



Report of: Leeds Dementia Partnership

Report to: Leeds Health and Wellbeing Board

Date: 30th September 2020

Subject: Living with Dementia in Leeds – Our strategy 2020-25

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 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

- Leeds has seen improvements in recent years as a dementia-friendly place, with more timely dementia diagnosis, support to live with the condition and support for carers.
- A partnership approach is well-established, with engagement of people living with dementia, carers, and service providers.
- The strategy document describes thirteen ‘building blocks’ to make Leeds the best city to live with dementia; and six commissioning priorities, where focused work and/or investment is most necessary to improve services.
- The strategy will be implemented via the Leeds Dementia Action Plan. This will be governed by Leeds Dementia Oversight Board.

Recommendations

The Health and Wellbeing Board is asked to:

- Agree the document “Living With Dementia In Leeds - our strategy 2020-25”.
- Note the establishment of the Leeds Dementia Oversight Board to ensure the strategy is implemented;
- Support the strategy through its members’ leadership roles.

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 (Appendix 1).

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 age.
- 2.2 Living well with dementia is the aim of treatment and support, for people to have opportunities to lead active, purposeful lives; and to carry on doing the things that matter most, for as long as possible.
- 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. There are opportunities to prevent dementia through improvements in population health and education, which connect the dementia strategy to the Leeds Health and Wellbeing Strategy.
- 2.4 NHS England sets the national ambition for ‘dementia diagnosis rate’ at 66.7%. Leeds first achieved this ambition in March 2015, and has continued to improve. At end February 2020, the diagnosis rate was 74.7%.
- 2.5 The Covid-19 crisis has had a significant adverse impact on people living with dementia and carers, because of both the virus itself, and the effects of social distancing measures. Many services have had to ‘pause’, eg: NHS services for memory assessment and diagnosis; face-to-face support, groups and day services. This has decreased the diagnosis rate and reduced access to timely support to live with dementia. Restrictions on care home visiting have left some people unable to understand why they have not seen close family. There has been positive and innovative use of digital technology to offer alternative ways to provide services and for family and friends to keep in touch.
- 2.6 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.
- 2.7 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).

- 2.8 Leeds Teaching Hospitals NHS Trust includes dementia training in their statutory & mandatory training programmes. The Trust has trained more than 6,000 staff and implemented dementia-friendly changes to care planning, ward environments and menus. “John’s Campaign” has been implemented, to offer flexible visiting hours for carers / families of people with dementia.
- 2.9 Leeds Community Healthcare likewise has dementia training as mandatory. The trust has developed clinical pathways for the prevention, recognition and treatment of delirium, anxiety and depression, recognising the increased risk of these conditions amongst people with dementia.
- 2.10 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 strategy document is included as an Appendix to this report.

3 Main issues

- 3.1 The strategy has a shared vision, designed to capture both community and service aspects, and emphasise the importance of joined-up 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”.*
- 3.2 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.
- 3.3 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:
- 3.4 ‘Reset and recovery’ from Covid-19 is included as a commissioning priority, 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. The NHS Memory Assessment Service in Leeds has restarted post-diagnosis support for people diagnosed just before the Covid crisis, and is making plans to resume diagnosis services.
- 3.5 ‘Demographics, diversity and emerging needs’ covers the ambition to understand and anticipate local population change (including the impact of Covid); and to continue to invest in community capacity to support people to live well.
- 3.6 ‘Annual review and care co-ordination’ seeks to ensure as a minimum 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.

- 3.7 '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.
- 3.8 '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.
- 3.9 '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.

4 Health and Wellbeing Board governance

4.1 Consultation, engagement and hearing citizen voice

- 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. Carer representation has been refreshed and at least four carers have attended each of the last two meetings.
- 4.1.2 The strategy has been discussed at the 'Up and Go' involvement group. Members were particularly concerned about housing options and making sure care would be there in a crisis.
- 4.1.3 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.
- 4.1.4 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
 - Leeds Teaching Hospitals Dementia Group
 - Complex Dementia Steering Group.

4.1.5 Links have been established with the NHS Leeds Clinical Commissioning Group work programmes for frailty, and for end of life care.

4.2 **Equality and diversity / cohesion and integration**

4.2.1 Equality, diversity, cohesion and inclusion - impact assessment has been completed (see Appendix 2). The strategy addresses diverse needs related to 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; the needs of people in rural areas; and the needs of LGBT older people.

4.2.2 Achievements to date include:

- Analysis of Leeds dementia diagnosis data by BAME classification reflects an expected, proportionate distribution compared to the Leeds population age 65+.
- 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 among those at particular risk of having rights and entitlements overlooked, including human rights. This is because the condition impairs abilities such as communication, understanding information, making plans, and acting independently. As the condition progresses, important decisions may depend increasingly on the understanding and care of others.

4.2.5 There are obstacles to accessing services, both psychological and practical, eg. the stigma associated with the condition; difficulties remembering or getting to appointments. These may be added to by social factors and stereotypes, eg. assumptions about women and caring roles; services not meeting language and cultural needs.

4.2.6 The strategy seeks to develop a rights-based perspective, taking practical steps to listen to lived experience and address inequalities, alongside dementia-friendly and person-centred approaches.

4.3 **Resources and value for money**

4.3.1 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.

4.3.2 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 **Legal Implications, access to information and call in**

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

4.5 **Risk management**

4.5.1 The strategy sets out the ambition of Leeds to be the best city to live with dementia, and invest in good quality services; whilst being practical about constraints. These include challenges such as workforce recruitment, training and retention; as well as financial resources.

4.5.2 The governance arrangements are outlined in the strategy document, with the Leeds Dementia Care Oversight Board reporting to the Leeds Health and Wellbeing Board.

5 **Conclusions**

5.1 “*Living with dementia in Leeds - our strategy 2020-25*” celebrates the progress made by partnership working and investment in new services, and is honest about the challenges we face if Leeds is to be the best city to live with dementia.

5.2 This 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 shape and influence this strategy.

6 **Recommendations**

The Health and Wellbeing 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;
- Support the strategy, through its members’ leadership roles.

7 **Background documents**

7.1 None.

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How does this help reduce health inequalities in Leeds?

It shows how health inequalities affect the risk of developing dementia and aligns to the Leeds Health and Care Plan to promote good health and a mentally healthy city. It has a strong focus on the needs of carers to have support and breaks to maintain health and wellbeing.

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

It identifies progress made, is honest about where improvements are needed, and takes a whole-person approach to dementia alongside frailty and long-term conditions.

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

It seeks best value from connecting the dementia strategy to other programmes of work (carers, long-term conditions, frailty, end of life care). It shows how timely diagnosis, support and innovative approaches can support people to stay well for longer. It sustains this preventive focus for people with more complex needs to be supported out of hospital.

Future challenges or opportunities

- recovery from Covid
- the funding of social care and the social care workforce
- NHS investment in frailty, care-co-ordination and social prescribing
- The strengths and energies of Leeds communities and partnership working.

Priorities of the Leeds Health and Wellbeing Strategy 2016-21

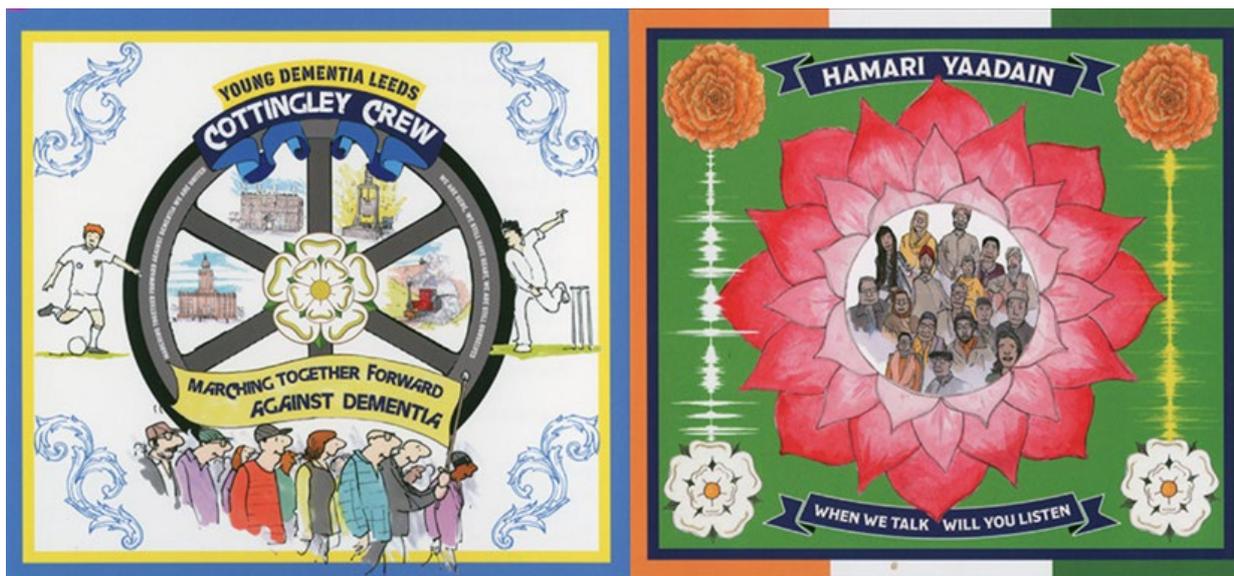
A Child Friendly City and the best start in life	✓ ¹
An Age Friendly City where people age well	✓
Strong, engaged and well-connected communities	✓
Housing and the environment enable all people of Leeds to be healthy	✓
A strong economy with quality, local jobs	✓
Get more people, more physically active, 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	✓

¹ The strategy describes evidence that education to age 20 reduces risk of dementia in later life.

Living with Dementia in Leeds – our strategy 2020-25

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 join up and work well together.

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“Banners For Hope And Change”, created as part of the IDEAL project.
 Hamari Yaadain Memory Café, Young Dementia Leeds with Ian Beesley, Tony Husband & Ian McMillan

People don't know what dementia is, and it's a bit scary at first... slowly I found I was becoming more confident and positive, learning coping strategies and picking up things.

Bob, living with dementia, Headingley.

All I can say is, keep loving the person you're caring for - it's still them, cultivate patience - they can't help frustrating you; and seek out help, both practical and social - some of your friends will vanish, not everyone can cope with the change in your loved one. The shining light in my darkness is that we have met some truly wonderful people. The volunteers and staff at the organisations who have helped us are truly amazing..... There really are some wonderful people in the world.

Brian, on caring for his wife, Crossgates

Introduction

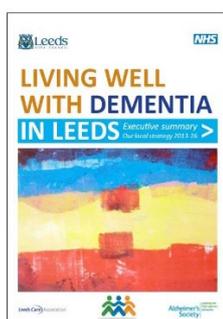
There are an estimated 8,700 people living with dementia in Leeds. To give an idea of what this means in our local neighbourhoods, there are about 9,500 streets in the Leeds City Council area; so the ‘average street’ is much more likely than not to have a person living there with dementia. There were, at the end of February 2020, approximately 6,500 people with a recorded diagnosis, ie. 75% of the total. Of the other 25%, some are in the earliest stages of experiencing symptoms, and some will be going through the diagnosis process. Others might be reluctant to acknowledge the concerns of others, reluctant to seek a diagnosis, or not know what to do next. Each person and family will experience the condition in individual and diverse ways.

The Covid-19 pandemic has affected people and families living with dementia, and so part of this strategy is about ‘reset and recovery’. We don’t know at the time of writing how long the pandemic will be with us, so we have to adapt and change, rather than just sit it out and wait. Memory Assessment Services, which diagnose dementia, were suspended for the Covid crisis, as were day centres and other opportunities for face-to-face contact – memory cafés, day centres, carers groups, and visiting at home. People have missed timely diagnosis and the connection to support and advice.

People in the later stages of dementia might not understand the need for social distancing, and people living in care homes are, at the time of writing, missing out on visits, tea and cake, and hugs with family and friends. There have been positive and creative responses to the restrictions – groups and cafés using the various online video applications, and services going back through their contacts to check in on people.

However, this strategy sets the direction for the next five years, building on what has been achieved since “Living Well With Dementia in Leeds” was published in 2013, and identifying what is still to be done. Most of this document was drafted before the Covid pandemic, and remains valid.

Above all, this strategy aims to offer hope, and to identify opportunities to improve the quality of life and support to live well with dementia. We all have our strengths and abilities, within ourselves and through our families, friends and support networks. A ‘strengths-based’ perspective is important for people with dementia to live as well as possible. At the same time, it is the case that dementia, as a progressive condition affecting the brain, causes loss and impairment of abilities which can, at times, feel overwhelming. Dementia can be extremely tough and challenging, affecting family and social life, finances, plans for retirement and much else besides.



This document looks forward, to describe the challenges and priorities for improving services. It is also an opportunity to show what has been achieved in the seven years since “Living Well With Dementia in Leeds – our strategy” was published in 2013.

