DERBYSHIRE COUNTY COUNCIL

DERBYSHIRE ADULT CARE BOARD

THURSDAY 15[™] MAY 2014 2:00PM TO 4:00PM CR1, COUNTY HALL, MATLOCK, DERBYSHIRE, DE4 3AG

AGENDA

| | <u>Time</u> | <u>Item</u> | <u>Lead</u> | Information/ Discussion/ Decision |
|---|-------------|---|---|---|
| 1 | 2:00pm | Welcome & Introductions | Cllr Neill | |
| 2 | 2:10pm | Minutes from the meeting held on 13 th March 2014 (attached) | Cllr Neill | Information |
| 3 | 2:20pm | Derbyshire Dementia Strategy Refresh (attached) | S Phillips/ D Gardner | Decision |
| 4 | 2:35pm | Better Care Fund (attached) | J Matthews | Information |
| 5 | 2:50pm | Transforming Care (attached) | J Vollor | Information |
| 6 | 3:00pm | Healthwatch – Executive Summary (attached) | P Arnold | Information |
| 7 | 3:20pm | Extra Care Contract - update | M McElvaney | Decision |
| 8 | 3:30pm | CCG 5 year Plans – North & South Unit of Planning (PowerPoint presentation) | L Wilmott- Shepherd/ N Cartwright | Information |

9 4:00pm **FINISH**

The next meeting of the Adult Care Board will take place on Thursday 17th July 2014 at 2:00pm in Committee Room 1, County Hall, Matlock.

DERBYSHIRE COUNTY COUNCIL

ADULT CARE BOARD

MINUTES OF A MEETING HELD ON THURSDAY 13TH MARCH 2014 AT 2:00PM DERBYSHIRE COUNTY COUNCIL, COMMITTEE ROOM 1, MATLOCK HQ

PRESENT:

| Cllr Clare Neill | CN | Derbyshire County Council Cabinet Member (Adult Care) Chair |
|-----------------------|------|--|
| Cllr Dave Allen | DA | Derbyshire County Council Cabinet Member (Health & Communities) |
| Cllr Lillian Robinson | LR | North East Derbyshire District Council |
| Mary McElvaney | MMcE | Derbyshire County Council – Acting Strategic Director (Adult Care) |
| James Matthews | JM | Derbyshire County Council – Adult Care |
| Andrew Milroy | AMi | Derbyshire County Council – Adult Care |
| Sue Knowles | SK | Derbyshire County Council – Adult Care |
| Jim Connolly | JC | Hardwick CCG |
| Niki Cartwright | NK | North Derbyshire CCG |
| Jayne Needham | JNe | DCC (Public Health) |
| Jacqui Willis | JW | NDVA |
| Lynn | LWS | Erewash CCG |
| Wilmott-Shepherd | | |
| Jo Smith | JSm | South Derbyshire CVS |
| Andrew Mott | AM | Southern Derbyshire CCG |
| Peter Arnold | PA | Derbyshire Healthwatch |
| Narinder Sharma | NS | Derbyshire Carers |

IN ATTENDANCE:

| Pauline Innes | PI | Derbyshire County Council Adult Care (Minutes) |
|---------------|----|--|
| Julie Vollor | JV | Derbyshire County Council – Adult Care |
| David Gurney | DG | Derbyshire County Council – Adult Care |

APOLOGIES:

| Andy Layzell | Southern Derbyshire CCG |
|------------------|--|
| Andy Gregory | Hardwick CCG |
| Avi Bhatia | Erewash CCG |
| David Collins | North Derbyshire CCG |
| Andy Gregory | Hardwick CCG |
| Karen Macleod | Derbyshire Probation |
| Brian McKeown | Derbyshire Police |
| Cllr Wayne Major | Derbyshire County Council |
| Roger Miller | Derbyshire County Council – Adult Care |

| Tony Morkane | Derbyshire County Council (Public Health) |
|------------------|---|
| Cllr John Lemmon | South Derbyshire District Council |
| Steven Lloyd | Hardwick Health CCG |
| Rakesh Marwaha | Erewash CCG |
| Jackie Pendelton | North Derbyshire CCG |
| Gavin Tomlinson | Derbyshire Fire and Rescue |
| Clare Watson | Tameside & Glossop CCG |
| Umar Zamman | Derbyshire Fire and Rescue |

| Minute No | Item | Action |
|---------------|--|--------|
| ACB 009/14 | WELCOME FROM CLLR NEILL AND APOLOGIES NOTED <u>MINUTES FROM THE MEETING ON 16[™] JANUARY</u> 2014 & MATTERS ARISING The minutes from 16 th January 2014 were accepted as a true and accurate record. <u>Matter Arising:</u> | |
| | PI to re-circulate Carers Memorandum of Understanding. | PI |
| 010/14 | SERVICES FOR PEOPLE WITH LEARNING DISABILITIES – INCLUDING PROGRESS ON TRANSFORMING CARE/ WINTERBOURNE VIEW ACTIONS Jim Connolly (JC) Hardwick CCG provided a verbal update to the Board on services for people with learning disabilities including a progress update on Transforming Care (Winterbourne View); the Board noted that Hardwick CCG is the lead CCG on Learning disability and Mental Health contracts. JC provided the following updates: Transforming Care (Winterbourne View) action plan is now being delivered, a total of 18 service users currently live out of county, plans are in place to return service users as soon as possible, in line with their individual needs; work is on-going. This will include ensuring advocacy is available to the individuals concerned. JC advised the Board that a Joint Solutions Group has been established, involving Senior Managers, and the first meeting is scheduled to take place 20th March 2014. These meetings will focus on the Transforming Care (Winterbourne View) group of people and others where the complexity of needs require additional oversight; the group will make funding recommendations in relation to specific continuing health care needs and shared packages. There is a Learning Disability Joint Commissioning Board that oversees all learning disability work, including Transforming Care and the Learning Disability Self-Assessment. There will be a transformational project based on Ashgreen | |

| | Hospital. A broader link needs to be developed around Support and Aspiration. Julie Vollor provided a verbal update to the Board on progress to date on the Learning Disability Self-assessment Framework and Community Lives. JV advised the Board that Adult Care Board members and the Health & Wellbeing Board had previously agreed the action plan which was drafted jointly with Learning Disability Partnership Board. JV to provide overview of figures around the numbers of people with learning disabilities in Derbyshire. Jaqui Willis informed the Board of a forthcoming consultation event that has been organised for people with a Learning Disability ClIr Dave Allen suggested that monitoring health checks could link in with the work of the Learning Disability Partnership Board. Mary McElvaney suggested that members from the Health & Wellbeing Board be invited to the Task Force / Good Health Group. Sue Knowles to provide future meeting dates, PI to circulate. MMcE to arrange for the Learning Disability Partnership Board structure to be circulated to Board Members. The Board requested a diagram setting out all the relevant groups and the structure, JV / JC to action. | JV SK MMcE |
|--------|--|------------------|
| 011/14 | BETTER CARE FUND (BCF) JM provided an update for the board and sought its support for the latest draft of the Better Care Fund Plan. The Better Care Fund Plan was considered and supported by the Adult Care Board at its last meeting on 16th January 2014. This early draft of the plan was endorsed by the Health and Wellbeing Board and submitted to NHS England. JM informed the board that there have been minor errors in the calculation of CCG contributions to the Better Care Fund for 2015/16, which meant that where CCGs make contributions to two or more Health and Wellbeing Boards these shares were not calculated correctly. The error does not change the total amount of each CCG's budget which is set aside for the Better Care Fund, but does change how the CCG's total contribution is shared between Health and Wellbeing Boards. JM informed the Board that the difference for Derbyshire will be £150,000. The final version of the plan has to be submitted to NHS England by 4th April 2014 and will be considered at the next meeting of the Health & Wellbeing Board on 3rd April 2014. JM provided an update on the main changes and informed the | |

| | Board that work is continuing on preparing the plan and the proposals for the use of Better Care Fund in 2015/16 (£57.51m) are being finalised | |
|--------|--|--|
| | being finalised. Cllr Neill requested that the latest version of the Better Care Fund (BCF) be circulated to Board Members for comments and requested all comments be submitted by close of play Friday 21st March 2014 to Iseult Cocking. Adult Care Board members noted and supported the latest draft of the Better Care Fund and further noted that it will be further amended to achieve a final plan. Cllr Neill informed the Board that the next Health & Wellbeing Board meeting is scheduled to take place on 3rd April 2014, this is an open meeting and if Board Members wish to attend they could do so. Further information available from James Matthews james.matthews@derbyshire.gov.uk Tel 01629 532004. | |
| 012/14 | JOINT COMMISSIONING PLANS UPDATE Julie Vollor (JV) provided an update to Board Members on Joint Commissioning Plans. In 2010, Joint Commissioning Strategies were produced for the main client / patient groups and are in the process of being updated and refreshed. In addition, a number of additional joint commissioning plans and activities are taking place. JV provided updates on the Joint Commissioning Strategies, the updating of the strategies has followed a similar process, based on the commissioning cycle (Review, Analysis, Plan, and Do), adapted as required to the specific needs of the client groups. The aim of the work has been to respond to the priorities of the Health and Wellbeing Partnership based on locally identified needs, the Joint Strategic Needs Assessment and key national strategies. <u>Mental Health</u>: In July 2013 the Adult Care Board approved a refresh of the Derbyshire Joint Vision and Strategic Direction for Adult Mental Health. The strategy relates to the mental health needs of people aged 18 and above, including people with a learning disability and people in transition from children and young people's services, or from prison or forensic services. JV updated the Board on key themes identified to date. <u>Dementia</u>: In November 2014 the Adult care Board endorsed a refresh of the Derbyshire Dementia Strategy based on a jointly agreed 'direction of travel' which covered 4 main themes: improved joint working (including integration), improved | |
| | communication, person-centered services, training and development). JV updated the Board on key themes identified to date. | |

| | Jaqui Willis informed the Board of the importance of Dementia Friends/ Champions training, especially for the voluntary sector <u>Carers</u>: In January 2014 the Adult Care Board approved the Carers Joint Memorandum of Understanding to safeguard the spend on carers support and establish a work plan and a work programme for the Carers Joint Commissioning Board for the period to April 2015. PI to forward Carers Joint Memorandum of Understanding to Narinder Sharma. Adult Care Board members noted the report. Further information available from Julie Vollor Julie.vollor@derbyshire.gov.uk Tel: 01629 532048 | PI |
|--------|---|----|
| 013/14 | HEALTH & WELLBEING FEEDBACK | |
| | Cllr Neill provided verbal feedback from the Health & Wellbeing Board Meeting held on 6th February 2014 with the following updates: Funding Transfer from NHS England to Social Care (Section 256) has now been signed off. Assistive Technologies: Housing Related Support Providers Forum taking Place on Friday 11th April 2014. Niki Cartwright lead officer for the Voluntary Sector. | |
| 006/14 | ADULT CARE PROPOSED BUDGET CUTS PROGRESS | |
| | David Gurney provided an update to the Adult Care Board about progress on the consultation about proposed Adult Care budget cuts. Consultation started on January 28th on four proposals which were discussed at Cabinet on January 21st. Three proposals have a direct impact on those clients who receive a FACS eligible service. These concern the raising of the FACS eligibility threshold from Higher Moderate to Substantial; an increase in the level of Co-funding contributions; and the introduction of a transport policy. The fourth proposal concerns phase 1 of a reduction in the Housing Related Support budget. Since the consultation started approximately 1300 questionnaires have been returned and staff in the Stakeholder Engagement Team have been invited to attend 32 meetings round the county. At present a high proportion of these events involve people with a learning disability. In addition to this, correspondence has been sent to all statutory agencies and local voluntary sector organisations inviting comments on the proposals. Adult Care recognises that any changes it makes – especially in terms of raising the eligibility threshold and reducing the Housing | |

| | Related Support – may have an effect on other agencies. It is | |
|--------|--|--|
| | important that a full and rounded picture is presented in the Cabinet report on the outcome of consultation and the Equality Impact Analysis. Responses are best received by email or by letter to maintain an audit trail. | |
| | Clir Neill informed the Board that £450,000 has been sourced from Business Rates and there has been an agreement for this money to go towards Housing Related Support. | |
| | • JW commented that HRS cuts would have a huge impact on people with a Learning Disability and further informed the Board that Fairplay and Enable are holding events in the near future to discuss the proposed cuts. | |
| | The Board noted that gaining information from Derbyshire County Council Website on the consultation is not easily accessible. DG informed the Board that Louise Swain is working closely with the Web Team to alleviate this issue, and further advised that records show there have been a large number of hits on the website, in the region of 2,000. | |
| | Link: http://www.derbyshire.gov.uk/council/have_your_say/consultation_search/Consultation_search_index/derbyshire_adult_care.asp | |
| | • The Adult Care Board noted the progress and supported the recommendation for individuals and organisations to respond to the consultation. | |
| | Further information available from David Gurney <u>david.gurney@derbyshire.gov.uk</u> Tel: 01629 532059. | |
| 007/14 | CCG INTEGRATION BOARD UPDATES • Verbal reports were made from the Integration Boards at Erewash, Hardwick and South Derbyshire CCGs. | |
| | The next meeting of the Adult Care Board will take place on Thursday 15 th May 2014 at 2:00pm in Committee Room 1, County Hall, Matlock. | |
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DERBYSHIRE ADULT CARE BOARD

15 May 2014

DERBYSHIRE JOINT DEMENTIA STRATEGY REFRESH

1. <u>Purpose of the Report</u>

The purpose of this report is to:

- To seek Board endorsement for the reviewed and refreshed Derbyshire Dementia Strategy 2014/2019
- To seek endorsement for the Joint Derbyshire Dementia Commissioning group to develop services based on the implementation plan up to 2019.

