

Report of: Director of Adults & Health

Report to: Scrutiny Board (Adults, Health & Active Lifestyles)

Date: 23rd July 2019

Subject: Living with Dementia In Leeds – developing the strategy for 2019-24

Are specific electoral wards affected? If yes, name(s) of ward(s):	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Has consultation been carried out?	<input checked="" type="checkbox"/> Yes <input 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: Appendix number:	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

Summary

1. 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 after diagnosis; 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 themed groups. This partnership approach has informed the development of a draft outline version of the next Leeds Dementia Strategy. Further engagement is proposed to develop it and build a shared vision, and consensus on objectives and next steps.

2. Best Council Plan Implications

- The proposed vision for the strategy reflects the 'Best City...' approach, recognising that living well with dementia depends on the kind of place we live in, and the understanding & awareness experienced in daily life.

- 'Dementia-Friendly Leeds' is a theme of the strategy which reflects this place-based approach and connects to the Best City priority of 'Age Friendly' Leeds.
- The strategy reflects the priorities of health inequalities, active lifestyles, self-care, and the way that dementia affects people's care and support needs.

3. Resource Implications

- There are no specific costs described in the strategy; some of the objectives will lead to development of 'commissioning intentions' with costed business cases for the Council and/or Clinical Commissioning Group.
- 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.

Recommendations

The Scrutiny Board (Adults, Health and Active Lifestyles) is asked to:

1. Note the progress made since the previous strategy "Living Well With Dementia In Leeds" was produced in May 2013;
2. Comment on and support the development of the refreshed strategy.

1. Purpose of this report

1.1 To provide an overview of:

- the previous Leeds Dementia Strategy highlighting the progress that has occurred to date across the partnership, and;
- the development of a refreshed strategy for the period 2019-24.

1.2 To describe the continuing work with partners which has made possible the achievements over the past 6 years; and the engagement to date to develop a draft version for the new strategy.

1.3 To describe the positive effect of active lifestyles, and the impact of health inequalities, affecting both the risk of developing dementia, and the opportunities to live well with the condition.

1.4 To describe the proposals for further engagement and consultation to develop the draft strategy.

2. Background information

2.1 Dementia is a condition which affects memory, and other aspects of brain functioning eg. concentration, ability to plan and make decisions, language and word-finding. It is caused by diseases of the brain, the most prevalent type being Alzheimers Disease which causes c. 60% of dementia. It is a progressive, long-term condition, for which risk increases with age¹. Living well with dementia is the aim of treatment and support, for people to have the right support to lead active, purposeful lives and to carry on doing the things that matter most, for as long as possible.

¹ www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia

- 2.2 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 as the older population increases, there is evidence that improvements in population health have offset demographic growth in recent decades².
- 2.3 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 2012³, and the “The State of Women’s health in Leeds” report (2019)⁴. 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.
- 2.4 There are relatively small numbers of people with more complex needs in dementia; in recent years service providers have noted an increase in these numbers, and concerns have emerged for people unable to leave hospitals because of difficulties finding long-term care. ‘Complex needs’ is a broad definition which includes: unmet emotional and psychological needs which can cause distressed behaviours such as agitation and aggression; and/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.
- 2.5 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.
- 2.6 The number of people in Leeds with a dementia diagnosis recorded on GP registers (end March 2019) is 6,423. NHS England publishes estimates of dementia prevalence for each NHS Clinical Commissioning group – this is derived from research into age-related risk, plus population data. It is designed to show approximately how many people are living with dementia, whether diagnosed or not. The estimate for Leeds (end March 2019) is 8,327 people aged 65+; numbers aged under 65 are harder to estimate but may be 300-400 people.
- 2.7 NHS England set the national ambition for ‘dementia diagnosis rate’ at 66.7%. This is the actual count of people aged 65+ on GP dementia registers, divided by estimated population prevalence, again for age 65+. Leeds first achieved this ambition in March 2015, and has continued to improve. During 2018-19, the diagnosis rate was always above 73.5%, and at end March 2019 was 75.0%.