During that time there has been excellent progress in Leeds to improve the diagnosis of dementia, and support to help more people and carers

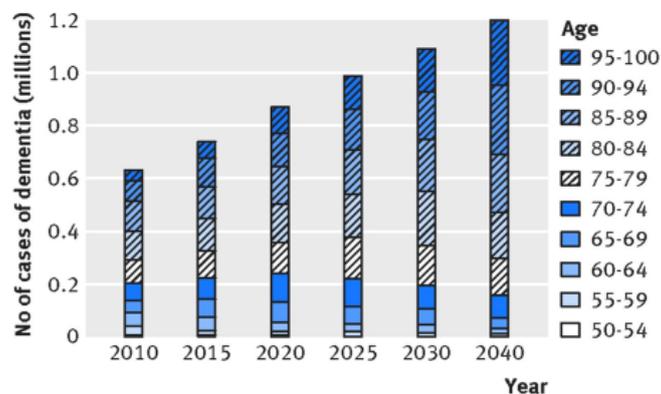
to live with the condition. Our ‘dementia-friendly’ social movement has grown, to make people more aware, reduce the sense of stigma around the condition, and sign up local business and community groups. Thousands of local NHS staff have been trained, and specialist support for community services and care homes has been enhanced.

However, significant challenges remain. The capacity and quality of services, particularly for people with more complex needs, is inconsistent. There are still people and families who miss out on the support available and feel isolated. The population living with dementia will increase, and become more diverse.

The number of people with dementia in the UK population has probably stayed roughly the same over recent decades. The evidence for this is a comparison of population samples twenty years apart, by the Cognitive Function in Ageing Study¹. This is a positive public health story, often overlooked in reporting about dementia. However, as the generation born in the years after 1945 approaches age 75 and beyond, it is likely that there will be demographic growth during the 2020s. Health inequalities are important, with increased risk of dementia linked to higher prevalence of heart disease, type 2 diabetes and high blood pressure. This makes it important to find ways in which we all can reduce the risk of developing dementia - “what’s good for the heart, is good for the brain”.

The prevalence of dementia in England and Wales is expected to increase, according to population modelling². However, the increase is slower than would be expected purely from population ageing – the good news is that the risk of developing dementia at any given age is, in general, gradually decreasing. People are living longer with dementia, alongside other long-term health conditions and frailty. The published research indicates that the largest growth will be in the oldest age-groups; the numbers of people aged under 90 with dementia in England and Wales, according to this forecast, will decrease from 2030.

Fig 3 Age specific estimated number of cases of dementia 2010-40 in men and women. (England and Wales)



Sara Ahmadi-Abhari et al. BMJ 2017;358:bmj.j2856



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¹ Fiona Matthews et al (2013): *A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II*. The Lancet 382:9902 [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)61570-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61570-6/fulltext)

² Ahmadi-Abhari et al (2017): *Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: modelling study*. BMJ 2017; 358. www.bmj.com/content/358/bmj.j2856

The level of dementia-related disability is likely to increase³, which is to be expected as more people live with dementia to age 90 and above. Hospitals and care services report that there are more people needing help with complex needs.

This document sets the course in Leeds for the next five years. The NHS has set out its [long-term plan](#), including “supporting people to age well”; “fully integrated community-based care”, and “improved support to care homes”. In Leeds we have real strengths in the sense of partnership and commitment, with people with dementia, families and carers, community groups, care providers, and many organisations beyond social care signed up to be ‘dementia friendly’. This strategy describes how that shared commitment will lead to better support people living with dementia in Leeds.

The Leeds Health & Care Plan - our principles

The Leeds Health & Care Plan sets out the ambition to create:

A friendly, healthy, compassionate city with a strong economy where we reduce health inequalities, promote inclusive growth and tackle climate change.

Preventing dementia means reducing the number of people who will develop the condition in later life. Action to address risk factors could delay or prevent 40% of dementia, according to *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission*⁴. The following recommendations will reduce the future prevalence of dementia in Leeds, and to give ourselves the best chance of a healthy later life.

Individually and together, we should:

- Be physically active regularly, stop smoking, drink alcohol in moderation, if at all; be a healthy weight; maintain a healthy blood pressure; and avoid & treat Type 2 diabetes. Promoting good health is a Leeds Health and Care Plan goal which offers positive opportunities for lifestyle change and enables us to age well. These can be difficult to achieve alone, and there are a range of local services and interventions to help us. For example, NHS Health Checks, offered to all aged 40-74, and the National Diabetes Prevention Programme help to identify people at risk of developing type 2 diabetes and provide help and support to enable healthy behaviours.
- Promote social contact, tackle loneliness, and treat depression. *A mentally healthy city for all* is another Leeds Plan goal.
- Look after our hearing. Seek support if you notice hearing loss and use hearing aids when needed to correct it. (This does not apply to Deaf people, who use British Sign Language as a first language; the risk factor is hearing loss in mid- and later life). It is well worth overcoming a reluctance to use hearing aids; when adopted early, they are an extremely effective intervention that reduce the risk and impact of dementia.
- Make Leeds a safer place. Road traffic incidents, assaults and falls are among the causes of brain injury, a serious condition which requires treatment & rehabilitation for the immediate effects. The evidence points also to longer-term risk of dementia.

³ Guzman-Castillo et al (2017): *Forecasted trends in disability and life expectancy in England and Wales up to 2025: a modelling study*. [www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(17\)30091-9/fulltext](http://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(17)30091-9/fulltext)

⁴ www.thelancet.com/commissions/dementia2020

- Educate our children well. The evidence is that education has the strongest protective effect up to 20 years of age; although life-long learning is recommended too.
- Breathe cleaner air. This is a risk factor for which evidence has accumulated in recent years. Brain health is among the benefits of action to improve air quality.

Many of the above factors are linked to preventing cancer and heart disease as well as dementia. All are subject to the wider social and economic determinants of health, and depend on local action to reduce health inequalities. These are things we can change through our collective efforts, and Leeds is seeking to change, through the *Best Council Plan* and *Health and Wellbeing Strategy*.



The *Leeds Health and Care Plan* has three statements that describe “*Our approach in everything we do*”:

- **We start with people**

For people living with dementia, this could be translated as: “*Don’t see dementia, see me*”: ‘Better Conversations’ inform person-centred care. When verbal ability is impaired, physical pain or emotional distress may be communicated through behaviour. ‘Think Family’ means recognising the expertise and needs of carers.

‘Home First’ means supporting people to stay well-orientated in familiar surroundings. For this to succeed as dementia progresses requires strengths-based values, skilled staff and effective partnership work. Support at home is all the more important to many people and families since the Covid crisis.

- **We deliver**

Dementia is everybody’s business - people living with dementia are to be found in all groups, activities and services which support older people. This strategy seeks to include people with dementia as Leeds invests in primary, community and preventive services; and as work continues with care homes and hospitals to improve quality.

- **We are Team Leeds**

Leeds Dementia Partnership brings local organisations together as a team with the shared goal of improving life with dementia in Leeds. Even a diagnosis of dementia usually involves a person’s GP, a scan at a hospital clinic, and specialist NHS memory service. People with dementia are among those especially vulnerable when moving from one service to another, and rely on good information sharing between professionals. Dementia-friendly Leeds widens this local ‘team-work’ to involve local communities, organisations and businesses. People and families living with dementia are part of our “friendly, healthy, compassionate city”.

The next section describes:

- *Thirteen ‘building blocks’*: the elements that have to be in place to make Leeds a good place to live with dementia;
- *Six ‘commissioning priorities’*: to give a focus for action and investment plans.

Thirteen Building Blocks to be the best city to live with dementia

- Population Health, Frailty & Dementia
- Timely Diagnosis & support
- Caring for a person with dementia
- Housing options, design and technology
- Integrated health and care
- Services for people with complex needs
- End of life care

- Dementia-friendly Leeds
- Research - making a difference for the future
- Diversity, inclusion & rights
- Younger people & rarer dementias
- Strengths-based & person-centred
- Arts & Creativity

Six commissioning priorities for health and social care

- Service 'reset & recovery' from Covid
- Demographics, diversity & emerging needs
- Annual review and care co-ordination
- Carer support and breaks
- Care quality, complex needs, timely transfers
- End-of-life care and planning ahead

The Leeds Dementia Action Plan

- a separate document
- updated quarterly
- owned by Leeds Dementia Oversight Board

What are the building blocks ?

The building blocks are the things we have to get right for people to live well with dementia. They:

- a. cover the 'dementia journey', from diagnosis and early support, to end of life care. Dementia is a progressive condition, and needs change over time;
- b. cover the diversity and individuality of people living with dementia
- c. show how everyone can make a difference, through community action and creativity.

Why these six priorities ?

There are six important areas of work where co-ordinated action and investment are required. The choice of priorities is informed by:

- a. Experiences and views voiced by people and carers living with dementia;
- b. A shared understanding of unmet needs and challenges for health and care in Leeds;
- c. Opportunities to make a difference within existing programmes of work;
- d. Identifying where co-ordinated action and investment are required.
- e. Balancing preventive support in the early stages with the needs of people with severe dementia and complex needs.
- f. The impact of Covid-19.

Thirteen 'building blocks' to be the best city to live with dementia

1. Dementia-Friendly Leeds People and places in Leeds are 'dementia-friendly'; we promote inclusion & understanding, and reduce stigma.
2. Timely diagnosis and support Timely diagnosis leads to support to live with the condition, and community capacity keeps pace with emerging needs.
3. Healthy ageing, dementia and frailty People with dementia benefit from initiatives to promote well-being in later life, and care co-ordination for people living with frailty.
4. Caring for a person with dementia Carers are treated as partners in care, and benefit from information, support, and breaks.
5. Younger people with dementia & rarer types of dementia People with younger onset of dementia benefit from specialist support, which recognises people's specific social, economic and clinical needs.
6. Diversity, inclusion and rights People's voices are heard, and rights are upheld when decisions are made. Services recognise and respond well to diverse needs.
7. Strengths, support networks and positive risk management Health and care professionals work to develop person-centred understanding, promote good conversations and positive choices about needs & risks.
8. At home - housing options, design and technology People are enabled by dementia-friendly environments, choices about housing and care, and innovative solutions.
9. Opportunities for arts and creativity People thrive on meaningful activity and occupation, and opportunities for self-expression and communication when life is difficult.
10. Research - making a difference for the future Opportunities for people living with dementia to take part in research to improve treatment and care.
11. Integrated health and care All NHS, care and support services are equipped and skilled to meet dementia care needs, and have timely access to specialist clinical support.
12. People with more complex needs & timely transfers of care People experiencing psychological distress, and people with dementia alongside multiple health conditions, have the right multidisciplinary support out of hospital.
13. Care at the end of life There is honesty about dementia as a progressive neurological condition, and opportunities to plan ahead to make the most of life.

1. Dementia-Friendly Leeds

People and places in Leeds are 'dementia-friendly'; we promote inclusion & understanding, and reduce stigma.

Leeds was one of six places to commit to the campaign for dementia-friendly communities at its launch in 2012, by the Prime Minister of the day at the Alzheimers Society conference. The campaign seeks to sign up organisations to local 'Dementia Action Alliances', and create individual 'Dementia Friends' via awareness sessions and online. The national total of Dementia Friends passed 3 million during 2019.

Dementia-friendly communities are at the heart of improving lives, letting people know that they're not alone, and still belong. People and organisations who are active in these local initiatives are true strengths and assets, making it easier to talk about dementia, to live life as fully as possible, and reduce the sense of stigma.



Dementia-Friendly Horsforth and Horsforth Town Council present 'The Last Memory' - a play by Talking Stock Theatre, at St Margaret's Church



Tea Cosy Café, Rothwell - the 100th café, March 7th 2020



Otley Town Council staff become 'Dementia Friends'



The 'In Touch' Club
Leeds Rhinos Foundation & Leeds Living with Dementia Peer Support Service



Dementia Information Roadshow, Kippax Community Centre:
Wendy Mitchell on living with dementia, and Peter Smith talks about dementia-friendly communities.



