



Report to Healthier Communities and Adult Social Care Scrutiny & Policy Development Committee

12th September 2012

Report of: Richard Webb, Executive Director, Communities

Subject: Transforming Support for People with Dementia who live at Home – an Involvement Exercise

Author of Report: Howard Waddicor, Commissioning Officer, Communities 0114 2057103

Summary:

This report is a summary of the responses to the Dementia Involvement Exercise undertaken from June 2012 to August 2012.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	X
Informing the development of new policy	
Statutory consultation	
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Community Assembly request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	X
Other	

The Scrutiny Committee is being asked to:

- Scrutiny is asked to comment on the themes identified and recommend others to be included in the Cabinet report

Background Papers:

List any background documents (e.g. research studies, reports) used to write the report. Remember that by listing documents people could request a copy.

Category of Report: OPEN

Report of the Director of Communities – Richard Webb

Transforming Support for People with Dementia who live at Home – an Involvement Exercise

1. Introduction

- 1.1 Sheffield has a long established, multi-agency Dementia Programme Board chaired by Richard Webb, Executive Director (Communities) with representation from Sheffield City Council, NHS Sheffield, Sheffield Health and Social Care Foundation Trust, Sheffield Teaching Hospitals, Dr Steve Thomas as the CCG Dementia lead and the Sheffield Alzheimer's Society. Its function is to deliver on the National Dementia Strategy (2009) built on by the Prime Minister's Challenge launched in March 2012.¹
- 1.2 To inform some of the changes needed to modernise the support for people with dementia who live at home, a report was submitted to the Sheffield City Council Cabinet on 26th May 2012 seeking approval to engage in a three month involvement exercise.
- 1.3 The purpose is to understand the key issues for people affected by dementia in order to plan support for the future. The growing number of people with dementia represents a significant issue for the city. The existing support arrangements will not meet the increase in demand or the changing expectations of people with dementia
- 1.4 This report draws together some of the emerging themes which will form the basis of a Cabinet Report on 26th September 2012 and sets out the next steps.

2. What did we ask?

- 2.1 The exercise began on 1/6/2012 and will finish on 31/8/2012. The key questions were:
 - How can Sheffield communities better understand the needs of people with dementia so that living at home is a safe and positive option?
 - What types of support work best for people with dementia living at home?
 - What are the features of good support for carers of people with dementia?
 - How can we facilitate change but protect existing users of services?
 - How can health and social care providers work closer together for the benefit of people with dementia?
- 1.2 Responses were sought from:
 - People with dementia
 - Carers of people with dementia
 - Providers of support

¹ [Prime Minister's challenge on dementia](#), DH, March 2012

- Community groups and organisations
- Other interested parties including NHS Sheffield, housing providers, the wider council and the voluntary community and faith sector

1.3 A range of activities were used to engage people:

- A carers' event was held on 31/7/12 at the Town Hall attended by over 50 carers. This has produced a significant amount of information, much that could have been predicted, but a number of important suggestions and comments on how services should be delivered.
- On Tuesday 21/8/12 a 'Talk to Us' day was held at the Showcase Sheffield exhibition centre, a shop-front on the corner of Pinstone Street and Cambridge St. inviting responses from
- Sheffield Alzheimer's Society has undertaken to work with a group of people with dementia and produced a report about their specific views.
- A postcard has been co-produced with carers inviting people to suggest ways in which Sheffield can lead the way in becoming a dementia friendly city by 2015 (see **Appendix A**)
- There have been specific meetings with a range of providers to invite comments from their perspective about what works
- A number of visits have also been made to carers who were unable to attend events
- All stakeholders have been invited to produce written responses to the 5 questions.

3 What does this mean for the people of Sheffield?

- 3.1 To help understand what the response means for future investment in dementia services representative contributions have been ordered in **APPENDIX B** into the different levels of social care investment. These levels reflect the intensity and cost of delivering support. Broadly Levels 1 and 2 and 2b include those support services that help people (including carers) before they have an eligible social care need. Level 3a delivers support to people who live at home including specialist interventions. Level 3b is for those people in care homes.
- 3.2 The responses summarised below in general emphasise the need to increase investment in a wider range of support for people with dementia in the early and middle stages to make sure that people have the best chance of living well at home.
- 3.3 Through better support for people at home we should successfully delay, or prevent, the need to fund more expensive support for people at Level 3b (care homes). Currently by far the biggest proportion of funding is at Level 4. A relatively modest shift in the proportion of people supported at this level would similarly enable an increase in the proportion of funding at the lower Levels 1, 2a and 2b.
- 3.4 What came through very strongly was that whilst this shift can reduce admissions to care homes it support needs to be maintained for the relatively small proportion of people with the most complex needs at home. This refers to those people, some of whom are currently

supported by the resource centres, who are most at risk of admission to a care home (Level 3a).