² <http://www.cfes.ac.uk/files/2015/08/Prevalence-paper-CFAS-2013.pdf>

³ <https://leedsobs.wpengine.com/wp-content/uploads/2018/03/Dementia.pdf>

⁴ https://observatory.leeds.gov.uk/wp-content/uploads/2019/03/State_Womens_Health_Leeds-1.pdf

- 2.8 Waiting times for people referred to the Leeds Memory Service have improved too. Over the past two years, over 90% of people have been seen within 8 weeks of referral. Over the past year, over 65% of people have been diagnosed within 12 weeks of referral.
- 2.9 Local strategy has stressed the importance of improving diagnosis as a gateway to support to live well with dementia; not as an end in itself. Since 2013, new investments in services have improved the local offer of support, in particular: the Memory Support Worker service (an Alzheimers Society partnership with Leeds and York Partnership NHS Foundation Trust); Carers Leeds Dementia Hub; BME Dementia Support (Touchstone Leeds); The number of Memory Cafes and singing groups has increased from approx. 40 to 60; voluntary effort and dementia-friendly local business initiatives accounts for about 50% of these groups.
- 2.10 Local people and communities in Leeds have risen to the challenge to make Leeds a dementia-friendly place. Over 150 organisations have 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 City Council funds a dementia-friendly Leeds co-ordinator role at Leeds Older People's Forum, helping local people, groups, and businesses to develop dementia-friendly and age-friendly approaches.
- 2.11 Leeds City Council has made important contributions to a dementia-friendly Leeds. For example:
- Parks and Gardens colleagues worked with dementia-friendly Rothwell to create a dementia-friendly garden at Springhead Park;
 - Revenues and Benefits are working to improve access to Council Tax discount and rewording the documents to use less stigmatising terminology.
 - Leeds Museums and Galleries work with the Adults & Health Peer Support Service to offer creative opportunities, eg. making a mosaic depicting objects from Leeds City Museum, and displaying it there.
- 2.12 Leeds Teaching Hospitals NHS Trust includes dementia training in their statutory & mandatory training programmes. All staff are required to undertake dementia training to Level 1, 2 or 3 depending on their level of interaction with people who have dementia. The Trust has 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.
- 2.13 Leeds Community Healthcare likewise has dementia training as mandatory, with more than 1,200 staff in the past year completing 'Tier 1' (dementia awareness); and 370 staff trained to 'Tier 2', 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 amongst people with dementia.
- 2.14 For people with higher levels of need, often in the later stages of dementia, there are new NHS services to support people with dementia and older people with mental health needs. These services provide a clinical specialist and multi-disciplinary approach. They include "intensive treatment teams" which offer timely intervention for people living at home, and in care homes, including during evenings and weekends. Since 2014, community NHS and social work colleagues have accessed three specialist LYPFT clinicians based in the Neighbourhood Teams.

This co-working has proved successful when people have physical health needs and frailty alongside dementia and mental health needs.

- 2.15 Of the c. 6,000 people who die in Leeds every year, approx. 15-20% have a dementia diagnosis. Leeds hospices are recognising the impact of dementia on people's needs at end of life. 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.
- 2.16 Although the above represents good progress to implement the 2013 Leeds dementia strategy, there is more to do if Leeds is to be 'the best city' to live with dementia. The following section outlines the priorities for improvement, and the local partnership working underpinning the strategy. A draft strategy document is included as an Appendix to this report.

3. Main issues

3.1 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 more capacity to offer carer breaks, and keep pace with emerging population needs, including diverse BME needs.
- Quality and capacity of social care, with multi-agency support, to offer: improved quality of life; reassurance for family carers; and to 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.

3.2 The following is a proposed statement for a shared vision for living with dementia in Leeds. It attempts to capture both community and service aspects, and emphasise the importance of joined-up care for people who are more likely to rely on others to share information and enable good transitions of care:

“For Leeds to be the best city to live with dementia, where people and carers are included in social, community and economic life; and supported by services which work well together”.

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

- i. Public Health initiatives empower people to reduce the risk of developing dementia;

- ii. People and places in Leeds are 'dementia-friendly'; we promote inclusion & understanding, and reduce stigma.
- iii. Timely diagnosis leads to support to live with the condition, and community capacity keeps pace with emerging needs.
- iv. Carers are treated as partners in care, and benefit from information, support, and breaks.
- v. 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.
- vi. 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.
- vii. 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.
- viii. 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.

3.4 An outline of a refreshed strategy for Leeds has been developed at Leeds Dementia Partnership (Appendix); it includes detail of progress achieved since 2013. This partnership 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 of Commissioning Manager, Dementia at the Leeds Carers Partnership Board.

