



DERBY CITY COUNCIL

## ADULT SERVICES AND HEALTH COMMISSION 19 JANUARY 2009

Report of the Corporate Director of Corporate and Adult Services

### DEMENTIA CARE AND SUPPORT SERVICES

#### SUMMARY

- 1.1 The number of people living with dementia is increasing as the population ages. It is estimated that, at the present time, 2,800 people in Derby are experiencing dementia and this will rise year on year (39% rise expected by 2025).
- 1.2 Dementia affects many and varied aspects of a person's physical and mental health and well-being, and that of their family. In particular older people who care for their husband / wife with dementia will often be placed under considerable physical and emotional pressure.

#### RECOMMENDATIONS

- 2.1 That the Commission note progress to date in the local development of dementia services and comment on investment priorities.
- 2.2 That the Commission support the development of a Derby Dementia Care and Support Strategy, jointly with NHS colleagues and the likely increased investment in dementia care and support services during 2009 – 12.

#### SUPPORTING INFORMATION

- 3.1 The growing incidence of dementia, the need for early identification, appropriate treatment, rehabilitation, support for carers and specialist social care and housing services are all identified as issues relevant to improving the future care and support of people affected by dementia. A National Dementia Strategy is in the process of being developed and is expected to include increased responsibilities for both the NHS and local authorities in all these areas (plus others). The Strategy was expected in Autumn 2008, and is now expected 'imminently'. It is not yet clear to what extent additional national funding will be available for implementation.
- 3.2 As part of our joint commissioning work programme with NHS Derby City we propose to develop a joint local commissioning strategy for dementia services with a joint improvement / investment plan. This is an area where both organisations have responsibilities and it is crucial that the services commissioned are co-ordinated and available across the pathway, from early recognition and diagnosis through to intensive health and social care support for those with moderate / advanced dementia.

- 3.3 In recognition of the level of support needed for people with dementia and their carers an additional investment of £500k (250k in 2008 / 9, 250k in 2009 / 10) has been allocated within the adult social care revenue budget. This recognises the very low level of specialist dementia social support services currently provided, and the need to extend and improve services for the future.
- 3.4 The focus of this initial investment has been discussed with local stakeholders. Their priorities are listed in Section 4 of the attached report (appendix 2). Further work and more detailed prioritisation is now being undertaken, with the initial improvement plan intended to be considered by Cabinet in March / April 2009. (The investment for 2008 / 9 has not yet been committed, pending the outcome of this local consultation and the publication of the National Strategy).

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<b>Background papers:</b>	None
<b>List of appendices:</b>	Appendix 1 – Implications Appendix 2 – Interim report of dementia priorities

## IMPLICATIONS

### Financial

- 1.1 Whilst an additional investment of 500k is contained within the adult social care budget, there are likely to be further improvements required with the publication of the National Strategy. It is not yet known whether any additional resources will be available nationally and / or to what extent local authorities will be required to identify additional resources to implement the strategy.

### Legal

- 2.1 None arising from this report.

### Personnel

- 3.1 None arising from this report.

### Equalities Impact

- 4.1 None arising from this report.

### Corporate objectives and priorities for change

- 5.1 This report links to the following Council priorities:
  - help us all to be healthy, active and independent
  - providing excellent services and value for money.

## Interim Report of Dementia Priorities – December 2008

### 1. Introduction and Summary of Suggested Next Steps

This report provides an overview of local need in Derby, including prevalence data; an overview of consultation with a variety of stakeholders; and analysis of national consultation and policy documentation. Recommendations are made that identify service areas requiring further investment locally, as well as a suggested process to develop dementia planning and commissioning within the city.

