Health and Well-being Strategy

Priority 6: Dementia

Update Report – August 2013

“I’d like a chance to die like my father did - of cancer, at 86.

Remember, I'm speaking as a man with Alzheimer's, which strips away you're living self a bit at a time.

Before he went to spend his last two weeks in a hospice he was bustling around the house, fixing things.

He talked to us right up to the last few days, knowing who we were and who he was.

Right now, I envy him. And there are thousands like me, except that they don't get heard.

So let's shout something loud enough to hear”

A quote from Terry Pratchett’s Alzheimer Speech 2008
1. Introduction

The Rotherham Health and Wellbeing Strategy sets out the following six key priority areas that will be delivered over the next three years to improve the health and wellbeing of Rotherham people:

Priority One: Prevention and early intervention
Priority Two: Expectations and aspiration
Priority Three: Dependence to independence
Priority Four: Healthy Lifestyles
Priority Five: Long-term conditions
Priority Six: Poverty

This document will focus on the cross – cutting theme of Dementia which has been identified as a key priority for the future provision of services. All partners are expecting an increasing demand over the next 3 years for services to support people with Dementia and their carers. Therefore, it is essential that Health and Social Care Commissioners work in partnership to commission new and innovative services within the increasingly challenging financial environment.

2. Background – What is the problem?

Dementia is now the greatest health concern for people over 55 and the economic cost of dementia is more than cancer, heart disease or stroke. Currently, in Rotherham there are 1688 people on the GP Dementia register compared with a predicted prevalence of 3034. It is estimated that by 2025 the number of people in Rotherham with Dementia will have risen to 4397, an increase of 54% from 2008 (JSNA 2011).

Increased referrals for diagnosis all too often results in an increase in the time people wait for services. As demand increases the challenge for the Health and Social care system will be to ensure the delivery of timely access to services within the financial resources available. This will be a challenge facing Health, Social care and the voluntary sector involved in the delivery of support for people with Dementia throughout the pathway provision.

3. Dementia Diagnosis rates across South Yorkshire and Bassetlaw – How does Rotherham Compare?

Nationally, only about 42% of people with Dementia have a formal diagnosis and too often, diagnosis comes too late. In Rotherham the figure is higher with about 59.9% of people with Dementia having a formal diagnosis, but as national policies require the reduction of undiagnosed Dementia, local rates of Dementia diagnosis will need to
Current, Rotherham has the second highest dementia diagnosis rate as illustrated in table 1.

### Table 1: Dementia Diagnosis rates across South Yorkshire and Bassetlaw

<table>
<thead>
<tr>
<th>Clinical Commissioning Group (CCG)</th>
<th>Diagnosis rate (NDP)</th>
<th>Diagnosis rate (Adjusted NDP)</th>
<th>CCG Diagnosis rate Ambition 2013/14</th>
<th>CCG Diagnosis Rate Ambition 2014/15</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Sheffield</td>
<td>65.81%</td>
<td>66%</td>
<td>67%</td>
<td>70%</td>
</tr>
<tr>
<td>NHS Rotherham</td>
<td>57.75%</td>
<td>59.61%</td>
<td>64.99%</td>
<td>69.99%</td>
</tr>
<tr>
<td>NHS Doncaster</td>
<td>53.58%</td>
<td>56.11%</td>
<td>60%</td>
<td>62%</td>
</tr>
<tr>
<td>NHS Bassetlaw</td>
<td>50.12%</td>
<td>45.31%</td>
<td>55%</td>
<td>60%</td>
</tr>
<tr>
<td>NHS Barnsley</td>
<td>47.18%</td>
<td>45.10%</td>
<td>51%</td>
<td>56%</td>
</tr>
</tbody>
</table>

In line with the national requirements the NHS Rotherham Clinical Commissioning Group (CCG) Quality Premium target and Health & Wellbeing targets require an increase in the Rotherham dementia diagnosis rates by March 2014 to 64.99% and by March 2015 to 69.99%.

