

VCSE Support for people living with Dementia – Needs Assessment 2024

1. Introduction

This needs assessment is being carried out by members of the East Riding System who are connected to the East Riding Dementia Delivery Group and the Humber and North Yorkshire Dementia Steering group which provide oversight and governance in relation to dementia strategy and workstreams. This needs assessment connects to identified priorities for action of these groups. The focus of this needs assessment is around the provision of support for people affected by Dementia prior, during and post diagnosis, with particular emphasis on community and VCS assets to inform ongoing co-produced and community approaches to inform commissioning intentions.

2. East Riding of Yorkshire Population Description

The previous Rapid Health Needs Assessment – Dementia Support (ERYC 2022) [Rapid-Health-Needs-Assessment-Dementia-Support-Oct-2022-v2.pdf \(eastridingsna.com\)](#) gives a detailed description of the East Yorkshire population, key facts include:

- The East Riding is a large area of 930 square miles with over half the population living in dispersed rural communities.
- Inequalities linked to indices of multiple deprivation are more concentrated in all coastal and some of the rural areas.
- The East Riding population is projected to rise by nearly 15,000 people between 2020 and 2040, from 343,200 people to 358,300 - an increase of 4.4%.
- The 65+ year old age group as a proportion of the overall population is projected to increase from 26.4% to 34.2% between 2020 and 2040.

3. Extent of Dementia

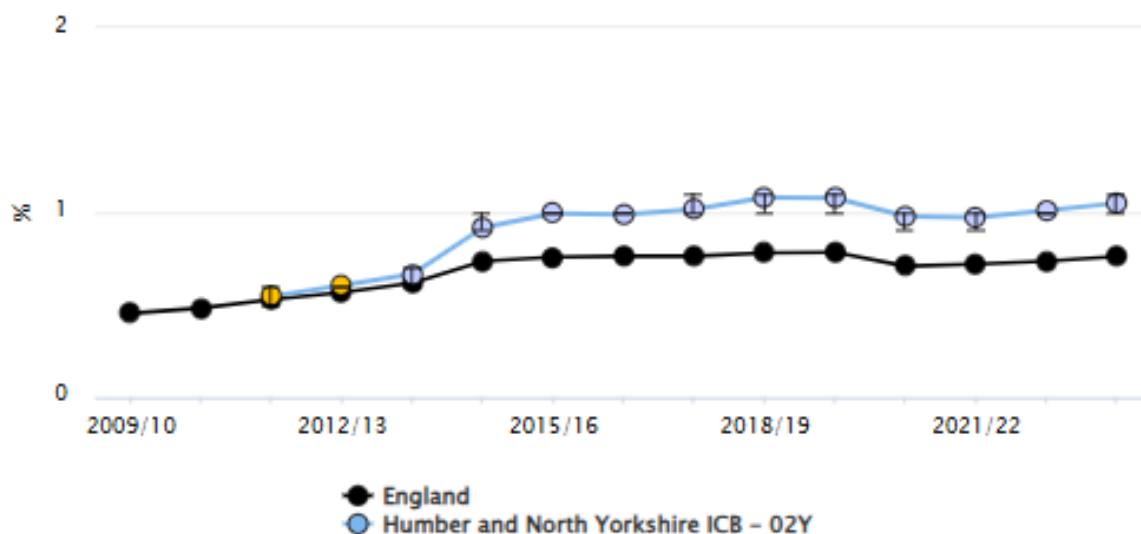
The number of people with a dementia diagnosis is recorded at each GP practice in the UK. Dementia diagnosis rates are also calculated by comparing recorded diagnoses to estimated prevalence. Estimates of prevalence are established using demographic data by area.

3.1 Count and prevalence of dementia in all age groups

Table 3.1 Number of persons (all ages) registered with dementia in the NHS ERY sub-ICS area and East Riding local authority area, with prevalence. 2023/24. Source: [OHID Fingertips](#)

Year	NHS ERY		ICB (%)	England (%)	ERY LA		Region (%)	England (%)
	Patient count	Prevalence (%)			Patient count	Prevalence (%)		
2023/24	3,306	1.1%	0.9%	0.8%	3,402	1.0%	0.8%	0.8%

Figure 3.1 Dementia prevalence trend (all ages), comparing NHS ERY sub-ICS with England.
Source: OHID Fingertip



An updated figure for NHS ERY sub-ICB is available for September 2024 which states that there are 3,422 registered patients (185 under the age of 65 and 3,237 aged 65 & over).