The following table summarises service areas that would benefit from short-term investment, and outlines some suggested next steps:

Priority area for short-term investment	Next Steps and implementation
<b>Training and development of workforce</b>	<ul style="list-style-type: none"> <li>• Identify baseline of training amongst social care staff and devise approach to improve levels of training for dementia skills and knowledge</li> <li>• Devise multi-agency approach to training to identify needs and resources available across the partnership</li> </ul>
<b>Support for people with dementia through personalisation agenda</b>	<ul style="list-style-type: none"> <li>• Consider what additional resources are required to facilitate dementia service user and carer access to individual budgets for services through the personalisation programme board</li> <li>• Investigate needs of social inclusion further through day services review with a view to commissioning further day opportunities and VCS provision</li> </ul>
<b>Development of dementia specific supported accommodation</b>	<ul style="list-style-type: none"> <li>• Develop a service specification for dementia specific residential care placements that defines service standards; clarifies expectations in service delivery; and rewards service delivery with an enhanced rate of payment.</li> </ul>
<b>Increase support available for informal carers</b>	<ul style="list-style-type: none"> <li>• Link with wider local strategic objectives for carers support including implementation of accredited informal carers support and training package (for example Expert Patient carers model)</li> <li>• Explore feasibility of commissioning additional support for carers to support them in their caring role – such as crisis support.</li> </ul>

### 2. Prevalence and Demographics

Within Derby at the present time, there are estimated to be around 2,800 people experiencing dementia (all population figures and projections are provided by POPPI, 2008). Dementia affects approximately 5% of those over 65 years and 20% over 80 years old. Whilst the majority of people experiencing dementia are over 65 there are also a small but growing number of people under 65 who are also affected.

The following table summarises the numbers experiencing dementia and details population predications for the future including the percentage increase. The figures include a likely rise in dementia prevalence of 23% by 2020 and by 39% by 2025 from present day figures.

	2008	2010	2015	2020	2025
Numbers projected to be experiencing dementia aged over 65	2,778	2,850	3,124	3,432	3,880
Numbers projected to be experiencing dementia aged under 65	56	56	57	62	66
<b>Total</b>	<b>2,834</b>	<b>2,906</b>	<b>3,181</b>	<b>3,494</b>	<b>3,946</b>
<b>Expressed as a % increase from current figures</b>	<b>-</b>	<b>3%</b>	<b>12%</b>	<b>23%</b>	<b>39%</b>

We also know that there will be a parallel impact on family members and carers and these needs must also be taken into account.

### 3. Local Consultation approach

An initial consultation took place during November and December 2008, whereby key stakeholders such as the Alzheimer's Society, local informal carers, and social care staff including the Community Mental Health Team were asked to identify their priorities for service areas for people with dementia. Priorities highlighted as part of a multi-agency county-wide event held in November 2008 have also been taken into account.

A national perspective of user needs has been enmeshed into the findings by drawing from key policy and consultation documents - such as the national draft dementia strategy (DoH, 2008); 'Social care: a lifeline for people with dementia and their carers' (Alzheimer's Society, 2007); 'Home from Home' (Alzheimer's Society, 2007) and 'Dementia: Out of the Shadows' (Alzheimer's Society, 2008).

Further work to build on the picture of local user needs will take place as part of the development of a draft local dementia strategy as outlined in section 5 below.

The following findings have therefore been gathered from local feedback and national findings. Please see appendix 1 for further detail of feedback received.

### 4. Local Consultation Findings

The main areas that the consultation identified as warranting development and investment were as follows:

- 1. Respite and Intermediate care** – to be provided both flexibly within the home if required, and also within a specialist environment. This could potentially be delivered as part of a specialist residential setting.
- 2. Day care and day opportunities** – the limited supply of day care facilities and opportunities was frequently cited by those consulted. This gap should be filled to a degree by individual budgets, although a demand for more traditional day services should be more fully investigated, as good quality day care was seen to provide both stimulation for users and valuable respite for informal carers.