### 4. Local Variations in Dementia Diagnosis Rates

The local data collected from the Rotherham GP dementia registers highlights that there is a significant variation in the dementia diagnosis rates across the borough with some practices having dementia diagnosis rates of over 80% whilst others are have diagnosis rates of fewer than 35%. Further work needs to be undertaken to explore why there is such a variation across practices.
5. Dementia Programme Work streams

A review of services across Health, Social Care and the voluntary sector undertaken in 2011/12 highlighted the wide range and variety of services currently commissioned to support people with Dementia and their carers. This configuration of services makes it sometimes fragmented, difficult to navigate, with potential problems arising in the transition of people from service to service and as a consequence they sometimes experience long delays to access services or end up being referred to an inappropriate service.

To address the challenges arising from the anticipated increase in people with Dementia, Rotherham Clinical Commissioning Group, RMBC and key stakeholders agreed to undertake a whole system review of the provision of Health and Social care services across Rotherham. To progress this work the following four groups were established:

- Dementia - Prevention Group
- Dementia – Early Diagnosis Group
- Living Well with Dementia Group
- Dementia and End of Life Care Group

The overall purpose of the groups to review the dementia pathway looking at the following different stages:

- Prevention, Promoting Healthy Lifestyles & Falls Prevention
- Recognise, Screen, Assess & Refer
- Post Dementia Diagnosis, Living Well & Dementia Friendly Communities
- End of Life

6. Rotherham Dementia Pathway

6.1. Prevention, Promoting Healthy Lifestyles & Falls Prevention

This part of the pathway focuses on the prevention of further complications, such as falls, promoting healthy lifestyles for the individual with dementia and their carer as well as working to reduce social isolation and reduce stigma.

What have we achieved?

- The development of a Multi-agency Dementia Prevention Group which has completed a Dementia Prevention gap analysis.
The rollout of the RMBC a Small Grants Scheme. Since its introduction the scheme has awarded 8 grants to support work on dementia.

The delivery of the Rotherham Dementia Awareness Week Event.

What work is ongoing?

- OTAGO Falls Prevention Training delivery through the Dementia Café Programme.
- The engagement of people with dementia & their carers in walking groups to promote physical activity.
- RMBC’s Dementia Champion’s initiative for RMBC employees and those with RMBC contracts.

What do we need to do?

Further work to promote healthy lifestyles for people with dementia and their carers through initiatives, such as:

- Making Every Contact Count – Promoting safe drinking messages to people with dementia & carer alcohol prevention.
- Dementia Café Healthy Lifestyle Awareness - Health Checks, Cook & Eat sessions.

6.2. Recognise, Screen, Assess & Refer

This part of the pathway focuses on:

- reducing unacceptable delays and developing more transparent waiting times
- improving access to services
- enabling the early diagnosis of dementia
• Undertake a review the future capacity, demand and delivery in view of the financial restraints and increasing demand.

What have we achieved?

• Case Finding – As part of the 2013/14 NHS Standard Contract Rotherham Clinical Commissioning Group (RCCG) & The Rotherham Foundation Trust (TRFT) have agreed a programme to screen those over 65 in hospital for Dementia.

• Case Finding - TRFT / RDaSH have agreed a Dementia referral pathway for those individuals identified through the above screening programme.

• The NHS Health Check (40-74) now includes Dementia Awareness.

• The rollout of the QTV Dementia Awareness programme as part of the Rotherham Dementia Awareness Week Programme of events.

• Delivery of the Alzheimer Society Dementia Champion’s training June 2013. This was attended by 12 Rotherham Residents.

• Partners have agreed standardised principles for Dementia Friendly Environments against which they will self-assess their organisations.

• RDaSH have submitted a funding bid for ‘Lighting Scheme for improving well-being, independence & sleep’ to be implemented at The Woodlands Hospitals. **Successful Bid.**

What work is ongoing?