3.2 Diagnosis rate at 65+ years

Table 3.2 Diagnosis rate at 65+ years - latest full financial year. Source: NHS England

Year	NHS ERY (65+ years)			ICB (%)	England (%)
	Registered patients	Diagnosis rate (%)	Total estimated patients with dementia		
2023/24	3,216	58.8%	5,469	58.6%	64.8%

Year	ERY LA (65+ years)			Region (%)	England (%)
	Registered patients	Diagnosis rate (%)	Total estimated patients with dementia		
2023/24	3,307	57.4%	5,761	66.5%	64.8%

Table 3.3 Diagnosis rate at 65+ years - recent update. Source: NHS England

Period	NHS ERY CCG	HNY ICB	England	ERY LA	Region	England
Sep-24	59.7%	59.8%	65.5%	58.4%	67.4%	65.5%

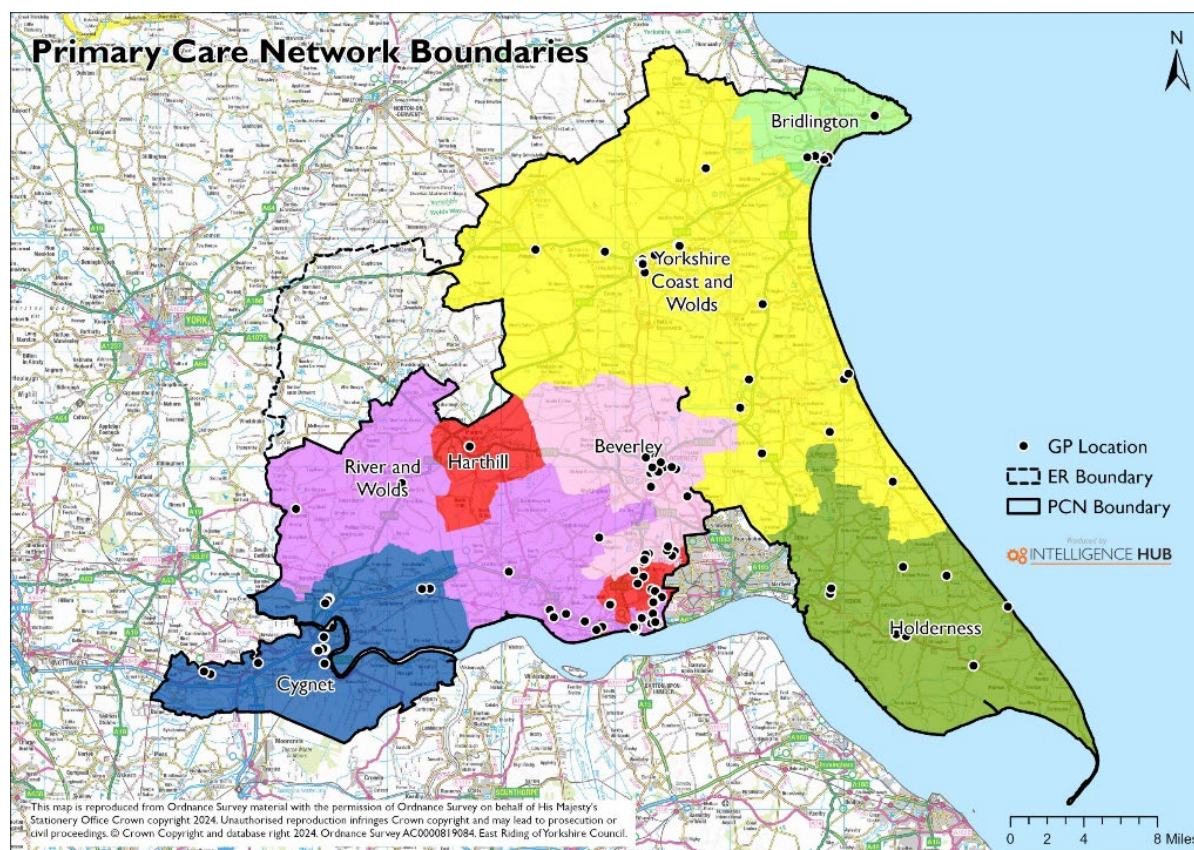
3.3 Diagnosis rate at 65+ years by East Riding PCN

Table 3.4 provides the prevalence of dementia (in persons aged 65 years and over) by East Riding PCN, which ranges from 53.5% in Yorkshire Coast and Wolds to 75.3% in River and Wolds. Figure 3.2, below the table, illustrates the PCN areas of the East Riding on a map.