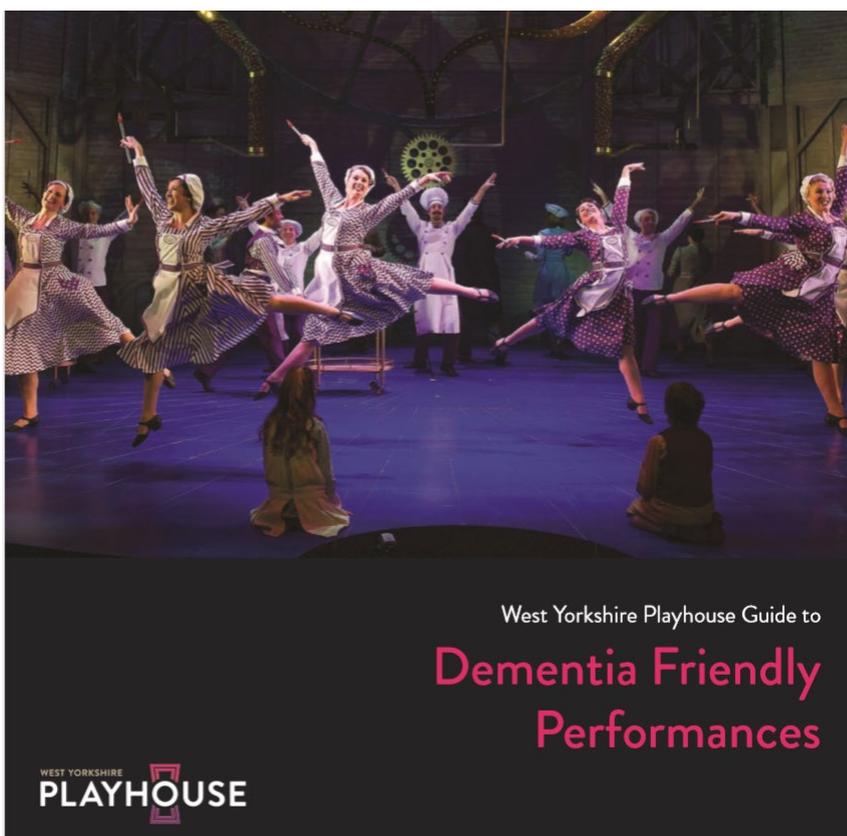
Achievements 2013-20

- ✓ Support and co-ordination of the campaign established with funding from Leeds City Council.
- ✓ 'Up and Go' involvement group established in 2016, for people living with dementia.
- ✓ [Leeds Dementia Action Alliance](#) now has over 200 organisations signed up, including the emergency services, sport, culture, leisure and transport.
- ✓ Leeds has achieved recognition as a dementia-friendly community, from the Alzheimers Society and British Standards Institute. Local initiatives at Horsforth and Morley have achieved recognition.
- ✓ Dementia-Friendly Rothwell has led the way for local communities with the Tea Cosy Café, local shops, pubs, work with schools, and the first dementia-friendly garden in a public park, working with Leeds City Council Parks and Gardens.
- ✓ West Yorkshire Police, building on initial work at Rothwell, have established the 'Herbert Protocol' for when people go missing; introduced dementia awareness for officers; and dedicated staff to act as contacts for concerns around dementia in districts and departments⁵.
- ✓ Further Dementia-Friendly community initiatives at Chapel Allerton, Otley, Roundhay, Wetherby, and the Elmet and Rothwell parliamentary constituency.
- ✓ Over 30,000 [Dementia Friends](#) in Leeds. Over 130 Leeds residents are Dementia Friends Champions and have run almost 2,000 awareness sessions.
- ✓ Leeds Playhouse was awarded "Best Dementia-Friendly Project" at the 2015 Alzheimers Society Awards. The 'Every Third Minute' festival won a National Dementia Care Award in 2018, in the 'Outstanding Arts and Creativity in Dementia Care' category.
- ✓ Sporting reminiscence activities hosted monthly at Leeds United FC, Leeds Rugby, and Yorkshire County Cricket Club.
- ✓ Creative opportunities are embedded in the work of Leeds City Council Museums and Galleries, and Libraries.
- ✓ Opera North presented a dementia-friendly performance of *La Bohème* in October 2019, and worked with local care homes to bring music to residents.
- ✓ Ten successful 'Dementia Information Roadshows' in 2018-19 at community venues in each Community Committee area.
- ✓ Leeds City Council Revenues & Benefits have worked in partnership with a person living with dementia and the Alzheimers Society, to improve access to Council Tax exemption / discount, and use friendlier language.
- ✓ Leeds Libraries and "100% Digital Leeds" supporting people to use devices, be online, and keep in touch, before and during the Covid-19 crisis.

⁵ www.westyorkshire.police.uk/advice/personal-safety-and-possessions/dementia-awareness/dementia-awareness

Our approach to make a difference 2020-25

- People living with dementia have chosen priorities for the dementia-friendly Leeds campaign: transport, shops and businesses, and arts & recreation.
- Maintain a dementia-friendly Leeds action plan, reporting quarterly to the Dementia-Friendly Leeds Steering Group.
- Contact memory café organisers and local groups which haven't met because of Covid-19.
 - offer support to re-establish safe face-to-face and/or digital alternatives;
 - identify people and carers who might have become disconnected from support, and/or deteriorated because of social distancing.
- Explore and focus on opportunities to make a difference eg.
 - influence the development of Leeds station as an age- and dementia-friendly public space.
 - whether social distancing means some places are quieter and more dementia-friendly.
- Grow the Leeds Dementia Action Alliance, reaching a wider range of businesses and partners; recognising that recovery from the Covid pandemic might limit opportunities.
- When engaging with businesses, discuss how to help employees who are working carers.
- Seek more opportunities to work with schools and reach children and young people.
- Gather evidence of how dementia-friendly actions have made a difference.
- More dementia-friendly initiatives in local communities, linked to age-friendly and other campaigns for inclusion.
- Further public information initiatives, working with community partners, including: an event with a BAME focus; and an event for people who are Deaf or hearing impaired.



Leeds Playhouse is a pioneer for dementia-friendly theatre. This 'how to' guide covers everything about putting on a production. People living with dementia are included to co-design the production, and plan the experience and welcome on the day. The guide is published by the Baring Foundation.

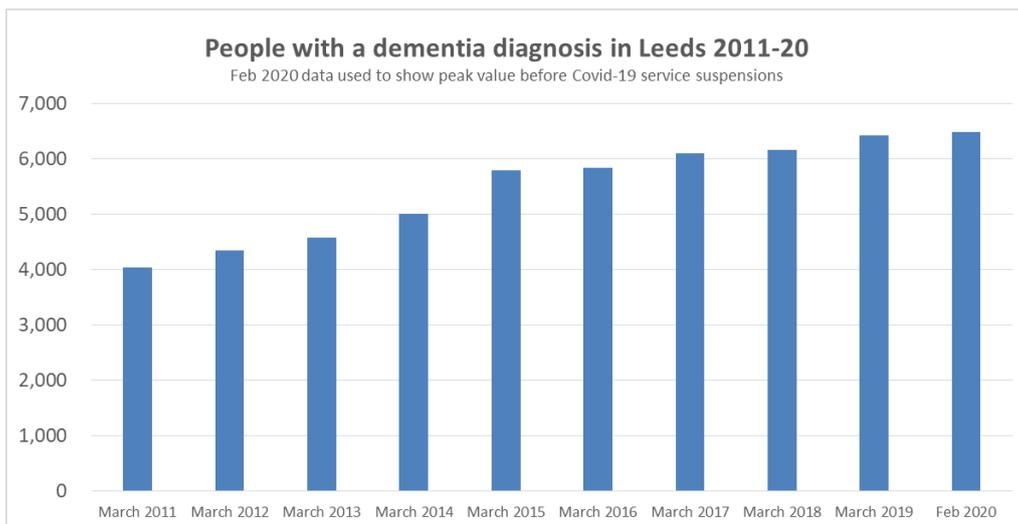
2. Timely diagnosis and support

Timely diagnosis leads to support to live with the condition, and community capacity keeps pace with emerging needs.

Diagnosis

For people living with dementia, it is a difficult decision to explore the possibility that something might be wrong. Dementia-friendly communities and better public awareness will help, but will never entirely take away the fears associated with the condition. Reactions to diagnosis can be a complicated mix of feelings. Sometimes there is relief that there is an explanation for what has been happening; for many it is a very low point.

The diagnosis of dementia in Leeds has improved consistently over recent years, thanks to the efforts by all our NHS providers, and other local organisations, to raise awareness, identify signs and symptoms, make the diagnosis and support people to live with dementia. The chart below shows the progress made; by February 2020 the official estimate from NHS Digital is that Leeds had a diagnosis rate of 74.7% (ie. actual number of people with a diagnosis, as a proportion of estimated prevalence).



Diagnosis rates will never reach 100% of estimated prevalence. This is because people must be supported to seek diagnosis in a timely way, but not 'ambushed' with it. For some frail older people approaching the end of life with other health conditions, it could be 'overdiagnosis' to explore mild symptoms of possible dementia – ie. there may be no benefit to going through the process.

Support after diagnosis

Most importantly, diagnosis is a gateway to support and an opportunity to offer people, families and carers a way ahead and come to terms with living with dementia. Although 'diagnosis rate' is still the thing that NHS England use to measure local services, diagnosis is not by itself an achievement. It must connect to meaningful support to live with dementia.

The approach in Leeds has been to create a support offer to everyone living with dementia. This has been achieved by investment in the Memory Support Worker

service, and continuing to build community capacity. Post-diagnosis support no longer depends upon whether or not a person is prescribed medication. The use of well-trained and skilled support workers has enabled clinical staff to be available in a more timely way, eg. to reduce waiting times for diagnosis.

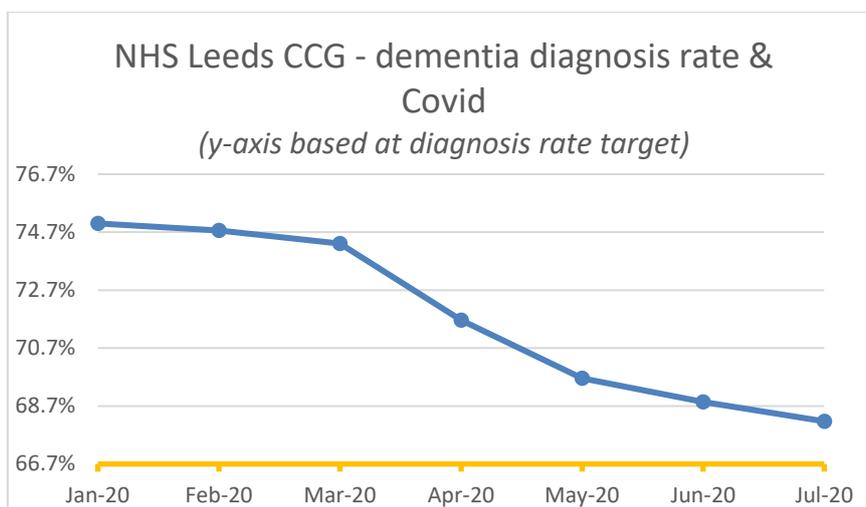
Leeds is fortunate to have many dementia-friendly organisations and volunteers who have set up and run groups such as Memory Cafés. It is our ambition to ensure that support is available to all; to keep pace with emerging needs; and to keep people supported in our communities for as long as possible.

Cognitive Stimulation Therapy (CST) is an approach to offering structured activity which is recommended in NICE guidance⁶. It is offered post-diagnosis by specialist NHS services, and two local Neighbourhood Networks have established groups offering CST or activities informed by the approach. A further innovation is the use of a 'Circles Of Support' approach to keep people connected and active.

Other post-diagnosis support is described throughout this document, such as services for (unpaid, usually family) carers; opportunities for arts and creativity; social care.

The impact of Covid-19

However, the Covid pandemic and suspension of memory assessment and diagnosis services has, not surprisingly, caused diagnosis rates to fall, both nationally and locally. The usual pattern in Leeds is that there are just over 1,000 people newly-diagnosed each year, whilst c. 1,000 people with a dementia diagnosis die each year. This leads to a modest net increase, as shown in the chart above. Most of the decrease shown below has been caused by the pause in diagnosis activity. In addition to this there have been 'excess' deaths related to Covid-19, ie. more people with dementia have died compared to what would normally be expected.



⁶ National Institute for Health and Care Excellence, NG97 'Dementia: assessment, management and support for people living with dementia and their carers'

Achievements 2013-20

- ✓ Leeds achieved the national ambition for a 66.7% diagnosis rate at March 2015, and continued to improve from there to 74.7% at end Feb 2020, with 6,493 people recorded with a dementia diagnosis on Leeds GP registers.
- ✓ Leeds Memory Service sees more than 90% of people within 8 weeks of referral; more than 65% have a diagnosis within 12 weeks of referral.
- ✓ Leeds Memory Service has consistently retained its accreditation by the Royal College of Psychiatrists' Memory Services National Accreditation Programme (MSNAP).
- ✓ The Memory Support Worker service started in October 2015, and supports 1,500 people every year.
- ✓ Information and leaflets about services available at www.leeds.gov.uk/dementia.
- ✓ 47 Memory Cafes and 13 singing groups, supporting all communities in Leeds.

Our approach to make a difference 2020-25

- Reset and recovery of memory assessment and diagnosis, to support people who have missed out during the Covid crisis, and return to pre-Covid level of dementia diagnosis rate.
- Set out an accessible local offer for people with a dementia diagnosis, in leaflet and online form.
- Continue to raise awareness of signs and symptoms, and improve the diagnosis and support pathway, including:
 - further reduction in waiting times
 - develop the post-diagnosis support offer, including the offer of Cognitive Stimulation Therapy.
- As people born in the years after 1945 reach the age of 75 and beyond, ensure capacity and diversity of provision keeps pace with demand, and supports people for as long as possible.
- Innovation and development in community support, to keep people well for longer, and support people further into the progress of dementia, where this is a safe and positive option.



The Memory Support Worker Service in Leeds.

Anyone can refer to the service for help.



3. Dementia, healthy ageing and frailty

People with dementia benefit from initiatives to promote well-being in later life, and care co-ordination for people living with frailty.

Dementia, frailty and mental health

The NHS Long-Term Plan considers dementia as a long-term condition linked to frailty and healthy ageing, often occurring with other long-term conditions more prevalent in later life. Traditionally, dementia has been ‘badged’ as a mental health condition, affecting cognition, mood and behaviour. Specialist services and professional expertise has developed within old-age psychiatry and other specialist clinical roles linked to older people’s mental health.

The Leeds strategy, going back to 2013, has sought to achieve the ‘best of both’: a ‘whole person’ approach to supporting people to live with dementia alongside other health conditions; and with timely access to specialist input when needed. The focus of support is primary care (GP practices) and community services (NHS, social care and community groups). The Memory Support Workers help people to navigate the system and join up services.