2. Information and Analysis

Background

National and Local Context

In 2009 the first National Dementia strategy was launched. There are approximately 750,000 people are estimated to live with dementia in the UK. It is estimated that approximately 11,500 people living with dementia in Derbyshire.

It is estimated that the over 65 population in the county grow from 156,200 to 204,700 by 2028. This will lead to increasing numbers of people with dementia as Derbyshire's population ages and lives longer. The prevalence of dementia increases with age; one in 14 people over 65 years and one in 6 people over 80 years has a form of dementia.

More than 50% of people are not currently diagnosed and therefore miss opportunities for treatment and support. Nationally, plans were announced in May 2013 to increase the numbers of people with dementia identified and given appropriate support from 45% to 66%. In Derbyshire specific joint targets and actions have been agreed.

In 2010 a Joint Derbyshire Dementia Strategy was produced led by Derbyshire Primary Care Trust (PCT) Adult Care Commissioning. It reflected the national strategy and mapped out priority areas for commissioning relating to diagnosis; an effective workforce; hospital care and community personal support. Progress made on the priority areas identified in the 2010 strategy is described in the refreshed 2014/2019 strategy (Appendix A).

"The £20 billion question: An inquiry into improving lives through cost-effective dementia services"

This reported in 2011 that dementia costs the community £20 billion per year and seeks to improve the cost effectiveness of health and social care services. Its main recommendations relate to a 'whole systems' approach; hospital environmental changes; greater effort to reduce admissions; better community pharmacy and care homes providing good quality life for people with dementia

The Prime Minister's Challenge (2012) focuses on increased diagnosis; better hospital dementia care; raising public awareness; research and dementia friendly communities. The concept of a dementia friendly community has already spawned the Derbyshire Dementia Action Alliance which is looking at developing community capacity rather than just traditional service solutions.

Strategy Development

During late 2013 a series of public engagement events were held involving: people with dementia and their carers, Travellers, people from BME Communities, LGBT people, farming communities and people with learning disabilities.

The main themes arising from local public engagement and national drivers were drawn together and taken to a Health Service 'Listening Event' in October 2013 including GP's where they were validated and endorsed. The event identified the need to take forward integrated services and management of dementia as a long term condition.

The main themes were presented to the Adult Care Board (ACB) on 14 November 2014. The refreshed strategy has developed an action plan based on these themes which include:

- Clear pathway
- Improve joint working
- Improve communication
- Services that are person centered
- Training and development

Proposed Further Action

It is proposed to now develop and deliver the strategy implementation plan through the joint Derbyshire Dementia Commissioning Co-ordination Group to which each Clinical Commissioning Group (CCG) is linked.

Hardwick CCG has a County lead role on the group for commissioning of NHS dementia services and each CCG has a structure for local development of dementia commissioning plans.

The role of the County strategy will be to ensure cohesion between local and county level; to promote an exchange of good ideas and avoid any 'reinventing the wheel' initiatives.

It is proposed that a framework for on-going public engagement will continue through existing engagement structures, such as Patient Participation Groups so that co-design is a feature of service design as the details are developed.

OFFICER RECOMMENDATION

To endorse the content of the implementation plan of the refreshed Derbyshire Dementia Strategy and the proposed way of delivering this.

Steve Phillips Commissioning Manager Adult Care & Dave Gardner Assistant Director Hardwick CCG

Document Classification: PUBLIC





Erewash; Hardwick; North Derbyshire; Southern Derbyshire; Tameside & Glossop Clinical Commissioning Groups

Derbyshire Joint Dementia Strategy: Living Well with Dementia

Full Version 2014



Derbyshire Joint Dementia Strategy reviewed and updated 2014 for the period 2014 - 2019

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Health and Social Care Contacts for this Strategy:

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|---|
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Contents

| Introduction1 |
|--|
| What is dementia?2 |
| What is shaping this strategy? |
| What has been achieved since 2010?7 |
| Analysis and Next steps13 |
| Implementation Plan for Derbyshire Dementia Strategy 2014155 |
| APPENDIX A: The Derbyshire Dementia Pathway254 |
| APPENDIX B: Engagement265 |
| APPENDIX C: Prevalence and Demographics in Derbyshire 2014 |
| APPENDIX D: List of NICE Guidance42 |

Introduction

Dementia presents one of the biggest health and social care challenges. People affected by dementia and their families and carers often face difficulties in trying to live well with the dementia. There are currently 800,000 people with dementia in the UK and it is predicted that there will be over a million people with dementia by 2021 (Alzheimer's Society. In Derbyshire this equates to over 10,000.

Around 50% of people do not have a formal diagnosis. This can mean being unable to access treatments and support. The prevalence of dementia is predicted to double in the next 30 years and this strategy will encompass actions to reduce the incidence of dementia by supporting possible lifestyle changes alongside new and revised intentions for health and care services.

To deal with this challenge this strategy will set out evidence based actions aimed at preventing the incidence of dementia within the population, slowing the rate of its progression once diagnosed and supporting individuals their friends and families to minimise the impact of dementia on independence and wellbeing.

It has never been more important to prioritise services that are cost effective, valued by people and avoid higher alternative expenditure. Spending on the NHS in the UK as a share of national income has more than doubled since its introduction in 1948, rising by an average of 4.8% in real terms1. This period of rapid growth has now come to a halt but funding pressures on the NHS continue to rise. The NHS is targeting efficiency savings of £20bn (known as the Nicholson challenge) by 2014/15 to meet this challenge. Looking further ahead, in July 2013 NHS England published the "Call to Action", which projected that the NHS may have to make a further £30bn of efficiency savings by 2020/21 to meet demand. Derbyshire's share of the £30 billion could be approximately £500m across providers and commissioners. Derbyshire County Council corporately has to make savings of £157 million over a 5 year period.

A Joint dementia commissioning group has been established to bring together Derbyshire County Council Adult Care (DCC), Clinical Commissioning Groups (CCG's), and Public Health to review and refresh an existing Derbyshire strategy which began implementation in 2010. The aim of the review is to keep the local strategy relevant to local views; local needs; best practice and national guidance on dementia care

We would like to take this opportunity to thank all the people with dementia and their carers who have already and continue to volunteer their time to give their views about this strategy and its implementation.

Tameside and Glossop CCG and Derby City have separate dementia strategies but collaborative working will ensure consistency of approach and an exchange of ideas.

What is dementia?

Dementia is an umbrella term for a range of conditions that affect the brain:

<u>Alzheimer's disease:</u> is the most common form of dementia where the chemistry and structure of the brain changes. 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.

<u>Vascular dementia:</u> is caused by reduced blood flow to the brain because there is a problem with the blood vessels which affects the supply of oxygen to the brain. Early signs of vascular dementia symptoms are slowness of thought, difficulty with planning, memory loss, trouble with language, and mood or behavioural changes. It may be prevented from progressing further if identified early.

<u>Lower incidence dementias:</u> dementia with lewy bodies (spherical structures develop inside nerve cells); fronto-temporal dementia (damage focused in the front part of the brain; behaviour initially more affected than memory); Korsakoff's syndrome (associated with heavy drinking over a long period); Creutzfeldt-Jakob disease (prions attack the central nervous system and invade the brain). HIV and AIDS (sometimes people develop cognitive impairment.

<u>Mild cognitive impairment</u>: is a recent term describing people who have some memory problems but do not have dementia.

<u>Testing</u>: There is no single test for dementia, but a range of blood tests and brain scans can help rule out reversible causes. Diagnosis is made by an assessment of symptoms and the use of brief questionnaires testing ability to remember facts, or draw simple diagrams.

Most dementias 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.

<u>Prevention and Cure</u>: There is no certain way to prevent all types of dementia. However reducing the risk of cardio vascular disease can reduce the risk of a stroke and so vascular dementia.

To reduce the risk of developing dementia and other serious conditions it is recommended that individuals:

Eat a healthy diet

Maintain a healthy weight

Exercise regularly

Do not drink too much alcohol

Do not smoke

Keep blood pressure at a healthy level

Healthy lifestyle programmes available across the County aim to motivate and support people to reduce unhealthy behaviours.

The Alzheimer's Society website offers useful further detail about 'what is dementia?' <u>www.alzheimers.org.uk</u>

Many documents about dementia refer to a 'dementia journey'. The fundamental aim of this strategy is for people to live well with dementia so there is a timely response to changing needs along the journey in accordance with National Institute for Clinical Excellence (NICE) guidance, described below. The Derbyshire Dementia Pathway is provided at **Appendix A**.

What is shaping this strategy?

In 2009 'Living Well with Dementia: A National Dementia Strategy' was published by the Department of Health for dementia services in England and Wales. It included nine statements to capture what people with dementia should expect in terms of their health and social care. These are included in the implementation plan derived from this report.

The national strategy picked out four priority areas:

- Good quality diagnosis and intervention
- Improved quality of care in general hospitals
- · Living well with dementia in care homes
- Reduced use of antipsychotic medication

The 2010 joint Derbyshire Dementia Strategy set out local actions consistent with the national strategy. This document refreshes the original Derbyshire strategy in the light of recent developments:

- <u>Views of local People:</u> A range of events involving people with dementia and their carers identified priorities which informed the 2010 strategy. A significant public engagement exercise was arranged in mid. 2013. Adding to feedback from existing dementia services. The details of this are provided at **Appendix B**
- <u>Population Predictions</u>: Local Authorities undertake and update a joint strategic needs analysis (JSNA). The JSNA estimates future population numbers and composition together with anticipated levels of health issues. The JSNA helps to understand anticipated service demand and to offer baselines to measure the success of outcomes of services. In short the number of people with dementia is predicted to double in the next 30 years. See also **Appendix C**



- Legislation: Further legislation has been passed since the Derbyshire dementia strategy started and the Care Bill is currently progressing through Parliament. It proposes a major reform of the law relating to care and support for adults and the law relating to support for carers. It will strengthen the direction of integration of health and social care and includes a duty to promote physical and emotional wellbeing and personal dignity.
- All Parliamentary Party Group Report (July 2011): four main conclusions included developing 'whole systems' to improve cost-effectiveness; hospital environmental changes to improve experiences of hospital stays and greater efforts to prevent inappropriate hospital admissions; better community services; care homes need to provide a good quality of life for people with dementia, as most residents will have some form of dementia. The report estimated the annual cost of dementia to the UK to be £20 billion in 2010 which is expected to grow to over £27 billion by 2018.
- Prime Minister's Challenge on Dementia (March 2012) This aims to deliver further improvements in dementia care and research by 201 through:
 - Increased diagnosis rates through regular checks for over 65s
 - Incentives for hospitals offering quality dementia care.
 - Innovation
 - Promoting local information on dementia services
 - Dementia friendly communities across the country*
 - > A high-profile public awareness campaign.
 - A dementia care and support compact signed by leading care home and home care providers
 - Better research (with funding increased from £26.6 million in 2009/10 to an estimated £66.3 million in 2014/15)**.
- <u>Government Mandate (November 2012)</u>: The Department of Health published its first Mandate between the Government and the NHS Commissioning Board, setting out the ambitions for the health service for the next two years. Key objectives of the Mandate include better diagnosis, treatment and care for people with dementia.

• <u>Everyone Counts (December 2012)</u>: The NHS Commissioning Board published planning guidance for Clinical Commissioning Groups (CCGs) for 2013/14. The planning guidance 'Everyone Counts: Planning for Patients 2014/15 re-iterates that CCGs must set local trajectories for Dementia.

*The aim of dementia friendly communities is to create communities in which people will understand more about dementia and people with dementia feel included and free from stigma. Practical steps to achieve this include Dementia Action Alliances being set up by the Department of Health and hosted by the Alzheimer's Society. A Derbyshire branch of the Alliance has started and is bringing together a range of organisations, many of which do not work directly with people with dementia but can play a role in assisting people to live well. There is also a programme to educate 1 million people to become 'dementia friends'.

**Research findings support the diagnosing of dementia early and offering information, support and advice to both the person with dementia and their relatives as early in the dementia trajectory as possible.

Research also shows that early diagnosis offers a chance for people to come to terms with dementia; to understand its prognosis when they are able to do so; make use of information about their condition as well as treatment options and to make decisions for the future.