3. **Supported Accommodation** – the need for a 'home for life' was emphasised' a lack of supply of specialist dementia residential care and nursing care was noted. Extra Care housing was also felt to be an excellent way of meeting people's needs in a way that promotes independence. The achievement of more positive outcomes for residents within supported accommodation was felt to be realised through service improvements such as appropriate environmental features and considerations (such as accessible gardens); on-going links with the community and voluntary sector organisations; enhanced activities being made available; and the training of staff to be improved and made available to all.
4. **Support for informal carers** - The message from informal and family carers overall was that support was needed to help them manage their caring role. This included better information about what services and support were available; support to help them manage risks confidently and competently; and provision of crisis support including respite when required. Training for carers was also seen as important – in treating them as part of the workforce, and to promote confidence.
5. **Support for people to remain at home** – homecare services that were specifically designed to meet the needs of people with dementia were perceived to be very valuable and much needed. Familiarity of staff and a personalised and flexible service were important factors of delivery. Assistive technology was also seen as a means of promoting independence at home. Crisis support that was available out of hours was also seen as a means to avoid admissions to longer term care.
6. **Training and Development** – Training to equip staff in their roles was highlighted as key area of service development across every aspect of provision, inclusive of carers and family members as above. Specifically, training should enable and support early diagnosis; promote personalised service delivery; develop communication skills; and support reminiscence and therapeutic interventions. On-going development of staff should be supported by access to information about services available to support staff in their role as information provider.

## 5. Next Steps for developing a strategic approach to dementia

The process for taking forward an approach to developing and commissioning services for people with dementia is suggested as follows:

- **December 2008 and January 2009** – further consultation and engagement work to take place with carers, users of service and local voluntary and community sector groups
- **January 2009** – draft strategy to be produced to provide basis for further discussion and engagement
- **February 4 2009** – local event to gain further feedback on our suggested approach to developing services for people with dementia. This event to have a wide range of stakeholders present and high levels of representation from user groups, carers, and local older people.
- **March 2009** - Council cabinet report to be presented outlining our suggested approach and next steps
- **Beyond March 2009** – on-going planning and development work to refine commissioning proposal and implement strategy. Clarification of decision-making and processes needs to be achieved.

## 6. Conclusions and Recommendations

To take the above findings into account in service delivery the following recommendations are made and suggestions for implementation. Many of the suggested routes are through existing work streams or projects:

Service Development Required	Implementation
<p><b>1. Improved provision of respite and Intermediate Care</b></p>	<p><b>Short-term:</b> Through work to create joint Intermediate Care service specification – dementia care needs to be considered by this work stream Further analysis of likely demand for dementia focussed intermediate care</p> <p><b>Medium/ long term:</b> Making dementia specific respite beds to be available within specialist settings – such as residential care Investigate feasibility of commissioning a respite service that is provided within the home in response to urgent needs of users and carers (via dementia specialist home care service/ VCS?)</p>
<p><b>2. More accessible day care and day opportunities</b></p>	<p><b>Short-term:</b> Further consultation to be carried out through day services review to better understand needs and to differentiate between needs of social contact and respite Ensure needs of people with dementia and their carers are taken into account through the personalisation programme, including identification of what support is required for people to express their needs through individual budgets Investigate feasibility of extending VCS day opportunities such as Alzheimer's cafés</p> <p><b>Medium/ long term:</b> Enhanced capacity of specialist day services within community – including within specialist residential settings and Extra Care housing</p>
<p><b>3. Develop supported accommodation that meets peoples needs</b></p>	<p><b>Short-term:</b> Commissioning residential care that specifically meets the needs of people with dementia through development of a new residential dementia service specification Build in residential needs of people with dementia to the Council Care Homes Review</p> <p><b>Medium/ long term:</b> Develop Extra Care housing that specifically meets the needs of people with dementia as part of the corporate target Following cabinet approval develop residential care that specifically meets peoples needs – by redeveloping existing stock</p>
<p><b>4. Increase support for informal carers</b></p>	<p><b>Short-term:</b> Provision of enhanced training for carers to support confidence, provision of practical advice, and awareness of services and support available</p> <p><b>Medium/ long term:</b> Investigate feasibility of commissioning crisis support service to support carers out of hours</p>

<p><b>5. Enhanced support for people to remain independent at home</b></p>	<p><b>Short term:</b>          Develop dementia specification for home care service          Promotion of Telecare to continue within community</p> <p><b>Medium/ long term:</b>          Consider commissioning additional voluntary sector services to support people with dementia to remain at home through provision of practical and emotional support          Consider feasibility of commissioning 'virtual Extra Care' support to meet people's care needs out of hours</p>
<p><b>6. Training and development for workforce</b></p>	<p><b>Short-term:</b>          Identify baseline of training amongst social care staff and devise approach to improve levels of training          Devise multi-agency approach to training to identify needs and resources available across the partnership</p> <p><b>Medium/ long term:</b>          Implementation of training amongst social care staff; and associated professionals such as supported housing workers; health professionals and voluntary and community sector          Identify training needs of carers through further engagement          Delivery of informal/ family carers training package</p>

