

**LINCOLNSHIRE HEALTH AND WELLBEING BOARD**

Open Report on behalf of Paula Jelly Senior Responsible Officer for the Dementia Programme

Report to	<b>Lincolnshire Health and Wellbeing Board</b>
Date:	<b>5 December 2023</b>
Subject:	<b>Dementia Programme Update</b>

**Summary: The NHS National Transformation Framework – The Well Pathway for Dementia**

Dementia is the leading causes of death in England and Wales. Dementia has a profound impact on the person with dementia's life, their family, and friends and the communities in which they live. Although age is the strongest known risk factor for dementia, dementia does not exclusively affect older people. Young onset dementia (defined as the onset of symptoms before the age of 65 years) accounts for up to 9% of cases.

The prevalence of dementia makes it one of the most pressing challenges for health and care services and remains an important issue for Lincolnshire given its ageing population profile.

This report provides a summary of activity and work in progress from the Dementia Programme to try and address some of the issues for Lincolnshire, it also provides an update on the development of the new Lincolnshire Dementia Strategy.

**Actions Required:**

The Lincolnshire Health and Wellbeing Board are asked to note the progress that has been made throughout the programme and partners contribute to the work of the Dementia Programme as appropriate.

The board needs to note that the standalone Memory Assessment Service (MAS) is subject to change as this is dependant on funding being secured.

## 1. Background

The re-established Dementia Programme Board is to both realise and deliver the ambition of the new Lincolnshire Dementia Strategy as agreed by the MHDLDA, reporting to the Dementia Core Programme Team. The Core team is currently being reformed due to changes in personnel with system partners.

The objective of the Board is to deliver the programme implementation and work collaboratively, across statutory and non-statutory commissioners, providers and with people with dementia and their families and carers, within the Health and Care system to address health inequalities and social determinants of dementia within a population health management framework.

The pending Major Conditions Strategy will aim to improve health outcomes and better meet the health and wellbeing needs of local populations. The strategy will recognise challenges facing society, specifically around multimorbidity in ageing populations. The strategic framework, which will underpin the final strategy, focuses action on:

Primary prevention: acting across the population to reduce risk of disease. Secondary prevention: halting progression of conditions or risk factors for an individual. Early diagnosis: to identify health conditions early, to make treatment quicker and easier. - Prompt and urgent care: treating conditions before they become crises. Long term care and treatment in both NHS and social care settings

The new Dementia Strategy for Lincolnshire will have a key focus on **prevention of avoidable cases of dementia, improving experience of people being diagnosed and living with dementia and championing participation, innovation, and research.**

**Dementia Strategy development:** The approach to developing the strategy has been to have conversations with people with dementia, their carers, those who live in Lincolnshire and our partners in health, social care the Voluntary, Community and Social Enterprise (VCSE), about their experience of health and care services and the impact of covid, what we should focus on to improve the care and support we provide. We have discussed all areas of dementia care, from activities aimed at preventing dementia, through to care at the end of people's lives. The above informed our draft goals and we have recently completed a period of engagement on the draft goals with system partners, people affected by dementia including Dementia UK and the Alzheimer's Society the feedback will be reviewed to develop the final draft strategy.

There have been 37 online responses, and we attended to Dementia Conference where 200 people took part in a tabletop exercise to feedback on the draft strategy goals, we have also undertaken several focus groups around the county meeting with people living with dementia and their carers.

Members of the Dementia programme Board (DPB) and people with lived experience are working together with the population health management team to develop a logic model identifying our activities and outputs including long/medium/short-term outcomes for the strategy delivery plan, utilising the intelligence/data to support this work.

We are also working with DAAs/DFCs this is to re-establish themselves to form a Dementia Network for Lincolnshire and be part of the DPB, these groups play a pivotal role in our communities to improve local support and access to services for people and will support development and delivery of the dementia strategy action plan.

Every-One have been and continue to support development of the strategy by supporting people to share their experience and have their voices heard, they are currently establishing a network of people with lived experience to work collaboratively with the DPB to identify opportunities for coproduction and codesigning service.