- <u>Clinical Commissioning Groups (April 2013)</u>: The creation from the 1st April 2013 of CCG's as autonomous statutory organisations (replacing Primary Care Trusts). CCGs are made up of groups of GP practices, are chaired by a local GP and now have responsibility for setting commissioning intentions.
- <u>Care Quality Commission's (CQC) review of dementia care (current 2013)</u>: CQC, the independent regulator of health and social care in England is inspecting hospitals and care homes in 22 local authority areas as well as consulting nationally and will publish a report in 2014 about people's experience of care across the different services they use and make recommendations.
- <u>NICE Guidance QS 30 Supporting People to Live Well with Dementia</u> (April 2013) and QS 1 both list 10 quality standards which commissioners of dementia care should aim to ensure are being provided within their services. These will be applied as the strategy is implemented and are listed at **Appendix D**
- <u>G8 summit (December 2013)</u>: A world dementia envoy was appointed to raise funds for research towards a cure. The UK committed a £90 million package to improve dementia diagnosis (a target of two thirds of people diagnosed by March 2015). Additionally leading British businesses also signed up to the cause with over 190,000 staff at M&S, Argos, Homebase, Lloyds Bank and Lloyds Pharmacy to learn to support customers who have dementia as 'dementia friends'.

- <u>Named GP's (from April 2014)</u>: Every person over 75 will have a named GP and the most vulnerable two per cent in each practice will receive an enhanced service.. People diagnosed with dementia and their carers will also be able to sign up to a new service on the NHS Choices website to get essential help and advice in the early stages of their condition.
- <u>Better Care Fund (from April 2015)</u>: Councils and the NHS are receiving funding via the Better Care Fund to work with each other and the voluntary sector. In Derbyshire this has resulted in DCC and the CCG's covering Derbyshire to agree spending plans linked to 7 objectives (building asset based communities; supporting people to remain independent/ in control; community support; reduced need for hospitalisation or admission to long term care; improved service outcomes/quality; reduce inequalities; develop infrastructure to achieve objectives. A set of metrics have to be in place as a framework for evidence of performance compared with objectives. The objectives give strong backing to the direction of this dementia strategy. Derbyshire has opted to include a local measure regarding the number of people diagnosed and the prevalence of dementia.
- <u>NICE dementia care pathway (2011 updated 2014)</u>: This is supported by a set of quality standards for services for people with dementia and are described in this strategy.

What has been achieved since 2010?

| What we said we would do | What we have done |
|---|--|
| Commission a direct access memory assessment service (MAS) | The number of clinics has increased. CCGs are commissioning dementia diagnosis with a mixed model of MAS centres (e.g. Staveley and Oakland Community Care Centres) and GP practice based sessions as they continue to raise the diagnosis rate. Further work referenced in implementation plan N2 below. |
| After diagnosis the person with dementia and their carer will be offered the Living Well Programme for information and education. | Community Mental health teams from Derbyshire Healthcare Foundation Trust and the Alzheimer's Society Dementia Support Service and Derbyshire Community Health Services are involved in offering sessions. The Programme has had very positive feedback when taken up and used and the aim is to increase take up. It has been found important that carers have a choice as to when they access the information they need. Many do not feel able to take in the information available at diagnosis as they may be too shocked or upset. Further work referenced in implementation plan N3 below. |

| What we said we would do | What we have done |
|---|--|
| Every person with dementia and their carer knows where to access information and support from / develop a dementia support service | A County service commissioned via Alzheimer's Society offers advice, information; home visits; dementia cafes; carers' information groups. Dementia Support workers increasingly link in with memory assessment |
| | clinics. Further work referenced in implementation plan N2/3/4below. Carers benefit from peer support and learning from each other. Some groups include younger carers and the timing allows attendance after work. This age group is often under particular stress as they struggle to care for parents as well as looking after their children. Ratings for the dementia support service are 91% satisfied or extremely so. Ratings about staff approachability, understanding and respect are |
| | higher. |
| Offer to provider organisations an E learning package for basic dementia training to be piloted with the private and independent sector | E Learning has been introduced as a training option. We will review the extent to which it is used. Further work referenced in implementation plan N13 below. |
| Develop training quality standards to be used as part of commissioning and contracting process | Social Care staff at the new centres; specialist staff and care homes staff across the Council and independent sector have participated in advanced dementia training. This continues. The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward excellence at local level and |
| | this is starting to make an impact on contracting by stipulating requirements for health service staff to have either dementia awareness training or more specialist training. |

| What we said we would do | What we have done |
|--|---|
| Provide dementia education and information programmes to carers of people with dementia in an accessible format | Community Mental Health Teams and the Dementia Support Service are both involved in offering sessions. Carer training is a key part of the Living Well Programme. Further work referenced in implementation plan N2/3/4 below. |
| Develop and promote the Dementia Information Prescription | A Dementia Information Prescription has been done but is not accessible at present because of website reorganisation. The availability of information now developed through the MAS and dementia support services will prompt a review of where to place the focus for making information available. |
| Develop a specific dementia section on the Derbyshire County Council website/ information portal. | This has been created and will be updated on a regular basis. |
| Offer dementia training for carers. 6 programmes to be offered, one in each locality. | Community Mental health teams and the Dementia Support Service are both involved in offering sessions. |
| Develop Community Care Centre in Staveley to provide residential care; short breaks; intermediate care; information and resources; day services; memory assessment services | The Staveley Centre was opened in 2011 and provides all services planned plus increasing health care and community use of the centre. A group of carers who originally undertook dementia training together continue to meet at Staveley as the 'STAG' group. They are self-supporting and have accessed funding for pamper days. They also use Crossroads to look after the cared for while they meet. They value Staveley Centre and the facilities there and continue to recruit members. |

| What we said we would do | What we have done |
|--|--|
| Exploration of the S. Derbyshire Specialist Dementia Home Care Service as a model for roll out for the rest of the County. | A two year pilot commenced in 2012 in Chesterfield testing out a specialist home service for people with dementia – run in partnership with the mental health team. It is being researched and compared with the S Derbyshire service. It is planned to be expanded in a pilot into the integrated care arrangements of primary care. |
| Develop Carer specific breaks that support Carers who meet the criteria for substantial support | A range of things are being offered e.g. short breaks; carers support via Derbyshire Carers Association including home visits, carers support groups, carers emergency grant; newsletter. Many Dementia carers have accessed the carer grant and also receive support from Derbyshire Carers Association. The need for a break is paramount and many ask for this from the grant scheme. Many also want a break with their loved one but with support from a family member for example. Further work referenced in implementation plan N7/11 below. |
| Develop a joint specification for intermediate care services to ensure patients with dementia are included | Specifications for intermediate care have been negotiated for Staveley and Oakland Community Care Centres and people with dementia are benefiting from intermediate care. A County strategy is being devised as part of integrated health and social care services. |
| Development of a further Community Care Centre in Swadlincote | Oakland Community Care Centre, Swadlincote, opened in 2013. The Centre is integrated on site with 88 extra care apartments. Take up of facilities including open community use has been excellent. |
| Development of six further Community Care Centres across the County (Adult Care Accommodation Care and Support Strategy) | The strategy is under review by DCC Elected Members. Plans are underway for the construction of further Community Care Centres at Heanor and Darley Dale. There will also be increasing availability of extra care apartments e.g. Chesterfield (2014); Alfreton (2014); Clay Cross including day services (2015). |

| What we said we would do | What we have done |
|--|---|
| Undertake audit to determine whether | An Audit has been undertaken. Prescribing rates for anti-psychotic |
| prescribing of anti-psychotic drugs for | medication have fallen. Further training work on managing behaviour |
| behavioural problems in dementia is in line with | without recourse to drugs is underway. |
| current guidelines | |
| Develop a culture at Staveley where staff are enabled to provide support to individuals without resorting to anti-psychotic medication | Staveley services are based on a social model of dementia care and have eliminated the use of anti- psychotic drugs where appropriate. A medicines management audit has been carried out with some of the primary care results to be reviewed. |
| Completion of dementia health equity audit | A Dementia Health Equity Audit was done and will be kept under review. Further work referenced in implementation plan N4 below. |

Other Developments

| Singing for the Brain | Found to be popular. Music therapist works across the County doing sessions and training some residential care staff. This service has been commissioned through the Alzheimer's Society |
|---|---|
| Older Peoples Mental Health Liaison Service | The service was commissioned for acute settings including Chesterfield and Derby Royal hospitals and has achieved good outcomes. It has now been superseded in Derby Royal with investment in RAID (a rapid assessment process). RAID for Chesterfield is due to be implemented in late 2013. |
| Housing Related Support: | Much of this fits with the Accommodation strategy where 24 hour support is being made available to enable people to stay in their own accommodation rather than a care home. |
| Social Model of Dementia Care | Services being commissioned using this model which relies on behavioural approaches and less reliance on medication, advanced training underpins this. |

| Derbyshire Dignity Campaign | Joint DCC/NHS campaign since 2010 to improve the experience of people using health and social care services. Bronze and silver awards |
|-----------------------------|--|
| | can be applied for. Applications at both levels are steadily increasing. |

Analysis and Next steps

Testing the themes: The themes emerging from national initiatives (described in this report); the priorities of Derbyshire people (Appendix B) and demographics (Appendix C) have been collated. They were tested and gained support at a NHS Listening Event in October 2013.

Endorsement of themes: The themes were then taken to the 14 November 2013 meeting of the Adult Care Board (ACB). The ACB has a mix of Elected Members (the Chair is the Cabinet Adult Care lead) and senior managers from the health and social care sector as well as other public services.

The ACB endorsed a proposed 'direction of travel' for the next stage of the joint dementia strategy with a recommendation that the joint Derbyshire Dementia Commissioning co-ordination group will develop and deliver precise plans and costed out priorities.

The themes within the direction of travel agreed by the ACB have been developed and have led to the formation of the implementation plan (see following section).



Making the Strategy Happen: The AC/ NHS joint commissioning group referred to in the introduction will ensure that the strategy is delivered. Hardwick CCG has a County lead role on the commissioning co-ordination group and each CCG has a structure for local development of dementia commissioning plans.

Continuing Engagement: It was proposed and agreed by the ACB that a framework for on-going public engagement will continue through existing engagement structures such as the over 50's forums, patient participation groups and Healthwatch Derbyshire so that co-design is a feature of service design as the strategy is turned to action.

Looking at the Evidence: Many excellent local initiatives are already underway across the County. The joint commissioning group ensure that the published evidence base of what type of interventions should be provided is prioritised for delivery and then local good practice which is in line with the evidence base is then also delivered.

In the course of researching the strategy initiatives which work well have been seen. As the strategy is delivered Commissioners will prioritise services which show evidence of good service results, value for money and invest to save outcomes e.g. The SHINE project has demonstrated benefits from investing in the training of nursing staff in Care Homes A project in 2011-12 funded by the Health Foundation (Shine awards) developed the role and basic awareness training in a small group of Homes in and around the City of Derby. Residents have been found to an improved experience (e.g. diet change) and to avoid costly interventions associated with aspiration pneumonia (e.g. GP call out, prescribed medication, acute hospital admission). Benefits are achieved by earlier implementation of a dysphagia care plan, timely management of symptoms, delayed involvement of dysphagia specialist, and better end of life planning.

An initial exercise for the Dementia Action Alliance will to scope the existing provision, identify gaps and prevent duplication thus ensuring the most effective use of limited resources.

Implementation Plan for Derbyshire Dementia Strategy 2014 'Living Well with Dementia'

NB The Joint Dementia Commissioning Group will ensure that systems are in place to ensure evidence of outcomes for each action named in this implementation plan. Reporting Milestones should offer clear make clear how outcomes have been evidenced, either completing the action or making progress clear so far. This plan will be reviewed half yearly by the Joint Commissioning Group and will remain a working, changing document.

