Leeds CITY COUNCIL

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Report of: **Director of Adult Social Care**

Report to: **Scrutiny Board – Health and Well-being and Adult Social Care.**

Date: **Wed 25th July 2012**

Subject: ***Living Well With Dementia In Leeds* – draft local dementia strategy**

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☒ Yes	☐ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☒ No

Summary of main issues

1. It is a national policy priority to improve services and quality of life for people with dementia and carers, most recently stated in *The Prime Minister's Challenge On Dementia* (Department of Health, March 2012). The local NHS and the Council have produced a draft strategy document, to outline the local response to the needs of the Leeds population and national policy priorities. This is *Living well With Dementia In Leeds*, which has been published in draft to give the opportunity for local people and organisations to comment, shape and influence local action.

2. Leeds City Council has responded positively to the call for dementia-friendly communities, issued in March 2012 by the Department of Health and Alzheimer's Society. Early steps towards this goal are covered in the strategy document.

3. The strategy document is based on the 'dementia journey': public awareness, early detection and diagnosis, early support, living well as dementia progresses, and end-of-life care. The document covers the different settings where people with dementia may have care and treatment. It addresses themes which are relevant throughout the dementia journey - long-term support, carer support, and the workforce.

Recommendations

4. Scrutiny Board is asked to:
   - Note the publication of the draft strategy.
   - Consider its response to the draft strategy and role in relation to improving services.

1 Purpose of this report

1.1 To inform members of the Scrutiny Board of the proposed steps to improve services and quality of life for people with dementia, families and carers.

1.2 To seek the response of Scrutiny Board to the information and proposed priorities.

2 Background information

2.1 Leeds has made considerable progress over the past 10 years to develop new services and improve the experience of older people with mental health needs, including dementia. In particular, there were significant new developments under the programme which ran from 2006 – 9 funded by the Department of Health (DH) under its Partnerships for Older People's Projects (POPPs); and a Peer Support Service initially supported by the DH as a demonstrator site under the National Dementia Strategy. These new services have reduced lengths of stay and improved outcomes for older people in hospital; and improved the early experience of support post-diagnosis for people and families. The new services have all been sustained by the Council and local NHS.

2.2 However, there remain gaps in provision, and the strategy highlights local commissioning aspirations to address this. Action is required to transform services towards early intervention, maintaining health and well-being, and thereby reduce costs of future care; and to meet the dementia quality standard developed by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE).

3 Main issues

3.1 Improving public awareness and reducing the stigma around dementia is an important starting point to encourage people to understand the condition and seek help with concerns.

3.2 Diagnosis of dementia is the exception rather than the rule. The number of people diagnosed on GP registers, (c. 4,000) is less than 50% of the expected numbers in the population (8,400). This is in line with the national picture. Awareness and education of GPs is important to make progress, and the three Clinical Commissioning Groups (CCGs) in Leeds have started to take action via their 'Target' training programmes.

3.3 Leeds has very good examples of early support for people and carers. There are 18 dementia cafes, 3 carer support groups, Leeds Peer Support Network, and a range of activities run by the local Alzheimer's Society and Neighbourhood Networks – such as 'Singing for the Brain' and reminiscence. The aspiration is to sustain and expand these activities.

3.4 It is proposed as an aspiration to improve support throughout the dementia journey, so that people with dementia, families and other unpaid carers have a named contact for information and access to support and expertise. It is envisaged that this would work as part of integrated health and social care

arrangements, for people who have other long-term conditions and physical frailty alongside dementia.

3.5 A particular challenge is to develop a systematic approach to workforce development, across all local NHS Trusts, and the statutory, private and voluntary sector providers of care and support for older people. This is the key to improving quality of care in hospitals, care homes, and with people living at home.

3.6 People with dementia can benefit from personalised approaches which address the individual needs arising from each person's personality, life history and the progress of the condition. There are good local examples of people benefiting from individual budgets, and the next step is for this approach to become widespread.

3.7 Local specialist palliative care services have led the way to improve access for people with dementia and other long-term conditions, and there has been a steady increase in recent years in support with people who do not have cancer, but have eg. dementia, heart failure, kidney failure, motor neurone disease. For people with dementia and families, it can be very helpful to take the opportunity to plan ahead and state one's wishes at an early stage in the condition, before one's mental capacity and communication abilities are impaired.

4 Corporate Considerations

4.1 Consultation and Engagement

4.1.1 The strategy is in draft and open for comment and engagement until the end of September 2012. There are not at this stage specific proposals for service changes, and any such proposals emerging from the strategy would require formal consultation.

