

Report of: Director of Adults & Health

Report to: Executive Board

Date: 21st October 2020

Subject: Living with Dementia In Leeds – our strategy 2020-25

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 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

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.
- Joint working is well-established through the Leeds Dementia Partnership and its forums and task groups. This partnership approach, with engagement of people living with dementia, carers, and service providers, has developed the Leeds Dementia Strategy.
- The strategy document describes thirteen ‘building blocks’, the elements that together can make Leeds the best city to live with dementia, and cover the different stages of dementia and the diversity of people living with the condition.
- There are six commissioning priorities, where focused work and/or investment is required to improve services, and where there are opportunities to make the most difference. People with dementia and carers have been particularly affected by the Covid crisis, and service ‘reset and recovery’ is included among these priorities.
- The strategy will inform the Leeds Dementia Action Plan. This will be owned by Leeds Dementia Oversight Board, reviewed and updated quarterly.

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 includes a section which connects it to Leeds Health and Care Plan priorities, including a friendly, compassionate and healthy city; tackling health inequalities; starting with people; and working as ‘Team Leeds’.

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 good quality care.

Recommendations

The Executive Board is asked to:

- a. Agree the strategy document “Living With Dementia In Leeds - our strategy 2020-25”.
- b. Note the establishment of the Leeds Dementia Oversight Board and its role to oversee the Leeds Dementia Action Plan and ensure the strategy is implemented;
- c. Note that the design of the ‘Plan On A Page’ and strategy document will be reviewed to align with the Leeds Health and Wellbeing Strategy branding and format.
- d. Note the role of the Commissioning Programme Lead, Dementia, to co-ordinate work to progress the strategy, supported by the partnership and governance arrangements described in the report. This is a joint role, working for the Council and NHS Leeds Clinical Commissioning Group.
- e. Consider the role of elected members in supporting and monitoring progress with the strategy.

1. Purpose of this report

1.1 To provide an overview of:

- The progress made since the previous strategy “Living Well With Dementia In Leeds” was produced in 2013;
- The development of a refreshed strategy for the period 2020-25.

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

Alzheimer's Disease which causes c. 60% of dementia. It is a progressive, long-term condition, for which risk increases with age¹. The aim of treatment and support is for people to live well with dementia; 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.

- 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. Covid-19 has also led to more deaths of people with dementia than would normally be expected, probably associated with the prevalence of dementia amongst the population living in care homes³.
- 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 2012⁴, and the "The State of Women's Health in Leeds" report (2019)⁵. 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. People may have 'complex needs' because of unmet emotional and psychological needs which are expressed as behaviours such as agitation and aggression; or complex needs may arise from a combination of dementia and other health conditions.
- 2.5 NHS England sets the national ambition for 'dementia diagnosis rate' at 66.7%. This is the actual count of people on GP dementia registers, divided by estimated population prevalence, for people age 65+. Leeds first achieved this ambition in March 2015, and has continued to improve. At end February 2020, the diagnosis rate was 74.7%.
- 2.6 However, NHS services for memory assessment and diagnosis were suspended during the Covid crisis, and only now starting to resume. Many support groups and services have also had to 'pause', and there are restrictions on care home visiting, which has left some people unable to understand why they have not seen close family. There has therefore been significant adverse impact on people living with dementia and carers. There has been some positive and innovative use of digital technology to offer alternative ways of keeping in touch and offering support.
- 2.7 Covid-19 has caused the deaths of a disproportionately high number of people with dementia. From March to June 2020, there were 13,840 deaths of people with dementia recorded in England and Wales which were known to involve Covid-19.

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

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

³ <https://itccovid.org/2020/08/19/impact-and-mortality-of-covid-19-on-people-living-with-dementia-cross-country-report/>

⁴ <https://leedsobs.wpengine.com/wp-content/uploads/2018/03/Dementia.pdf>

⁵ https://observatory.leeds.gov.uk/wp-content/uploads/2019/03/State_Womens_Health_Leeds-1.pdf

This was 27.5% of all recorded Covid-19 deaths in that period. Looking at deaths not attributed to Covid, but above the normal expected number, there were 5,049 'excess deaths' of people with dementia from 4th January to 10th July in England and Wales.