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-----------------|---|--|------------------------|--|
| Prevention | N 1a. Improving awareness and understanding: prevention (KEY ACTION) | 1. NHS health checks in GP practices which include dementia awareness and signposting in accordance with the national statutory NHS health check programme | May 2015 | North & South Derbyshire CCG Implementation Groups (1) |
| | | 2. Primary care clinicians conducting NHS health checks are aware of and participate in the dementia awareness e-learning training resource. | May 2015 | As in (1) |
| | | 3. Continued support and investment in public health lifestyle and behaviour change programmes are preventing or reducing the impact of dementia e.g. reducing cardio vascular disease, preventing falls and infections. | May 2015 | As in (1) & Derbyshire Public Health Service (2) |
| | | 4. Annual primary care reviews of people with existing cardio vascular disease or diabetes includes a dementia awareness and signposting element (backed | May 2015 | As in (1) & (2) |

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-----------------|--|---|------------------------|---|
| | | by dementia awareness training). 5. People not meeting FACS eligibility criteria are given information about universal services with the transition to potential reduced availability being managed. | Dec 2014 | DCC Adult Care (AC) (Prevention) (3) & Fieldwork (4) |
| | | 6. Support systems are in place where people have medication only needs for support | May 2015 | As in (1) & AC (Direct Care) (5) |

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-------------------------------|--|--|------------------------|--|
| | N 1b. Improving awareness and understanding: good quality environments for people with dementia | | | |
| Person Centred Services | Alternatives to traditional. 'service' solutions | 7 Initiatives are developed via the Derbyshire Dementia Action alliance to promote dementia friendly communities. This includes: 7.1 Building on community strengths and expertise from carers/volunteers as an asset | Apr 2016 | As in (1) (3) & AC Commission/g (6) Capital Invest Team (7) |
| | | 7.2 Public awareness further raised to challenge stigma7.3 Practical measures taken to challenge isolation | | |
| Improved Joint Working | Transport | 8. Link made with operation of new Corporate transport policy to mitigate impact of loss of licence by people with dementia. | Dec 2014 | As in (6) |

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-------------------------------|--|---|------------------------|--|
| | N 2. Good quality early diagnosis and intervention for all | | | |
| Improved Joint working | Timely diagnosis | 9. Increased diagnosis rate with timeliness evidenced by increased access to treatment and support (qs1,2) | May 2015 | As in (1) |
| | | 10. Diagnosis is proportionate, by the right person and efficient (qs1,2) | May 2015 | As in (1) |
| Improved Joint Working | Learning disability | 11. Services are better adapted to better recognise, screen and diagnose people with a learning disability | Dec 2015 | Hardwick & N Derbyshire CCG Contract Teams |
| Improved Communic ation | N 3. Promoting local information about dementia services | 12. An Information plan shows improved information access to people and carers including provision of Well Being zones. | Dec 2015 | As in (1) & (3) & Contracted Dementia Support Service |
| | N 4. Provide support following diagnosis | | | |
| Person centred | Access | 13. The dementia support service is re-commissioned and accessible at an increased number of Health | May 2015 | As in (1) & (6) |

| County | What do we want to achieve? Coded to | Outcomes we aim to achieve | Reporting Milestone | Organisation |
|-------------------------------|---|---|------------------------|---|
| Theme | national objectives | | Wilestone | Lead |
| services | | outlets 14. A named contact person is available to assist a person at each point on a clear support pathway without the need to keep repeating personal information (cross ref 43). | May 2015 | As in (1) & (4) |
| | | 15. The Health equity audit is renewed and relevant follow up actions put in place | Apr 2015 | As in (3) |
| | N 5. peer support & learning and volunteer engagement | | | |
| Improved Joint Working | Improve dementia care at home | 16. Integrated treatment/ support e.g. referral to dementia support service and living well programmes help more people to live well at home (ref also 26; 29-31;42). | Oct 2015 | As in (1) (6) |
| Improved communic ation | Engagement | 17. People's experience of dementia is used to assist their communities through e.g. buddying; training | Dec 2015 | As in (1) (4) Acute Hospitals (8) |
| | | 18. Engagement with local people continues when working out details of strategy. | May 2015 | As in (1) via Patient Participation (9) & AC (Engagement) (10) |
| | N 6. Good Quality care for | | | |

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-------------------------------|--|--|------------------------|-------------------------------------|
| | people with dementia (KEY ACTION) | | | |
| Person Centred services | Improve Dementia Care at Home | 19. Coverage of the specialist dementia home care service extended, with learning captured and contributing to service improvement (see also Research) | Dec 2014 | As in (6) & Hardwick CCG (11) |
| | | 20. Prompt appropriate provision of assistive technology facilitated to people FACS eligible or not. | Oct 2014 | AC (Accomm. & Support) (12) |
| | Living well with dementia: | 21. The Joint Commissioning group defines and responds to key points arising from public engagement: i. e. stimulation; better advocacy; Dementia friendly health services; better continence management. | Oct 2015 | Joint Commiss/g Group (13) |
| | Dignity | 22. The Derbyshire dignity campaign increased numbers of silver award holders and launches the gold | Apr 2015 | As in (6) |
| | | 23. The use of 'This is Me' profiles is extended and used to promote person centred care in all dementia care services | Dec 2014 | As in (1) (6) |
| | Young Onset | 24. All developments based on a social model of dementia care. | May 2015 | As in (1) (6) |
| | Promoting Independence and Re-ablement | 25. Service gaps for people with young onset dementia are identified and addressed | Dec 2015 | As in (1) (6) |
| | | 26. Integrated working is achieving positive results in | May 2015 | As in (1) |

| County Theme | What do we want to achieve? Coded to | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|-------------------------------|---|--|------------------------|---|
| meme | national objectives | | | Leau |
| | | promotion/ maintenance/recovery of independence e.g. care homes with access to physiotherapists & mental health nurses | | Director for Care Home Quality (15) |
| | Cultural Appropriateness | 27.Excellent examples of culturally personalised services are available and shared to highlight what can be achieved | May 2015 | As in (1) (6) |
| Improved communic ation | N 7. Supporting Carers | 28.The Carers strategy addresses dementia and expressed wishes of carers of people with dementia | Dec 2014 | As in (6) |
| Person centred services | N 8. N 6. Hospital Admission and avoidance (KEY ACTION) | 29. Reduced unplanned admissions of people with dementia ore to avoid the need to admit to hospital (acute/ dementia wards) | Dec 2015 | As in (8) |
| | | 30. Investment in community services through an exchange of hospital beds where not needed for replacement elsewhere where needed. | | As in (1) |
| | | 31 Development of Community support teams and care coordinators to identify those people at highest risk of health deterioration to prevent hospital admission | | As in (1) |
| | | 32. A dementia dashboard is created demonstrating outcomes for people with dementia. | | As in (1) |
| | | 33. Identify any instances where capacity to support people with behaviour that challenges may be insufficient and make recommendations. | | As in (1) (6) |

| County | What do we want to | Outcomes we aim to achieve | Reporting | Organisation |
|-------------------------------|--|--|-----------|--|
| Theme | achieve? Coded to national objectives | | Milestone | Lead |
| | | 34. Improve in-patient experiences e.g. Butterfly scheme and mental health liaison teams in acute settings | | As in (8) |
| | N 11. N 6. Quality care in care homes | | | |
| Person centred services | Residential care minimise admissions | 35. The need to admit people to long term residential care reduced to bring Derbyshire admissions in line with comparator Local Authorities. | May 2015 | As in (1) (4) (6) |
| | | 36. A Rapid Access Interface Discharge (RAID) programme reduces unnecessary delays to hospital discharge. | May 2015 | As in (8) |
| | | uscharge. | Dec 2014 | As in (1) (6) (7) |
| | Maximise experience | 37. Care homes and hospitals supported to develop more dementia friendly physical and social environments as part of a policy of joint commissioning | | (8) AC (Contracts team) (15) |
| | | of best care. | May 2015 | As in (1) (5) (6) |
| | Anti – Psychotic Medication | 38. Enable more care homes to support people without relying on anti-psychotic medication e.g. use of activity and improved communication skills | | (8) (14) (15) |
| Training | N 13. | | | |
| and developm ent | Learning Networks for professionals | 39. Networks are set up to ensure successful local initiatives are known, shared and adopted (qs5,6) | Dec 2015 | As in (1) (5) & via Memory Assessment Service |
| | Mental Capacity Act | 40. The training plan to ensure more staff have an understanding of the Mental Capacity Act. | Dec 2015 | AC DOLS team |

| County Theme | What do we want to achieve? Coded to national objectives | Outcomes we aim to achieve | Reporting Milestone | Organisation Lead |
|------------------------------|---|---|------------------------|------------------------------|
| | Staff training | 41. The training plan for Derbyshire Professionals and Carers ensures staff are appropriately dementia trained. | Dec 2015 | As in (2) & NHS Workforce |
| | N14. Joint Commissioning Strategy | | | |
| Improved Joint Working | Integrated working and cross service developments (KEY ACTION) | 42. Increase integration of health and social care services at local level through joint structures and finance to address dementia as a long term condition. | Dec 2015 | (As in 1-7) |
| | Integrated working and cross service development | 43. Dementia support pathways are publicised starting with GP's giving choices as dementia develops. | May 2015 | As in 1-7) |
| Research | N16. Research (DH responsibility) | 44. Continued involvement of Derbyshire residents in research (qs7,9) | May 2015 | As in (9) (10) |
| | | 45. Commissioning intentions are evidence based (qs3,40) e.g. the specialist home care service; utilisation of Derbyshire Health Watch. | Oct 2015 | As in (1((6) |

National Objectives dementia strategy 2009 (Some paraphrasing)

- N 1 Improving awareness and understanding:
- N 2 Good quality early diagnosis and intervention for all
- N 3 Promoting local information about dementia services
- N 4 Provide support following diagnosis
- N 5 Peer support and engagement and

- N 6 Good Quality care for people with dementia
- N 7 Supporting Carers
- N 8 Care of people living with dementia in general hospitals is improved
- N 9 Improved Intermediate care
- N10 Housing and Housing related support
- N11 Quality care in care homes
- N12 Good quality End of Life Care for people with dementia
- N13 Informed and effective workforce
- N14 Joint Commissioning Strategy for dementia
- N15 Improved assessment and regulation
- N16 Research
- N17 National and regional support

| Phase 1 Pre-Clinical | Phase 2 Mild Cognitive Impairment | Phase 3 Early Dementia | Phase 4 Middle Dementia | Phase 5 Late Dementia |
|---|---|---|---|---|
| Focus on maintaining independence and good health Preventative action includes promotion of - awareness raising - healthy lifestyle | Early stages of dementia but no diagnosis Continue to focus on maintaining indpendence Referral to Memory Assessment Service Access the Dementia Support Service Potential for an Adult Care assessment of need | Diagnosis confirmed Focus on providing emotional and practical needs Individual diagnosis and treatment plan created Adult Care assessment of need to take place = Carer assessment Potential for minor adaptations to home May be able to access Adult day services | May have moderate or complex needs resulting in loss of function & independence Annual GP review If no prior exposure to health service - may enter at crisis point now Potential for carer burnout Specialist Home Care or Respite Care may be appropriate | Potential for admission to Long Term Care or Hospitalisation Focus on supporting person and carer though perosn centred care approaches including end of life support Adulat Care need review Carer Review Potenital admission to residential or nursing care |

APPENDIX B: Engagement



Stakeholder Engagement Team

67

Nov 2013

Dementia Strategy Refresh 2013/14

Dementia presents one of the biggest health and social care challenges. Around 50% of people (428,000) in England, Wales and N Ireland living with dementia do not have a formal diagnosis. This can mean being unable to access treatments and support. The incidence of dementia is set to rise significantly. In December 2010 an All Parliamentary Group (APPG) on Dementia began an inquiry into how to improve outcomes for people with dementia and their carers. A stimulus for the inquiry was pressure on health and social care budgets and an urgent need to improve cost-effectiveness. Dementia was estimated to cost the UK £20 billion in 2010 which is expected to grow to over £27 billion by 2018.

Over the last 3 months, Derbyshire County Council (DCC) and Clinical Commissioning Groups (CCG's) in Derbyshire have joined together to review and refresh an existing Derbyshire strategy which began implementation in 2010. The aim of the review was to ensure that the local strategy was still relevant to local views; local needs; best practice and national guidance on dementia care.

Perspectives 67 provides a summary of the views and comments captured at a range of engagement workshops and events, questionnaires, face to face interviews and telephone interviews. Over 250 people took part including people with dementia, family carers, 50+ forums, people attending dementia cafes, people living in rural communities, health and social care staff, mixed stakeholder groups, BME communities including gypsy and travellers, and LGB and T groups in Derbyshire are included.

Top Priorities

- Being supported to stay in your own home for as long as possible;
- Training staff need greater cultural awareness and need to fully adopt a person centred approach;
- Early diagnosis and timely help to avoid crisis;
- One point of contact;
- Communication Listening and understanding carers concerns;
- Support:
 - signposting for people not meeting eligibility criteria;
 - support for people experiencing early onset dementia;
 - support to help carers feel able to cope with dementia;
 - support/help to relieve 24/7 caring role;
 - better listening to and understanding of carers concerns;
 - good quality support to enable social interaction.

BACKGROUND

Aim: To involve a wide range of stakeholders to refresh and confirm the priorities in the Derbyshire Dementia Strategy. To add to and develop further a Derbyshire dementia network of people with dementia, carers, relatives and people working in the field of dementia prevention and dementia support.

1.2 OVERVIEW OF THE CONSULTATION METHODOLOGY

A mixed approach was used to engage including workshops, information and engagement events, attending existing events and forums as well as interviewing people living, caring and supporting people with dementia.

