



Hope of a Life Still to be Lived

A five year plan for dementia in Humber and North Yorkshire (2024 – 2029)



NHS Humber and North Yorkshire Integrated Care Board

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Programme Partners

















































Introduction

The Humber and North Yorkshire Integrated Care System (ICS) is made up of health and care services across six geographical areas:



- East Yorkshire
- North Yorkshire
- Vale of York
- North Lincolnshire
- North East Lincolnshire

Our Vision: To ensure that everyone in Humber and North Yorkshire who is affected by dementia has access to timely, high quality, and meaningful support. To give people with dementia and their families a hope of a life still to be lived after a dementia diagnosis.

Developing our Plan

Hundreds of people living with dementia across Humber and North Yorkshire, along with their care partners and families have been working with health, care, and support services to develop this dementia plan.

Local people living with dementia and their families, along with engagement leads and our many fantastic voluntary and community organisations, contributed significantly to develop our shared priorities.

Local Alzheimer's Society services work in partnership with the Humber and North Yorkshire Integrated Care System to hold a number of engagement events including workshops, a survey, the big chatty bus, and our joint conference in the Spring of 2024.



People involved in developing this plan have requested that it be kept simple, focussed, and accessible. A commitment has been made to writing this plan following the principles of the Innovations in Dementia guidance 'How to write and produce better information for people with dementia'.

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Priorities on a Page

Communication

People with dementia at whatever age and stage should be kept included and informed as to what is happening.

Education

We should all have opportunities to learn and to teach each other. People with dementia can and should play a big role in creating and delivering these learning opportunities.

Prevention

There's a need to do health promotion and raise awareness about dementia. People with dementia can play a big role in this too.

Our Six Key Priorities:

Underpinned by Lived Experience

Future-proofing

Ensuring our services are sustainable now and in the future, and reflective of the changing needs of our local population.

Innovation and Research

Improving access to research in HNY and ensuring all of our communities have the opportunity to be involved as equal partners.

Accessibility

Improving the accessibility of all services and support. The process of getting a diagnosis needs to be clear, simple and consistent.

Prevention

Some causes of dementia are preventable and there are actions that can be taken to reduce the risk of developing dementia. There is a need across HNY for education and awareness raising about brain health to people of all ages. This needs to be included within all aspects of the community such as schools, community centres and employment, in partnership with health and social care services, and voluntary sector organisations.

We will:

 Make sure people can easily access prevention information in an accessible format.

- Ensure services work better together to promote healthy lifestyles to lower the risk of developing preventable dementia.
- Promote 'Making Every Contact Count' (MECC) We will make the most of day to day interactions with people to help support them in making changes to their physical and mental health and wellbeing.
- Work with under-represented groups of people to ensure they have equitable access to prevention and early intervention.
- Improve the support offer to those with Mild Cognitive Impairment (MCI) to help address risk factors linked with progression to dementia and ensure timely follow ups.



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Education and Learning Opportunities

People living with dementia and their families told us that education and learning opportunities for everyone is a key priority. It must be meaningful, accessible, and equitable for everyone. People with lived experience also want to be able to access education and training to help them better understand the condition, and better support each other.

We will:

- Do a full review of all training available to people with dementia and their carer partner.
- Do a review of all training available to people who work with or support people with dementia.
- Work with people with lived experience to explore the findings of these reviews and identify gaps and areas for improvement.
- Build on the above by coproducing a new training framework that ensure people have access to training that is meaningful and effective.



Communication



People living and working in Humber and North Yorkshire felt that we could maximise the resources we have across our communities and improve how we communicate. We need to better communicate how and where people can access help and support, and for services to talk to each other more. Many of the people with lived experience of dementia told us they want help to have a bigger voice and to still be able to communicate as their illness progresses.

We will:

- Work with people with lived experience and with organisations across HNY to ensure that we are using resources effectively to support people's communications needs.
- Work with our communications teams alongside people with lived experience to improve how we keep people informed about dementia across HNY.
- Develop resources that communicate the importance and benefits of timely diagnosis to everyone.
- Work with all relevant partners to improve information sharing across HNY for things like consent, Lasting Power of Attorney, dementia diagnosis flags, carer flags and contingency planning.
- Work more with under-represented groups of people living with dementia to ensure they are fully included and that they are being heard.

Accessibility

People across Humber and North Yorkshire found it difficult to navigate dementia pathways before, during and after diagnosis. Many people felt that there are too many barriers to accessing care and support and it left them feeling fearful and lacking hope. It was particularly difficult for people recently after diagnosis as many do not have a single point of contact once they are discharged from the diagnosing service.

We will:

- Develop website content that improves access to information for emotional and practical support for people with dementia, their families, and people working in dementia services.
- Work with our voluntary sector organisations and our communications teams to develop alternative ways to access the information for those without internet access.
- Work towards an improved model of support where people can access help more easily and at the time it is needed.
- Work with our organisations to ensure all pathways are made easier to navigate, and meet the needs of people experiencing cognitive impairment.



Future Proofing

We have an aging population across Humber and North Yorkshire. It is likely that more people will develop dementia over the coming years. There are developments in how dementia will be diagnosed and in medications used to treat dementia. Without making changes to the way in which we currently work, our dementia services will not be sustainable, and people may face longer waits for a diagnosis and post-diagnostic support.

We will:

- Work with all relevant services to measure the current demand and capacity and predict future demand and capacity requirements.
- Work with primary care, memory services and other diagnosis services to improve pathways and understand what would be needed to reduce waiting times.
- Have a focus on understanding 'System readiness' for Disease Modifying Treatments and working with NHS England to ensure people have equitable access to potential new treatments.
- Consider future proofing within the scope of the education and training priority to ensure our workforce meets the needs of our community in the longer term.



Research and Innovation

Whilst there is currently no cure for dementia, there are lots of new interventions being developed that can help people with the condition to have a better quality of life. People living and working in Humber and North Yorkshire want greater opportunities to take part in research within this area, and with people living with dementia as equal research partners. Greater access to research and innovation can bring more opportunities to develop learning across HNY. We will work in partnership with the Innovation, Research, and Improvement System (IRIS) to make sure that people with Dementia in Humber and North Yorkshire get access to the latest innovations and research, and that the results of research studies are put into practice in our region.

We will:

- Be key collaborators on the Blood Biomarker Challenge for the next five years. This is to research a blood test that can detect Alzheimer's Disease.
- Work with our organisations to ensure as many sites as possible are signed up to the Trials Delivery Framework

 a national register of dementia research sites that matches the right people to the right place for the right project.
- Develop a Humber and North Yorkshire research group that brings together researchers across all organisations, with lived experience involvement, to explore opportunities for research, innovation and learning.







If you would like to find out more about the Humber and North please get in touch.

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