

Leeds Health & Wellbeing Board

Report author: Tim Sanders
Tel: 0113-247-8923

Report of: Director of Adult Social Services and Clinical Director, Leeds North Clinical Commissioning Group

Report to: Health and Wellbeing Board

Date: Wednesday 22nd May 2013

Subject: Living Well with Dementia in Leeds – our local strategy 2013-16

Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

Summary of main issues

Living Well with Dementia in Leeds: Our local dementia strategy 2013-16 has been prepared by the Leeds Integrated Dementia Board. It collates a wide range of information and evidence about needs and services, and sets out a shared purpose and priorities. It has been co-produced with a wide range of partner organisations.

The local strategy is complemented by an action plan. Recent progress includes significant additional investment in memory services from 2013-14, to reduce waiting times, increase the number of people diagnosed, and improve post-diagnosis support.

“Dementia-friendly communities” is an initiative to promote positive attitudes and access to services in everyday life, beyond health and social care. The report considers the potential role of the Health and Wellbeing Board to promote dementia-friendly Leeds.

Recommendations

The Health and Wellbeing Board is asked to:

- Consider the strategy and its priorities, and support it as a basis for co-ordinated action across all local agencies which support people with dementia and carers.
- Sponsor the formation of a Leeds Dementia Action Alliance to promote positive attitudes and accessible services throughout local communities, businesses and service providers.
- Comment on the development of the actions to deliver the strategy, including the opportunities offered by other health and well-being initiatives.

1. Purpose of this report

- 1.1 To give an overview of the strategy document, *Living Well with Dementia in Leeds: Our local dementia strategy 2013-16* (summary at Appendix 1, full document at Appendix 2).
- 1.2 To describe how the strategy will be promoted and published alongside its action plan (Appendix 3).
- 1.3 To explain the rationale for setting up a Leeds Dementia Action Alliance, and invite Health and Well-Being Board to sponsor this initiative.
- 1.4 To show how the strategy and action plan will contribute to the objectives of Leeds Joint Health and Wellbeing Strategy.

2. Background information

- 2.1 The Department of Health Mandate to the NHS Commissioning Board (NHS England) includes a clear statement of the government's goal, *that the diagnosis, treatment and care of people with dementia in England should be among the best in Europe*. It asks NHS England to work with Clinical Commissioning Groups to make measurable progress by March 2015, *driving significant improvements in diagnosis of dementia*. Furthermore:

*because people with dementia, their carers and professionals rightly need to feel confident that a diagnosis of dementia will improve the lives of people with the disease, the Board should work with CCGs to support local proposals for making the best treatment available across the country.*¹
- 2.2 The strategy document was produced by engaging with people with dementia and carers, local NHS trusts, social care providers, voluntary and community organisations, social enterprises and other statutory bodies. Appendix 4 shows a list of those who contributed, either at engagement events or in writing. The views contributed by people with dementia and carers were important, and are evident in the strategy document, but the numbers of people were small, and the strategy includes working with Leeds Involving People to improve participation and influence.
- 2.3 The strategy gives an overview of local services involved along the “dementia journey” and brings together a wide range of policy and evidence. Feedback on the draft document indicated that people found it useful to have the descriptive local information.
- 2.4 The national Dementia Action Alliance (DAA) was formed in 2011, supported by the Alzheimer's Society. The Yorkshire and Humber Regional DAA was launched in Leeds in November 2012. These bodies support larger-scale initiatives, and enable shared learning with other places with the commitment to become

¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127193/mandate.pdf.pdf
paras. 2.10 – 2.12

dementia-friendly. Understanding what works well is important at this stage, when practical action is required to achieve an aspiration. The local DAA will use the same sign-up and action planning arrangements as the national and regional groups, but focus on local businesses, organisations and community groups.

3. Main issues

- 3.1 The following paragraphs are a summary of the strategy and action that is already in progress. The introduction proposes a shared vision and sets out demographic information about numbers of people with dementia and the expected growth in numbers. It emphasises a positive approach to growing older, in line with the Leeds *Ageing Well* principles². It proposes a person-centred view of living with multiple health needs, because it is estimated that 90% of people with dementia have other physical and mental health conditions.
- 3.2 The strategy describes a co-ordinated approach to improve awareness, diagnosis, and post-diagnosis support. This illustrates the value of a multi-agency approach, to ensure that the many initiatives to identify and refer people with possible dementia, do not lead to increased waiting lists, or to people with a diagnosis but little help as a result. An additional £400K has been allocated to increase capacity of the Leeds memory service during 2013-14, and the new posts are now being advertised. In the past year there have been new investments to develop further dementia cafes and pilot new activities such as singing groups and creative arts.
- 3.3 Leeds made the commitment to become a dementia-friendly city in March 2012. The “Tea-Cosy” dementia café at Rothwell and Otley Town Council have launched local dementia-friendly campaigns. Practical steps have included awareness raising talks to supermarket staff across Leeds and a Rothwell neighbourhood policing team. The local networks include bus operators, retailers and a leading provider of dementia-friendly signage. Funding has been identified to co-ordinate and support a Leeds Dementia Action Alliance, so that local groups and businesses can have support to develop plans and share learning, and to increase the profile and activity of the campaign.
- 3.4 It is proposed that a Leeds Dementia Action Alliance would be the best way to attract and involve people and organisations, who can contribute to Leeds being “dementia-friendly”; to publicise good initiatives and campaign to change attitudes and promote awareness. It is an opportunity for Leeds Health and Wellbeing Board to demonstrate its role within the wider community as well as health and social care.
- 3.5 Although dementia only accounts for approx. 3 - 4% of people with long-term conditions in Leeds, it is associated with a much higher proportion of care costs. It is estimated that 80% of people in care homes, and 25% of people in hospital, have dementia, alongside other long-term conditions. The Care Quality

