewed and updated however it is current here as of February 2011.
<table>
<thead>
<tr>
<th>What do we want to achieve?</th>
<th>Quality statement</th>
<th>What will we do to achieve this?</th>
<th>Timescale</th>
<th>Responsible organisation</th>
</tr>
</thead>
</table>
| Good quality early diagnosis | I was diagnosed early | • Commission a direct access memory assessment service which will maintain strong links with the dementia peer support service  
• After diagnosis the person with dementia and their carer will be offered the Living Well Programme which will provide information, education and other help straight after diagnosis  
• Every person with dementia and their carer knows where to access information and support from | Phase 1: April 2011  
Full roll out: end August 2011 | NHS Derby City |
| Easy access to care, support and advice following diagnosis | I understand, so I make good decisions and provide for future decision making | • Develop a dementia support service so that people with diagnosis will receive help and guidance to access the care and support they need  
• Link to Dementia Café and other | July 2011  
July 2011 | Derby City Council |
<table>
<thead>
<tr>
<th>An informed and effective workforce across all services</th>
<th>I get the treatment and support which are best for my dementia, and my life. I am treated with dignity and respect</th>
<th>existing Peer Support options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Work with provider organisations to pilot and roll out an E learning package for basic dementia training</td>
<td>May 2011 Derby City Council &amp; NHS Derby City</td>
</tr>
<tr>
<td></td>
<td>• Develop training quality standards to be used as part of commissioning and contracting process</td>
<td>End of July 2011</td>
</tr>
<tr>
<td></td>
<td>• Commission a dementia education programme pilot for carers of people with dementia and evaluate success</td>
<td>April 2011</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Home respite available to support people with dementia and their carers</th>
<th>Those around me and looking after me are well supported</th>
<th>Provided the carer with a break while the person with dementia benefits from contact and meaningful activity in their home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Achieved Derby City Council</td>
</tr>
</tbody>
</table>

| Extend Assistive Technology to support people living with dementia and | Those around me and looking after me, are well supported | • Pilot telecare for people with dementia  
<p>|                                                                       |                                                                 | • Evaluate success of the pilot and plan how to provide telecare for people with dementia after the end of the pilot |
|                                                                       |                                                                 | March 2011 Derby City Council |</p>
<table>
<thead>
<tr>
<th>Improve the physical health care of people with dementia</th>
<th>Integrated Care Pathway Project has the following aims:</th>
</tr>
</thead>
</table>
| *I get the treatment and support which are best for my dementia, and my life*  
*I can expect a good death*  
*I am treated with dignity and respect* | • Improved liaison between specialist Mental Health staff and staff at the Royal Derby Hospital  
• Better access to diagnostics for people with dementia  
• Improved recording of dementia as a diagnosis when a person is in hospital  
• Pilot of Green Medication and Communication Bag and evaluate success |
| | April 2011  
July 2011 | NHS Derby City |

<table>
<thead>
<tr>
<th>Provide peer support and learning networks</th>
<th>Develop peer support services that provide people with dementia and carers opportunities to socialise and share learning.</th>
</tr>
</thead>
</table>
| *I know what I can do to help myself and who else can help me*  
*Those around me and looking after me, are well supported* | • 10 dementia cafes across Derby City  
• 3 carers support groups |
| | Achieved  
| | Derby City Council |
| Quality care in nursing and residential care homes | I can enjoy life, I feel part of a community and I'm inspired to give something back | • Befriending services for people with dementia and their carers  
Explore ways for service to be commissioned after the national funding for the Peer Demonstrator Site ends | End of July 2011 | NHS Derby City and Derby City Council |
|--------------------------------------------------|---------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|------------------|-------------------------------------------------|
| I am treated with dignity and respect I get the treatment and support which are best for my dementia, and my life I can expect a good death I am confident my end of life wishes will be respected | • Develop quality schedules for nursing homes and residential care homes which will guarantee levels of quality of care  
• Put monitoring arrangements in place  
• Pilot specialist dementia input into care homes to reduce the inappropriate use of anti psychotics | End of September 2011  
End of November 2011 |
5.0 What have we achieved already?

Significant work has already taken place across the city in response to the National Dementia Strategy. Examples of good practice have been included below:

5.1 Home based respite service
Respite was identified as one of the top local priorities for action in Derby. Carers have told us that they want and need short breaks which offer the person they care for some quality social time. In response Derby City Council has commissioned a home based respite service. This service provides the carer with a break while the person with dementia benefits from contact and meaningful activity in their home. The activities offer the person with dementia some quality social time which may include spending time gardening, baking, playing chess or painting.

To access the home based respite service the carers respite needs need to be identified by an assessment. An assessment is carried out by a Care Manager. If you would like to be assessed you need to speak to your Care Manager. If you don’t already have a Care Manager you can contact Derby City Council’s Carers Breaks Information and Support Service, which is based at the Council's Adult Social Services local office at 29 St Mary's Gate, Derby DE1 3NU, telephone: 01332 717777.

5.2 Derby City Peer Support Service
Derby City Council have commissioned from the Alzheimer’s Society, a network of dementia cafes, befriending services and carer support groups increase contact and engagement opportunities
for people with dementia and their carers. Peer help people to socialise, share learning and develop their own support networks.

Since September 2010 there have been ten dementia cafes operating across the city. The cafes offer a mix of informal drop in and structured activities such as Singing for the Brain. A befriending service has also been set up which offers individual support to people with dementia and their carers. After receiving training and support volunteers will visit people with dementia in their own homes or take them out and about in the community to help them fulfil their interests. Volunteers have also been recruited to support carers of people with dementia. Support for carers may come in many forms depending on what the volunteer and the carer both want from the relationship.

Carers support groups are an additional method of supporting carers. We have increased the numbers of support groups from one to three. Carers can now benefit from support from other carers in their area or access information sessions on a variety of subjects.

It is not always clear to people with dementia and their carers what the most appropriate course of action is when problems arise. Dementia cafes provide a focal point for advice and information which will help people navigate their way through the dementia pathway. Informing people early on of the advice and support they can access will reduce the feeling of isolation and prevent future crises. Work is continuing to develop strong links with memory assessment services and GPs to ensure people are directed to dementia cafes for the support they need.

For more information on accessing Peer Support in Derby contact the Alzheimer’s Society by emailing derby@alzheimers.org.uk or telephone 01332 208845.
6.0 Contact Information

If you have any comments or questions on the information contained in this Derby City Dementia Strategy please contact us with your feedback. If you are a person with dementia or caring for someone with dementia and you would like to get involved in any of the projects we would like to hear from you. Contact details are as follows:

<table>
<thead>
<tr>
<th>NHS Derby City</th>
<th>Derby City Council</th>
</tr>
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<tbody>
<tr>
<td>Rachel Gibson</td>
<td>Phil Holmes</td>
</tr>
<tr>
<td>Cardinal Square</td>
<td>Middleton House</td>
</tr>
<tr>
<td>10 Nottingham Rd</td>
<td>27 St Mary’s Gate</td>
</tr>
<tr>
<td>DERBY</td>
<td>DERBY</td>
</tr>
<tr>
<td>DE1 3QT</td>
<td>DE1 3NN</td>
</tr>
<tr>
<td><a href="mailto:Rachel.gibson@derbycitypct.nhs.uk">Rachel.gibson@derbycitypct.nhs.uk</a></td>
<td><a href="mailto:Phil.holmes@derby.gov.uk">Phil.holmes@derby.gov.uk</a></td>
</tr>
</tbody>
</table>