



Report of: Leeds Dementia Partnership

Report to: Leeds Health and Wellbeing Board

Date: 25 April 2019

Subject: Progressing the Leeds Dementia Strategy

Are specific geographical areas affected? If relevant, name(s) of area(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
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 type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, access to information procedure rule number: n/a Appendix number: n/a	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

Summary of main issues

There is strong local commitment to Leeds developing as a dementia-friendly place, and to improving local services for people with dementia. This has underpinned improvements in recent years including timely dementia diagnosis, support to live with the condition and support for carers. The priorities for further work include ensuring good quality care for people with more complex needs; care planning and review offered by GP practices; opportunities for people to plan for the later stages of dementia; and end of life care. Joint working is well-established through the Leeds Dementia Partnership and specific groups, which has led to an outline of the next Leeds Dementia Strategy; and further engagement is proposed to develop it and build consensus on the next steps.

Recommendations

The Health and Wellbeing Board is asked to:

- Note the progress made since “Living Well With Dementia In Leeds” was agreed in May 2013;
- Comment on and support the development of the proposed strategy.

1. Purpose of this report

This report seeks to:

- Provide an overview of the previous Leeds Dementia Strategy highlighting the progress that has occurred to date across the partnership.
- Provide an overview of the development of the next iteration of the Leeds Dementia Strategy to date, including how it will help deliver the Leeds Health and Wellbeing Strategy and Leeds Health and Care Plan.
- Describe the continuing engagement with partners which has made possible the achievements over the past 6 years, and proposals to develop the strategy in partnership.
- Take into account the impact of health inequalities on the risks of developing dementia, alongside other long-term conditions and frailty.
- Reference the important challenges and barriers, to be addressed by working in partnership, with the support of Leeds Health and Wellbeing Board.

2. Background information

- 2.1 The older population of Leeds is expected to increase, and become more diverse, as people approach later life who were either born in the UK in the years from 1946; or who came to the UK post-war particularly from Caribbean and South Asian countries. Although dementia prevalence is expected to grow in line with population ageing, there is evidence that improvements in population health have offset this demographic pressure in recent decades.
- 2.2 There is emerging evidence that health inequalities affect the risk of developing dementia, particularly linked to heart and circulatory disease and Type 2 diabetes. This means that the geographical spread of dementia prevalence is more even than might be expected from only considering the age structure of (eg.) ward populations. This view is supported by data from the Joint Strategic Needs Assessment in 2012¹, and the “The State of Women’s health in Leeds” report (2019)². The highest prevalence of diagnosed dementia per head of population is found in the more affluent areas with the oldest populations; whereas the more deprived areas had the highest *age-standardised* prevalence, ie. the higher risk at any given age. The pattern is also influenced by the location of care homes and housing schemes for older people, ie. what happens in the years following diagnosis.

¹ <https://leedsobs.wpengine.com/wp-content/uploads/2018/03/Dementia.pdf>

² https://observatory.leeds.gov.uk/wp-content/uploads/2019/03/State_Womens_Health_Leeds-1.pdf

This chart is Fig 45 from *The State of Women's Health in Leeds* (2019). It shows the tendency for age-standardised rates of dementia diagnosis (figures are per 100,000 population) to be higher where index of multiple deprivation is higher.



- 2.3 A challenge emerging for local partners in recent years has been an increase in the relatively small numbers of people with more complex needs in dementia. 'Complex needs' refers to unmet emotional and psychological needs which can cause distressed behaviours such as agitation and aggression; or the combination of dementia and physical frailty as people live longer with several long-term conditions. The local care economy has struggled to keep pace, given funding and recruitment challenges. This, more than absolute numbers of people with dementia, is proving the important issue to address.
- 2.4 Dementia is a long-term neurological condition associated with growing older. For c. 90% of people with dementia, it is found with other long-term conditions. However, it is traditionally a clinical specialism within mental health services, and there are important connections between dementia strategy and mental health strategy, in particular:
- The 'co-morbidity' of dementia with mental health conditions, especially depression and anxiety.
 - Meeting NHS standards for treatment and response for crisis services and acute hospital liaison services.

3. Main issues

- 3.1 There are an estimated 8,500 people living with dementia in Leeds, of whom just over 6,400 have a diagnosis. Since 2013, the number of people in Leeds with a dementia diagnosis – ie. recorded on a GP register and thus known to the NHS – has increased by 40%; a result of NHS and partners organisations improving the identification and assessment of symptoms and improving the diagnosis pathway.