Table 3.4 Diagnosis of dementia by East Riding PCN, September 2024 (source: [HNY ICB dashboard](#))

East Riding PCN	Prevalence of dementia (65+ years)
River and Wolds	75.3%
Harthill	60.1%
Holderness	59.7%
Bridlington	59.5%
Beverley	58.2%
Cygnets	54.1%
Yorkshire Coast and Wolds	53.5%

Figure 3.2 Map of East Riding PCNs

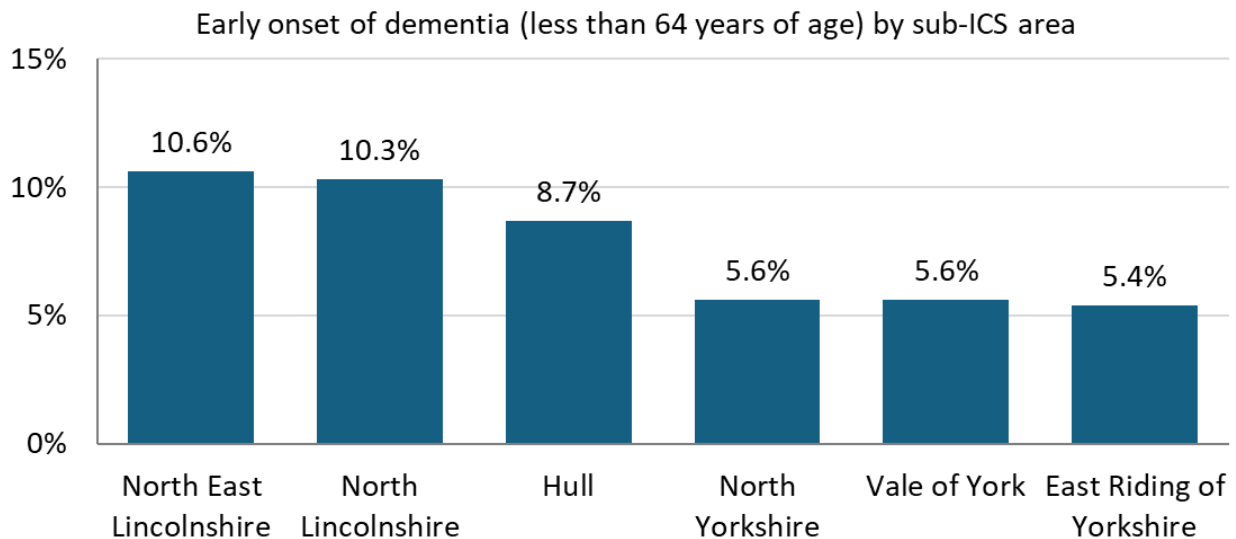


3.4 Early onset of dementia (less than 64 years of age)

As of September 2024, NHS ERY sub-ICS had 185 patients registered with dementia before the age of 65, this equated to 5.4% of all patients (of all ages) registered with the condition. The previous year (September 2023) it was 5.5%.

The prevalence of under 65 years olds in other sub-ICS areas within the ICB are shown in Figure 3.3, it shows the East Riding of Yorkshire to have lowest prevalence (5.4%) of early onset of dementia of the sub-ICS areas, almost half that of North East Lincolnshire (10.6%).

Figure 3.3 Early onset of dementia by sub-ICS area. (source: [HNY ICB dashboard](#))

