



'Bring
Me
Sunshine'

Living Well With Dementia
in North Yorkshire

Signatories to the Living Well with Dementia Strategy:

 <p>Airedale, Wharfedale and Craven Clinical Commissioning Group</p>	 <p>Hambleton, Richmondshire and Whitby Clinical Commissioning Group</p>	 <p>Harrogate and Rural District Clinical Commissioning Group</p>	 <p>Scarborough and Ryedale Clinical Commissioning Group</p>
 <p>Vale of York Clinical Commissioning Group</p>	 <p>Tees, Esk and Wear Valleys NHS Foundation Trust</p> <p>Representing Mental Health Trusts</p>	 <p>York Teaching Hospital NHS Foundation Trust</p> <p>York Teaching Hospitals - representing acute hospital providers</p>	 <p>Craven District Council - representing District Council members</p>
 <p>North Yorkshire County Council</p>	 <p>NHS England</p>	 <p>healthwatch North Yorkshire</p>	 <p>Dementia Forward</p> <p>Support for today, planning for tomorrow</p>
 <p>Making Space Health & Social Care Services</p>	 <p>Alzheimer's Society United Against Dementia</p>	 <p>Age UK Improving later life</p> <p>Age UK - representing the voluntary sector</p>	 <p>SELBY DISTRICT COUNCIL</p> <p>Selby District Council - representing District Council officers</p>

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Foreword

Welcome to the North Yorkshire Dementia Strategy - 'Bring Me Sunshine'.

This strategy brings together organisations from across Health and Social Care and the Voluntary Sector to speak with one voice on our aspirations for making North Yorkshire a place where people can live well with dementia.

Today, more than 10,000 people across North Yorkshire are living with dementia. That's 10,000 people living with a life changing diagnosis, but also 10,000 families and groups of friends offering support and energy to a loved one. What has become very clear through the creation of this strategy is how personal dementia is to so many people. This strategy is built on the personal feedback of over 1300 North Yorkshire residents who shared their stories with us, both good and bad, to help shape the future direction of services and support for people living with dementia and their carers.

The current context around health and social care is hugely challenging, this strategy highlights key areas where professional training, organisational development and public

awareness of dementia will make a huge difference to the lives of many people across North Yorkshire. It is through the sharing and refinement of our current successes that we will achieve the most in pushing forward to make North Yorkshire a dementia friendly county.

Most essential of all is spreading the message that it is possible to live well with dementia and that people living with dementia have a valuable role to play in the lives of their communities.

Above all, this strategy is a call to action. Whilst this strategy highlights many examples of outstanding work from across the county, we know there is much more still to be done. It is only by working together across public, private and voluntary sectors, in partnership with our communities, that we will be able to achieve the goal of making North Yorkshire a truly dementia friendly place to live and work.

Councillor Michael Harrison
Executive Member Health and Adult Services

Who are 'we'?

This strategy would not have been possible without the input of people living with dementia and carers from across North Yorkshire. From the outset it was clear that maintaining the genuine voice of people was vital to making this strategy compelling and worthwhile. With this in mind the strategy is written with two distinct voices:

'We', 'Us', 'Our' or 'I' refers to people living with dementia and their carers in North Yorkshire.

'The Partners' refers to the signatories to the strategy as set out on page two from across the statutory, voluntary and community sectors.

Purpose and scope of the North Yorkshire vision for dementia support

This strategy brings together the experiences of those of us living with dementia and our carers, along with a wealth of health and social care expertise and best practice from both North Yorkshire and beyond to describe a collective ambition for dementia support over the next five years.

This approach centres on our experiences as the people living with dementia and our carers and it is our stories which have informed every aspect of this document.

It has only been possible through the significant input from the Alzheimer's Society, Dementia Forward and Making Space, all of whom have been part of the editorial group and who have been able to involve people living with dementia in the development of the strategy.

In particular they led in the planning and delivery of a hugely valuable and uplifting Dementia Congress, in October 2016, with people living with dementia and their carers. The name of this Strategy is derived from that Congress, 'Bring Me Sunshine' was the title of the conference - suggested by one of the dementia singing groups, as one of the songs that they love. It symbolises the message that although living with dementia brings many challenges, it does not automatically have to stop people enjoying life.