The strategy will be finalised with the aim to be launched at the beginning of 2024, the delivery plan will have a clear project plan encompassing the workstreams below that will set out key deliverables and milestones. The Dementia programme board will have responsibility to oversee this to ensure that we achieve the changes required to improve dementia care and support for people affected by dementia, including clear information, advice, and support on reducing the risk of getting dementia.

In the meantime, it has been imperative that we have identified and continued with work that is important for Lincolnshire this is to ensure we are aiming to achieve national targets set and that we are able to continue to improve health and care services whilst scoping and developing the strategy.

**Prevention Agenda:** Focused prevention programme aimed at raising awareness of the importance of good brain health across all age and reducing the risk of dementia. Utilising health inequalities data to support delivery.

Even though there is no cure for dementia the most recent updated study on dementia prevention published (Lancet, 2020) found that around 40% of dementia cases worldwide might be attributable to 12 potentially modifiable risk factors. As such a proportion of predicted dementia is potentially preventable, by tackling the identified risk factors that we can change, such as smoking, diet, physical activity, and social isolation.

Smoking is one of the biggest risk factors for dementia and can double an individual's risk, because it causes narrowing of blood vessels in the heart and brain, and oxidative stress, which damages the brain.

Task and Finish group established with the following remit of work.

- Developing information and advice for people on preventing avoidable dementia encouraging people to age well,
- Highlighting the 12 modifiable diseases that increase the risk of dementia by embedding this into other associated public health campaigns.
- Funding has been secured to develop a resource of video/animations, and marketing campaign, this will be accessible for the public and for professionals to use across health, care, and education. It will aim to raise awareness across the life course of what's good for

the heart is good for the brain. A quotation/tender exercise has started to find an organisation to develop the brief for the animations.

- Review and develop protocols to encourage uptake of NHS health checks and ensure risks associated with dementia including early signs of dementia are recognised ensuring appropriate advice and support is available.

**Dementia Diagnosis Rate (DDR) Target:** Nationally mandated DDR target of 66.7% - Lincolnshire currently DDR stand at 64.8%, which whilst below National target is above current regional average and on an upwards trajectory with work being carried out across primary and secondary care to improve the target for Lincolnshire. DDR Task and finish Group recently established. Review and develop the dementia pathway/s to support people identified with Mild Cognitive Impairment (MCI).

Primary Care: Case Finding PCNs/ Practices encouraged to case find: All practices have been provided with the information about the dementia quality toolkit (DQT) that is available on both EMIS and SystemOne and advised to run this annually. This has been embedded as part of a dementia checklist and available on the Lincolnshire Dementia page. The DQT will identify patients with mild cognitive impairment (MCI). An annual review of all patients with mild cognitive impairment (MCI) as part the locally developed primary care dementia pathway but is not mandatory for primary care to do a follow up but needs to be embedded in practice. MCI follow up is established in Lincolnshire Partnership Foundation Trusts (LPFT) memory assessment pathway.

The Diagnosis Advanced Dementia Mandate (DiADeM) Tool: this has been embedded as part of the primary care dementia pathway for patients with advanced/severe presentation of dementia in care homes. The DiADeM tool is being used in areas of the county where there is the capacity and confidence amongst care coordinators/practitioners in the community.

To explore and promote the impact of the tool for diagnosing advanced dementia in care homes the ICB dementia lead is in the process of commencing a pilot in a one of the PCNs, working with the frailty nurse who is the Enhanced Health in Care Home (EHCH (lead)). The pilot will be written up and shared across primary care/care homes to support the roll out across Lincolnshire care homes. The Dementia Assessment Referral to GP (DeAR GP) has been promoted across Lincolnshire Care Homes. DeAR-GP, developed by the Health Innovation Network and supported by Alzheimer's Society, is a simple paper-based case-finding tool which has been designed for use by care workers to identify people who are showing signs of dementia. DeAR-GP acts as a communication between care workers and health professionals. The DiADeM is an excellent follow-on tool from the DeAR- GP.

LPFT: Continued LPFT recruitment against 23/24 funding for dedicated Memory Assessment Practitioners nearly at WTE funded capacity (n=10) with increased assessment and diagnostic output.