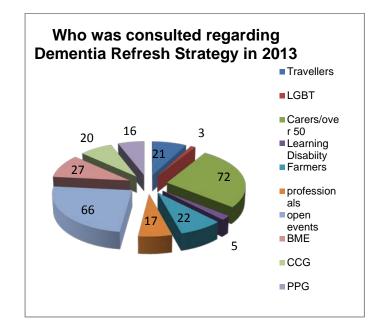
Specific events included attending farmers markets, Patient Participation Groups, dementia cafes, Black Minority Ethnic forums, Community Care Centre dementia events at Oaklands. The Stakeholder Engagement linked with team the Alzheimer society, Mind CVS, Derbyshire Rural Action and NDVA along with Derbyshire Clinical Commissioning Groups.

The Stakeholder Engagement Team used a range of trained, paid peer reviewers to carry out interviews with clients living in residential and nursing care homes who have dementia, their carers and relatives and with staff working in this sector.

In addition the Team commissioned help from specialist, local practitioners including a farmer liaison worker, gypsy and traveller liaison worker and representatives from Derbyshire's Black Minority Ethnic community and Lesbian Gay Bisexual and Transsexual groups. People with early onset dementia were invited to give their views. Derbyshire fieldwork assessors and Direct Care staff, Community Mental Health Teams and GP surgeries were also asked for their assistance.

The locally established 50+ forums were involved through DOPAG - (Derbyshire Older Peoples Advisory Group) which has older people representatives from across Derbyshire. Other existing forums were also approached and invited to take part in the consultation.

The project was managed by the Stakeholder Engagement Team, based in Adult Care at Derbyshire County Council. The Healthwatch Derbyshire team assisted with the engagement, working collaboratively to share and build a network of dementia stakeholders to be involved in the refresh of the dementia strategy and also remain engaged ahead as details of existing and new services are worked out.



1.3 DEMOGRAPHICS

Over a period of 4 months the Stakeholder Engagement Team developed and identified the network in which it gauged views on the current dementia services and what stakeholders would envisage to be pivotal to providing an excellent service for future developments.

During the consultation the Team were supported by various specialists liaison workers from the groups identified which enabled engagement directly with groups and individuals.

The Stakeholder Engagement Team successfully interviewed over 21 people with an interest in dementia from the farming community. 27 representatives attended a group forum from the Black Minority Ethnic Community. Over 22 1 to 1 interviews were carried out via the traveller liaison worker.

A group of 66 people with dementia and their carers were interviewed at the various Alzheimer cafes which are held around Derbyshire and their views captured. Stakeholder Views were sought via the liaison worker at Derbyshire Friend together with a generic email to all Derbyshire County Council employees who are networked via the employee support group for LGBT.

1 to 1 interviews were carried out with carers of people with downs syndrome together with professionals working within the Learning Disability community. Voluntary sector providers and campaign groups were also invited to submit their views.

Two events were held; one in the north and one in the south of the county. This was via an open invite and over 66 people attended over the two events. Professional views were also sought from GP's and staff working with people with dementia in both health and social care settings. Views were also sought from the Patient participation Groups in the Hardwick PPG and Erewash PPG.

We also used other recent research in our consultation which included:

- Stonewall Report (LGBT in later life) 2010
- 'What am I afraid of' a film that highlights the concerns relating to dementia for the LGBT community. This is a collaborative film between several agencies i.e. Senior Human Right Derbyshire, Derbyshire Friend, Age UK and Comic Relief.
- Younger People with Dementia Report 2013 (Sue Whetton Derbyshire County Council Service Manager)
- The Evaluation of the Specialist Homecare Service 2013 (Sophie Heffernan DCC)
- National Voices Campaign
- 'Tell us more' report by South Derbyshire CCG and Derby City

1.4 QUESTIONS ASKED

To encourage participation the Team asked 4 very open questions to determine people's views. The questions were:

- What do you or would you value most?
- What is most difficult?
- Where are the gaps?
- What are the top 3 priorities?

During the consultation with the PPG's the questions were varied slightly to include

• Thinking about your surgery/community what can we do to make it more dementia friendly? If you had an experience of being referred to hospital what could the hospital have done differently?

1.5 FINDINGS

Over 250 stakeholders took part in the engagement sessions. Below is a summary of the comments and provides some analysis of the common themes emerging from the discussions.

What do you or would you value most?

All stakeholder groups stated that:

Being supported to stay in their own home for as long as possible was paramount - however this support needed to be flexible enough to enable people to carry on with their life style i.e. timings of home care calls.

The following are some of the views/experiences that were captured

'We need to look at alternatives to acute hospital settings. Look at facilities for acute hospital treatment to be provided at home e.g. Infections being treated with IV antibiotics.'

'coping to care for someone with incontinence is difficult and extra help is needed – perhaps allowing more pads and considering a charge for these.' Transport is an issue and very often the dementia sufferer loses their driving licence and further reduces their independence early on.

The gypsy community told us that often they felt professionals feel intimidated by some of their behaviour but the issue is lack of cultural awareness. To quote one participant 'in the gypsy community we have a huge respect for our elders and they will still be the head of their family even if they are suffering from dementia – so it is a very difficult thing for us to have to start making decisions for them especially if they are distressed or angered by the choices made.....it makes it so difficult to pass the care of your loved one on to outsiders who only have time to see to their basic daily needs.'

Good quality support for social

interaction. There was much praise for the work of the Alzheimer's Society and the support groups that they run such as the dementia cafes and singing for the brain. However there is a need to promote these opportunities further.

The following are some of the views/experiences that were captured...

'Should encourage activities that stimulate someone with dementia with specific services for young sufferers and their carers e.g. signing for the brain.'

'Emotional support is an important as practical support'

'I really value time to allow me to go out and not worry about the person I care for – this helps relieve the stress of caring.'

'Singing for the brain was a wonderful distraction which everyone attending seems to like. More of these would help.'

The PPG (Patient Participation Group) raised issues about the ability to be able to complain without the fear of repercussion or it affecting the standard of support or care their loved one received.

What do you find most difficult?

Lack of cultural awareness The following are some of the views/ experiences that were captured:

'The fear that you would have to hide your relationship and that for the remainder of your life in residential care would 'mean having to go back in the closet' -LGBT community

The Romany gypsy community feared losing their cultural identity as they felt residential care accommodation would not cater for this need.

24/7 caring role This comment was reiterated by stating that the caring role is hard work, frustrating, tiring and isolating.

Change of relationship – People interviewed commented that it was difficult to cope with a loved one that you do not recognise any longer and they do not recognise you.

Listening and understanding carers concerns – here carers voiced many negative experiences and said they felt that their concerns and observations needed to have an equal waiting during the diagnostic part of their pathway.

Lack of joined up working – the PPG highlighted the need and importance of all the agencies having a joined up approach.

Consistency of Care – again the PPG highlighted the need for consistency of the care and support which was being provided. They suggested that the larger GP practices should adopt the precedent of once a GP has been allocated to try (wherever possible) to ensure that it was the same GP that sees the dementia patient. They also felt that the approach to consistency needed to be managed.

Gaps

Training and cultural awareness – This has already been commented on when people interviewed were asked what people found most difficult when receiving services for dementia. Although this was largely identified by the hard to reach communities we interviewed – it was also evident that overall people receiving services for dementia and their carers felt more time could be spent in identifying cultural needs and that this would be helped if a person centred approach was adopted.

One point of contact – This was a problem for many participants feeling that there were far too many agencies to deal with at a difficult time.

Support for people and carers not meeting eligibility criteria – again a concern across all communities was that if you do not meet any ones criteria you do not receive any support. To quote one carer:

'Care in the community is ok – but if you cope you are left to cope.'

A drive to increase the numbers of volunteers which are needed to help with care and stimulation of patients.

To ensure that the 'this is me' document was well known and used throughout agencies supporting and caring for the dementia patient

Support for early onset dementia

clients was identified as an area requiring particular attention that was person centred, holistic and age appropriate.

Priorities

Training – participants reported a great need for training around cultural awareness to ensure a person centred approach.

Early, timely diagnosis to help avoid crisis – With all sections of the communities which were interviewed early diagnosis was an issue. To a large extent this was linked to the carers concerns – that their voice had little standing in any consultations. It was felt that the delay in getting diagnosis often lead to crisis moments. The following are some of the views/experiences that were captured ...

'took over 8 months to get a diagnosis'

'It took two years to get medication'

The appropriateness of the memory test carried out – doing the alphabet backwards ... sometimes the fact that memory tests are not culturally appropriate can often lead to indications of a problem being missed' The BME forum offered to work with professionals on this issue to ensure that the test is fit for purpose.

'Being recognised as a carer by your GP 'I appreciate the fact that my GP respected my mother, when she wrote raising concerns about my father. Dad had a lack of insight to his changing behaviour and mental health and was unlikely to go to the doctors of his own volition. The GP was able to broach the issues sensitively and supportively and a 'memory clinic' appointment was set'

'once labelled as having a learning disability this becomes predominant – overriding factor information passed to GP's by professionals working with people with LD should be taken on board by GP for referral and utilised for diagnosis' LD health professionals

'At the point of diagnosis a person with a learning difficulty should be referred to the LD Health team.'

LD professionals highlighted the 'need for screening and they recommended this from the age of 30.' Carers 'appreciated appointments being kept on time with the GP as this avoided the person with dementia becoming agitated and adding to stress of caring.'

'Having access to an interpreter during an appointment.' BME community.

Clean well maintained accommodation

 as we have already mentioned this was a particular concern for the Romany
 Gypsy community – however this was also echoed across all groups.

Access to services for all

PPG's supported "Easy access to relevant services and education about these services and their availability"

Other Helpful suggestions and developments

Identifying Dementia patients

Participants advocated for a system in place that 'flags' dementia patients in A&E on admission to make a smoother journey for their patient and to adopt the butterfly scheme – a small blue butterfly that identifies people who have dementia and is particularly helpful when people go into hospital – this is currently operational in over 100 Trusts.

"Hospitals have no concept of someone's usual patterns of behaviour but don't want to listen to the people that know them best".

Developing Dementia Friendly Communities

1 village in Derbyshire has a 'winter meeting (community association) to identify any vulnerable members of the community.

Importance of evening Support

People with dementia often experience what is called 'sun downing i.e. they become more anxious/agitated in the evening. This can be very isolating and challenging for family carers and has a huge impact on their emotional well-being. Services should be more accessible to include support in an evening – this may also enable people to stay at home for longer.

Joint Working

People advocated the advantages of joint working.

'At our present stage we have been most encouraged by the care received from the NHS Memory Clinic and the Assessment follow up at Lee Hurst, Walton Hospital together with unrequested help and Adult Care who have anticipated our needs and provided physical aids.'

Drop in sessions at GP surgeries

Was suggested would help support carers and encourage people to come forward and find out more about the illness. It was suggested that this did not have to be run by the GP themselves but could be run by specialist shared workers who visit the surgery every third Tuesday In the month.

Assessment and memory tests should tie in with the Annual Health Assessment.

It was suggested by a GP that it would be feasible to ask for a CT scan at the same time as the blood test to try and cut down waiting times.

Publicity on Dementia

It was suggested that a TV campaign similar to the stoke FAST campaign would raise awareness of dementia – however the BME community had reservations that further publicity would also need to be done as not all their community watch English TV.

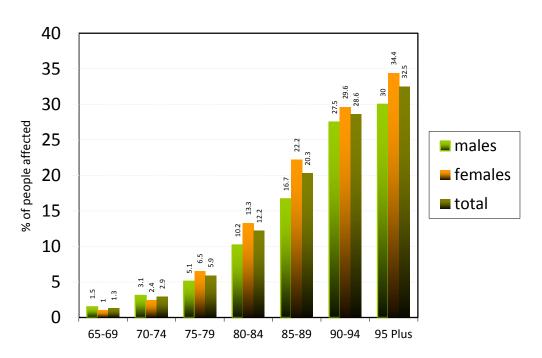
The PPG suggested to use free door to door magazines to raise awareness of dementia but also to provide information on benefits and services in the area.

WHAT HAPPENS NEXT

Information from this consultation was shared with the Derbyshire Adult Care Board in November 2013 who supported the overall recommendations presented to them. A Joint Adult Care/ NHS Commissioning group will work to deliver the strategy including how to both feedback progress to members of the public and also when to engage people further regarding detailed planning.

APPENDIX C: Prevalence and Demographics in Derbyshire 2014

Figure 1



Late Onset Dementia by Age and Sex

- Dementia UK Consensus estimates¹ •
- The incidence of dementia is positively correlated with age i.e. as age • increases the percentage of people affected by dementia increases. Between the ages of 65 & 69 only 1.3% of people are affected but between 85 & 89 the proportion increases to 20%
- Between 65 and 74, the incidence rate is higher for males than for females •
- The incidence rates for late onset dementia are reversed with females after • age 74 having a greater pre-disposition to dementia than males.
- Recent research² suggests that there may be a lower prevalence in UK than • previously predicted; nevertheless the number of people with dementia will rise greatly over the next 2 decades.