Alongside the messages about what matters to people living with dementia, we have set out to describe the current position in terms of the numbers of us currently living with dementia, along with other useful but less

well known information about people living with young onset dementia and people living with dementia and a learning disability.

The main focus of the document, however, is the rich information gathered through extensive engagement with over 1300 people and the key priorities that this has allowed us to develop.

These principles and priorities will shape the approach to dementia in North Yorkshire through the lifetime of the strategy. We will aim for a clearer, simpler and more person centred system of support and information for people living with dementia and their carers.

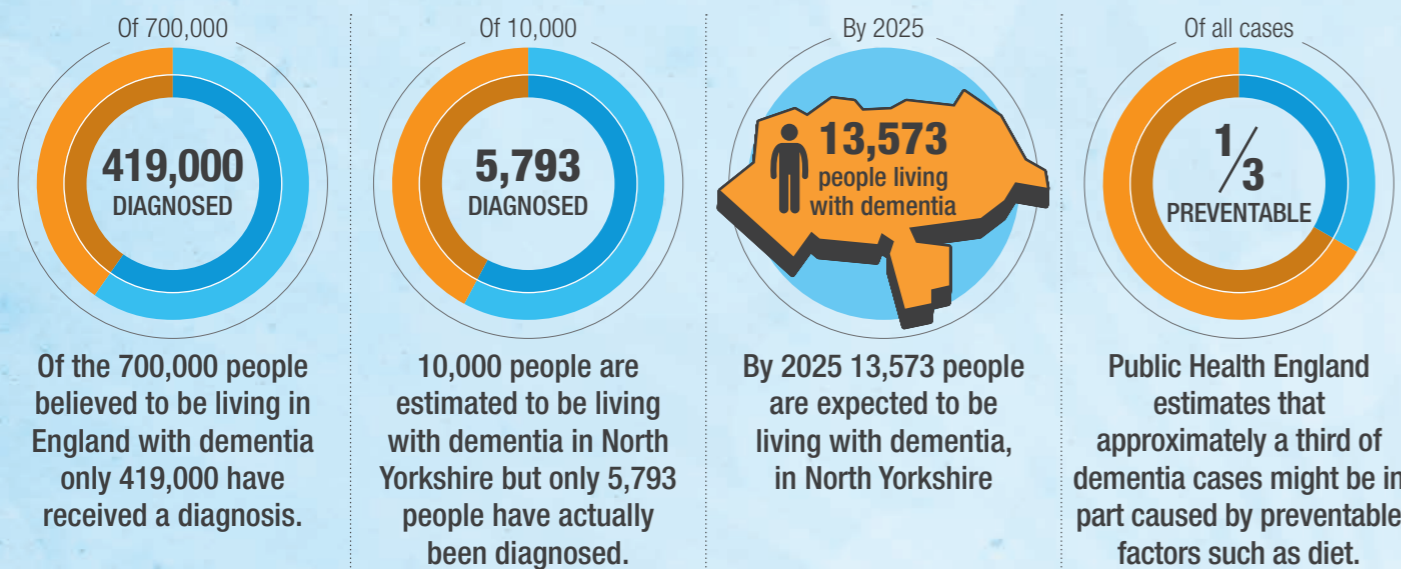
All partners are committed to the delivery of the four Principles and five Key Outcomes outlined on Page 32.

"We don't care about your organisational boundaries, we care about getting the support and help we need at the right time"

"Local community networks are our strongest asset if we can motivate and educate them"

What's the Picture?

Current population estimates are forecasting significant increases in the numbers of people living with dementia.



In addition we know that:

Over 65,000 people in North Yorkshire identified themselves as carers at the last census. In North Yorkshire in 2015/16 the Carers Resource Centres, funded by the Council and the Clinical Commissioning Groups had over 1,800 referrals. In the same time period over 3,200 carers assessments have been undertaken on behalf of the County Council, to help adults look at the different ways caring affects their lives, and agree how their own needs will be supported.