- 3.2 The dementia diagnosis rate for Leeds is 74.4% (end February 2019); this compares well with NHS England target (66.7%); West Yorkshire & Harrogate area (72.7%); and Yorkshire and Humber region (71.5%).
- 3.3 There are now services in place to ensure that diagnosis leads to an offer of information and support for people to live with the condition, and access the range of activities and services that community groups in Leeds offer. The Memory Support Worker (MSW) service supported over 1,300 people in 2018-19 and the evaluation of the service was very positive regarding people's experience of the service. The MSWs are integrated with Neighbourhood Teams and specialist memory services, including sharing of information via clinical systems and secure email; as the condition progresses there is timely access to clinical involvement and assessment of care needs. Carers Leeds provide a 'Dementia Carer Hub' which supports c. 1,200 unpaid carers each year via 1:1 support, groups, and training courses. There is a hospital-based dementia carer support worker within this team which has become a valued role in supporting hospital discharge planning and avoiding readmissions.
- 3.4 Local people and communities in Leeds have risen to the challenge to make Leeds a dementia-friendly place, with over 150 organisations signed up to the Dementia Action Alliance, and approx. 29,000 Leeds residents have registered as Dementia Friends (c.24,000 attending an awareness session, and 5,000 signing up online). Leeds has 47 Memory Cafés that meet at least monthly, of which 25 rely on voluntary and business initiatives which are not funded from any health or social care budget.
- 3.5 New services are in place for people living with dementia in the later stages. The Leeds & York Partnerships NHS Foundation Trust (LYPFT) has completed (March 2019) a major service redesign that has reinstated specialist older people's services, including intensive and out-of-hours interventions for people living at home and in care homes. Since 2014, community NHS and social work colleagues have accessed three specialist LYPFT clinicians based in the Neighbourhood Teams, to co-work and manage risks with people whose dementia and mental health needs make it more difficult and complex to plan and implement care and treatment.
- 3.6 Both Leeds Teaching Hospitals and Leeds Community Healthcare NHS Trusts include dementia training in their statutory & mandatory training programmes. All staff are required to undertake dementia 'tier one' training and those clinical staff who are in regular contact with people living with dementia are required to undertake 'tier two' training which is one full day, face to face training. Leeds Teaching Hospitals have trained more than 6,000 staff and implemented dementia-friendly changes to care planning, ward environments and menus; and "John's Campaign" to ensure flexible visiting hours for carers / families of people with dementia. Leeds Community Healthcare have trained more than 1,200 staff in the past year to 'Tier 1' (dementia awareness); and 370 staff at 'Tier 2' level, appropriate for clinical staff. The trust is also developing clinical pathways for the prevention and treatment of delirium, anxiety and depression, recognising the increased risk of these conditions for people with dementia.
- 3.7 Leeds hospices are recognising the impact of dementia on people's needs at end of life, recognising that of the c. 6,000 people who die in Leeds every year, approx. 15% have dementia (although it is not necessarily the primary cause of death. Since 2016, the two hospices have provided the one-hour Dementia Friends session to

106 staff and volunteers; and developed a 'Dementia Care Training for Hospice Staff' course in collaboration with the University of Bradford and provided this for 142 staff.

3.8 Significant challenges remain, including:

- Addressing the variation in quality of the care plan and annual review that GP practices offer to people living with dementia. The Leeds approach is to support clinicians to have better conversations with people who live with long-term conditions, based on agreeing goals and actions. This is known as 'Collaborative Care and Support Planning', and in the 9 months from April-December 2018, 1,739 people (27% of those with a dementia diagnosis) had an annual review using this approach – this is a promising start to build on.
- Developing new capacity to offer carer breaks, and keep pace with emerging population needs, including diverse BME needs.
- Improved quality and capacity for social care, with multi-agency support, will avoid unnecessary hospital admissions and ensure timely discharge. Progress has been made in the past year with winter 2018-19 seeing a consistent month-on-month reduction in people delayed in The Mount (LYPFT specialist inpatient care) awaiting specialist care home beds.
- Offering more opportunity to plan ahead for the later stages of dementia, and continuing to improve the quality of end-of-life care.

3.9 The following eight themes are proposed for developing a refreshed dementia strategy:

- Public Health initiatives empower people to reduce the risk of developing dementia;
- People and places in Leeds are 'dementia-friendly'; we promote inclusion & understanding, and reduce stigma.
- Timely diagnosis leads to support to live with the condition, and community capacity keeps pace with emerging needs.
- Carers are treated as partners in care, and benefit from information, support, and breaks.
- People living with dementia are recognised as diverse, services are competent to respond to diverse needs, and there is support to overcome specific barriers to diagnosis and support.
- Leeds has the right quality & capacity of care services to support people with more complex needs in dementia, and only be in hospital when medically necessary.
- All NHS, care and support services are dementia-inclusive, skilled, and work together. As dementia progresses, people's pathways through services can be complex and the highest standards of co-working and information-sharing are required.
- There is honesty about dementia as a progressive neurological condition, and opportunities to plan ahead for the later stages of the condition and make the most of life.