² http://www.healthycities.org.uk/uploads/files/a_framework_of_principles_for_ageing_well_final.pdf

Commission have identified that: *the increasing complexity of conditions and greater co-morbidities experienced by people are impacting on the ability of care providers to deliver person-centred care that meets individuals' needs.*³ The Leeds Integrated Health and Social Care programme is therefore supporting a project to improve the capacity of community health and social care staff to work with people with dementia. There are already mental health liaison services available to support people in care home and hospital settings, and the strategy identifies that a similar approach – linking specialist mental health services to primary and community care - is key to meeting people's needs at home.

- 3.6 Families and carers say that they wish to have better information, covering the impact of dementia, how the condition may progress, and about local services. The strategy describes the emotional and physical demands which particularly affect carers of people with dementia, and lead to needs for a diverse range of services for support and breaks. Carers Leeds have started offering the Alzheimer's Society's "Carers' Information and Support Programme" (CrISP) and have been given additional funding to cope with the demand. In 2011-12, £300K was allocated to increase home-based carer breaks.
- 3.7 All health and social care providers are responsible for ensuring that people with dementia receive care and support from staff who are appropriately trained⁴. Leeds Teaching Hospitals Trust have developed a three-tiered approach, which offers basic awareness training to eg. ward clerks and porters; training in person-centred care for nursing and health care assistant staff; and a leadership level. There are more than 90 older people's care homes and 30 domiciliary care providers in Leeds, and it is a particular challenge to ensure that the sector offers a consistently high standard of dementia care.
- 3.8 Dementia often causes a person's well-being to deteriorate faster than the progress of the underlying organic condition. For example, the condition can lead to loss of confidence to go out, or the ability to carry out the sequence of steps to make a snack or cup of tea. Communication difficulties can cause frustration, isolation or boredom. This means that there are opportunities to promote living well with dementia even if the condition itself cannot be treated. Local projects to develop eg. reminiscence, creative arts and reading aloud are being supported with short-term funding and / or working together to obtain external funding. Increased investment has been sustained for the care homes mental health liaison to promote education and training for care home staff, and a preventive approach, alongside responding to more urgent needs. A local guideline is being developed to avoid inappropriate use of anti-psychotic medication and increase awareness of services that can reduce agitation and aggression.
- 3.9 People with dementia too often suffer indignity from the assumption that one cannot participate in decisions and make choices; and opportunities are missed

³ *The State Of Health And Adult Social Care In England*

http://www.cqc.org.uk/sites/default/files/media/documents/cqc_soc_201112_final_tag.pdf

⁴ <http://publications.nice.org.uk/dementia-quality-standard-qs1/quality-statement-1-appropriately-trained-staff>

for people to consider “advance decisions” about care and treatment at the early stages of dementia. Making advocacy services available at key points in the journey – eg. after diagnosis, or after a care home admission - could promote individual rights, and avoid some unnecessary admissions to hospital near to end-of-life. Traditional service provision, based on specific tasks at predetermined times, is often too inflexible to meet needs. A small number of people with dementia in Leeds are benefitting from the flexibility of an individual budget to purchase social care, supported by Leeds Centre for Integrated Living. Increasing access to more flexible support, and to advocacy services are identified as priorities.