Healthy ageing & reducing the risk

A ‘healthy ageing’ approach includes reducing the risk of developing dementia and other conditions. The risk factors and opportunities to prevent dementia are described in the earlier section on the Leeds Health and Care Plan. There are two further points:

- The NHS Healthcheck, offered to everyone aged 40-74, is an opportunity to discuss lifestyle choices, support available to make positive change, and the risks of heart disease, cancer and other conditions as well as dementia.
- People must not be blamed for, or further stigma attached to, dementia. We can do our best to improve our chances, but to develop dementia is to be unlucky.

Frailty and Population Health Management

Leeds City Council and local NHS organisations have adopted the approach of ‘Population Health Management’. This considers ‘cohorts’ of people at different stages of the life-course and different health needs. Local NHS data indicates that there are some 32,000 people who live with moderate to severe frailty, and/or are near to the end of life; of whom more than 4,000 have a diagnosis of dementia.

Frailty refers to a reduction in our resilience and ability to cope with illness and adverse events. It means it might take only a small change to cause a crisis. For example, people with dementia are particularly susceptible to episodes of acute delirium, which may be perceived as ‘dementia getting worse’, and it is important to prevent when possible, and offer opportunities for recovery. The Leeds frailty programme seeks to improve resilience and prevent crisis as far as possible, and for urgent care services to respond in a timely way when necessary.

Annual review and support planning

GP practices are funded to do annual reviews with people living with dementia, and with a range of long-term conditions. This review is an important opportunity to ‘check in’

with people, to see if a person's dementia has progressed, whether carers are struggling, and whether more support is needed. This is especially the case for people who didn't feel the need for support straight away after diagnosis, and might be 'lost' to services without a regular 'check in'. Improving the quality and consistency of reviewing is a high priority for this strategy, and NHS investment in healthy ageing and frailty is a real opportunity to achieve this.

Public Health in Leeds has worked with GP practices to develop 'Collaborative Care and Support Planning' (CCSP) with people with long-term conditions. This approach is based on 'Better Conversations' about living with health conditions. The conversation is focused on goals that people would like to achieve, and agreeing actions to achieve them. The idea is to have one conversation about the person, rather than separate conversations about different diseases. Dementia is included in this approach; we know that 2,800 people with a dementia diagnosis had a CCSP review in the 12 months to September 2019. Work is in progress to understand to what extent the reviews recorded goals related to dementia.

Care co-ordination and teamwork

Finally, the NHS Long-Term Plan envisages that "Expanded neighbourhood teams will comprise a range of staff such as GPs..., pharmacists, district nurses, community geriatricians, dementia workers...". In Leeds, we can claim to have already achieved the integration of Memory Support Workers into neighbourhood teams alongside clinical staff. There will be further opportunities arising from NHS England investment in care co-ordination and social prescribing.

Achievements 2013-20

- ✓ Identifying health inequalities, linked to heart disease and Type 2 diabetes, as risk factors for developing dementia; dementia is included in the "One You" campaign⁷.
- ✓ Memory Support Workers are established as part of Leeds Neighbourhood Teams, older people's mental health services, and linked to GP practices.
- ✓ Leeds Community Healthcare "Dementia, Depression & Delirium" pathway.
- ✓ A holistic approach to living with dementia, other long term conditions and frailty.

Our approach to make a difference 2020-25

- Reduce the risk of dementia: 'One You Leeds', take-up of the NHS Healthcheck, diabetes prevention programme.
- Improve quality and consistency of the annual dementia review.
- Explore innovative approaches eg. using community venues for review; a six-month review after diagnosis.
- Ensure there is access to support in the months / years after diagnosis, for people who don't take up services immediately post-diagnosis.
- More opportunities and support to plan ahead for the later stages of dementia.
- Taking the opportunities offered by the further development of social prescribing, and introduction of care co-ordinator roles.

⁷ <https://oneyouleeds.co.uk/dementia-reduce-your-risk/>

4. Caring for a person with dementia

Carers are treated as partners in care, and benefit from information, support, and breaks.

Carers are “living with dementia” too

A local carer, speaking at a Dementia Information Roadshow event in 2019, used a revealing phrase when telling her and her husband’s story:

*“When we got **our** diagnosis...”*



Eugene Harris and Diana Smith-Harris. Photo from Alzheimers Society “Dementia Together” magazine, April/May 2019.

‘Living with dementia’ applies to families, friends and carers as well as the person experiencing the condition itself. Research⁸ indicates that:

- 85% of people with dementia are supported by an unpaid carer; for Leeds this is an estimated 7,400 carers.
- 34% of carers of people with dementia are ‘economically active’; so Leeds has c. 2,500 carers of people with dementia who combine unpaid caring with paid work.

The impact of caring

Most people with dementia live at home (c. 25-35% live in care homes), and even when dementia becomes “severe”, an estimated 50% of people live at home⁹. Perhaps 1,000 carers in Leeds are supporting people with the effects of the later stages of the condition: eg. psychological distress, disturbed sleep pattern, continence care, support to stay safe. As well as the physical demands of caring, there is the emotional impact of seeing someone close to you change as the condition progresses, and perhaps the gradual sense of loss.

Carers may struggle to put their own needs first, and even to articulate one’s own needs when in the habit of speaking for the person with the condition. Carers want to know that other care arrangements are available, whether in an emergency, or for a planned appointment, for holidays, for a hospital stay and, as carers said in the course of consultation on this strategy, “what if I die first?”. This point is followed up in the “At Home – Housing Options... section).

⁸ Various sources, collated in Lewis *et al* (2014): *The Trajectory of Dementia in the UK – Making a Difference* (Alzheimers Research UK). www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf

⁹ Alzheimers Society – *Dementia UK report*: www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report

Covid-19, families and carers

The Covid-19 pandemic has had a huge impact on carers and support services for carers. Carers have been faced with many different challenges, such as:

- being unable to visit the person they care for, or restricted in visiting, particularly if the person lives in a care home;
- coping without services that offer a break from caring - eg. day centres, community groups.
- having to make tough decisions about what to do for the best - eg. helping with personal care when it was difficult to source gloves, masks and other protective equipment (PPE).
- coping when the person with dementia doesn't understand the need for social distancing.
- coping with bereavement when they were unable to say goodbye in person.

Jackie Powell, who cared for her husband Keith at home, has spoken very movingly and powerfully of the impact of Covid-19. Until "lockdown", he attended the Young Dementia Leeds day centre, run by Community Links, five days a week. The loss of routine and activity caused a rapid decline as if "he fell off a cliff". This led to serious falls, loss of balance and co-ordination, and extremely interrupted nights. Eventually he had to move to a care home where Jackie was unable to see him for many weeks.

www.youtube.com/watch?v=QU4SkuGX9CM (the video was made by Jackie with Carers Leeds)

Carers Leeds and other services have adapted by eg. offering telephone support, and running carers groups on 'Zoom'. As services started to open again, this may cause difficulties readjusting, and making decisions about vulnerability to Covid-19.

What sustains caring and makes it a satisfying role ?

When carers are able to stay positive about life with dementia, it is often because:

- there are opportunities to do things together, and to feel that the original relationship with the person is still there;
- when the carer's expertise and views are respected by professionals;
- when there are opportunities to learn about dementia and share experiences with others;
- when there are opportunities to take a break and have even a couple of hours a week to choose how to spend the time;
- when there is support from services which offer good quality, person-centred care. This can lessen feelings of guilt about sharing the care with others;
- when the carer can develop coping strategies to be more patient, and accept the changes that come with dementia;
- finding ways to get a good night's sleep.

Achievements 2013-20

- ✓ A 'Dementia Carer Hub' at Carers Leeds, with over 1,000 carers supported per year. Services include....
 - ☆ 1:1 support offer for carers
 - ☆ hospital-based support at St James.
 - ☆ information and education sessions for carers
 - ☆ carers' support groups.
- ✓ 'Working carers' initiative with large local employers .
- ✓ Leeds hospitals signed up to "John's Campaign", so carers can support people with dementia beyond usual visiting hours.
- ✓ Recruiting carers to join Leeds Dementia Partnership

Our approach to make a difference 2020-25

- The Leeds Carers Partnership Strategy: *Putting carers at the heart of everything we do*
- Identify carers, especially in primary care (GP practices)
- Strengthening and listening to the voice of carers.
- Reach more carers of people with dementia with a positive offer of support, and reduce the isolation experienced by carers.
- Once carers have been identified and supported by services, keep in touch. Dementia is a progressive condition and carers are likely to need more help as time goes on.
- Improving capacity and choice for carer breaks.
- Offer support and substitute care which enables carers to prioritise their own health and well-being.



Carers Leeds trip to Morecambe
National Dementia Carers Day, September 2019

5. Younger people with dementia & rarer types of dementia

People with younger onset of dementia benefit from specialist support, which recognises people's specific social, economic and clinical needs.

Prevalence and people's needs

There are c. 200 people in Leeds who are aged under 65 with a dementia diagnosis¹⁰. The overall prevalence of younger-onset dementia is hard to estimate, but there may be a further 100-200 people without a diagnosis. Younger people with dementia have specific needs which reflect the medical and social circumstances of developing the condition at this time of life. The provision of specialist services is supported by the National Institute for Health and Clinical Excellence (NICE) guideline on dementia. The need for such services requires a holistic view of family, social and clinical aspects, rather than whether a person has reached the age of 65.

Younger-onset dementias show a higher prevalence of rarer types, eg. frontal-temporal dementia and post-cortical atrophy. There is generally a wider range of symptoms such as behavioural disinhibition and personality changes. The diagnosis of dementia can be more complex at a younger age, with a combination of factors – eg. stigma, medical complexity – leading to longer diagnosis processes and a lower 'diagnosis rate' for this population. Very rare types of dementia may occur when brain cells are affected in the progression of neurological conditions such as Huntington's Disease.

Socially, people may be at a particular stage of family life and career / employment, and there may be particular impact on social networks. Younger-onset dementia is more likely to have financial consequences, sometimes very severe, arising from eg: loss of employment and income (for the carer as well as the person with dementia) and affect long-anticipated plans for retirement. People may have young grandchildren and important family roles with childcare; or their own children may still be financially dependent, eg. in higher education or even younger (Office of National Statistics data shows that the average age of parents is increasing). People with younger-onset dementia often have parents who are ageing, perhaps with care and support needs of their own.

Dementia and people with a learning disability

The onset of dementia tends to be younger for people with a learning disability, particularly Downs Syndrome, in which the risk of developing with dementia at any given age is approximately the same as for a person thirty years older without the syndrome. In Leeds, NHS community learning disability services manage a specialist diagnosis pathway. The culture and practice of person-centred care is of long standing in services for people with learning disability, and may help providers of care and support to adapt to dementia care. However, when a person with a learning disability has lived into adulthood with parents in the caring role, Carers Leeds report that the development of dementia can present new difficulties, and sometimes affect both generations in the family.

¹⁰ NHS Digital, monthly data publication.

Services for younger people with dementia and carers

There have been improvements to services in the past three years (see 'Achievements' below). However, carers of younger people with dementia report that residential care services may involve the person being placed in an environment with people much older; and that people often have to go to care homes outside Leeds. required for both carer breaks and longer-term care, and there is potential for providers to meet demand more locally, with carers reporting that this would be preferable to placements outside Leeds.

Achievements 2013-20

- ✓ 'Young Dementia Leeds' provides day services for younger people with dementia at a day centre and at home.
- ✓ The service has moved to new premises with a new provider (Community Links), and are offering more choices of activity, working with partners to offer eg. creative arts and cookery. A Memory Café has been added to the service offer.
- ✓ Carers Leeds are part of Young Dementia Leeds and offer dedicated support and a group for carers of younger people with dementia. This has extended support to many carers who don't use the day services.
- ✓ Younger people with dementia team (NHS specialists) delivered 'Target' training session to GPs, leading to increase in number of people with a diagnosis in 2019.

Our approach to make a difference 2020-25

- Involve the 'Mindful Employers' network, and other local employers, to increase access to 'reasonable adjustments' for people who develop dementia whilst in paid employment.
- Work with care home and supported housing providers to develop provision in the Leeds area.
- Work with the new carers group who are committed to campaigning and improving services.
- For people with a learning disability who develop dementia, to improve access to diagnosis and understand specific support needs, eg. for older parent carers.



Carers Support Group at Young Dementia Leeds

6. Diversity, inclusion and rights

People's voices are heard, and rights are upheld when decisions are made. Services recognise and respond well to diverse needs.

'Diversity' has many aspects, and for people living with dementia it is important that person-centred care is informed by an understanding of social and cultural factors, alongside personal history.

Most people with dementia are aged 80+, and the condition is more common in affluent areas where people live longer. These tend to be more rural areas, where there can be difficulties accessing services. Some villages have well-established Memory Cafés, whereas people in some places have to travel to access services. However, the age-related risk of developing dementia is higher for people at a disadvantage from health and social inequalities. This means that the geographical spread of people living with dementia is more even - between inner city, suburban and rural areas - than might be expected from the age profile alone.