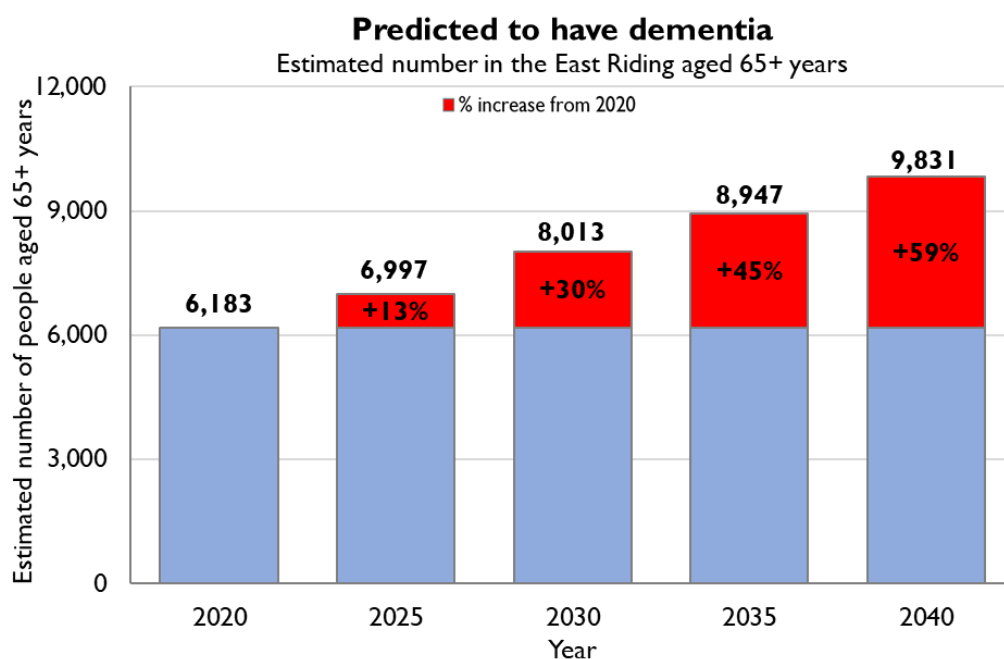


3.5 Future Projections

The graph below shows the predicted rise in dementia in the East Riding local authority population.

Figure 3.4 East Riding residents predicated to have dementia.

Source: Projecting Older Peoples Information (POPPI)



The Chief Medical Officer’s Report 2023 – Health in an ageing society highlights the concerns around the impact of an ageing demographic in the UK. Rural and coastal areas such as the East Riding are particularly affected where we already have an ageing demographic which will grow with continued migration of older people to the area on retirement.

This next section highlights the inequalities in health experienced in rural and coastal areas in East Riding.

4. Deprivation in the East Riding

Overall, the East Riding is generally considered to be an affluent area, however, there are substantial variations in deprivation levels within the local authority area. Small geographic areas (known as Lower Super Output Areas, ‘LSOAs’) within the East Riding are allocated a deprivation decile (or quintile) based on their 2019 index of multiple deprivation (IMD) score and how they compare to other LSOAs nationally.

Figure 4.1 displays LSOA areas of the East Riding as deprivation deciles, with the more deprived areas coloured red or dark orange. Coastal areas such as Bridlington and Withernsea both contain communities which are not only some of the most deprived in the East Riding and also within England overall. An interactive map can be accessed from this link: [Intelligence Hub](#).

Figure 4.1 Map of overall deprivation using IMD 2019, Source: [Intelligence Hub](#).