4. Corporate considerations

4.1 Consultation and engagement

4.1.1 The strategy content will be developed further through to the end of 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. A large-scale engagement event is planned for the autumn.

- 4.1.2 A period of public consultation will be arranged, to promote and invite comment on a later draft of the draft strategy.
- 4.1.3 Health and Wellbeing Board considered the matter in April, noting the progress made to date, and commenting in support of developing the draft. Points included the importance of active lifestyles to reduce the risk of dementia; support for people with younger-onset of the condition to have reasonable adjustments to stay in employment; and the training needs of the social care workforce.
- 4.1.4 Health and Wellbeing Board will be invited to consider the final draft of the strategy later in 2019-20.

4.2 Equality and diversity / cohesion and integration

- 4.2.1 The development of the strategy will address diverse needs related to eg. health inequalities, younger-onset dementia and people from BME origins. It will recognise the different experiences of people with dementia and family care-giving related to gender; and the needs of LGBT older people.
- 4.2.2 Specific achievements and actions are identified in the equality, diversity, cohesion and integration impact assessment. Achievements to date include:
 - the commissioning of a BME dementia support worker with Touchstone Leeds, and establishment of Memory Cafes by diverse BME community groups;
 - establishment of GP-hosted memory clinics to improve access to services and avoid long travel distances to outpatient locations;
 - increased access to support, via Memory Café and carer support service, for people living younger-onset of dementia.
- 4.2.3 Planned actions include:
 - Co-design and commission an evaluation of experience of diagnosis and support of people from BME communities.
 - Hold an engagement event with sensory impairment services in Leeds;
 - Seek opportunities to improve enable people in paid work to have reasonable adjustments to stay in work.
- 4.2.4 The effects of dementia as a health condition is different for each individual , and similarly the interaction of 'protected characteristics' defined in equalities legislation, requires a person-centred approach. For example, the degree to which a person can continue to speak English as a second language will depend on the type of dementia, and on the time of life when the person learned English.
- 4.2.5 People with dementia are at particular risk of having rights and entitlements overlooked, including human rights. Everyone living with dementia faces barriers to accessing services, eg. the stigma associated with the condition and difficulties remembering and getting to appointments. Additional barriers linked to inequalities can further disempower and increase reliance on others. Therefore a strong, rights-

based approach is required, alongside dementia-friendly initiatives, and a person-centred approach to individual needs.

4.3 Council policies and best council plan

- 4.3.1 The strategy document will state clearly how it supports the Leeds Health and Care Plan. For example, reducing the risk of dementia aligns to *Living a healthy life to keep myself well*; improving capacity for social care aligns to *Hospital care only when I need it*.
- 4.3.2 The proposed vision above takes the 'Best City...' ambition from the 'best Council' plan, and recognises the importance of Leeds being an inclusive, dementia-friendly place to live.
- 4.3.3 This in turn connects to the ambition for an age-friendly city; as well as ageing being the main risk factor for dementia, there are aspects in common such as changing social attitudes, and access needs arising from mobility and sensory impairment.
- 4.3.4 There is a particular connection to the Inclusive Growth Strategy. The ambition to create better jobs and tackle low pay, is relevant to investment in recruitment and training of the care workforce; including attracting younger people into careers in health and care.

Climate Emergency

- 4.3.5 The clearest connection is the promotion of active lifestyles, which reduce the risk of developing dementia, benefit living well with dementia and may, through eg. walking to work and to shops, reduce 'carbon footprint'.

4.4 Resources, procurement and value for money

- 4.4.1 There are no specific costs described in the strategy; some of the objectives will lead to development of 'commissioning intentions' with costed business cases for the Council and/or Clinical Commissioning Group.
- 4.4.2 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.

4.5 Legal implications, access to information, and call-in

- 4.5.1 The strategy itself will set out positive ambitions and plans to improve support for people with dementia and carers to live with the condition. Adopting the strategy will require a decision to be made within the relevant legal framework.
- 4.5.2 There may be particular legal implications for the actions and projects that arise from the strategy, eg. to understand impact of any proposed service changes. These would be managed appropriately as separate specific decisions to the adoption of the strategy.

4.6 Risk management

- 4.6.1 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 Scrutiny Board (Adults, Health and Active Lifestyles) is asked to:

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

7 Background documents

None⁵

⁵ The background documents listed in this section are available to download from the council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.