3.5 Key themes emerging included:

Levels 1 and 2 and 2b

- The importance of creating a **dementia-friendly city**. Whilst health and social care support is crucial to living well, people with dementia and their carers also live in communities which need to better understand the issues they face. This is particularly important in the early stages when people still want to do the things that they have always done.
- There is a clear view that there is **no single answer** to what is right for people with dementia. The experience of dementia and the resources each individual has to manage varies which means that a range of support opportunities is required.
- **Early diagnosis** is crucial and early access to support to help plan for the future is something most people recognise, often with hindsight, is valuable.
- There is too little **information** for people about what is available and what might help. It was also recognised that people need help understanding what the right kind of support is.
- Providing opportunities for **carers** to have a break – both planned and in a crisis - enables them to live their own lives and be confident about the support offered to the person with dementia. In addition all those involved with the person with dementia need to understand the emotional impact on the carer and take time to acknowledge that.

Level 3a

- Improving the way **health and social care** and other public services work together to support people to live at home can improve the experience of people with dementia. This applies especially to people with dementia discharged from hospital to make sure they are safe and that the levels of community support is adequate to sustain them.
- It was very clear that people with more **complex needs** should have access to the right amount of individualised support, using community resources, alongside an integrated range of more formal health and social care interventions. This was viewed as vital to reduce the likelihood of admission to a care home or hospital. The key message is that the support for this group should have the same personalised approach but be delivered by skilled staff in settings that are appropriate to their needs. Not everybody who was at this level was able to be supported through the existing resource centre model.

- **Home support** providers even specialist support, seem to lack the skills and understanding of how to support people with dementia. Particular concern was raised about those people who live alone.

Level 3b

- **Care Homes** Though not specifically part of the exercise, views were expressed about the support that people have received in residential and nursing care. Though many found the support good there was evidence of inconsistencies and a lack of skill in supporting people with dementia – even in specialist units.

3.6 Similarly, views were expressed about services that are the responsibility of NHSS / Clinical Commissioning Group (CCG). People reported the need for improvements in:

- The level of **understanding in primary care** about the impact of dementia. Many respondents highlighted the role that particularly GPs have in prompt referral to the memory service and the subsequent support for the patient and any carer.
- Some people reported **delays** following referral to the memory service although many reported positively on the support they received both during and after diagnosis.
- Many carers recounted very difficult and distressing experiences for people with dementia in **hospital**. In particular they expressed concern about a lack of tolerance and understanding of the way in which dementia affects people.

4. What will happen next?

- 4.1 The results will be analysed in more detail and the implications for existing investment in dementia services will be considered including opportunities for joint commissioning with NHS/CCG.
- 4.2 An outline plan for how services will be changed will be drawn up and included in a report to Cabinet on 26th September 2012. This will include any comments made by Scrutiny

5. Recommendation

- 5.1 Scrutiny is asked to comment on the themes identified and recommend others to be included in the Cabinet report

Howard Waddicor
 Commissioning Officer
 August 2012

APPENDIX A: Dementia Friendly City Postcard



Sheffield Leading the Way - a dementia friendly city by 2015



Tell us what a dementia friendly Sheffield looks and feels like by 2015 in words or pictures:-

NO STAMP
NEEDED

Freepost NEA5527
Quality & Development Team
Corporate Mail Facility
Town Hall
Sheffield
S1 2ZZ

“ I have dementia... but I also have a life ”

For more information please visit www.sheffield.gov.uk/dementia
or contact Howard Waddicor, Phone: 0114 205 7130
Email: practicedevelop@sheffield.gov.uk

03/12/14

Alternatively, return to us in person: Main Reception,
Redvers House, Union Street, Sheffield S1 2JQ