In addition to the above recommendations – there is a need to develop better strategic links between organisations and a joint approach to planning and delivering services. This can be achieved in part through the development of a draft strategy in the short-term, and by on-going planning in the longer term through clarification of appropriate structures.

The areas for investment that are deemed to warrant short-term investment are clarified within section 1 with suggested next steps for delivery.

**Jenny Appleby – Commissioning Manager: Older People's Services, 12.12.08**

## Appendix 1 – Summary of feedback received through consultation November/ December 2008

Recommendation within the Draft National Dementia Strategy	Feedback and priorities
<b>1. Increased public and professional awareness of dementia</b>	<ul style="list-style-type: none"> <li>• Links with Alzheimer’s Society to be strengthened</li> <li>• Reduce stigma through local awareness raising about older age and dementia specifically</li> <li>• Promote health prevention work to minimise risk factors –identify needs of vulnerable groups</li> </ul>
<b>2. An informed and effective workforce for people with dementia</b>	<ul style="list-style-type: none"> <li>• Training for all staff as essential – this to developed in partnership with specialist services</li> <li>• Training to support diagnosis of dementia</li> <li>• Training re communication skills as important</li> <li>• Training to be delivered to carers to support them as part of the workforce</li> <li>• Assessment services in CMHT felt to be performing well although possibly under resourced</li> <li>• Information about what services are available to be communicated across all agencies</li> <li>• Valuing staff to improve stability and aid retention</li> <li>• To emphasise and promote dignity</li> <li>• Pay for staff was cited as an issue acknowledging the specialist skills required</li> <li>• Important role of GPs in providing information and advice</li> </ul>
<b>3. Good quality early diagnosis and intervention for all</b>	<ul style="list-style-type: none"> <li>• Partnerships with CMHT to be developed</li> <li>• Training to professionals to emphasise how diagnosis can be explained in simple terms</li> <li>• Maximise access routes to assessment including self and open referral system.</li> <li>• Assessments to be delivered in community setting</li> <li>• More capacity of specialist assessments</li> <li>• Early assessments for carers and users very important</li> <li>• Easier access to SALT assessments</li> </ul>
<b>4. Good quality information for those with dementia and their carers</b>	<ul style="list-style-type: none"> <li>• Alzheimer’s Society run cafes seen as positive although insufficient geographical coverage and not frequent enough</li> </ul>
<b>5. Continuity of support and advice</b>	<ul style="list-style-type: none"> <li>• Navigation seen as important throughout all parts of the pathway to support diagnosis and on-going support</li> </ul>

<b>6. Improved quality of care in general hospitals</b>	
<b>7. Improved home care for people with dementia</b>	<ul style="list-style-type: none"> <li>• Trained and experienced staff as essential</li> <li>• This service if delivered appropriately was seen as highly valued</li> <li>• Focus on enablement was stressed as important</li> <li>• Consistency of care staff important – dedicated staff employed on a permanent basis not sessional, and services delivered on a geographical patch basis might assist</li> <li>• Short calls were not deemed as appropriate and had potential to be stressful and cause distress if not enough time to complete a task</li> <li>• Care staff to take time to ‘orientate’ users by supporting them with correspondence and writing Christmas cards etc</li> <li>• To form part of emergency response service that supports people to remain at home inclusive of night time provision</li> <li>• Service to be available 7 days per week</li> <li>• Better integration with continence services</li> </ul>
<b>8. Improved short breaks for people with dementia and their family carers</b>	<ul style="list-style-type: none"> <li>• Appropriate facilities to support respite required – this is seen as a major gap with demand far out-stripping supply</li> <li>• Quicker access required</li> <li>• Respite services to be available in the home seen as important – eg a care package at home for a week</li> <li>• Carers may wish to take a break with the person they care for and have a support worker to accompany them</li> <li>• Respite to be linked with provision in specialist residential care or day care environment to build familiarity</li> <li>• Respite that is available during a crisis to support carers</li> </ul>
<b>9. A joint commissioning strategy for dementia</b>	<ul style="list-style-type: none"> <li>• Better links with CMHT are required to aid service development</li> <li>• Robust multi-agency design of services</li> <li>• Information sharing across agencies</li> </ul>
<b>10. Intermediate care for people with dementia</b>	<ul style="list-style-type: none"> <li>• Importance of enabling independence and maintaining skills</li> <li>• Needs to be more tailored towards people with dementia as at present is difficult to access and deemed as unsuitable for rehabilitation</li> <li>• Should cater for people with mental health needs who have physical/ medical needs as well</li> </ul>