There are people from the many different and diverse 'Black, Asian and Minority Ethnic' (BAME) communities in Leeds who have experienced old age and increasing risk of dementia for several decades (eg. older people who identify as Irish, Jewish and other European origins); and the past one or two decades (eg. many older people of south Asian and Caribbean origins). South Asian and Caribbean populations in particular have a 4-5 times higher risk of developing Type 2 diabetes, which in turn is linked to increased risk of dementia. Dementia can take away the ability to speak English for people who learned it as a second language. Reported experience is that people from south Asian communities are looking to use eg. residential short stays for carer breaks and the language capability of services is a difficulty. Local organisations have worked with GP practices to support assessment of memory and cognition in the diagnosis process.

More women have dementia than men, because women are more likely to live beyond age 80; men are marginally more likely to have younger-onset dementia. There is evidence that unpaid caring is more likely to affect women, in the caring tasks carried out, and at a younger age¹¹.

Lesbian, gay, bisexual and transgender older people have grown into adulthood and later life at a time of changing social attitudes and inclusiveness, and both developing dementia and coming into contact with care services can lead to difficulties and uncertainties. Alzheimers Disease in particular can take away recent memories and lead to a sense of the past being the current reality, which can be distressing for the person and loved ones to eg. be back in a time when sexuality or gender identity was more often concealed.

People need, and are entitled to expect, mainstream services to work well and be competent with diverse needs – eg. Memory Services, hospital care. However, specific

¹¹ *Will I Care ?* - Carers UK report (2019): www.carersuk.org/images/News_campaigns/CarersRightsDay_Nov19_FINAL.pdf
This considers unpaid caring as a whole, it is not a dementia-specific study.

services are often valued, such as support to overcome barriers to access; memory cafés where mother tongue language is used & understood; groups for older LGBT people.

Dementia is itself a disabling condition and important rights are conferred under equalities legislation and the legal framework for mental capacity. These cover access to services, social inclusion, and decision-making. 'Dementia-friendly' approaches have had considerable success to improve understanding of the condition and acceptance of people living with dementia. A rights-based approach will complement and strengthen inclusion and quality of services.

Achievements 2013-20

- ✓ Memory cafes and groups supporting local Caribbean, Irish, Jewish, south Asian people with dementia and carers.
- ✓ In 2018, Touchstone BAME Dementia Service in Leeds won the Championing Diversity category at the Alzheimer's Society awards. This service is commissioning by the NHS in Leeds.
- ✓ Establishment of BAME Dementia Forum.
- ✓ Dementia awareness promoted via Dementia Friends Champions in community organisations.
- ✓ A BAME dementia event in 2015, leading to a grants process and new service developments.
- ✓ Memory Clinics established in 7 GP practices to reduce travelling distances. People in the Wetherby area can attend Memory Clinic hosted at Crossley Street Surgery, rather than travel to Knaresborough.
- ✓ The number of people from BAME communities in Leeds with a dementia diagnosis, matches the expected number in proportion to the BAME population aged 65+.

Our approach to make a difference 2020-25

- A rights-based approach, to complement dementia-friendly initiatives and person-centred care; ensuring rights are upheld at key decision when decisions are made.
- Obtain funding and commission research into the experience of people with dementia and carers of diverse BAME origins in Leeds.
- Improve access to Memory Cafés and other groups in rural areas.
- Dementia awareness and addressing barriers to seeking support with older LGBT people.
- Develop care and support services with language and cultural competence.



Touchstone Leeds 'Hamari Yaadain' Café



Adapting to Covid: the Café goes online

7. Strengths, support networks and positive risk management

Health and care professionals work to develop person-centred understanding, promote good conversations and positive choices about needs & risks.

A strengths-based approach to social care offers supportive conversations to connect people to a range of resources and groups; respond effectively at times of crisis; and plan for the longer term. It seeks to avoid the often undignified and diminishing experience of the 'gift and entitlement' model, of being assessed to see if eligibility criteria are met. Hand-in-hand with this approach is 'asset-based community development', building on the strengths of communities to offer opportunities for people to live well and to be active and involved.

The ambition for people in Leeds to live well with dementia, and to benefit from person-centred care, fits very well with these approaches. This continues to be the right approach as dementia progresses to its later stages, when it becomes all the more important to: understand what approaches work to communicate with a person and promote emotional well-being; support family carers, who are a huge resource for many people in the later stages of dementia; enable community groups to access the right help to continue meeting people's needs.

'Positive risk management' means taking a person-centred approach to why a person might be behaving in certain ways and presenting risks, and looking at creative ways to reduce and monitor risks; and balance different risks, preferences and rights.

Interventions such as residential care resolve many concerns, but can create other risks related to eg. the loss of a sense of belonging, or understanding why strangers are in one's living space.

The care of older people has traditionally focussed more on personal care, meals and routine daily living, and less so on social activity and access to the community. For people with dementia, involvement and meaningful occupation are beneficial and can be crucial to maximise brain function and individual ability.

Direct Payments and other kinds of personal budget can offer person-centred solutions, acknowledging that people and carers living with dementia nearly always need additional support to co-design and manage the care arrangements.

This is an example of good practice in Leeds, showing how a strengths-based and person-centred approach can improve quality of life and manage risks:

Here is an example of good practice in Leeds, showing how a strengths-based and person-centred approach can improve quality of life and manage risks:

"The final appointment of the day was a lady with dementia who has been going out on the buses and getting lost, and her husband has had to either go and find her or call the police. He wanted to be able to keep her at home with him, but couldn't be with her 24/7. Her son and daughter-in-law came 3 hours from their home also to be at the appointment. The lady lacked a lot of insight in to the risks and was quite adamant in that she didn't want any help, or anyone to stay with her when her husband wasn't there. She said she was going to continue to go out as it is boring to be in the house all day. We discussed some alternative things that she could go and do in the community, such as neighbourhood networks and local groups who could put on transport, or where her husband could drop her off. She was happy to try this out as she said she liked to get out of the house and spend time with people. I also suggested a GPS tracker, although she was initially

reluctant when I explained this could be used in case of an emergency she was willing to try this to help her family not to worry.

.....

“I referred her to [*the local neighbourhood network*] and the Memory Support Worker who will visit to suggest some other groups she could join in with and sort out the Herbert Protocol for the police. I made a referral to Telecare for the GPS tracker, and I emailed the son with what was discussed and what has been done so far. We agreed to meet again in around a month and see if these changes have helped or whether we need to look at some other options.” (Social Worker at a local ‘Talking Point’, 2017).”

Achievements 2013-20

- A team of three “Dementia and Mental Health Liaison Practitioners” has been established, offering specialist support and co-working with NHS colleagues and social workers in Neighbourhood Teams.
- Recovery approaches have been promoted in contracts for Community Care Beds, and introduction of short-term additional funding for people to leave hospital or avoid admission.
- Dementia-friendly approaches have strengthened community networks and assets – eg. increase in Memory Cafes.
- Memory Support Workers and Dementia Carer Support Workers offer conversations which listen to people’s concerns and connect people to community groups and activities.

Our approach to make a difference 2020-25

- Explore and take opportunities to include dementia in work on better conversations, strengths-based social work and asset-based community development.
- Train staff in support planning with people living with dementia.

8. 'At home' - housing options, design and technology

People are enabled by dementia-friendly environments, choices about housing and care, and innovative solutions.

Digital Innovation

Good design can involve small things that make a big difference to the ability of people to live well and independently – for example, signage which reminds a person where the toilet is. Technology has huge potential for everything from peer support, monitoring for personal safety, reminders and prompts, meaningful activity and even care & companionship. It is important that digital technology is used in an enabling way that offers less restrictive options to support living well and personal safety.

Bringing together the expertise of people with dementia and carers, with design and technical expertise will co-produce useful innovation. It is likely that the most useful solutions will be those adaptable for each individual.

A woman in east Leeds attends a group at her local neighbourhood network for people with dementia, each week. Her son lives in the south of England, and has set up a webcam in her house. From his work, he can see if she's up and ready, and calls her on the phone to remind her if need be.

We have set up a new Digital Inclusion Programme through Memory Lane Trust Community Interest Company. This idea was taken from 100% Digital Leeds. So far we have distributed 15 tablets (some with cellular SIM cards) and 16 Alexas to our clients.

We hold daily Zoom meetings online to deliver companionship and meaningful activities. We have twice a week exercise classes and various quiz, bingo and singalong sessions. Up to 30 people are joining the meetings each day and feedback is wonderful that this is helping to improve their day to day wellbeing. We are working to expand the programme to many more over the coming weeks and hope to sustain these activities even after Covid 19.

We have also delivered more than 40 afternoon teas on Saturdays.

from Memory Lane Day Centre, Yeadon
June 2020

Leeds Libraries were awarded a small grant by the 'Widening Digital Participation' programme in 2019, to explore with people and families living with dementia how digital technologies could improve quality of life¹². Little did they know at the time how positive and practical the work would turn out to be as preparation for social distancing, with people and services needing alternative ways to meet and talk.

Housing Options

People living with dementia and carers are ready to consider moving in the earlier stages of dementia; and extra care / supported housing is seen as a positive option. This was the consensus at a conversation about this strategy during 2019, at the Leeds 'Up and Go' group for people living with dementia. Spouses / partners in the caring role do worry about what would happen if they were to need to go into hospital, or were to 'be the first to go'. Extra care housing offers reassurance that alternative care arrangements would be there in a crisis.

¹² The programme was funded by NHS Digital and The Good Things Foundation. The full report from 100% Digital Leeds is available here: <https://digitalinclusionleeds.files.wordpress.com/2020/06/leedsdementia-report2020.pdf>

People value connections with where they live, and this supports the Leeds approach of planning extra-care development to local geography. Concern was expressed that, as dementia progresses, extra-care housing should continue to support people as a 'home for life', and that further moves to care homes are kept to an absolute minimum.

Design for health & care environments

The independent sector tends to use standard designs for care homes, and recent experience suggest that opportunities have been missed to apply best practice to new developments. One option, suggested by developments in Liverpool, is that the local authority can design and build new specialist accommodation, even if it does not directly provide the care.

The specialist inpatient accommodation at The Mount has been improved as far as possible with redecoration and improved lighting, but there are limitations arising from adapting traditional mental health wards for dementia care. Longer-term, Leeds has the ambition to offer purpose-built accommodation using best-practice dementia care design.

Achievements 2013-20

- Dementia-friendly design has been implemented as wards have been redecorated at Leeds Teaching Hospitals.
- Dementia specialist wards at The Mount have had environmental improvements.
- Successful 'Widening Digital Participation' project by Leeds Libraries & 100% Digital Leeds, to improve understanding of how digital developments can support living with dementia.
- 'Smart House' at Assisted Living Leeds includes options to enable people to live at home with dementia.
- Accommodation and care for people with dementia is included in extra-care housing developments.

Our approach to make a difference 2020-25

- Applying best design principles to dementia care environments – housing, care homes and hospitals.
- Improving choices and outcomes for housing with care for people with dementia.
- Co-design: so that physical environments and digital solutions are informed by real-life experiences, and investment is directed by what people need.

9. Arts and creativity

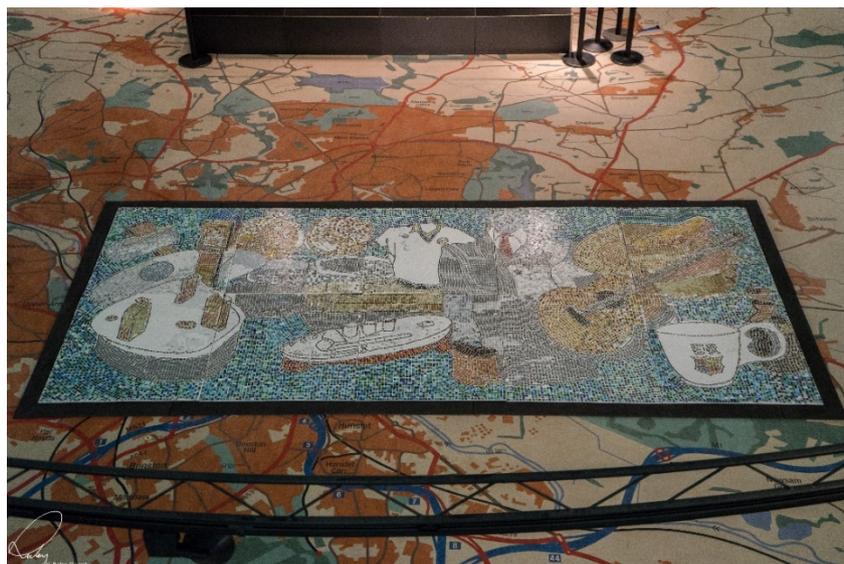
People thrive on meaningful activity and occupation, and opportunities for self-expression and communication when life is difficult.

Good things come from taking part in creative activity – feeling calm, making connections, opportunities to take the lead, self-expression, lifting the mood. Some people with dementia report that they feel less inhibited at trying new and different things than they might have before developing the condition. People living with dementia have chosen “arts and recreation” as one of our top three priorities for dementia-friendly Leeds.

There are excellent local examples of arts organisations, creative artists and community groups working together, and the challenge for Leeds is to extend these opportunities to more people, especially people in the later stages of dementia, and move from successful ‘one-off’ projects to sustained provision, including empowering carers and care staff to learn creative ways of communicating and working with people.



The two Leeds banners¹³



Leeds City Museum - mosaic¹⁴

each group which took part now has its own section of the mosaic.