- Continued recruitment against 23/24 funding for additional/dedicated Memory Assessment Service (MAS) Consultants (x2 WTE). Currently a x1 WTE recruited/in practice with further 0.4WTE about to commence – all increasing diagnostic capacity.
- 24/25 LPFT business case informed by capacity & demand modelling for stand-alone/dedicated MAS service (to build on 23/24 business planning process) completed (submitted Nov 1<sup>st</sup> for stage 2 business planning deadline). To progress to system prioritisation (stage 3 business planning) in Jan/Feb 24. If supported to commence expansion from April 24 with estimated 18–24-month implementation and associated impact/upwards trajectory on MAS waits and DDR.
- Continued work on LPFT data to improve DDR associated reporting – focus on improved diagnostic numbers per month. Push to increase coding outcomes for all MAS referrals.
- Work underway to explore capacity for delivery of MAS clinics from primary care/GP settings at PCN level. Additional clinic capacity required to optimise MAS delivery capacity.
- LPFT Virtual Assistant due to 'Go Live' Q4 23/24. This is expected to expand access routes to LPFT MAS.
- Review of current MAS waiting lists to identify referrals from 24hr care settings that can be targeted via DiADeM.
- LPFT to train selected staff in DiADeM to undertake assessment of identified cohort from waiting lists Q4 23/24.

**Memory Assessment Service** - to have a standalone memory service for Lincolnshire. LPFT Memory Assessment Services benchmarked regionally via NHSEI MAS audit. Feedback from that identified LPFT/OPFD MAS as an outlier for being delivered within generic CMHT model, rather than as a stand-alone service function.

Demands of OP CMHT continue to rise year on year in-line with known predictive demographics of Lincolnshire as an aging county. Lincolnshire currently has circa 180,000 + over 65s. This is predicted (ONS) to increase by 46% to 250,000 by 2041.

LPFT have submitted a business case to support investment to move towards a 'stand-alone' MAS model. If approved this will improve the dementia diagnosis rates (DDR) for Lincolnshire and reduce memory assessments waits. Awaiting outcome.

Earlier diagnosis for people that opens the door to future care and treatment. It will also help people to plan while they are still able to make important decisions on their care and support needs and on financial and legal matters, prevent crisis situations and enable people to get on with living.

**Antipsychotic Medication** - Reduction of inappropriate Antipsychotic (AP) prescribing for people with dementia. Lincolnshire ICS to be under/in line with National average. Appropriate use of antipsychotic medication and use of Nonpharmacological treatment

In line with the National priority, a cross organisational task and finish group (LPFT, ICS, Primary Care, Arden Gem) has been running and has reduced AP prescribing in dementia back to the targeted pre-pandemic levels.

The group have conducted audits across primary care and care homes to identify where and why medication was initiated, frequency and quality of medication reviews, discharge to primary care guidance to inform actions to improve local pathways.

Improvements made:

- Reduction of inappropriate Antipsychotic (AP) prescribing for people with dementia. Lincolnshire ICS to be under/in line with National average and not an outlier BPSD pathways reviewed and updated (NICE guidance, including AP prescribing)
- Primary care BPSD > CD + PC Clinical lead.
- Secondary care BPSD Pathway – aligned to PC pathway. Updating pathways and non-pharmacological options/actions.
- Refocus key ethos of AP review. Clear down-titration process/protocol (linked to 6-week review).
- Clear GP discharge information standards. Review, discontinuation & re-access processes.

#### **Complex Dementia – managing challenging behaviour (all settings)**

- We are in the early stages of discussion to implement the role of Dementia ambassadors in care homes.
- The cross organisational task and finish group is in place for the appropriate use of Antipsychotic Medication they have detailed plan to manage this to better support people with dementia and people in caring roles to manage challenging behaviour.
- The recovery college are working with carers to develop a training course to support carers in their caring roles.
- We are looking to undertake a workforce review to develop education and training programmes for supporting people with dementia and improve access for carers and care professionals.