- 2.8 The reasons for these 'excess deaths', where Covid was not recorded, are not certain, and there may be more than one explanation. It is known that older, frailer people often do not present with symptoms of cough and fever. Rather, there may be 'hypoactive delirium', where a person becomes less active and more confused. It has also been suggested that some deaths might be "linked to longer-term changes, such as changes to practice in care homes to combat COVID-19"⁶. Whilst it is difficult to prove cause-and-effect, the concern is that the impact of social distancing and care home visiting restrictions, as described above, could be contributing to excess deaths.
- 2.9 A recent Alzheimers Society report, "*Worst hit: dementia during coronavirus*"⁷ explores the impact on people with dementia and carers, of the virus itself, social distancing measures, service suspensions and reductions, and restrictions imposed for people in care homes:
- 95% of family carers the charity surveyed said extra caring hours had negatively impacted their physical or mental health, with 69% of over 1,000 people the charity spoke to reporting feeling constantly exhausted, 64% feeling anxious, 49% feeling depressed, and 50% developing problems sleeping.*
- 2.10 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; BAME 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.
- 2.11 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.
- 2.12 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 have responded to comments by a local person who lives with dementia, by involving her and the Alzheimers Society in rewording the Council website and documentation. As well as feeling friendlier and less stigmatising, this has increased the take-up of Council Tax discount.

⁶ Office of National Statistics data, summarised in the Alzheimers Society report at 2.9, and originally sourced here: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/28december2019to10july2020>

⁷ <https://www.alzheimers.org.uk/news/2020-09-29/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>

- The Living With Dementia Peer Support Service (Adults and Health) have formed the Leeds Dementia Cultural Partnership which includes Leeds Playhouse, Yorkshire Dance, Opera North, and colleagues in Leeds Museums and Galleries. The strategy document gives examples of people benefiting from creative opportunities, and pioneering work in Leeds.
- Call Centre staff have been trained by the Alzheimers Society in “Supporting People With Dementia Over The Phone”.

- 2.13 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.
- 2.14 Leeds Community Healthcare likewise has dementia training as mandatory, with 1,389 staff completing ‘Tier 1’ (dementia awareness); and 754 staff trained to ‘Tier 2’, appropriate for clinical staff. The trust has developed a clinical framework for dementia, delirium and depression (‘3Ds’). These have been published by the National Institute for Health and Care Excellence (NICE) as a ‘Shared Learning’ example, and ‘highly commended’ in this year’s NICE Shared Learning Awards
- 2.15 The above, and other initiatives described in the strategy document, represents significant progress. However, 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. The strategy document and ‘Plan On A Page’ are included as Appendices to this report.

3. Main issues

- 3.1 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; emphasise the importance of joined-up care for people with dementia; and reflect our ‘Best City’ ambition:

“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”.

- 3.2 The strategy identifies thirteen ‘building blocks’, which together make up the ambition for Leeds to be the ‘best city’. Each of these has a section which describes and celebrates the progress made in recent years; and seeks to be honest about the challenges ahead. Six health and care commissioning priorities then describe the areas of work which most need co-ordinated effort, further investment, and where there are opportunities to connect with other work programmes for Leeds. These are as follows:
- 3.3 ‘Reset and recovery’ from Covid-19 is included as a commissioning priority in the strategy, to resume memory assessment and diagnosis; for face-to-face services to restart safely and/or as digital alternatives; and to promote quality of life for people living in care homes.
- 3.3.1 The Memory Assessment Service in Leeds, provided by Leeds and York Partnership NHS Foundation Trust, invited new referrals from GPs from October 1st.

The service had already restarted face-to-face visits during August for post-diagnosis support. People diagnosed just before the Covid crisis were offered timely telephone support.

- 3.3.2 Leeds Older People's Forum are contacting all Memory Cafes to fully understand the impact of social distancing on our community capacity, and to offer support with recovery, including alternative methods of support. The initial findings will be reported to an additional meeting of Leeds Dementia Partnership in November 2020.
- 3.3.3 Five day centres for people living with dementia re-opened between July and early September. Memory Lane Day Centre at Yeadon re-opened in July, and the Council's 'complex needs' centres, and Community Links Young Dementia Leeds centre re-opened in early September). After local restrictions were imposed, these centres reviewed their risk assessments, and remained open with additional health protection measures, taking into account the adverse impact on people and carers if they were to close again.
- 3.3.4 Leeds has led the way in requesting that a person-centred, partnership approach be applied to family relationships for people in care homes. The Council's letter to government prior to local restrictions included the proposal for "*easing on care home visits so one family member - who is regularly tested - can visit relatives*"⁸. Updated national guidance on care home visiting was published on 21st September and local partnership working continues.
- 3.4 'Demographics, diversity and emerging needs' covers the ambition to understand and anticipate local population change (including the impact of Covid); and to invest in community capacity to support people to live well.
- 3.5 'Annual review and care co-ordination' is a priority, to ensure that there is a conversation with the GP or a member of the practice team about living with dementia, at least once a year. This gives the opportunity to discuss whether there have been any changes, and offer further support / referral to other services. This work is aligned to local work on frailty, so that people with dementia are included in NHS investment in care co-ordination and social prescribing.
- 3.6 'Carer support and breaks' reflects the ambition to identify more carers, and invest further in carer support and breaks. Caring for a person with dementia can be very tough, emotionally and physically. The work of Leeds Dementia Partnership and the dementia strategy is closely aligned to the Leeds Carers Partnership Strategy.
- 3.7 'Care quality, complex needs and timely transfers' has a focus on social care, and the challenges of providing good quality care for people living with dementia, and avoiding delays for people leaving hospital. There has been some good progress in improving NHS support for care homes, and offering personalised care and joint funding for people with more complex needs. Further work has the ambition to improve support at home as well as in care homes, and develop specialist provision.
- 3.8 'End of life care and planning ahead' reflects the fact that approximately one in six deaths is a person with a diagnosis of dementia, and this can affect the understanding and management of pain and other symptoms. Planning ahead is important for everyone, and for a person with dementia the best opportunity is earlier in the progress of the condition.