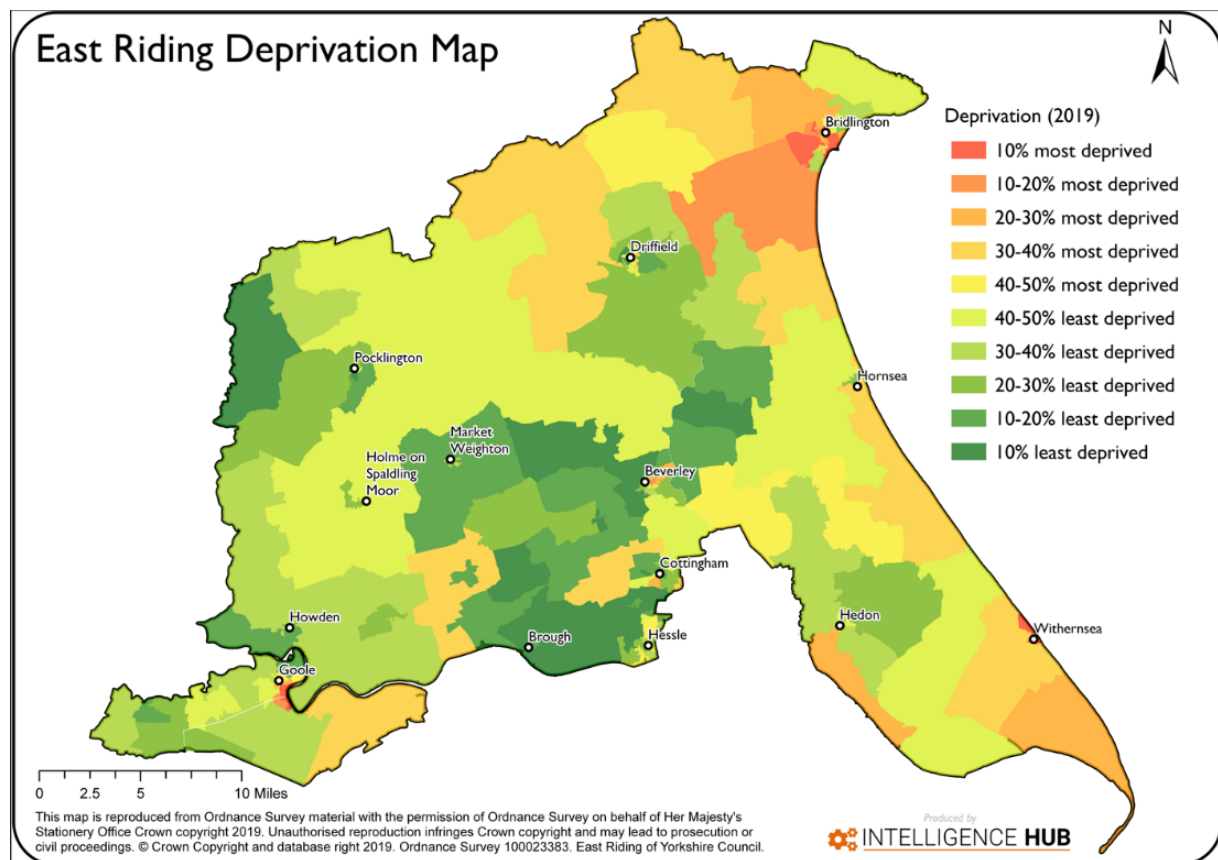


Table 4.1 Percent of 65+ year olds in each East Riding local deprivation quintile in 2023.
Source: ONS 2023 mid-year population estimates.

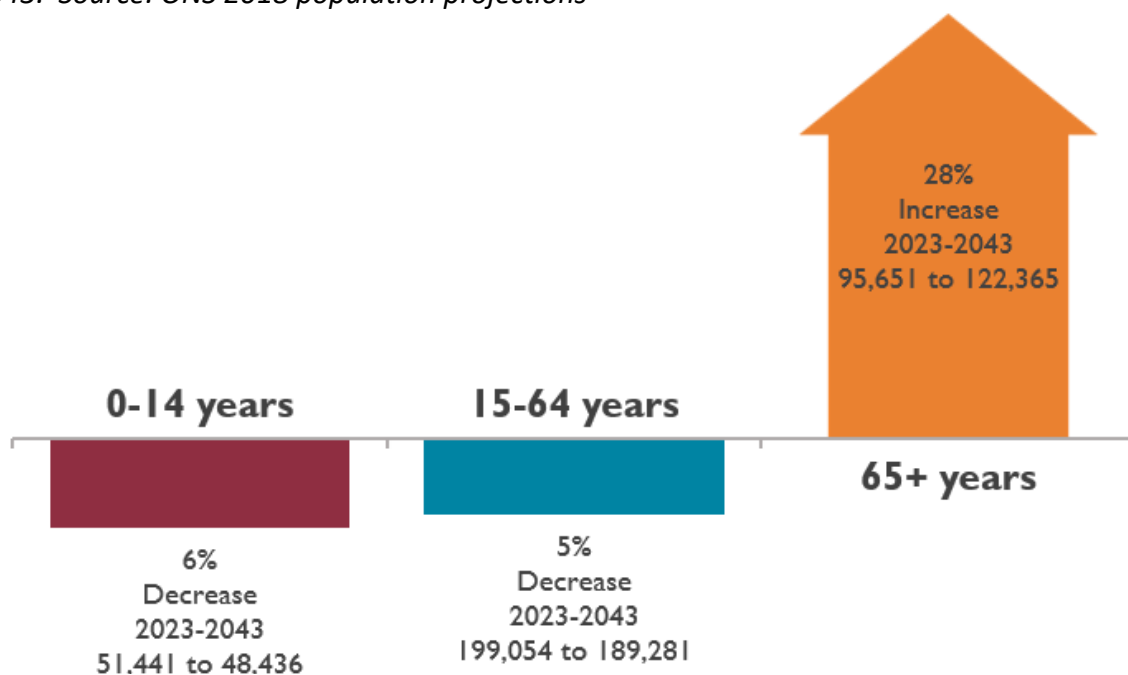
Local IMD 2019 quintile	Q1 (most deprived)	Q2	Q3	Q4	Q5 (least deprived)	ERY overall
ERY LA 65+ resident count	2,090	2,923	8,795	12,475	16,758	43,041
ERY all age resident count	19,394	26,445	66,019	97,620	136,831	346,309
65+ as % of all ages	10.8%	11.1%	13.3%	12.8%	12.2%	12.4%