#### **Palliative and End of life Care (PEoLC)**

- Working with PHM to develop robust data - how many dementia patients on PEOL register, how many have an ACP and RESPECT.
- Working with PEOL Delivery Group to explore how we can adopt elements of the Derbyshire toolkit to strengthen the PEOL offer for people with dementia.
- Enhanced Health in Care Homes is dedicated to improving PEOL for people in care homes of which dementia patients are covered.

#### **Developing specialist Young Onset Dementia (YOD) pathway for Lincolnshire.**

Working group established was paused this will be resumed.

New Pathway to be implemented.

## 2. Conclusion

Nationally there are **85,000** people living with dementia in the UK, and by **2025** it is expected that there will be over **1 million** people living with dementia and by **2040** this could be **1.6 million**.

In Lincolnshire there are currently **8300** people living with a confirmed diagnosis of Dementia, with **7948 (95.8%)** people being 65+ the average age being 82, of this number there are **5829 (72%)** of people that have Comorbidities, and there are also **352 (4.2%)** people in Lincolnshire that have young onset dementia (under the age of 65). Dementia prevalence is predicted to increase across Lincolnshire in all districts over the next 5 years, and based on the projections provided by POPPI, in Lincolnshire the population is expected to grow by **11% by 2041**, with **30%** of the population to be over 65.

It's important that the Dementia Programme raises awareness of dementia and encourages people to seek help, the aim will be for the not only the public but professionals to be more aware of dementia and to understand dementia better. To reduce other people's fear and misunderstanding of people with dementia. We need to respect that dementia is a life limiting disease and the biggest killer in the England and Wales, treatment, care and support is needed before and at the point of diagnosis this will ultimately help those dealing with memory issues thrive because it ensures they spend less time anxious and more time enjoying as active a life as their conditions permit.

There are **1873** people in Lincolnshire that are identified as having a Mild Cognitive Impairment (MCI); Patients without a Dementia Diagnosis. Follow up by the GP is not mandatory, but there is a real opportunity to do some focused work with people to support people to make informed lifestyle choices to prevent and delay the progression to dementia, and possibly identify any other underlying causes for memory loss.

Research tells us that up to **40%** of dementia is preventable and shows that supporting brain health and reducing dementia risk is not only the right thing to do – it could also save money for the public purse. Preventing dementia by targeting just three specific risk factors – tackling high blood pressure, providing hearing aids, and helping people to quit smoking – could save the economy **£1.9** billion per year and reduce the number of cases of dementia by nearly **10%**. Only **34%** of UK adults think it's possible to reduce their risk of dementia. Health and care professionals can promote evidence-based messages to middle-aged adults to help reduce their risk of getting dementia.

The dementia programme needs to have parity and support from the system to identify opportunities for financial investment, opportunities to submit cases for change that will support the changes needed for improvement.

For the VCSE community continuing to be committed to work with health and care to develop and improve services for people is imperative and we need to recognise that financial and non-financial support will be required.

Colleagues across the system to pool resources, skills, and access to spaces to upskill the workforce and unpaid carers, and support and services to be available when and where it is needed. To be able to be innovative and develop options for virtual and digital tools to support people at home and people to access health and care services from all our communities.

### 3. Joint Strategic Needs Assessment and Joint Local Health & Wellbeing Strategy

The Council, NHS Lincolnshire Integrated Care Board and the Lincolnshire Integrated Care Partnership must have regard to the Joint Strategic Needs Assessment (JSNA) and Joint Local Health and Wellbeing Strategy (JLHWS).

Strong strategic alignment with Joint Health and Wellbeing Strategy and the MHDLDA Alliance which prioritises dementia as areas for development and improvement. The JSNA data has been pivotal to this report ensuring that we are aware of the expected prevalence for the aging population for Lincolnshire this will help us to forecast future needs and finances that may be required. Identifying our communities in greater need and be able to tackle health inequalities. It will also support us to measure the impact of the dementia programme on the trajectory of the disease.

### 4. Consultation

N/A

### 5. Appendices

These are listed below and attached at the back of the report	
Appendix A	Key feedback from engagement on the draft strategy goals

### 6. Background Papers

No background papers within Section 100D of the Local Government Act 1972 were used in the preparation of this report.

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