¹³ <https://phm.org.uk/exhibitions/the-unfurlings-a-banner-display/>

¹⁴ www.leedsinspired.co.uk/projects/mosaic-leeds-paul-digby



Yorkshire Dance have brought music and joy to people in care homes with “In Mature Company”¹⁵. and used ‘dementia care mapping’ as an evaluation technique to show how the sessions improve mood and interactions during and after the sessions.

photo from the Yorkshire Post, 15th January 2019

Achievements 2013-20

- A range of creative opportunities established by the Leeds Living With Dementia Peer Support Service working with Leeds Playhouse, Leeds Museums and Galleries, and other partners.
- Many one-off creative projects carried out by third sector partners with local artists – eg. Mosaic project at Leeds City Museum; Pavilion Arts work with Touchstone and Leeds Irish Health and Homes.
- Fifteen singing groups for people with dementia in Leeds¹⁶.
- People in two local groups have produced banners, working with artist Ian Beesley and poet Ian McMillan, as part of a national project.
- Leeds Playhouse staged the award-winning “Every Third Minute” festival, curated by people living with dementia.
- Dementia-friendly performances pioneered at Leeds Playhouse, and adopted by Opera North.
- Leeds Playhouse has produced a “Guide To Dementia Friendly Performances” to provide best practice advice based on its award-winning performance model¹⁷.
- ‘In Mature Company’, a Yorkshire Dance Project to work in local care homes, 2018-21.

Our approach to make a difference 2020-25

- Creative arts for living well - explore and take opportunities offered by developments in social prescribing.
- To offer music, art and creativity for people experiencing psychological distress in the more advanced stages of dementia, to improve well-being and enable less restrictive care.
- Work with the care sector to offer creative opportunities for people in care homes and day centres; including training for artists to engage with people with dementia. Build on the success of one-off projects to develop a sustained approach.
- Work with the Leeds Arts and Health Network, including our universities, to evaluate creative initiatives and develop evidence for investment.

¹⁵ Funded by ‘Time To Shine’, Leeds Lottery-funded programme to tackle loneliness.

<https://yorkshiredance.com/project/in-mature-company/>

¹⁶ <https://www.leeds.gov.uk/docs/Singing%20Groups%20in%20Leeds.pdf>

¹⁷ https://leedsplayhouse.org.uk/latest_news/west-yorkshire-playhouse-launches-guide-staging-dementia-friendly-performances-dementia-awareness-week/

10. Research - making a difference for the future

Leeds is ambitious to create opportunities for people living with dementia to take part in research to improve treatment and care.

But I am determined to be heard. And so I ask questions, lots of them, this brain that still works so well on good days set on proving to them why I've chosen to take part in this trial, to understand more about this disease, to empower myself.

Wendy Mitchell, from her book "Somebody I Used To Know"

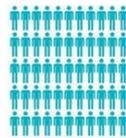
There are three important steps to enable people to take part in dementia research:

- awareness of opportunities and how to get involved. Everyone - with and without dementia - can sign up to 'Join Dementia Research': www.joindementiaresearch.nihr.ac.uk
- obtaining informed consent, which is built into the ethics of research studies;
- the practicalities of taking part - local researchers consult with people living with dementia to design research studies.

Involvement in research not only contributes to progress in treatment and care, it enables people to feel more hopeful and useful. Leeds & York NHS Partnership Foundation Trust have produced a video with people explaining why they're involved in research: <https://youtu.be/ywNhEUHWxV0>

Leeds has real opportunities to increase involvement, with three universities, three NHS Trusts and the Leeds GP Federation.

Join Dementia Research in numbers



46,676
volunteers
registered



36,357
participants have
joined a study



452
studies have
used the service



97
studies are currently
open to recruitment



1,464
researchers have been
trained to use the service



273
research sites have
used the service



These statistics are accurate as of 29th February 2020

Achievements 2013-20

- When diagnosed, people in Leeds are routinely offered information about 'Join Dementia Research'. 1.5% of people with a dementia diagnosis in Leeds have signed up; this is too low, although it compares to a national average of 1% (at October 2019).
- 1,167 people have participated in 46 studies in the field of 'dementia and neurodegeneration' in Leeds NHS Trusts (again, data from October 2019).
- Leeds Beckett University has opened its Centre for Dementia Research, and has a lead role in important research areas. The 'What Works' study for dementia education and training was funded by Health Education England:
www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/
- University of Leeds has developed the 'SIDECAR' tool for measuring well-being of carers of people with dementia.
- Local NHS Trusts and universities are engaged in a range of research collaborations.

Our approach to make a difference 2020-25

- Increase the numbers of people, with and without dementia, in Leeds who are signed up to 'Join Dementia Research'; promote and encourage throughout the care and support sector.
- Ensure staff to signpost people to research opportunities, using the 'LEARN' tool:
<https://learn.joindementiaresearch.nihr.ac.uk/>

11. Integrated health and social care

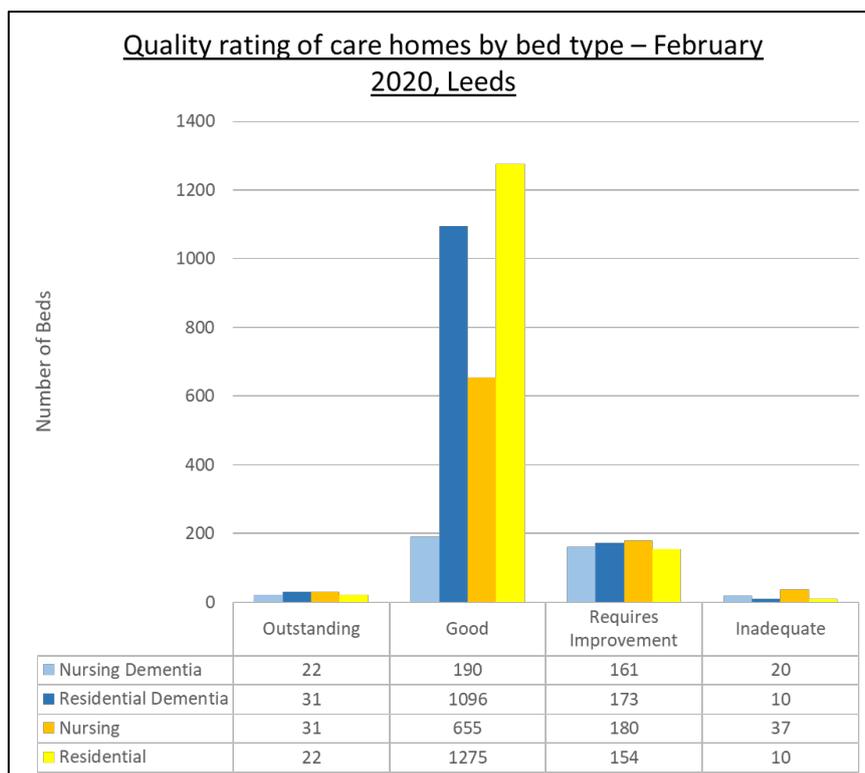
All NHS, care and support services are skilled at meeting dementia care needs, and have timely access to specialist clinical support.

A national concern

The Alzheimers Society's 'Fix Dementia Care' campaign shares examples of poor experiences of care services, and identifies national concerns including the expense to families of self-funding and 'topping up' care; shortage of government funding, variable care quality and lack of staff training.

Care home quality in Leeds

There have been significant improvements to the quality of care homes in Leeds in recent years, as judged by the Care Quality Commission (CQC). However, for people and families seeking specialist dementia care, it is more difficult to find a care home rated 'Good' or better by the CQC. The chart below shows the lower proportion of 'Good' homes when nursing and/or dementia specialist care, especially dementia nursing care, is required. Leeds City Council's Care Quality Team has been established to work with the local care sector, and has adopted dementia care as a priority.



Workforce, training and investing in quality

Good quality dementia care depends upon recruiting, training and retaining the right staff in sufficient numbers. This is especially a challenge in the social care sector, where pay is low, there are limited opportunities for promotion and career development, and high staff turnover. The relative success of the Leeds economy in retail and other areas means that there are alternatives on offer which can seem more attractive than working in social care.

There is a particular connection to the Leeds 'Inclusive Growth Strategy' and its ambition to create better jobs and tackle low pay. The 'Step Into Care' programme works to

promote careers in social care, and support both young people, and middle-aged / older workers, into the workforce. Boosting the pay and conditions of a largely private sector workforce is likely to require increased funding via contracts. This is a cost against local authority budgets, whilst also being an investment in the Leeds economy. Good quality care helps unpaid carers and family members to remain in paid work. When low-paid workers are better rewarded, this has a knock-on effect in stimulating the local economy. However, in the context of local government funding, especially with the additional spending and loss of income from the Covid pandemic, this remains a real challenge.

Support at home - developing the Leeds offer

Domiciliary care is a vital service to support people at home, including in the later stages of dementia (50% of people with severe dementia live at home). People require a flexible approach to care delivery, which is able to adapt to how they are on a given day, and what help they need. Staff require the skills to build relationships and trust, and find creative ways to help people who might not be fully aware of, or acknowledge, support needs. Consistency of staff is especially valued, because of the importance of a good relationship and understanding.

The approach of 'do with' rather than 'do to' is best practice for everyone who has care and support needs, and especially so for people living with dementia, who may be able to physically do tasks with a little prompting, and may react defensively (as anyone would) to having personal care carried out without consent and co-operation being achieved.

Support at home is likely to be a more favoured option for families during, and perhaps after, the Covid-19 pandemic. Restrictions on care home visiting, and concerns about outbreaks, seems to be a factor for families to 'go the extra mile' to keep caring for people at home in the more advanced stages of dementia. This is an opportunity to articulate clearly what the Leeds support offer looks like, to promote the good services we have and to understand what improvements people and families need.

Day centres are a positive option for many people living with dementia and carers, offering social experience and meaningful occupation for people attending; and for carers, a break, or even vital support to stay in employment.

NHS services

Access to specialist NHS services is an important aspect of good quality care. People with dementia who receive social care need a multi-disciplinary approach with good working relationships, and timely access to expert colleagues who can advise and co-work when required. The reintroduction of specialist older people's services, from March 2019, by Leeds and York Partnership NHS Foundation Trust (LYPFT) was a significant step forward. People living at home, and in care homes, can benefit from both care co-ordination and intensive interventions.

Leeds Teaching Hospitals Trust (LTHT) has a long-established Dementia Steering Group, which co-ordinates across clinical areas and support services on eg. staff training, improvements to ward environments, food choices and menus, ensuring that glasses,

hearing aids and dentures are properly used. People with dementia are vulnerable to being disoriented in hospital, and upon leaving hospital; and to episodes of delirium linked to acute illness. This is considered further in the next section.

Leeds Community Healthcare and Leeds Teaching Hospitals have both developed dementia training for staff, and made it part of the 'statutory and mandatory' training at the appropriate level for each staff role. Leeds Community Healthcare have developed a "Dementia, Delirium and Depression" pathway, which was launched in 2019, and offers staff guidance and support on best practice in treatment and care.

Achievements 2013-20

- LYPFT service redesign has introduced specialist older people's teams (March 2019), to work more closely with Neighbourhood Teams to support the older population living with dementia, mental health needs and frailty.
- Over 6,000 staff trained in dementia care by Leeds Teaching Hospitals, including ward clerks, housekeepers and porters as well as nursing staff; improvements to ward environments, introduction of 'Know Who I Am' document, dementia-friendly food choices and menus.
- 370 Leeds Community Healthcare clinical staff 'Tier 2' trained; 1,200 staff trained at 'Tier 1' (March 2019 data)
- An improved training offer from Leeds City Council for care providers and social work staff, including leadership in dementia care.
- Leeds City Council has established a Care Quality Team which is prioritising work with care homes to better support people with dementia.

Our approach to make a difference 2020-25

- Be honest and open about the concerns regarding care quality, and make best use of all our procurement, contract management, care quality and training initiatives to achieve service improvement;
- Acknowledge the costs of good dementia care, and seek affordable ways to work with providers to match funding to care costs.

12. People with more complex needs & timely transfers of care

People experiencing psychological distress, and people with dementia alongside multiple health conditions, have the right multidisciplinary support out of hospital.

‘Complex needs’ in dementia refers to:

- people who experience emotional and psychological distress and associated behavioural needs; and/or
- people with multiple health conditions and needs, with dementia having a significant impact on how needs are understood and met.

Sometimes distress and behaviour is a short-term response eg. to how a person is being treated, or finding oneself in an unfamiliar place or confusing environment. Small changes in approach, and thinking creatively, can make a big difference. It is always important to seek to understand from a person-centred perspective. It is usually unhelpful to label a person as having ‘complex needs’ without trying to understand the person and possible reasons for being distressed.



This ‘word map’ shows what staff in Leeds Teaching Hospitals wrote to indicate moods and behaviours for people identified with dementia¹⁸.

The frailty perspective is especially important when considering complex needs. ‘Frailty’ leaves us “vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection or a change in medication or environment”. The more severe the dementia, generally the more likely it is that more complex needs will emerge, sometimes suddenly, in response to physical and psychological triggers. Hence an approach based on ‘recovery’ is important, to discover for each person what might settle over time with appropriate treatment and care, and what is more severe and enduring.