Table 4.2 highlights the increase in the proportion of 65+ year olds within areas of the East Riding, between 2011 and 2021. All of the areas shown increased in this age group, with coastal areas experiencing a 24% increase and rural areas a 34% increase. These increases follow a national trend outlined in the Chief Medical Officer’s annual report 2023: health in an ageing society (Whitty, 2023).

Table 4.2 Population change Census 2011 v 2021 within the East Riding, residents aged 65+

Area	Census 2011 (65+yrs)		Census 2021 (65+yrs)		Change	
	Count	Proportion	Count	Proportion	Count	% increase (count based)
Rural	30,308	21.0%	40,578	27.1%	10,270	33.9%
Urban	41,147	21.7%	49,928	25.9%	8,781	21.3%
Coastal	20,037	25.2%	24,826	31.4%	4,789	23.9%
Non-Coastal	51,418	20.2%	65,680	25.0%	14,262	27.7%
ERY overall	71,455	21.4%	90,506	26.4%	19,051	26.7%

Figure 4.2 Population projections for 3 age groups in the East Riding, between 2023 and 2043. Source: ONS 2018 population projections



More East Riding demographic information can be found on the Council’s Intelligence Hub website (<https://intel-hub.eastriding.gov.uk/>).

Our coastal areas such as Bridlington and South East Holderness are particularly affected by inequalities in Health and this overlaps with the greater size of the older population in these areas.

5. People with dementia receiving support from Adult Social Care

Each quarter, the Council make an Adult Social Care (ASC) Client Level Data return to NHS England. These returns include counts of ASC clients with dementia from assessment and review forms which have a mandatory field for comorbidities (one of which is dementia) and from non-mandatory sections for health conditions (where some workers have recorded dementia).

As of 14 October, there were a total of 1,789 active ASC cases with a recording of dementia, two thirds (66%) were female and one third were males (34%). The ages of the clients ranged from their early 30s through to over 100 years, approximately 47 clients (2.6% of the overall ASC client cohort with dementia) were under 65 years of age. With 97.4% of the clients recorded as having an ethnicity as ‘white’, it matched exactly the proportion reported for the East Riding population overall in the 2021 Census. Almost 2% (34 clients) were reported to be carers themselves of other people.

Table 5.1 below highlights the main primary support reason for the clients (with a recording of dementia) with over 84% of the cohort having a primary support reason of either ‘Support with Memory & Cognition’ or ‘Physical Support: Personal care support’.

Table 5.1 Primary support reason for East Riding ASC clients recorded with dementia.

Primary Support Reason (clients with dementia)	Client count	% of cohort with dementia
Support with Memory & Cognition	865	48.4%
Physical Support: Personal care support	643	35.9%
Physical Support: Access & mobility only	113	6.3%
Unknown	71	4.0%
Mental Health Support	44	2.5%
Sensory Support: Support for dual impairment	13	0.7%
Learning Disability Support	12	0.7%
Social Support: Support for Social Isolation/Other	12	0.7%
Social Support: Support to Carer	9	0.5%
Sensory Support: Support for hearing or visual impairment	7	0.4%
Total	1,789	100.0%

6. Regional Strategy

Hope of a Life Still to be Lived: The Humber and North Yorkshire Dementia Strategy (2024-2029) [13-NHS-HNY Dementia Plan 2024 v4.pdf](#).

This strategy was developed by people living with dementia across Humber and North Yorkshire, along with their care partners and families alongside health, care, and support services. The strategy highlights six key priorities:

- **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.
- **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.
- **Future proofing:** Ensuring our services are sustainable now and in the future, and reflective of the changing needs of our local population.
- **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.
- **Communication:** People with dementia at whatever age and stage should be kept included and informed as to what is happening.