<p><b>11. Improved dementia care in care homes</b></p>	<ul style="list-style-type: none"> <li>• Specialist care homes required –this resource was seen as much needed and in demand</li> <li>• Training and support to mainstream residential care homes to enable those who develop dementia to remain their as long as feasible</li> <li>• Current homes to be updated and improved to better meet needs</li> <li>• Residential care to be well staffed and training to be delivered to reduce frustration of staff and residents, to promote better retention rates – to have positive impact on service and residents</li> <li>• Needs to be more stimulating to residents</li> <li>• Joint residential and nursing care provision to avoid transfers when condition deteriorates</li> <li>• Need for more EMI beds in Derby</li> <li>• Continuity of support to be provided in residential care such as VCS support and other community services and agencies</li> </ul>
<p><b>12. Improved registration and inspection of care homes</b></p>	
<p><b>13. Other areas highlighted include:</b></p>	<p><b>Day Care:</b></p> <ul style="list-style-type: none"> <li>• Specialist and flexible day care required – this is seen as a major priority with many citing waiting times and lack of supply</li> <li>• Day care to be more personalised and tailored to people’s interests and needs e.g. shopping/ garden centre visits to help social inclusion</li> <li>• To incorporate reminiscence work</li> <li>• To be activity based e.g. walking, singing, knitting</li> <li>• Day care to allow people to be listened to and encouraged</li> <li>• Transport seen as important to enable access to day care – if possible with escort to reassure that person will get there safely</li> <li>• Day care to be provided at home or in centre</li> <li>• Day care to link with specialist residential provision/ Extra Care</li> <li>• To be available at weekends as well as weekdays</li> </ul> <p><b>End of life care:</b></p> <ul style="list-style-type: none"> <li>• End of life care for people with dementia to be flexible, accessible and person-centred</li> <li>• Better links with health to access Liverpool Care Pathway in residential settings</li> <li>• Training as imperative to promote positive outcomes for users and carers</li> </ul>

**Carers Support:**

- Specialist resource centre that provides a range of support including peer support and practical advice
- Dedicated carers support service to work with families, carers and service users
- More peer support
- More support for carers following diagnosis, to support users in turn
- More work with carers on individual basis to identify solutions in partnership to their needs – help carers to support themselves
- Importance of assessments for carers (early)
- Make health checks available to carers to support well-being
- Emergency and out of hours support to be available to support carers in crisis
- More information to be made available to carers regarding day to day situations they may encounter
- Aftercare support to be made available to carers when they have lost their partner/ family member and thus their role as a carer
- Advocacy
- Sitting services needed

**Assistive technology:**

- Assessment and access to telecare – need for on-going funding

**Housing/ Extra Care:**

- Extra Care housing seen as an invaluable means of supporting people to remain independent in a safe environment
- Use of research to inform of appropriate design for housing/ care settings
- Importance of having accommodation on one level with safe garden access
- A 'home for life' seen as really important wherever this may be – concept of bringing services to the person

**Other suggestions:**

- Alternative therapies to be made available
- Advocacy and safeguarding needed to support those who may receive poor outcomes from services

- Advocacy as important particularly for self-funders
- Crossroads service very valued and much in demand
- Need to more fully understand needs of BME users and carers – including lack of acceptance of dementia in certain communities