People with severe dementia are an estimated 12% of the population with dementia; and people with behavioural needs linked to emotional distress (eg. ‘agitation’, ‘irritability’) are 5-16% more prevalent among people with dementia¹⁹. Combined with the data below on prescription of anti-psychotic medication, it is estimated that there are 500 - 1,000 people in Leeds with more complex needs in dementia.

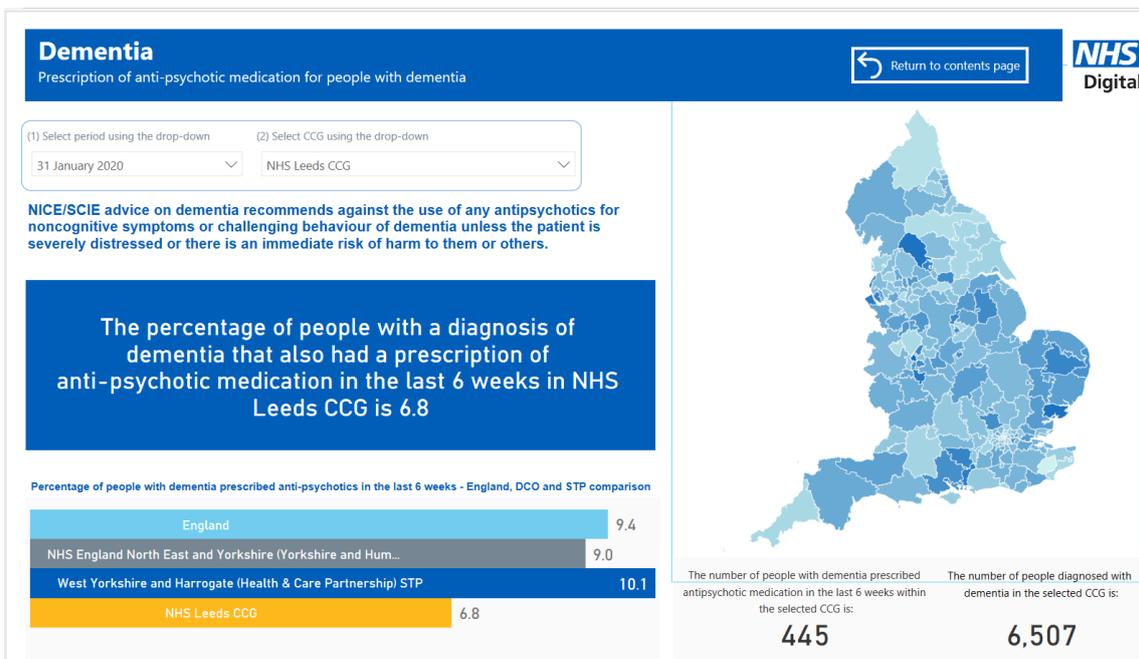
¹⁸ George Crowther (2015): A Summary of the service improvement project, ‘Describing the population with dementia in Leeds Teaching Hospitals Trust’.

¹⁹ Savva *et al* (2009): *Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population*. BJPsych 194

Care homes are understandably more reluctant to take people whose needs are more complex, unless they are satisfied that funding of the care will enable sufficient staffing, and that specialist support will be available when necessary. This can lead to people waiting in hospital for a suitable placement to be identified, sometimes being assessed and turned down by many care homes.

Person-centred care, to understand the roots of emotional and psychological distress, must always be the ‘first-line’ approach to presenting behavioural needs and risks. In 2011, an NHS-wide *Call To Action* sought to stop the inappropriate prescribing of low-dose anti-psychotic medication in dementia, and ensure that any prescribing is kept under review. These medications are sometimes used to manage behavioural presentations of distress, but have harmful side effects including risk of falls and stroke.

NHS prescribing audits in Leeds during 2012 showed that c. 10% of people with a dementia diagnosis were given antipsychotics, and action included repeat audits and the production of a local guideline. The chart below shows that local action has had a sustained effect: 6.8% of people with a dementia diagnosis had had a prescription in the six weeks to end January 2020, lower than the England average of 9.4%.



During 2017-18, a range of initiatives started to address concerns about people experiencing long delays leaving hospitals. The LYPFT care homes service was enhanced to create an “Intensive Care Homes Treatment Team”; additional funding was offered to care homes to enable short-term additional support for people making the transition from hospital, or to avoid admission for people experiencing episodes of distress. There have been good examples of people supported to leave hospital and avoid admission, with a multi-agency approach to supporting care homes to look after people. A programme of work has been set up to develop new services for people with the most complex needs, and achieve further, sustained improvement to timely transfers of care.

During the Covid-19 crisis period, LYPFT seconded staff to strengthen the ‘Intensive Home Treatment Team’, to support people in their own homes. This has had some success at working with families to avoid hospital admissions. Support at home may

now be a preferred option for more people, as described above. NHS and domiciliary care providers working in partnership - in a similar way to that described for care home providers - is likely to offer the best way forward to improve support and manage crises at home.

A successful example of a person-centred, recovery approach:

A gentleman who had been on Ward 1 at The Mount for almost a year. He needed 3-4 people for personal and continence care, resisting having help because he saw care staff as strangers who were attempting to undress him. Providing care was stressful, increased his agitation, and so was carried out as infrequently as possible on a 'best interests' basis.

A care plan was developed which involved speaking quietly, approaching from the side and holding his hand and giving him plenty of time. However, he made little progress on the ward. A Leeds nursing home agreed to accept him for discharge from The Mount, with help from the Intensive Care Homes Treatment Team, and funding for additional staff time. Within a week he was accepting personal care on a 1:1 basis and the additional funding ended after expenditure of less than £1K.

Achievements 2013-20

- NHS clinicians in Leeds have sustained a low level of prescribing of antipsychotic medication.
- Leeds City Council has increased fees for dementia specialist care home placements.
- LYPFT Intensive Care Homes Treatment Team piloted from July 2018 and established long-term from April 2019.
- Pilot of the 'Dementia Transition Fund' – a scheme to fund additional care needs to support transition from hospital / prevent readmission.
- Hospital bed-days lost to delayed transfers of care reduced by c. 50% in winter 2018-19 compared to previous winter.

Our approach to make a difference 2020-25

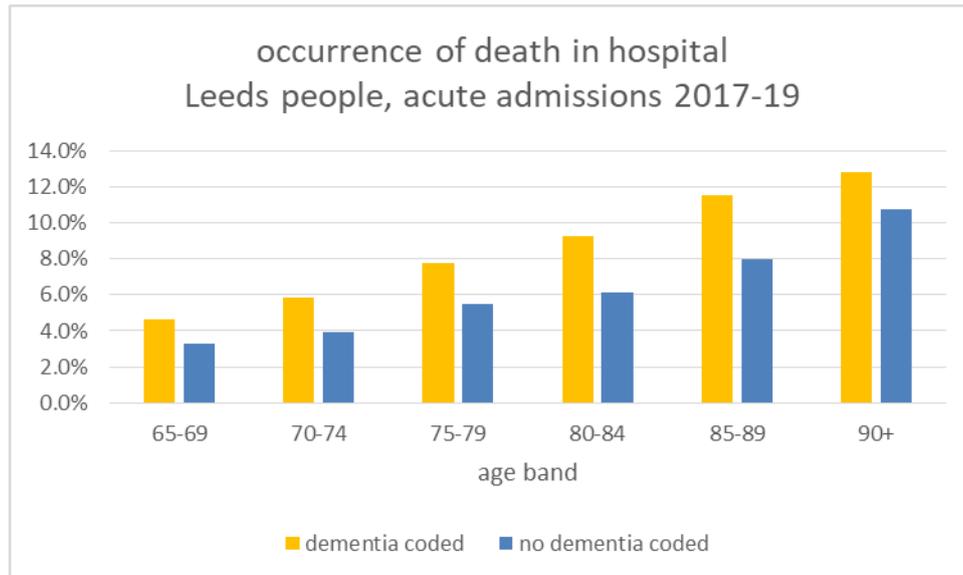
- A new programme of work to develop very specialist bed capacity;
- Focus on timely support to avoid hospital admission where appropriate;
- Identify the best funding and procurement option for care services, to ensure the right supply and quality of care for people with more complex needs.
- Develop medium-to-longer-term care options for people with enduring and complex care needs.
- Consider 1:1 care and overnight options for people and carers living at home with more complex needs - aim to invest in support at home as well as care homes.
- Approaches offering arts and creativity for people to express themselves and cope with emotional distress.

13. Care at the end of life

There is honesty about dementia as a progressive neurological condition, and opportunities to plan ahead & make the most of life.

People with a dementia diagnosis make up approximately 15% of the people who die each year in Leeds; and approximately 15% of people with a dementia diagnosis die each year. These numbers indicate how significant dementia is in developing and improving end of life care.

Dementia is a significant risk factor for being admitted to hospital, having a longer stay in hospital, and for dying in hospital – see chart below:



It is an ambition for this strategy to enable more people with dementia to be where we would wish to be at the end of life, an ambition shared with the Leeds Palliative and End-of-Life Care Strategy. This has developed seven outcome statements, for people to:

1. Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care.
2. Have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics.
3. Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing.
4. Receive care that is well-coordinated.
5. Have their care provided by people who are well trained to do so and who have access to the necessary resources.
6. Be assured that their family, their carers and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
7. Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed.

For people with dementia, the opportunity to influence care may come at an earlier stage of the condition, whilst the capacity to think through and decide what we want is relatively intact. This is not easy to do in the face of a progressive condition; people often manage dementia 'one day at a time' rather than looking too far ahead. NHS England colleagues supporting the West Yorkshire and Harrogate Integrated Care

Partnership have supported a training programme to facilitate advance care planning (ACP), and Leeds now has NHS and third sector staff equipped to train colleagues as ACP facilitators. The idea is that anyone who is known and trusted by a person can have the important conversations about wishes and preferences.

End-of-life care and dementia benefits from the perspective of dementia as a life-limiting neurological condition, ultimately affecting a range of physical functioning alongside cognitive abilities; and one which impairs the ability of a person to communicate symptoms such as pain and discomfort. Indeed, the frustrations associated with not being able to explain symptoms may manifest as agitated behaviour, and be misinterpreted.

Achievements 2013-20

- Dementia included alongside other long-term conditions in electronic Palliative Care Co-ordination System (ePaCCs)
- Leeds guidance produced on recognition and management of end-stage symptoms in dementia.
- Dementia training for 142 staff at Leeds hospices.
- A recognised pain assessment tool for people with dementia is available on Leeds Community Healthcare patient record.

Our approach to make a difference 2020-25

- Enhance hospice & palliative care teams with Admiral Nursing posts (specialist dementia nursing roles).
- More & better conversations about advance care planning, to avoid unnecessary A&E attendances, admissions and medical treatments towards the end of life.
- To improve symptom recognition and pain relief, by establishing a consistent approach to assessing pain, discomfort and other symptoms.

1. Service 'reset and recovery' from Covid-19

Why is this a priority ?

- People and carers living with dementia have been particularly affected by the Covid-19 crisis; both the virus itself and the impact of social distancing.
- The Covid crisis has led to important services being 'paused' for diagnosis of dementia and support to live well.;
- Restarting services is subject to social distancing and other health protection measures, which will affect service capacity;
- There are opportunities to implement learning to make positive changes in eg. use of digital technology; support at home.

What will NHS and Council commissioners do ?

- Support NHS service providers to re-establish services, amend pathways and redefine objectives;
- Work with community organisations and social care providers to explore options to resume safe face-to-face activities, consider digital alternatives, and understand the impact of the Covid crisis.

The outcomes will be...

- The Leeds dementia diagnosis rate will be stabilised and recover towards pre-Covid level.
- Support to live with dementia in Leeds will recover and be available in new ways.
- People and families will be able to make informed decisions about what services and activities to access.

2. Demographics, diversity & emerging needs

Why is this a priority ?

- The population with dementia is anticipated to increase in England and Wales by more than 10% in the next five years, affecting demand on services;
- BAME older populations are likely to increase at a higher rate than the 'White British' population;
- Community organisations have demonstrated their ability to support people and carers, and are seeking opportunities to strengthen provision.

What will NHS and Council commissioners do ?

- Work with universities to develop demographic projections for Leeds;
- Meet demand by investing in capacity for diagnosis and community support;
- Evaluate the experiences of people from BAME populations to understand barriers to accessing support;
- Develop effective approaches to reducing dementia risk linked to health inequalities.

The outcomes will be...

- The risk of developing dementia will be reduced.
- Service development anticipates and keeps pace with emerging needs.
- Inclusive access to services.

3. Annual review & care co-ordination

Why is this a priority ?

- The annual review is an important opportunity for people and carers not receiving support to discuss the progress of the condition and be connected to community services;
- There are good examples of care planning and review in primary care, and opportunities for investment in primary care to improve quality and consistency for all.
- People and carers who do not access support are at risk of poor health outcomes and presenting in a crisis;
- NHS England investment in healthy ageing and frailty, including care co-ordination and social prescribing, must include people living with dementia.

What will NHS and Council commissioners do ?

- Include dementia in the Leeds 'Healthy Ageing' programme;
- Ensure new care co-ordinator roles work effectively with Memory Support Workers.
- Evaluate how the Collaborative Care and Support Planning approach to annual review is working for people and carers living with dementia.