¹ 2006, Produced by King's College London & LSE ² The Lancet, Tuesday 16th July, 2013

| | | | | | Percentage change from 2006 to: | | | |
|--------|---------|---------|---------|---------|---------------------------------|-------------|------|------|
| Aged: | 2013 | 2018 | 2023 | 2028 | 2013 | 2018 | 2023 | 2028 |
| 65-69 | 51,300 | 47,700 | 48,100 | 54,800 | 33% | 24% | 25% | 42% |
| 70-74 | 35,900 | 47,900 | 44,900 | 45,300 | 11% | 49% | 39% | 41% |
| 75-79 | 28,300 | 32,100 | 43,000 | 40,400 | 8% | 22% | 63% | 54% |
| 80-84 | 20,700 | 23,200 | 26,700 | 36,000 | 5% | 18% | 36% | 83% |
| 85 | | | | | | | | |
| plus | 20,000 | 22,700 | 26,900 | 32,200 | 13% | 28% | 52% | 82% |
| All 65 | | | | | | | | |
| plus | 156,200 | 173,600 | 189,600 | 204,700 | 16% | 29% | 41% | 55% |

| Table 1: Derby | vshire Older | Population | Increases | $2013 - 2028^3$ |
|----------------|--------------|-------------|-----------|-----------------|
| | | i opulution | 110100000 | 2010 2020 |

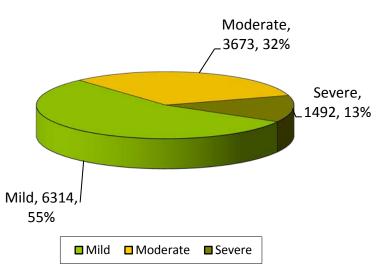
• Significant growth in Derbyshire's older people's population

- An increase of 55% of people aged over 65 between 2013 and 2028
- An increase of 82% of people aged 85 or over between 2006 and 2028
- Given that dementia is a disease that is strongly associated with increasing age, we can expect to see large increases in prevalence, as the Derbyshire population ages and lives longer
- Increasing numbers of people with dementia from the oldest agegroups in the population have multiple physical impairments; hospitalisation for treatment of their physical impairments can serve to exacerbate distress due to dementia and the effects of disorientation, confusion, anxiety and depression
- Research⁴ reliably demonstrates that people with dementia who are admitted to hospital receive poorer quality care than people without a dementia.

³ 2010-based, sub-national population projections, ONC, © Crown Copyright

⁴ Published July 2013, National Audit of Dementia, Royal College of Psychiatrists

Figure 2



The Number of People with Dementia by Severity in Derbyshire 2013

- It is estimated that there are just under 11,500 people affected by a dementia in 2013 living in Derbyshire
- At any one time, the majority of people (55%) have a mild condition.
- A smaller number of people are moderately affected (32%).
- Just under 1500 people in Derbyshire in 2013 have a severe dementia (13%)

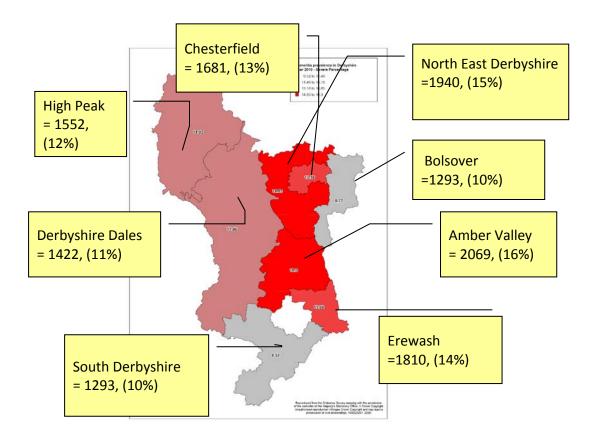
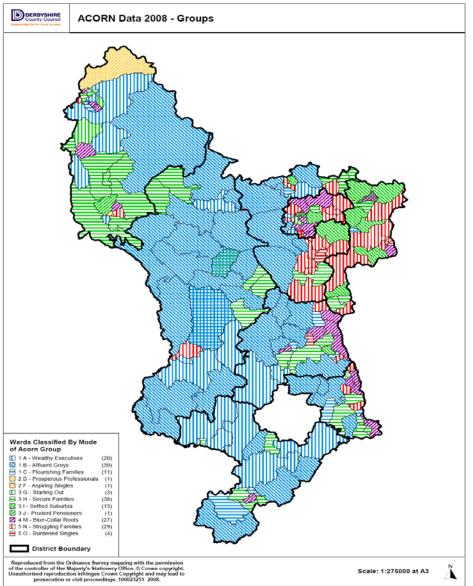


Figure 3: Late Onset Dementia by District 2018

- Dementia UK Study divides severity into Mild (55%), Moderate (32%) and Severe (13%). If we apply these figures to Derbyshire it means that there will be 7,100 people affected by *Mild Dementia*, *4*,150 by *Moderate Dementia*, and 1700 by *Severe Dementia* by 2018.
- This gives a total of just over 12,900 people affected by dementia in Derbyshire in 2018.
- If we break the figures down further by district, we obtain the distribution of dementia as shown in Figure 2 above.
- Though not the largest in terms of absolute numbers, 2 areas of particular concern are Derbyshire Dales due to its very rural nature, and Bolsover, due to its tendency of not accessing community resources effectively combined with high social deprivation.
- Anecdotal evidence suggests there are more than the estimated number of people affected with dementia in Bolsover due to a higher incidence of vascular dementia, caused by its heavy industrial past specifically in relation to coal mining.
- Together in those 2 districts, there will be over 2000 people affected by dementia.
- The numbers will grow to 17,800 in Derbyshire by 2028.

Figure 4



- Figure 4 shows Derbyshire's Residential Neighbourhood Classification (ACORN).
- ACORN classifies areas according to a range of marketing and other socio-economic data.
- The Predominant group in Derbyshire Dales is "Affluent Greys" in contrast to Bolsover which is "Struggling Families".
- We know that Dementia is not associated with social class.
- There are marked differences in life expectancies between the west and east side of the county ie males in Bolsover can expect to live 15.2 years at age 65 compared with 17.1 years in Derbyshire Dales.
- Despite the contrasting socio-economic fabric of the two districts, both are disproportionately affected by dementia: Derbyshire Dales because of its ageing population living in predominantly rural isolated situations and Bolsover because of its coal-mining legacy (and increased levels of vascular dementia) and high social deprivation.

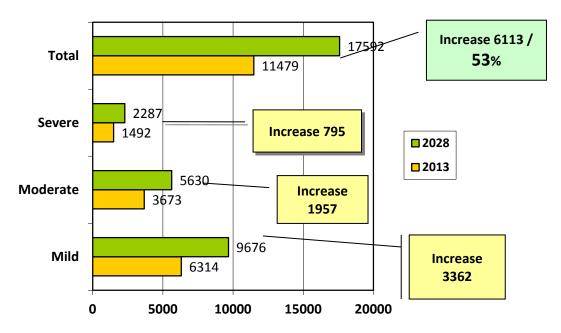


Figure 5: Late Onset Dementia Projections to 2028

- Because of the ageing of the population in Derbyshire, Dementia will rise quite dramatically between now and 2028.
- The estimates give a rise of about 6100 people.
- By 2028, it is estimated that almost 18,000 will be affected by dementia, a rise of 53%.
- Mild Dementia will rise by just over 3,300 people, Moderate by just over 1957 and severe by just under 800.

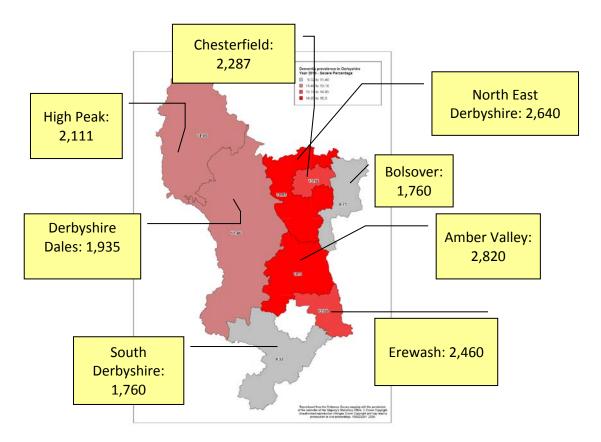


Figure 6: Total Dementia by District 2028

- The map illustrates the estimated number of people affected by dementia in 2028 based on population projections.
- The number in Derbyshire Dales will rise to just over 1900.
- There will be just under 1800 people affected in Bolsover.
- All areas will have significant numbers of people affected by dementia
- The total number of people affected by 2028 will be close to 17,800

Early Onset Dementia

| ĺ | | | | | Total |
|-----|------|---------|---------|---------|---------|
| | Age | 18 - 24 | 25 - 49 | 50 - 64 | (18-64) |
| | 2013 | 0 | 30 | 180 | 220 |
| | 2018 | 0 | 30 | 200 | 230 |
| | 2023 | 0 | 30 | 210 | 240 |
| | 2028 | 0 | 30 | 210 | 240 |
| - 2 | | | | | |

Table 2: Early Onset Dementia Prevalence in Derbyshire

Source: Planning4care

Prevalence estimates suggest that there are only 220 adults in Derbyshire with early onset dementia (before 65th years of age). Whilst small in number, the onset and progression of the condition can be devastating to the lives of working age adults and their families, whilst age appropriate provision is still being developed.

One subgroup of people who have a disproportionate likelihood of developing early onset dementia is people with Down's syndrome. It is estimated that 330 Derbyshire 18 - 64 year olds have Down's syndrome, of who 40 have early onset dementia⁵. The projected number of 18 - 64 year olds with Down's syndrome (and with Down's syndrome and dementia) are projected to remain stable between 2013 and 2028.

⁵ Planning4care, (with prevalence of dementia among people with Down's syndrome based on Coppus et al (2006) [Dementia and mortality in persons with Down's syndrome, Journal of Intellectual Disability Research, vol 52, pp 141-155]).

Commissioning discussions for social care should focus on:

- 1. The number of people aged 65 plus affected by dementia will grow substantially over the next 2 decades.
- 2. The number of older people caring for a spouse or family member affected by dementia will grow significantly too. The number of people providing informal care to a family member increased between 2001 and 2011 by over 6,000 in Derbyshire
- 3. People with dementia do not respond as well to hospitalisation as people without the condition. They tend to become more confused and their overall condition worsens.
- 4. Carers need much more support to enable them to continue to care and not to "burnout". They need training in how to cope with dementia. They need more respite opportunities and more domiciliary support in times of crises (cf Specialist Home Care Service).
- 5. With better support, and a more personalised service, the negative impact of dementia can be ameliorated and early admission rates to residential or nursing care can be reduced
- 6. We must work to achieve "dementia-friendly communities"; there are some very simple, low-tech as well as high-tech interventions that can be deployed. Electronic payment swipe cards for carers of people with dementia would most likely increase the numbers taking up a *Personal Budget* option, medicine dispensers that obviate the need for supervised medication dispensing, and door systems that can "remind" people that it's not time to go out.
- 7. There need to be more "dementia friends" who will voluntarily provide befriending services.
- 8. Fundamentally, at present there is a national mis-match between growing need and support levels. As a consequence too many people are being left to care without help.
- 9. There needs to be far more publicity about dementia and its impact on an individual put into the public's awareness. Only then can communities start to become "dementia friendly".
- 10. Whilst the number of Derbyshire people with early onset dementia is relatively small (220), it will be important to ensure that provision and support are relevant to their needs. Given that some of these people will have jobs or run a business, have families of their own, and be younger, the necessary support will not simply be just replicating the support needed by older people with dementia.
- 11. For those under or over 65 years with dementia, there may well be a need for welfare rights support to successfully claim some of the benefits they and their carers may have entitlement to.

APPENDIX D: List of NICE Guidance

NICE Quality Standards – Dementia (QS1)

<u>Statement 1</u>. People with dementia receive care from staff appropriately trained in dementia care.

<u>Statement 2</u>. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

<u>Statement 3</u>. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

<u>Statement 4</u>. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

<u>Statement 5</u>. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of :

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities of Care.

<u>Statement 6</u>. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

<u>Statement 7</u>. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

<u>Statement 8</u>. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

<u>Statement 9</u>. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

<u>Statement 10</u>. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia

NICE Quality standard for supporting people to live well with dementia – QS30

<u>Statement 1</u>. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.