• To continue to rollout the Alzheimer Society’s Dementia Champions & Dementia Friend Training across the district.

• To continue to rollout the Dementia Friendly Environments Initiative programme across Rotherham.

• The rollout of the TRFT Dementia Friendly Environment & Dementia Champions programme.

• The rollout the 2013/14 Dementia Quality Outcomes Framework (QOF) a national
To develop a Voluntary Sector Led Rotherham Dementia Alliance.

**What do we need to do?**

- To develop and agree standard Dementia Coding across Rotherham practices. Once this has been agreed a guidance document for primary care will be developed.

### 6.3. Post Dementia Diagnosis, Living Well & Dementia Friendly Communities

This part of the pathway focuses on:

- Supporting people with Dementia to live in community settings and maintain their independence for longer by developing high-quality, compassionate community care.

- To ensure Provider Medication policies are in line with Contract requirements.

- The reduction of inappropriate admissions to hospital by providing better community support, such as specialist services and carers support.

- To ensure that people with Dementia do not stay longer in hospital than those without Dementia.

- The reduction in the delay discharges experienced by people with Dementia.

- To improve carers support and quality of life (reduction in carer fatigue).

**What have we achieved?**

- Anti-psychotic Register established by RDaSH.

- Reduction of the use of anti-psychotics in Rotherham from 18 – 10% during 2012/13.

- TRFT Pre-discharge check list for antipsychotic medication in place.

- Dementia Café procurement undertaken and awarded.

- RMBC Bronze to Platinum Dementia training programme in place.
What work is ongoing?

- Rotherham CCG and RDaSH are working to develop a Memantine shared-care protocol.
- Rotherham CCG and Crossroad are undertaking a review of the service in place to increase a more flexible and personalise approach to carers respite care.
- Work to standardisation Patient & Carer Information across organisation.
- The Social Prescribing Project has awarded funding to the Expert Patient Programme to enable them to deliver the ‘Caring with Confidence’ course. Funding has also been awarded to Crossroad to provide respite care to release carers to attend the ‘Caring with Confidence’ course.
- TRFT is currently rolling out a programme of Dementia training across its workforce.
- Develop an Adult Mental Health Liaison Service.

What do we need to do?

- To undertake the Anti-psychotic Nurse-led reviews across Care Homes. This initiative has struggled to recruit to the post and as a result has been delayed.
- To engagement Primary care service in the Bronze to Platinum Dementia training provided by RMBC.
- To further work to eliminate areas of duplication across the pathway.
- Develop & redesign services to promote independence and help people with dementia to live within the Community for longer.
- Improve carers support and quality of life (reduction in carer fatigue).
6.4. End of Life Care

The focus of this part of the pathway is to ensure the End of Life Care (EOLC) pathway meets the needs of people with Dementia.

What have we achieved?
- Stakeholder End of Life Care (EOLC) Event Held attended by partners from across the district.
- An EOLC Multi-disciplinary Group established & Action plan in place.

What work is ongoing?
- Work is underway to establish an EOLC Register across the borough. Initial GP pilots have been completed and the wider rollout of the register across the borough is due to commence.

What do we need to do?
- Further work needs to be undertaken to ensure the End of Life Care pathway meets the needs of people with dementia.

6.5. What can the Health & Wellbeing Board do to support the programme
- Continue the dementia workforce development programme
- Strong leadership to break down barriers on joint working
• Continue to support the further development of the dementia pathway
• Support the development of a Dementia Friendly Community in Rotherham

6.6. Final challenge

Why not join the Prime Minister’s Challenge and become an Alzheimer Dementia Champion or Dementia Friend and help build a Rotherham Dementia Friendly Community.

Dementia Friends is about giving more people an understanding of dementia and the small things that could make a difference to people living in the community.

To find out more go to the Alzheimer Society website on