The outcomes will be...

- People and carers will be connected to support and not 'slip through the net';
- Presentations in crisis will be reduced as far as possible;
- We will make best use of new investment and include people with dementia in new services.
- More people will have advance care plans, anticipating the later stages of dementia.
- There will be a reduction in serious falls for people with dementia.
- More people will have a care plan and review, including medication review.

4. Carer support and breaks

Why is this a priority ?

- There are opportunities to identify and reach carers in primary care and other health and care settings, aligned to the Leeds Carers Partnership Strategy.
- There are support services proven to be effective which could reach more carers.
- There are specific gaps in local provision reported by carers.
- Caring for a person with dementia can be very demanding, and many families show great determination to keep people at home when dementia becomes severe.

What will NHS and Council commissioners do ?

- Ensure access to care home short-stays bookable in advance;
- Ensure access to support for BAME carers, including short-stays with language and cultural competence;
- Seek to invest further in hospital-based support, education, and follow-up to keep in touch with carers who have had an episode of support.

The outcomes will be...

- More carers connected to support, and less risk of presenting in crisis;
- Improved health, and ability to sustain the caring role.

5. Care quality, complex needs, timely transfers

Why is this a priority ?

- It is more difficult to find a good quality care home when specialist dementia care is required.
- There are delays for people leaving hospital, especially for people with the most complex needs.
- The largest increase in people with dementia in the next five years is projected to be people aged 75-79, who are the most prevalent age group among those admitted to specialist NHS services and be delayed in hospital.

What will NHS and Council commissioners do ?

- A programme of work to develop new specialist beds for people with more complex needs in dementia from June 2020, and longer-term develop purpose-built accommodation.
- Sustain support to care homes to meet more complex needs;
- Seek to invest in support at home for people with more complex needs.
- Promote the dementia training and support offer for care providers
- Local NHS Trusts' action plans to train staff, improve care quality and environments.
- Creative and innovative approaches to offer meaningful activity and self-expression.

The outcomes will be...

- Significant reduction in delayed transfers of care for people with dementia;
- Significant increase in specialist care homes rated 'Good' or better.

6. End of life care & planning ahead

Why is this a priority ?

- People with dementia are more likely to be admitted to hospital, have longer hospital stays, and to die in hospital, compared to people in the same age group without dementia.
- Dementia impairs the ability to communicate symptoms, and make decisions.
- There are opportunities in the earlier stages of the condition to plan ahead for the later stages.

What will NHS and Council commissioners do ?

- Seek to invest in Admiral Nursing roles to work with palliative care teams;
- Include the needs of people with dementia in the End Of Life Care programme.

The outcomes will be...

- More people will be at their preferred place of care at end of life.
- More people who die with dementia will have a record on the Electronic Palliative Care Co-ordination System (EPaCCs)
- More people will receive effective treatment and symptom control in the community (a reduction in the number of unplanned hospital admissions in last 90 days of life).
- More carers will be well supported during the last phase of their loved one's life and services will be put in place to ensure that symptoms and pain are well managed. (% very satisfied with symptom management).

Taking Action, partnership working and governance

- *how we will make progress and co-ordinate action.*

These commissioning priorities form the focus of the “Leeds Dementia Action Plan”, which is ‘owned’ by the Leeds Dementia Oversight Board. This Board in turn is accountable to the Integrated Commissioning Executive and ultimately the Leeds Health and Wellbeing Board. The Action Plan will be reviewed and updated quarterly, as actions are completed and as investment is agreed, to turn ambition into reality. The following diagram outlines these arrangements, established during 2019-20, and which will evolve during the lifetime of this strategy:



Appendix 2

Equality, Diversity, Cohesion and Integration Screening



As a public authority we need to ensure that all our strategies, policies, service and functions, both current and proposed have given proper consideration to equality, diversity, cohesion and integration.

A **screening** process can help judge relevance and provides a record of both the **process** and **decision**. Screening should be a short, sharp exercise that determines relevance for all new and revised strategies, policies, services and functions.

Completed at the earliest opportunity it will help to determine:

- the relevance of proposals and decisions to equality, diversity, cohesion and integration.
- whether or not equality, diversity, cohesion and integration is being or has already been considered, and
- whether or not it is necessary to carry out an impact assessment.

Directorate: Adults & Health	Service area: Commissioning
Lead person: Tim Sanders	Contact number: 0113 378 3853

1. Title: Living with dementia in Leeds – our strategy 2020-25

Is this a:

Strategy / Policy

Service / Function

Other

If other, please specify

2. Please provide a brief description of what you are screening

The impact of developing and setting policy to support living well with dementia in Leeds. This includes:

- Leeds as a dementia-friendly and inclusive place;
- services which offer diagnosis and support;
- partnership with and support for families / carers
- the quality and capability of health and social care services to work well with people living with dementia.

The effect of dementia is different for every individual, and a person-centred approach is the only way to understand how the biological, psychological and social factors interact. All the 'protected characteristics' are relevant for the local population living with dementia, and the condition is itself a disability. This increases the risks for individuals, that needs will not be communicated and understood. People with dementia may rely entirely on others doing the right thing to uphold human rights and other legal entitlements.

1. Relevance to equality, diversity, cohesion and integration

All the council's strategies and policies, service and functions affect service users, employees or the wider community – city wide or more local. These will also have a greater or lesser relevance to equality, diversity, cohesion and integration.

The following questions will help you to identify how relevant your proposals are.

When considering these questions think about age, carers, disability, gender reassignment, race, religion or belief, sex, sexual orientation. Also those areas that impact on or relate to equality: tackling poverty and improving health and well-being.

Questions	Yes	No
Is there an existing or likely differential impact for the different equality characteristics?	✓	
Have there been or likely to be any public concerns about the policy or proposal?		✓
Could the proposal affect how our services, commissioning or procurement activities are organised, provided, located and by whom?	✓	
Could the proposal affect our workforce or employment practices?	✓	
Does the proposal involve or will it have an impact on <ul style="list-style-type: none">• Eliminating unlawful discrimination, victimisation and harassment• Advancing equality of opportunity• Fostering good relations	✓	

If you have answered **no** to the questions above please complete **sections 6 and 7**

If you have answered **yes** to any of the above and;

- Believe you have already considered the impact on equality, diversity, cohesion and integration within your proposal please go to **section 4**.
- Are not already considering the impact on equality, diversity, cohesion and integration within your proposal please go to **section 5**.

4. Considering the impact on equality, diversity, cohesion and integration

If you can demonstrate you have considered how your proposals impact on equality, diversity, cohesion and integration you have carried out an impact assessment.

Please provide specific details for all three areas below (use the prompts for guidance).

How have you considered equality, diversity, cohesion and integration?

(**think about** the scope of the proposal, who is likely to be affected, equality related information, gaps in information and plans to address, consultation and engagement activities (taken place or planned) with those likely to be affected)

- Commissioning Leeds Older People's Forum to support and co-ordinate dementia-friendly Leeds, and support people living with dementia to form a group to give voice to the experience in Leeds – this is the 'Up & Go' group.
- Carers are represented directly on Leeds Dementia Partnership, and contribute lived experience to the discussions.
- A series of ten Dementia Information Roadshows were held during 2018 and 2019. At nine of these, the speakers included a person living with dementia and a carer, and other contributions came from the audience.
- Gaining knowledge and understanding by a range of methods: - studying demographics, gathering information and participating in events over the 5 years since the previous dementia strategy. This includes Leeds BAME dementia forum; a BAME dementia event in 2015 followed up with a report and grant funding programme; experience of LGBT older people; faith and older people.
- The development of the strategy included a consultation event in October 2019, with a workshop on the needs of people in BAME communities; and another on diversity, inclusion and rights. This was followed up with a small group meeting to discuss approach and actions.
- Improvements by Leeds GP practices in the recording of ethnicity has enabled analysis of dementia diagnosis data. This shows that recorded diagnoses for people in the main Census BAME groupings is in the expected proportions compared to people aged 65+ in those population groups.
- There are 50 Memory Cafes in Leeds which cover all geographical areas, and diverse BAME communities (Irish, south Asian, Caribbean, Jewish).
- BAME dementia support is provided by Touchstone Leeds; this was originally funded by a series of grants (from 2011 onwards) and is now a longer-term contract with NHS Leeds Clinical Commissioning Group.
- Supporting Leeds Gypsy and Traveller Exchange have produced a resource for commissioners of dementia services.
- Establishing GP-hosted memory clinics, to reduce travel distances and the sense of stigma, compared to attending outpatient locations.
- Improving day services for younger people with dementia and enabling more people to access support via a new Memory Café and carer support worker.

• **Key findings**

There are a range of considerations which influence eg. strategy, service design, staff training needs, sometimes in quite nuanced ways. For example:

- whilst age is the main risk factor for developing dementia, age-related risk is higher for

people at a disadvantage from health and social inequalities; so needs are present in all local communities.

- Carers of people with dementia are at particular risk of health inequalities, related to eg. lack of sleep, putting one's own needs second, the emotional and psychological effects of loss on the relationship with the person.
- People with dementia are particularly vulnerable at points of transition between services, eg. to and from hospital, or changes of where one lives. Important factors are the changes in environment causing disorientation; and increased reliance on professionals and systems to share information, especially when small details make a big difference.
- dementia is an increasing concern for the diverse Leeds BAME communities. There are some populations which are decreasing in numbers as younger generations might not identify on the Census as eg. 'Irish'; but dementia is still an important concern as the populations grow older. Older people who came to the UK from Caribbean and south Asian origins are developing dementia, and assumptions cannot be made about patterns of family life.
- Dementia can take away the ability to speak English for people who learned it as a second language. Reported experience is that people from south Asian communities are looking to use eg. residential short stays for carer breaks and the language capability of services is a difficulty.
- LGBT older people have grown old at a time of changing social attitudes and inclusiveness, and both developing dementia and coming into contact with care services can lead to difficulties and uncertainties. Alzheimer's disease in particular can take away recent memories and lead to a sense of the past being the current reality, which can be distressing for the person and loved ones to eg. be back in a time when sexuality or gender identity was more often concealed.
- Dementia is usually 'co-morbid' with one or more other long-term conditions. An holistic approach to living well with long-term conditions / disabilities is required to support people to live well with dementia; with access to specialist support when required.
- Acquired hearing loss is a risk factor for dementia, and the importance of supporting people to access and use hearing aids is important.
- Younger people with dementia (generally under age 65) have specific needs related to both the prevalence of different types of dementia, and family, social and economic circumstances. Leeds has a specialist NHS younger dementia team, and day services for younger people with dementia. There is an active carers group whose experiences have influenced this strategy.
- People with learning disabilities, particularly Down's Syndrome, are at greater risk of developing dementia, and difficulties in recognising symptoms and diagnosing the condition. Therefore, when adults with a learning disability are supported by older parent carers, there is risk of dementia for both generations.
- Generally, people wish for mainstream services to work well and be competent with diverse needs – eg. Memory Services, hospital care. However, specific services are often valued, such as a memory café where mother tongue language is used and understood; groups for older LGBT people.
- 'Dementia-friendly' approaches have had considerable success to improve understanding of the condition and acceptance of people living with dementia. However, a rights-based approach will complement and strengthen inclusion and

quality of services.

• **Actions**

The strategy includes a range of initiatives arising from engaging with people and organisations:

- A whole-person approach to living with dementia, long-term conditions and frailty.
- Seeking funding to commission an evaluation of the experience of people from BAME communities of dementia diagnosis and support, and develop commissioning intentions from the findings (a proposal from the BAME dementia forum).
- Engagement and listening via events or otherwise, with BAME communities, people who are Deaf or hearing impaired; people in rural areas; LGBT older people. . A BAME dementia roadshow had been scheduled for May.
- Work with the 'Mindful Employers' network for working-age adults with dementia to have reasonable adjustments to stay in paid work for as long as possible.
- Ambition to commission residential short stays with language and cultural competence.
- Develop a 1-2 hour training session on dementia and diversity: "well-informed person-centred care".

5. If you are **not already considering the impact on equality, diversity, cohesion and integration you **will need to carry out an impact assessment.****

Date to scope and plan your impact assessment:

Date to complete your impact assessment

Lead person for your impact assessment
(Include name and job title)

6. Governance, ownership and approval

Please state here who has approved the actions and outcomes of the screening

Name	Job title	Date
Caroline Baria	Deputy Director, Commissioning, Adults & Health	1 st July 2019
Date screening completed		1 st July 2019

7. Publishing

Though **all** key decisions are required to give due regard to equality the council **only** publishes those related to **Executive Board, Full Council, Key Delegated Decisions or a Significant Operational Decision.**

A copy of this equality screening should be attached as an appendix to the decision making report:

- Governance Services will publish those relating to Executive Board and Full Council.
- The appropriate directorate will publish those relating to Delegated Decisions and

Significant Operational Decisions.

- A copy of all other equality screenings that are not to be published should be sent to equalityteam@leeds.gov.uk for record.

Complete the appropriate section below with the date the report and attached screening was sent:

For Executive Board or Full Council – sent to Governance Services	Date sent: N/A
For Delegated Decisions or Significant Operational Decisions – sent to appropriate Directorate	Date sent: N/A
All other decisions – sent to equalityteam@leeds.gov.uk	Date sent: N/A