APPENDIX B: Key Themes Identified

Level	Types of support	People with dementia	Themes emerging
1. Promoting lifelong health and wellbeing	<ul style="list-style-type: none"> • Support for everyone. • Building personal and community resilience • Public Information. 	<ul style="list-style-type: none"> • Awareness campaigns • Stroke reduction campaigns 	<ul style="list-style-type: none"> • Dementia Friendly Communities can make a difference but this will be a long term impact – less relevant for people with dementia now • Importance of awareness for all – individuals carers and professionals – especially in primary care • Dementia Alliance would be welcomed – anything that gets people to understand the needs • Early diagnosis crucial – especially important for early onset dementia. Helps people make adjustments and plan for the future. It gives people access to anti-dementia medication • Using ‘well- being’ cafes (similar to Muslim Elder Support Projects) is a way to share healthy lifestyle information and reduce vascular dementia • Organisations like banks often unhelpful to people who forget passwords or where one partner loses capacity to manage finances and will sometimes refuse to deal with carers • “Increasingly organisations, including Sheffield City Council, require people to conduct business online, or in person. This presents barriers to people with dementia and others. There is learning here from some utility companies such as British Gas who have established a vulnerable people team that can respond flexibly and sensitively”

Level	Types of support	People with dementia	Themes emerging
<p>2. Early, short term, or one off interventions promoting recovery and independence</p>	<p>a) Community based Support for people who are close to needing significant support.</p> <ul style="list-style-type: none"> • Investment in third sector and community organisations. • Self Help • Specialist advice and information • Carer support • Befriending • Assistive technology • Lunch clubs 	<ul style="list-style-type: none"> • Dementia Cafes • Dementia Adviser service • Peer support • Link to primary care to support post diagnosis 	<ul style="list-style-type: none"> • Dementia cafes are well regarded. Key features are the peer support and the availability of experienced, thoughtful staff who can help advise informally. • Question about whether there should be cafes solely for people with dementia? • Caring and Coping, Coping with Forgetting are valuable in terms of understanding and managing but also create basis for peer support - Needs to be available for all – waiting lists are too long • Proactive information, advice and support crucial. The Dementia Adviser service could be a basis for local model. To cope with increasing rates of diagnosis there needs greater investment • Blue Badges for people with dementia? – the criteria is not currently not clear but people with dementia are not excluded • Carer's need information about what is available. The type of information they require varies depending on their own circumstances and level of need • The needs of the carer and the person with dementia are not always the same but the carer needs to be sure that the person with dementia is safe and is getting the right support. • Flexible, personalised services that respect individual difference are fundamental. There is no one solution • Dignity and respect should be at the heart of all interventions • Admiral Nurses – a helpline available online and via telephone. There is a debate to be had about whether Sheffield would benefit from the service • 'Singing for the Brain' and 'Lost Chord' work well for people who find other forms of communicating difficult • Carer breaks fund help carers decide what support they need • Accurate and early information about contributions to the cost of services help people make decisions • The 'Help Yourself Directory' is a good source of information for people at all stages

Level	Types of support	People with dementia	Themes emerging
	<p>b) Acute or specialist</p> <ul style="list-style-type: none"> • Short term or intensive support. • Reablement. Equipment and adaptations 		<ul style="list-style-type: none"> • Long delays were reported in the social care assessment process • Some expressed concern that self-directed support may exclude people with dementia. Some carers reported that it could be onerous at a time when support should be timely. Others welcomed the opportunity but found it more problematic as an individual's capacity to choose diminished. • There is a concern that support planners lack specialist knowledge • Joined up working health and social care is – access to Rapid Response Team and CPNs • Responses to crises need to be better co-ordinated and if need be truly rapid if admissions to care are to be avoided • Avoid too many people being involved – co-ordinate care better • Crises can be avoided by effective contingency planning • Home support, even specialist services, seem to lack the skills and understanding of how to support people with dementia. Particular concern was raised about those people who live alone.
<p>3. Medium to long term care and support focused on stability and quality of life</p>	<p>a) Community based</p> <ul style="list-style-type: none"> • Personal Budgets. • Medium to long-term assistance to continue living at home. • Home support • Day opportunities 		<ul style="list-style-type: none"> • Resource centre model works well for people with most complex needs, though not everybody wants this. • People value the skills offered by resource centres – they say that for some people the private sector cannot offer the same level of care • Can the private sector be trusted to deliver the quality of support? • People need good care not just en-suite facilities • Consistent care – familiar faces make a difference to the wellbeing of people with dementia • Not all support should be in day centres or respite care – some people do not want that or say that the experience only adds to their confusion and distress • “My dad would hate to go to a day centre but my mum needs a break”

Level	Types of support	People with dementia	Themes emerging
	b) Acute (or away from home) <ul style="list-style-type: none"> • Medium to long-term 24 hour assistance to live safely. • Residential and nursing care. 	Residential and Nursing care	Concern about the skill levels in some care homes