4.1.2 The draft itself has been written following initial engagement with partner organisations, comment from the Leeds Integrated Dementia Board, and includes content from the Leeds event held during dementia awareness week on 23rd May 2012.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 Older people in Leeds play an important part in the economic, social and community life, as eg. leaders, entrepreneurs, volunteers, grandparents and carers. Dementia is a condition that is more prevalent with age, but should not be allowed to stigmatise older people, or people living with mental ill-health.

4.2.2 *Living Well With Dementia In Leeds* is intended to address the diverse needs of the whole community affected by the condition, including families, neighbours and friends of people with the condition. The main risk factor for dementia is ageing, and therefore is more prevalent in areas with longer life expectancy. These are generally the least deprived and more rural areas surrounding the city. This in turn gives rise to needs for access to information and access to services associated with rural areas.

4.2.3 There is some evidence that people in more deprived areas are, at any given age, more at risk of dementia. This might be linked to vascular dementia, which can affect people with cardio-vascular disease.

4.2.4 People with learning disabilities, particularly people with Down's Syndrome, are at risk of dementia, and other conditions linked to ageing, at a younger age. As health and life expectancy improve, we expect to find more people with both learning disability and dementia.

4.2.5 Older people from black and minority ethnic (BME) populations are affected by dementia, and may require services that respond to cultural needs. For example, providers of reminiscence activities need to recognise that communities may have specific s life experiences, and not assume that all cultural and historical events are universally shared experiences. Leeds Irish, Jewish and some eastern European communities are ageing groups within the population. Most people of Caribbean and south Asian origin came to the UK more recently and the numbers of older people are expected to increase significantly in the coming years.

4.2.6 Therefore it is likely that proposals and plans emerging from the strategy will have implications for equality and diversity, and will be subject to equality impact assessment as required.

4.3 Council policies and City Priorities

4.3.1 Leeds has announced its commitment to becoming a dementia-friendly city. The Executive member for adult social care and the Chief Executive both addressed a local dementia event on 23rd May.

4.3.2 The *Better Lives* programme within the Department of Adult Social Care will address the needs of people with dementia and carers, for example in the support for social enterprises to develop personalised services; development of extra-care housing; ensuring an integrated approach to dementia with NHS colleagues as part of developing support for older people with long-term conditions.

4.3.3 A dementia needs analysis is planned, as part of developing the Joint Strategic Needs Assessment (JSNA). The draft strategy includes specific areas which this will cover and what the information will tell us to improve the strategy and plans.

4.4 Resources and value for money

4.4.1 There are no specific expenditure proposals in the strategy document. It is hoped that the commissioning aspirations will lead to investment in new services, based on the ambition to transform health and social care and reduce future care costs.

4.4.2 To minimise costs whilst ensuring access, the strategy document is published online and printed copies are available on request.

4.5 Legal Implications, Access to Information and Call In

4.5.1 The draft strategy does not itself constitute a key or major decision, but may give rise to key and major decisions in future. These will be addressed according to Council procedures as they arise.

4.6 Risk Management

4.6.1 The demographic growth in the number of older people in Leeds, means that the number of people with dementia in Leeds is expected to increase by 40% in the next 15 years, from an estimated 8,400 to over 12,000. This means that to do nothing is likely to lead to a corresponding increase in service costs. The strategy is intended to reduce this risk by prioritising early detection, diagnosis and support, and maintaining well-being as far as possible throughout the dementia journey.

4.6.2 There is a reputational risk to publishing a strategy at an early stage in development, without a specific action plan and investment proposals. However, stakeholders may also welcome the opportunity to comment and discuss the strategy at an early stage.

5 Conclusions

5.1 Dementia has been identified as a national and local priority, *and Living Well With Dementia in Leeds* summarises our local response. It will develop in response to comment and discussion on the draft, and an action plan will be published with the strategy late in 2012, to implement our local priorities.

6 Recommendations

6.1 Scrutiny Board is asked to:

- Note the publication of the draft strategy.
- Consider its response to the draft strategy and role in relation to improving services.

7 Background documents[1]

- *Living Well With Dementia In Leeds* – draft strategy document.
- *Consultation questionnaire*
- Short questionnaire for people with dementia and families.

All available at www.leeds.nhs.uk/consultations .

[1] The background documents listed in this section are available for inspection on request for a period of four years following the date of the relevant meeting. Accordingly this list does not include documents containing exempt or confidential information, or any published works. Requests to inspect any background documents should be submitted to the report author.