<u>Statement 2</u>. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

<u>Statement 3</u>. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change

<u>Statement 4</u>. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

<u>Statement 5</u>. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

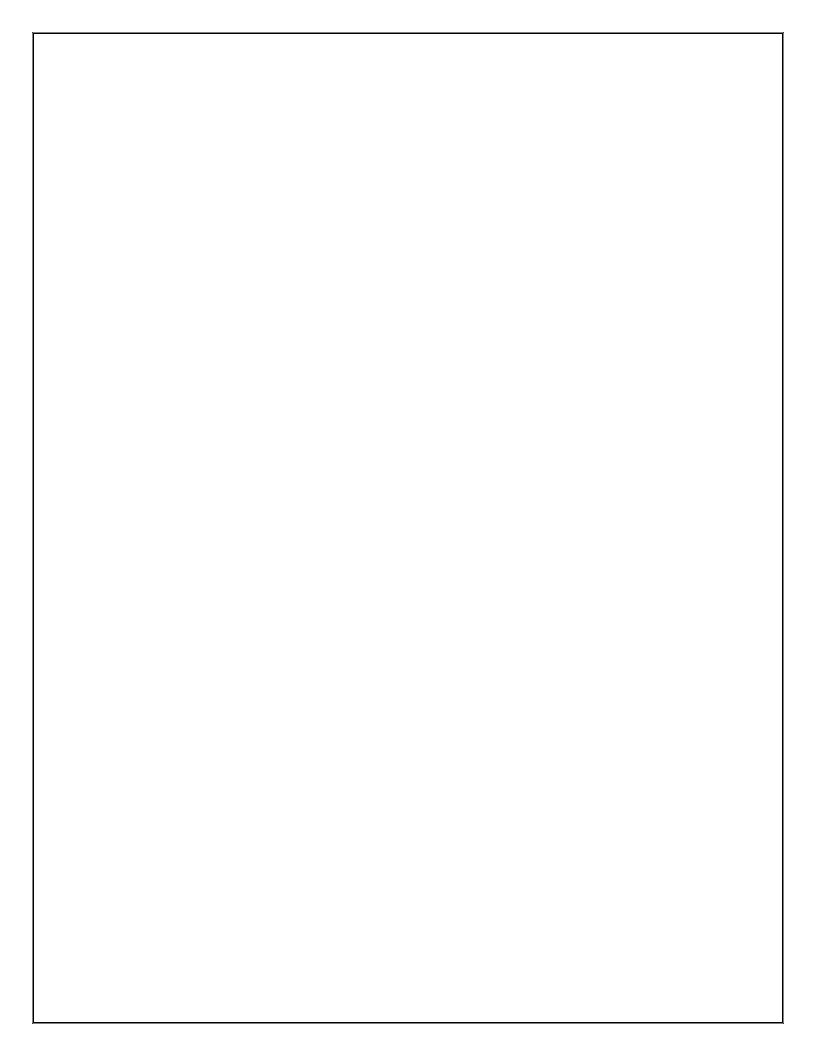
<u>Statement 6</u>. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

<u>Statement 7</u>. People with dementia live in housing that meets their specific needs.

<u>Statement 8</u>. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

<u>Statement 9</u>. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

<u>Statement 10</u>. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.



DERBYSHIRE COUNTY COUNCIL

ADULT CARE BOARD 13th MARCH 2014

BETTER CARE PLAN/FUND UPDATE

1. Purpose of the Report

To update the Adult Care Board on the progress that has been made in the Better Care Plan and Fund (BCF)

2. Information and Analysis

At the last meeting of the Adult Care Board on 13th March the most up to date version of the BCF was supported, but it was recognised that it would change prior to its submission to the Health and Wellbeing Board on 3rd April. Attached is the BCF Plan that was approved at the Health and Wellbeing Board and submitted to NHS England on 4th April 2014.

Since then, work has continued on a number of tasks.

These include:

- Developing proposals for the infrastructure to support the BCF, including the development and management of the pooled budget, the co-ordination of the overall programme and the establishment of the BCF Programme Board.
- Identifying how the reviews of the current integrated services will be undertaken.
- Reviewing the current services funded by the transfer from NHS to the County Council.

To date, the feedback that we have received from NHS England about the BCF concerns the performance targets that we submitted as outlined in Part 2 of the BCF Plan. Three of the targets were challenged. For both Delayed Transfers of Care and Avoidable Emergency Admissions the improved performance that we proposed was considered to be too low. Following discussions with NHS England, the CCGs and Adult Care have agreed on additional stretch. These are outlined in the attached document and were supported by the Chair of the Health and Wellbeing Board.

The third target that was challenged was the locally determined target covering the diagnosis of dementia. After negotiation this was accepted by NHS England as satisfactory, including the timing of its measurement.

We are awaiting further feedback from NHS England and the Local Government Association about the overall plan.

3. OFFICER'S RECOMMENDATIONS

- That the progress on the BCF is noted and that support is given to the actions being undertaken.
- That regular reports are submitted to each Adult Care Board updating on progress given the scale and urgency of delivering improved integration.

PUBLIC

DERBYSHIRE COUNTY COUNCIL

REPORT FOR ADULT CARE BOARD

15th May 2014

Progress Report on the Implementation of the Winterbourne View (Transforming Care) Review Recommendations and Concordat

Purpose of the report

To provide the board with an update on progress made in meeting recommendations set out in *Transforming Care: A national response to Winterbourne View Hospital: Department of Health Review* and the accompanying *Concordat: Programme of Action* (December 2012).

To seek approval for the outline Joint Plan for People who have Behaviour that Challenges.

Progress on the key recommendations:

Recommendation:

Health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to communitybased support as quickly as possible and no later than 1st June 2014. NHS England figures (March 2014) identified that out of the 2,577 people with learning disabilities currently in in-patient beds only 260 had a moving date and of those only 172 were before 1st June.

Progress:

- In Derbyshire all hospital placements have been reviewed and six people have or will have moved to community based support by 1st June 2014. Two people are currently appropriately placed. Five people have outline plans that are subject to on-going clinical discussions. The need to obtain second opinions from independent psychiatrists has been identified for some individuals.
- At the request of the Winterbourne Joint Improvement Programme Team (Gateway ref: 01438) a submission containing narrative descriptions of the arrangements in place for all discharged individuals, and plans for those not yet discharged was made on 4th May 2014.

Recommendation:

Every area will put in place a locally agreed joint plan for high quality care and support services for people of all ages with challenging behaviour that accords with the model of good care.

Progress:

- An outline plan (attached) has been completed and presented to the Learning Disability Joint Commissioning Board and Hardwick Clinical Commissioning Group. It is proposed to present the plan to the Health and Wellbeing Board in July 2014. The development of further specific work streams will be developed and progress on implementation will be reported and monitored using the established governance structure: the Learning Disability and Autism Joint Commissioning Boards, Learning Disability Partnership Board, Adult Care Board, The Derbyshire Safeguarding Adults Board and the Health and Wellbeing Board.
- The plan will incorporate the following guidance '*Positive and Proactive Care: reducing the need for restrictive interventions*' (Department of Health, April 2014), '*A positive and Proactive Workforce*' (Skills for Care and Skills for Health, April 2014) and the commissioning tool '*Ensuring Quality Services*' (Local Government Association February 2014).

Recommendation

The strong presumption will be in favour of supporting the plan with pooled budget arrangements with local commissioners offering justification where this is not done.

Progress:

 In response to pooled budgets arrangements a new Joint Solutions Group has been developed. The group will provide a health and social care shared response to people with complex needs who do not meet the criteria for Continuing Healthcare funding. The group will include commissioning and operational leads across health and social care. Whilst not formally a pooled budget the approach meets the intended outcome which is to ensure that individuals receive appropriate support without delay due to financial barriers between health and social care commissioners.

Other Developments:

An increase in the additional non-recurrent investment for Derbyshire County Council and Derby City Council has been allocated via Hardwick CCG to extend the previously agreed 12 month social work post (due to end in April 2014) to December 2014. This will enable the completion of discharge arrangements for all individuals and ensure continuity of case management during the early stages of the new support arrangements. From May 2014 this post will support Derbyshire County individuals only, Derby City will make their own arrangements for social work support and reporting on progress for City clients.

RECOMMENDATIONS

- 1. The Board notes the contents of this report and agrees to receive regular updates on the joint delivery of the Action Plan.
- 2. The Board approves the outline Joint Plan for people with a Learning Disability who have Behaviour that Challenges.

Deborah Jenkinson

Service Manager - Commissioning

Joint Plan on a Page 2014-2017 to commission the range of local health, housing and care support services to meet the needs of people with a learning disability of all ages with behaviour that is challenging - based on the principle of an ordinary life for all citizens.

What we will do

childrens Health and Social Care

Challenging Behaviour Charter

care/support at home or as

close to home and provide

more reliable support for

Provide high quality person

Promote and prioritise joint

• Offer Personal Budgets and

Personal Health Budgets

Provide joint solutions to

individual funding and risk

Commissioners will review

specialist learning disability

behaviour training to provide

positive behaviour support for

investment in positive

all ages

sharing.

centred appraoches, prevention

and early intervention services .

Sign up across adult and

commissioners to the

Promote delivery of

families and carers

PUBLIC

What is Challenging behaviour

- Challenging Behaviour is behaviour "of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion".
 (Challenging behaviour – a unified approach; RCPsych, BPS, RCSLT, 200
- •The term "challenging behaviour" has been used to refer to the "difficult" or "problem" behaviours which may be shown by children or adults with a learning disability including:
- Aggression (e.g. hitting)
 Self injury (e.g. head banging)
- •Destruction (e.g. throwing objects)
- •Other behaviours (e.g. running away)
- Challenging behaviour can put the safety of the person or others at risk or have a significant effect on the person's every day life
 Note - this plan links to Countywide Autism Strategy.

How many people do we need to plan and buy housing and support for?

- •Behaviour that challenges: is displayed by 10 to 15 per cent of adults who have a learning disability (see Emerson & Einfeld, 2011)
- In Derbyshire there are estimated to be 210 adults with a LD who dispaly significant challenging behaviour.
- In Derby City there are estimated 70 adults with a LD who display significant challenging behaviour
- •We will work with Children and Young peoples services including CAMHs to more accurately identify the number of people with behaviour that challenges.
- •We will also identify those at risk of developing behaviour that challenges
- health services against the national core service specification toolkit and develop new care pathways to strengthen health and social care responses for adults with a LD.
- Support communities and providers to manage the care of people with complex needs living in their local areas to stay living in their own home, to prevent unnecessary hospital admissions, unnecessary out-ofarea packages and to support people to be moving back to their home area

What we will do

- The new pathways / offer will be defined to ensure that any inpatient services commissioned by the CCG's are only utilised after responsive intensive community interventions have been delivered and agreed jointly with Adult social care
- Introduce a Care coordination process for individuals who have complex needs.
- Design individual community appraoches that deliver;
- a reduction in the prevalence and incidence of behaviour that challenges amongst people of all ages who have learning disabilities and / or autism
- a reduction in the number of individuals placed in more restrictive settings which are inappropriate for their needs (for example, inpatient hospitals, 52-week school/ college placements or residential care homes), especially those that are out of area.
- a reduction in the inappropriate use of psychoactive medication, restraint, and seclusion to manage behaviour that challenges
- Prioritise the management of and approaches to behaviour that challenges in quality montioring processes.
- Contunue to work closely with Housing colleagues to ensure access to a variety of accommodation.
- Develop future workforce plans, market management and community capacity building to support care closer to home.

What it will mean for the future

- •People with a learning disability or autism and behaviour which challenges will be able to say:
- •1. My home is in the community;
- •2. I am treated with compassion, dignity and respect;
- •3. I am involved in decisions about my care and support;
- 4. I am safe and protected from avoidable harm, but also have my own freedom to take risks;
- •5. I am helped to live with my family or helped to keep in touch with my family and friends;
- •6. Those around me and looking after me are well supported;
- •7. I am supported to make choices in my daily life;
- •8. I get the right treatment and medication for my condition;
- •9. I get good quality general healthcare;
- •10. I am supported to live safely in the community;
- •11. Where I have additional care needs, I get the support I need in the most appropriate setting;
- •12. My care and support is regularly reviewed .

The joint plan will provide greater personalisation and a focus on community support that promotes independence from early childhood and throughout adult life. This will be achieved collaboratively across education, health, social care and housing with involvement of providers, partnership boards, families, carers, and self-advocacy groups.

AGENDA ITEM: 5

Challenging Behaviour - National Strategy Group (CB-NSG) Charter Published 2009, Re-published 2013

Rights and Values:

1) People will be supported to exercise their human rights (which are the same as everyone else's) to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.

2) All children who are at risk of presenting behavioural challenges have the right to have their needs identified at an early stage, leading to co-ordinated early intervention and support.

3) All families have the right to be supported to maintain the physical and emotional wellbeing of the family unit.

4) All individuals have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This will be individually-tailored, flexible, responsive to changes in individual circumstances and delivered in the most appropriate local situation.

5) People have the right to a healthy life, and be given the appropriate support to achieve this.

6) People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.

7) People have the right to supports and services that create capable environments. These should be developed on the principles of positive behavioural support and other evidence based approaches. They should also draw from additional specialist input as needed and respond to all the needs of the individual.

8) People have the right not to be hurt or damaged or humiliated in any way by interventions. Support and services must strive to achieve this.

9) People have the right to receive support and care based on good and up to date evidence.