⁸ <https://www.bbc.co.uk/news/amp/uk-england-leeds-54280453>

4. Corporate considerations

4.1 Consultation and engagement

- 4.1.1 The strategy has been developed by the Leeds Dementia Partnership. 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.
- 4.1.2 Carer representation at Leeds Dementia Partnership has been refreshed and at least four carers have attended each of the last two meetings.
- 4.1.3 The strategy has been discussed at the 'Up and Go' involvement group, composed of people living with dementia and carers, and supported by Leeds Older People's Forum. This particularly influenced the section on housing options.
- 4.1.4 People's experiences and views were also voiced at the series of 'Dementia Information Roadshows' held during 2018-19. Although the primary purpose of these events was to share information, they turned out to be a useful source for the strategy.
- 4.1.5 A consultation event was held in October 2019, attended by 80 colleagues from statutory and third sector organisations and carers. 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 BAME Dementia Forum
 - Leeds End-Of-Life Dementia Group
 - Diagnosis & Support Pathway Redesign Group
 - Leeds Teaching Hospitals Dementia Strategy Group
 - Specific events and task groups. Eg. A series of workshops during 2017-19 on timely transfers of care and complex needs, involving care home and NHS providers.
- 4.1.6 Specific quotes, narratives and examples are included in the strategy document.

4.2 Equality and diversity / cohesion and integration

- 4.2.1 The strategy addresses diverse needs related to eg. health inequalities, younger-onset dementia and people from BAME origins. It recognises 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 BAME dementia support worker with Touchstone Leeds, and establishment of Memory Cafes by diverse BAME 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 with younger-onset dementia.

- 4.2.3 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 well-informed, 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.
- 4.2.4 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 has a section which describes how it supports the Leeds Health and Care Plan. The 'Plan On A Page' and strategy document will be designed to align with the Leeds Health and Wellbeing Strategy branding and format.
- 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 strategy seeks to care and support people closer to home, in line with the 'Home First' approach of the Leeds Health and Care Plan. This is consistent with reducing carbon emissions.

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 NHS Leeds Clinical Commissioning Group. The strategy sets out the priority areas where there is ambition to invest.
- 4.4.2 People with dementia are supported by all health and care services which support older adults. The Alzheimers Society estimates that people living with dementia are, at any one time, approx. 25% of acute hospital inpatients; and 80% of people living in care homes. Therefore there is potential for investment to delay or reduce uptake of high-cost services, by promoting well-being and, where appropriate, avoiding admissions.
- 4.4.3 The overall approach is consistent with the Leeds Plan shift towards early intervention and prevention, and out of hospital care.

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

- 4.5.1 The strategy sets out positive ambitions and plans to improve support for people with dementia and carers to live well. 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 specific decisions in their own right, separate 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, training and retention; as well as financial resources.
- 4.6.2 The governance arrangements are outlined in the strategy document, with the Leeds Dementia Care Oversight Board reporting to Integrated Commissioning Executive, and thence to Leeds Health and Wellbeing Board.

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, and recent work has strengthened the voice of people living with dementia and carers to influence this strategy.

6 Recommendations

The Executive Board is asked to:

- Agree the strategy document “Living With Dementia In Leeds - our strategy 2020-25”.
- Note the establishment of the Leeds Dementia Oversight Board and its role to oversee the Leeds Dementia Action Plan and ensure the strategy is implemented;
- Note that the design of the ‘Plan On A Page’ and strategy document will be reviewed to align with the Leeds Health and Wellbeing Strategy branding and format.
- Note the role of the Commissioning Programme Lead, Dementia, to co-ordinate work to progress the strategy, supported by the partnership and governance arrangements described in the report. This is a joint role working for the Council and NHS Leeds Clinical Commissioning Group
- Consider the role of elected members in supporting and monitoring progress with the strategy.

7 Background documents

None⁹

8 Appendices

- 8.1 “Living With Dementia in Leeds - our strategy 2020-25”
- 8.2 “Plan On A Page”
- 8.3 Equality, Diversity, Cohesion and Integration impact assessment.

⁹ 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.