7. Lived experience

Good Life manifestos

People attending the Good Life with Dementia courses provided by Innovations in Dementia from 2022-24 create their own manifesto designed to be heard by all. Summary of the manifestos by CoPilot provided the following information.

People living with dementia across various places in the East Riding share their experiences and emphasise the need for understanding, support, and inclusion.

- **Life Continues After Diagnosis:** Despite a dementia diagnosis, individuals can still lead fulfilling lives and engage in many activities.
- **Intelligence and Capability:** People with dementia remain intelligent and capable, wanting to continue enjoying their hobbies and interests.
- **Need for Support and Understanding:** Support and acknowledgment of their feelings are crucial as they adjust to their diagnosis.
- **Importance of Inclusion:** Inclusion in conversations and social situations is vital, and it is frustrating when others speak for them or take over tasks.
- **Peer Support and Respect:** Peer support helps individuals feel less alone, and they want to be treated with respect and patience.
- **Maintaining Independence:** People with dementia strive to maintain their independence and continue doing things for themselves.
- **Communication Challenges:** Effective communication is essential, and they need space to express their wishes without pressure.

- **Adjustments and Accessibility:** Adjustments should be made to accommodate their needs, and environments should be designed to be accessible.

8. National Standards and Guidance

The **Dementia Statements** are published by the Alzheimer's Society at: [The Dementia Statements, the law and the NHS | Alzheimer's Society](#)

These describe outcome areas that matter to people with dementia, and their carers:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

The Alzheimer's Society explains patient experience as a legal and NHS requirement connecting to the statutory duty to involve people, statutory duty to have regard to the need to reduce inequalities (Health and Social Care Act 2012), statutory duty to remove discrimination (Equality Act 2010) statutory duty on both public bodies, and publicly-funded services, to promote enjoyment of human rights and avoid discrimination on the grounds of any personal characteristic (Human Rights Act 1998). Provision of a 'good experience' of care for patients is one of the five core domains of the NHS Outcomes Framework

NICE Guidance

Current guidance from the National Institute of Clinical Excellence: NG 97 Assessment, management and support for people living with Dementia and their carers provides evidence based recommendations shown at: [Overview | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE](#) Recommendations include:

- Encourage and enable people living with dementia to give their own views and opinions about their care.
- After diagnosis direct people to relevant services for information and support.
- Ensure that people living with dementia and their carers know how to get more information and who from if their needs change.
- Service providers should design services to be accessible to as many people living with dementia as possible.

- Interventions to promote cognition, independence and wellbeing: offer a range of activities to promote wellbeing that are tailored to the person's preference.
- Person centred and outcome focused training for care and support providers which includes understand the person as an individual and their life story.

From diagnosis to end of life: The lived experience of dementia care and Support (Alzheimer's Society 2020) is available at: [pathway report full final.pdf](#).

This report considers the Dementia Statements and is grounded in the voices of people affected by dementia. The report looks at four stages of NHS England's Well Pathway for Dementia all of which are complemented by services provided by VCSE organisations, groups and volunteers. The report calls on system partners including local government to drive change to improve care and support for people living with dementia. Gaps identified, particularly in the Supporting Well and Living Well parts of the pathway include:

- Post- diagnostic support interventions need to be evidence based.
- Information provided at the point of diagnosis is not being delivered in the right way, if at all.
- Support to navigate the complexity of the health and social care system is needed to get the right care and support, there is limited access to ongoing care and support.
- Many people receive most of their support from their unpaid carer, but carers struggle to access support services for their own wellbeing.

9. Current provision

In September 2024 system partners contributed to an Adult Social Care report on Dementia to the Health, Care and Wellbeing Overview and Scrutiny Committee. The full report aimed to encompass all services available to residents of the East Riding, pre, during and post diagnosis and can be viewed at [Health, Care and Wellbeing Sub-committee \(eastriding.gov.uk\)](#) with the presentation of the report at: [Health, Care and Wellbeing Overview And Scrutiny Sub-Committee 10 September 2024 \(youtube.com\)](#)

The report including information from the VCSE providers, groups and volunteers who deliver services to support people, pre, during and post diagnosis:

The Alzheimer's Society has a contract with the council to provide a dementia advice and support service. This includes provision of a helpline which can be contacted by telephone or email. Dementia advisers offer appointments at a range of community venues or at a person's home to provide support and information tailored to individual's needs. The majority of service users are people who are caring for a person with dementia, but individuals with dementia themselves are also supported. The organisation also runs nine activity support groups across East Riding and runs a carer's information course. From July 2023 to June 2024 the Alzheimer's Society had 670 referrals for people seeking dementia support and advice services. Research into social cost benefit analysis of dementia adviser services found that for every £1 invested in post-diagnosis support, £3.84 of benefits are achieved.