- 3.10 Leeds Teaching Hospitals Trust is improving personalised care by use of a “Know Who I Am” document which staff complete with the person and family; and seeking to improve carer support and ward environments. The trust has achieved the national target for screening, assessing and onward referral of people with possible dementia; and from April 2013 there are further incentives for staff training and a monthly audit of whether carers felt supported during hospital admissions.
- 3.11 Specialist mental health services in Leeds have undergone significant changes in the past year. Leeds and York Partnership Foundation Trust is training its community teams that work with adults, in dementia and the mental health needs of older people; improving the care environment for inpatients at The Mount; and developing the new capacity in memory services and care homes liaison, as described above.
- 3.12 The older people’s care home sector is, increasingly, caring for people with dementia, often alongside other long-term conditions and frailty. Leeds care homes are now working to a new service specification and quality standard, which incentivises care quality with the payment of a higher weekly fee for Council-funded residents, when set standards are achieved. This approach aims to reward investment in eg. staff training. Improved confidence and capability for dementia care will reduce hospital admissions and other care costs.
- 3.13 Care at the end of life must not be overlooked as an important service for people with dementia. It can itself be a terminal condition and main cause of death; or people may die with dementia when the primary cause is another health condition. The early stages of dementia may be, with the right help and sensitive conversations, be a good opportunity to prepare for the later stages, eg. with advance decisions, making a lasting power of attorney. Specialist palliative care services are developing a clinical guideline to detect and manage symptoms such as pain and nausea, with people who may not be able to communicate well, or co-operate with treatment.
- 3.14 It is proposed to create a Leeds dementia page on www.leeds.gov.uk to publish the strategy and action plan, and to update the action plan as progress is achieved and new actions and investments are agreed.

- 3.15 The strategy and its action plan will therefore contribute to the Leeds Joint Health and Wellbeing Strategy, in particular to the following outcomes:
- People will live full, active and independent lives
 - People's quality of life will be improved by access to quality services.
 - People will be involved in decisions made about them.
- 3.16 The summary document (Appendix 1) includes dementia-specific indicators and examples of health and well-being strategy indicators where a dementia 'sub-set' could potentially be used to monitor progress.

4. Health and Wellbeing Board Governance

4.1 Consultation and Engagement

- 4.1.1 The strategy has been overseen by the Leeds Integrated Dementia Board, which includes a CCG representative, all local NHS providers, adult social care, third sector and private provider representatives. The first draft of the strategy was influenced by the "Better Lives For People With Dementia Event" in May 2012, and then put out for consultation for 3 months, from September to July 2012. A focus group involving all three CCGs, senior clinicians, Leeds Alzheimer's Society and commissioners was held in September. The draft document was published on the NHS Leeds website, along with a short questionnaire intended for people with dementia and families / carers; and a longer questionnaire intended mainly for staff. Appendix 4 lists the organisations involved and some of the points which influenced the strategy.

4.2 Equality and Diversity / Cohesion and Integration

- 4.2.1 Dementia is itself a condition which causes cognitive and other impairment, and affects a diverse range of local people. It is suggested by community groups and professionals that poor understanding of the condition, and stigma attached to it, may present particular barriers to diagnosis and support in some minority ethnic communities. It is estimated that there are 100-200 older people living with dementia in Leeds Caribbean, Irish, Jewish, and south Asian communities.
- 4.2.2 Age is the main risk factor linked to dementia, and thus dementia is most prevalent in the more affluent and rural areas within the Council boundary, where life expectancy is longest. However, at any given age, the risk of developing dementia is highest in the more deprived, inner-city areas of Leeds.
- 4.2.3 A screening form has been completed in relation to the report content and the proposed decision being taken (Appendix 5). The "Key findings" section details aspects of the strategy document with reference to equality and diversity, and proposed actions under the strategy to address them.

4.3 Resources and value for money

- 4.3.1 The strategy document sets out a shared purpose and priorities, with specific investments to be set out in the action plan. The strategy contrasts the relatively

small investment in diagnosis and early support, to the high cost of people with dementia going into hospitals and care homes.

4.4 Legal Implications, Access to Information and Call In

4.4.1 There are no direct legal implications of this report. There is no confidential information or implications regarding access to information. It is subject to call-in.

4.5 Risk Management

4.5.1 The costs of caring for people with dementia would rise by c. 2% each year if change is not achieved as part of better management of dementia as a long-term condition, and developing integrated health and social care. Therefore doing nothing would itself be a risky strategy.

4.5.2 Dementia is a complex condition which requires co-ordination of strategy and care over many organisations. This creates risks to delivery. Therefore this strategy is put forward to co-ordinate development between agencies; inform providers and external funders what priorities we wish to see investment in; and encourage organisations to work to a shared vision.

5 Conclusions

5.1 The partner organisations who are represented on Leeds Integrated Dementia Board have set out a joint approach to improving health, social care and daily life in Leeds for people with dementia and carers. Progress is being made in key areas and key investments have already been identified and actions are in progress.

6 Recommendations

6.1 The Health and Wellbeing Board is asked to:

- Consider the strategy and its priorities, and support it as a basis for co-ordinated action across all local agencies which support people with dementia and carers.
- Sponsor the formation of a Leeds Dementia Action Alliance to promote positive attitudes and accessible services throughout local communities, businesses and service providers.
- Comment on the development of the actions to deliver the strategy, including the opportunities offered by other health and well-being initiatives.

Appendices

Appendix 1 - Summary of strategy

Appendix 2 - Strategy document, *Living Well with Dementia in Leeds*.

Appendix 3 - Action Plan

Appendix 4 - Organisations contributing to the development of *Living Well With Dementia in Leeds*.

Appendix 5 - Equality impact screening tool