3.10 An outline of a refreshed strategy for Leeds is proposed at Appendix 1, alongside further detail of progress achieved since 2013. This proposed approach has been

developed primarily at Leeds Dementia Partnership, which meets quarterly and is a well-attended meeting involving: managers and clinicians from the three Leeds NHS Trusts and NHS Clinical Commissioning Group; Leeds City Council; Alzheimers Society, Carers Leeds, Advonet; Touchstone Leeds; Black Health Initiative; Leeds Irish Health & Homes; Leeds Older People's Forum; Leeds Care Association; Leeds Beckett University. Carer representatives have attended regularly for most of the past five years, and this now needs refreshing as people have moved on. The partnership will seek to recruit and support a person living with dementia from the 'Up and Go' involvement group. There is, in addition, continuing and regular engagement of partners, looking at specific aspects of the strategy through the following active groups:

- Dementia-Friendly Leeds Steering Group
- Leeds BME Dementia Forum
- Leeds End-Of-Life Dementia Group
- Diagnosis & Support Pathway Redesign Group
- Leeds Teaching Hospitals Dementia Strategy Group
- A series of workshops during 2017-19 on timely transfers of care and complex needs, involving care home and NHS providers.
- Attendance at the Leeds Carers Partnership Board.

4. Health and Wellbeing Board Governance

4.1 Consultation, engagement and hearing citizen voice

The proposed outline strategy will be developed through spring, summer and autumn 2019. As well as the above arrangements, there will be involvement of people living with dementia via the 'Up & Go' group, and Leeds Older People's Forum will lead engagement on people's priorities for making Leeds dementia-friendly. Carers will be involved via Carers Leeds acting as both a channel of communication and a proxy 'voice' able to distil the experience of working every year with over a thousand carers of people with dementia.

Scrutiny Board (Adults, Health and Active Lifestyles) will also be consulted as part of development of the strategy.

4.2 Equality and diversity / cohesion and integration

The development of the strategy will address the diverse needs outlined above and in Appendix 1, related to health inequalities, younger-onset dementia and people with BME origins and needs related. In addition, it will recognise the different experiences of people with dementia and family care-giving related to gender; and the needs of LGBT older people. It is reported, for example, that the effects of dementia on orientation to time, together with uncertainty about the inclusivity of service provision, may lead people to go 'back into the closet'.

4.3 Resources and value for money

There are no specific costs described in the strategy. The overall approach is consistent with the Leeds Plan shift towards early intervention and prevention, whilst

recognising that dementia is a difficult, progressive condition that requires investment in quality and capacity for social care, and end of life care.

4.4 Legal implications, access to information and call-in

There are no legal implications, access to information or call in implications to this report.

4.5 Risk management

The strategy will seek to set out the ambition of Leeds to be the best city to live with dementia, whilst being practical about constraints, which includes challenges such as workforce recruitment and development, as well as financial resources. The financial and reputational risks will be managed by the governance of Council and Clinical Commissioning Group in the development of the strategy.

5. Conclusions

- 5.1 Much has been achieved since 2013 to improve diagnosis and support to live with dementia in Leeds.
- 5.2 The need for further work arises both from areas identified in the 2013 strategy that have proved difficult to progress; and from emerging needs and challenges experienced by people and carers living with the condition, and by service providers.
- 5.3 Partnership working in Leeds is long-standing and well-supported. However, people living with dementia, and unpaid carers, do not as yet have a strong voice in setting priorities and developing solutions, and further work is necessary to support stronger involvement.

6. Recommendations

The Health and Wellbeing Board is asked to:

- Note the progress made since “Living Well With Dementia In Leeds” was agreed in May 2013;
- Comment on and support the development of the proposed strategy.

7. Background documents

- 7.1 None.

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How does this help reduce health inequalities in Leeds?

Growing older is the primary risk factor for dementia; health inequalities are associated with increased risk of developing dementia at any given age. The strategy takes the approach of joining up primary, community and specialist care and support for people living with dementia alongside other long-term conditions and frailty.

How does this help create a high quality health and care system?

The report shows good progress on identifying and diagnosing dementia, including reduced waiting times, and introducing support worker roles which enable people and carers to live with dementia, and co-ordinate timely access to a range of services. The report highlights improvements required in dementia care, the work in progress particularly for people with more complex needs, and the next steps to develop the Leeds strategy.

How does this help to have a financially sustainable health and care system?

The strategy describes: diagnosis and support services to enable people and carers living with dementia to stay active and connected; and integrated and timely support from specialist and community services to optimise use of inpatient services. People with dementia who are admitted to hospital are at increased risk of remaining there for too long, and steps taken in 2018-19 have supported more timely transfers of care.

Future challenges or opportunities

The report identifies areas of unmet and emerging need, alongside initiatives and opportunities to improve services. These are: demographic change; carer breaks; support planning and better conversations with people with long-term conditions; people with more complex needs; planning ahead & end of life care.

Priorities of the Leeds Health and Wellbeing Strategy 2016-21

A Child Friendly City and the best start in life	
An Age Friendly City where people age well	✓
Strong, engaged and well-connected communities	✓
Housing and the environment enable all people of Leeds to be healthy	✓
A strong economy with quality, local jobs	✓
Get more people, more physically active, more often	✓
Maximise the benefits of information and technology	✓
A stronger focus on prevention	✓
Support self-care, with more people managing their own conditions	
Promote mental and physical health equally	✓
A valued, well trained and supported workforce	✓
The best care, in the right place, at the right time	✓