Innovations in dementia also has a contract with the council to provide co-produced dementia support programmes. Their focus is involving people with dementia in ways that support people to live with hope and keep control of their lives. Current projects include roll out of the "Good Life with Dementia course" delivered by people with dementia for people with

dementia, this includes the development of peer support groups, connecting the national DEEP network of dementia voices. Course participants also create an information booklet provided to people on diagnosis via Memory Assessment Services and distributed throughout the network of dementia support groups in the East Riding (see background documents). Participants also participate in delivery of workforce dementia training, dementia strategy, workshops, and research. This service worked with 74 people with dementia from across the East Riding from July 2023 to June 2024.

Butterflies memory loss support group is a charity, grant funded by the council to develop their co-produced approaches to dementia support, they are also facilitating the “good life with dementia” course and associated peer support groups to increase the reach in East Riding. This charity has many years of experience of supporting people with Dementia with people travelling from across East Riding to their support groups in Hull and Cottingham. They have recently started a specific group for people on the waiting list for memory assessment and this has been highlighted as a gap. Butterflies also support carers who still have a role as an unpaid carer after a loved one has moved into residential care.

Additional voluntary sector groups, often led by community volunteers, also provide support for people to live as well as possible with dementia in their communities. This includes The Right Minds group, Bridlington, As time goes by café, Hornsea, All Saints Market Weighton, and Howden memory café. These groups are part of the Dementia Inclusion Network, facilitated by Public Health and Innovations in Dementia. The Network supports communication, information sharing, collaboration, and co-production across VCSE and partner services with people affected by dementia, ensuring they have an active part in the development and delivery of ongoing support. The network governance feeds into the strategic dementia delivery group and creates a pathway for the voice of lived experience to influence strategy and policy. Members of the network regularly deliver four peer support groups, nine activity groups, one memory cafe and one young onset support group.

Figure 9.1 Map of Peer, Activity and Support Groups



During 2024, 741 people affected by dementia (either the person with dementia themselves or someone in their life who supports them) have received advice, information, participated in courses, activities, research and contributed to policy and strategy development through council commissioned dementia support programmes.

10. Conclusion

Support for people with Dementia to live as well as possible in the community still remains an ongoing need for provision as part of a system wide approach to dementia support, pre, during and post diagnosis. Voluntary sector groups and organisations are well placed in communities, have flexibility and authenticity and are often seen as more approachable than statutory services. There is a need for improving the number of people coming forward for diagnosis, not only to hit targets but to ensure that people receive appropriate support to live as well as possible with the condition during and after diagnosis and that their care partners, families and community also have increased resilience within the landscape of the predicted increases in dementia projections.

East Riding of Yorkshire council priority service outcomes of “Empowering and Supporting Communities” and “Protecting the Vulnerable” are served by ensuring there is support for the public and workforces to be involved with raising awareness, knowledge, understanding and training about dementia. That the voices of people with dementia are central to this work and they have role in delivering services and contributing to strategy and policy. Co-produced services provided by the voluntary sector have a role in supporting people to live independently and have potential to prevent, reduce and delay the need for Adult Social Care intervention.

VCSE support organisations are becoming established as an important of NHS pathways pre, during and post diagnosis for a range of long term health conditions and neurodiversity. Using Cost Benefit Analysis, the Alzheimer’s Society has demonstrated that for every £1 invested in dementia post-diagnosis support, £3.84 worth of benefits are achieved. Without this type of investment, a substantial amount of benefit to the wider system and the public would be lost.

NHS targets for diagnosis are to reach 66.7% of estimated prevalence. Ongoing efficiencies are being made in Memory Assessment Services to improve diagnosis rates, improvements in community awareness raising add to the quantity of people coming forward for diagnosis and assist in reaching the target. Innovative ways to support people pre and during diagnosis are being considered and require further development.

Further role out of support programmes needs to be targeted in terms of inequalities experienced in East Riding, taking into account those living alone with dementia, in rural and coastal locations, where access to services, including transport is more challenging and for people experiencing young onset dementia.