Action to be taken:

1) Children's and adults' services will construct long term collaborative plans across education, social and health services and jointly develop and commission support and services to meet the needs of children and adults with learning disabilities, their families and carers.

2) Local Authorities and the NHS will develop and co-ordinate plans to:

- Reduce the exposure of young children with learning disabilities to environmental conditions that may lead to behavioural challenges.
- Promote the resilience of young children with learning disabilities who face such environmental conditions.
- Provide early intervention, support and services that will meet the individual needs (including communication needs) of young children who are showing early signs of developing behavioural challenges.

3) Active listening to the needs of the family will lead to the provision of appropriate and timely support, information and training.

4) People will be supported to have a good quality of life by individuals with the right values, attitudes, training and experience.

5) The NHS and services will proactively plan to ensure that people receive the same range, quality and standard of healthcare as everyone else, making reasonable adjustments when required. People will have an individualised health action plan and be supported to have access to annual health checks to ensure all health needs are met.

6) People and their family carers will receive support and services that are timely, safe, of good quality, co-ordinated and seamless. They will be proactively involved in the planning, commissioning and monitoring of support and services including both specialist and general services.

7) A person-centred approach that enables and manages the taking of risk will be used to ensure that people have access to family and social life, relationships, housing, education, employment and leisure.

8) Local authorities and the NHS will know how many children and adults live in their area and how many they have placed out of area. On the basis of information from person-centred plans all agencies will plan and deliver local support and services.

9) Services will seek to reduce the use of physical intervention, seclusion, mechanical restraint and the inappropriate or harmful use of medication with the clear aim of eliminating them for each individual.

10) All services and agencies will strive to improve continually, using up to date evidence to provide



Executive Summary

'What Good Looks Like' Enter and View Programme

1. Background to Enter and View Programme

Enter and View is seeing and hearing for ourselves how services are being run and allows Healthwatch Derbyshire to collect the views of service users at the point of service delivery. This might involve talking to staff, service users and visitors or observing service delivery.

It is not an inspection; it is about giving patients, service users and the general public a voice, so they can speak up about their care, whether that be praise, criticism or ideas for improvement.

2. Visit Details

Service providers involved in this Enter and View programme, including date and time of visit:

- Bramble Lodge Care Home, West Hallam 27th January 2014, 2.00pm 4.00pm.
- Castle Court Care Home, Swadlincote 10th February 2014, 10.30am 1.25pm.
- Cedar Court Nursing Home (Dementia Unit), Bretby 11th February 2014, 10.30am 12.45pm.
- Dent House Nursing Home, Matlock 3rd February, 11.30am 1.30pm.
- The Leys Care Home, Ashbourne 14th February, 1.30pm.
- Milford House Care Home, Milford 12th February 2014, 5.00pm 7.00pm.
- New Bassett House, Shirebrook 14th February, 10.30am.
- Pendlebury Court, Glossop 7th February 2014, 1.00pm 3.00pm.
- The Risings Home for the Elderly, Glossop 28th January 2014, 3.00pm 5.00pm.
- The Spinney Care Home, Brimington, Chesterfield, 28th January, 9.30am 11.30pm.

3. Authorised Representatives

Enter and View visits are conducted by Authorised Representatives for Healthwatch Derbyshire who are trained volunteers. A full list of our Authorised Representatives can be found on our website at www.healthwatchderbyshire.co.uk.

This programme was conducted by the following Authorised Representatives:

- John Beavis
- Jas Dosanjh
- Madeleine Fullerton
- Amy King
- Holly Pawlitta
- Lesley Surman
- Anne Walker
- Grace Wood



4. Acknowledgements

We would like to thank the staff, residents and visitors we engaged with at the care homes, all of whom welcomed us warmly and with whom we had interesting and informative conversations. Their contribution was most valuable.

We would also like to thank our newly recruited and trained Authorised Representatives who have shown real commitment and dedication to this programme, and a willingness to learn and develop as a result of experience.

5. Disclaimer

Please note that these reports relate to findings found on the specific date and times specified above. They do not represent all service users and staff, only those who contributed within the restricted time available.

6. Purpose

Healthwatch Derbyshire wants to ensure that everyone who lives in Derbyshire, including those who live, work or have friends/family in a care home, get the opportunity to engage with Healthwatch and to have their say about the health and social care services they are receiving.

For the purpose of this programme, we wanted to observe 'What Good Looks Like' within a care home setting. Hence 10 care homes were randomly selected who had been awarded the Derbyshire County Council Bronze Dignity Award.

The purpose of the Enter and View visit was to:-

- Identify examples of good working practice.
- Observe residents and relatives engaging with the staff and their surroundings.
- Capture the experience of residents and relatives and any ideas they may have for change.

7. Methodology

All visits were announced Enter and View visits.

Authorised Representatives conducted short interviews with some of the staff of each care home. Topics such as quality of care, safety, dignity, respecting and acknowledging the resident's and their families' wishes and staff training were explored.

Authorised Representatives also approached residents and their visitors at each of the care homes to informally ask them about their experiences of the home and, where appropriate, other topics such as accessing health care services from the care home may also have been explored to help with our wider engagement work.

A large proportion of the visit was also observational, involving the Authorised Representatives walking around the public/communal areas and observing the surroundings to gain an understanding of how the home actually works and how the residents engaged with staff members and the facilities available. There was an observation checklist prepared for this purpose.



Each visit was approximately $1 \frac{1}{2} - 2$ hours in duration.

8. Findings

All 10 Enter and View reports (each available to view separately on our website at <u>www.healthwatchderbyshire.co.uk</u>) highlighted, in the main, the good practice that we observed and reflected the appreciation that residents and relatives felt about the care and support provided.

The good practice we observed, which was common across the 10 care homes is listed below:

- Staff were friendly, helpful and patient.
- The staff/resident relationship was observed to be positive and supportive.
- There was an open door policy for visitors.
- Residents were generally happy with the food menu.
- Activity programmes were available, good facilities and opportunities existed for the residents to enjoy recreation and social activities, if they so wished.
- Resident's individual needs and wishes were taken into consideration and accommodated.
- The Dignity Principles appeared to be put into practice.
- Residents reported being happy with the service.
- Residents appeared to have choice and control over how they lived.
- Relatives and friends were positive about the care and the welcome they received.
- The homes were well-presented, warm, comfortable and smelt fresh, although some of the homes were in need of refurbishment and renovation.

Areas of good practice that we felt are worthy of a special mention:

- Wet Rooms Cedar Court Nursing Home has converted its bathrooms into wet rooms, which supports residents to maintain their independence for longer around bathing, and takes away the distress some residents experienced using hoists and baths. Residents liked the showers and are now able to wash themselves easily and independently. It started with just one wet room but, due to its popularity, all bathrooms were converted and the site now has only one bath.
- **Dementia Café** Bramble Lodge Care Home has a Dementia Café encouraging residents to reminisce and share memories. This is a very pleasant room which is available to families, friends and residents to meet together in an informal setting, and has a fully equipped serving area.
- Independent Advocacy Service visits Pendlebury Court has use of an Independent Advocacy Service, 'Advocacy Alive', which allows residents to raise concerns with someone independent of the home and have support in dealing with these concerns. The representative visits the home unannounced every two months, talks to the residents and feeds back to the Manager if there are any problems.
- **Dignity Tree** There were a number of ways of encouraging residents to say how they would like to be treated e.g. Pendlebury Court and The Leys did this through the use of a Dignity Tree, i.e. the residents, staff and relatives are all invited to write on a leaf what dignity means to them and stick it on the tree, this information is then used to inform policy and practice. We felt this was a lovely concept and promoted dignity and respect. Cedar Court has also implemented this in their home as a result of Healthwatch Derbyshire sharing this good practice.



Recommendations were low risk and minimal, but included:

- Addressing signage issues, both inside and outside the home.
- Providing information to explain what different coloured uniforms meant, and identification issues.
- Keeping people informed about the future of some of the homes as the uncertainty was causing anxiety and concern amongst residents, relatives and staff.

Additional observations

During our Enter and View visits we picked up a number of comments on the 3 areas below and, as a result, felt they were worthy of further investigation. We therefore consulted all 10 care homes involved in this programme and asked them to comment.

These were:

• **The Bronze Dignity Award** - The majority of care homes in this project felt that the Bronze Dignity Award had raised morale and motivation in their home. They said it gave carers a greater insight into what needed to be done and why.

Many felt proud of their achievement and were planning to go for the Silver Dignity Award in the near future (although some expressed concern about the amount of paperwork needed for this).

Some also said that it had raised their reputation and kudos in the community and staff commented how nice it was to be recognised for good work and that makes them strive for better.

One of the care homes had a 'Dignity Champion Award' for the staff to aspire towards.

A senior officer said, "It provides staff with the opportunity to reflect on their practice and to anticipate people's needs better so that they can be supported safely and with dignity."

When we spoke to a nurse about the Bronze Dignity Award she said, "I've seen so many changes here in the past two years." She expressed a huge amount of praise towards the improvements the home had undergone and expressed a hope that she had personally contributed towards these improvements.

• Access to staff training

This was raised as an issue by a number of the care homes, mainly in terms of the location of the training.

It was stated that Derbyshire County Council (DCC) training is of10 hard to access due to limited numbers available and mainly regarding distance as only a few places are available in South Derbyshire. This is not an issue for some as they have an in-house training programme, but it was an issue for others.

Training in the Glossop area seems to be a big issue, with one member of staff saying that, "Staff training resources have reduced greatly in Glossop, which has meant that staff have either been required to travel to Doveholes, the nearest venue for DCC training, or providers have



been required to provide training in-house. The latter, whilst manageable, does mean that staff miss out on networking and sharing good practice with employees across a range of services."

One of the managers commented that she did, at one point, work very hard to bring training to the Glossop area by joining up with neighbouring homes to ensure numbers were viable for the training to go ahead. It was clear that there was a need. This soon became too much for one individual to co-ordinate and, as soon as the manager pulled away from undertaking this responsibility, training ceased to be delivered in Glossop.

• Hospital Admission and Discharge

Whilst we were exploring relationships with other service providers from the care homes perspective, the issue of hospital admission and discharge was raised. It became apparent that this wasn't always handled well, causing difficulties for the care home and the residents.

Three hospitals were named specifically, Royal Derby Hospital, Tameside Hospital and Queens Hospital, Burton-on-Trent but, it is our belief, that some of these points also relate to Chesterfield Royal Hospital given the location of the care home.

The range of issues identified was as follows:

- Loss of paperwork sent with the residents to hospital, or paperwork not being consulted, resulting in patients being put at risk or being caused distress.
- Discharge information is often poor with limited information regarding any future treatment or care, or there is no discharge information at all.
- Information is inaccurate and at times has been for the wrong resident, including medication and letters sent about someone else.
- Medication isn't correct, sent post-discharge or even incorrect dosage.
- Residents arriving after 8pm at night when the home was advised they would be arriving mid-day or the home not receiving any notice at all that a resident is going to be discharged, so preparations hadn't been made.
- Residents being discharged more ill than when they went in.
- The hospital wanting to discharge a patient with suspected C.difficile before they had received the test results back.
- Transport to hospital appointments being lengthy and hard to organise.
- Residents discharged with clothes and possessions lost and, in one case, wearing only a blanket.
- Medicines and aids or equipment that the home sent the person into hospital with are frequently not returned.
- Due to a problem with the hospital not returning patients medication with them on discharge, one home now sends residents with an individual medicine administration record instead of sending the medication.
- One resident was returned to the care home in an unfit state and had to be returned to hospital because appropriate actions had not been taken to control their diabetes during the discharge period. The resident was found to be in a diabetic coma when she arrived at the home and the manager had to insist the ambulance crew took her back to the hospital.

9. Summary of Findings



- In the main all 10 Enter and View reports highlight the good practice that we observed and reflect the appreciation that residents and relatives felt about the care and support provided.
- There were a number of areas of good practice which were worthy of a specific mention:
 - The Wet Rooms at Cedar Court Nursing Home.
 - The Dementia Café at Bramble Lodge Care Home.
 - The use of the Independent Advocacy Service from Advocacy Alive at Pendlebury Court Care Home.
 - The Dignity Tree's in operation at Pendlebury Court, The Leys and most recently Cedar Court.
- Healthwatch Derbyshire recommendations following on from the Enter and View visit were low risk and minimal.
- There were 3 additional observations made during the Enter and View visits:
 - Firstly that the Bronze Dignity Award appears to have been a key driver in improving standards in Care Homes.
 - Secondly, that access to staff training, especially in terms of the location of the training, is an issue.
 - Thirdly, admission to hospital and the subsequent discharge is causing difficulties for care homes and their residents and is proving to be an area of high risk.

10. Recommendations

- Derbyshire County Council to note the issue regarding availability and location of training.
- All agencies to note the issues stated regarding admission and discharge from hospital, as this is an area of high risk and concern, and needs further investigation. We appreciate that this is a complex area that needs commitment from all agencies involved to achieve resolution.