16.9% of the population in North Yorkshire live in areas which are defined as "super sparse" (fewer than 50 person/km). The issues of living in a rural area and access can increase people's feelings of social isolation and has an impact on commissioning and provision of support.

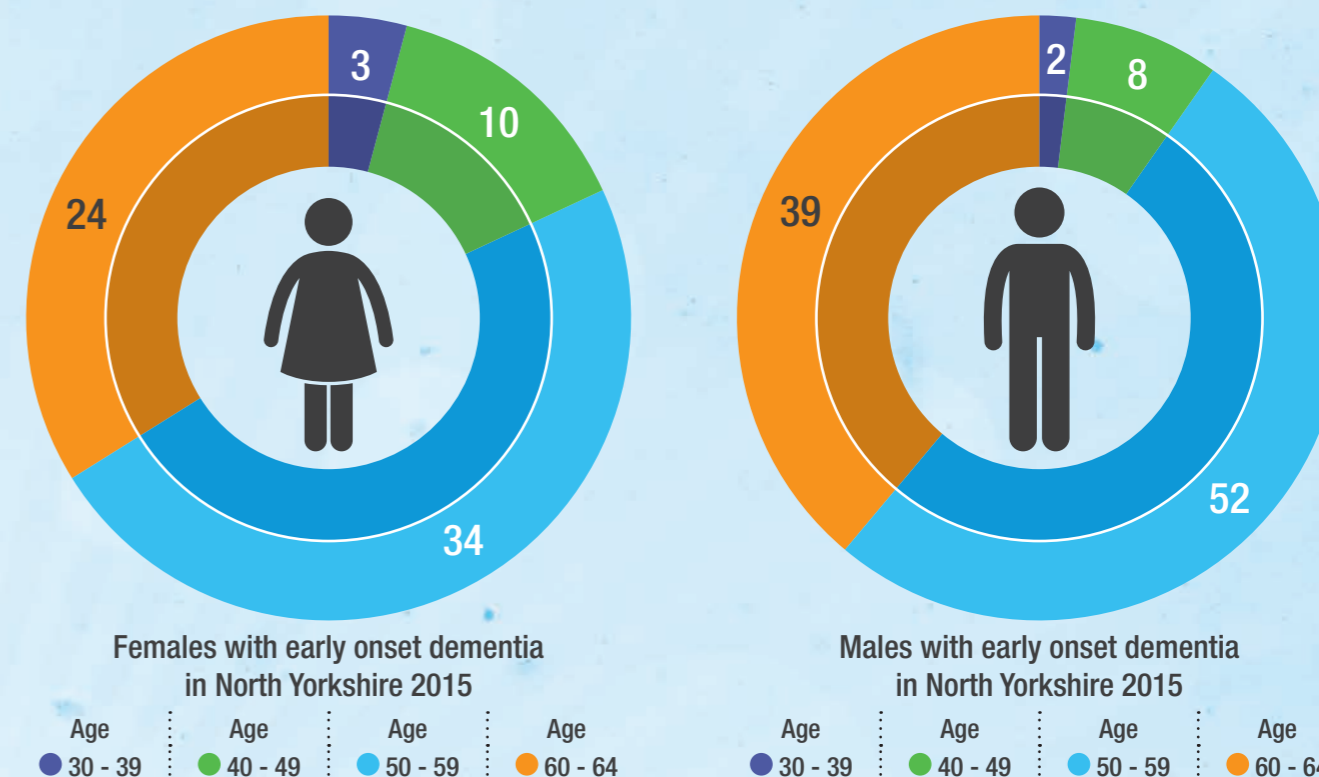
Most people living with dementia are likely to be older people, with one in four people over 85 at risk of the conditions that cause dementia.

There are other groups of people also experiencing memory loss and other difficulties caused by dementia, with young onset (aged 64 or under) and people with a learning disability as two groups that are often overlooked.

Young Onset Dementia

- It is difficult to know the exact number of people who were originally diagnosed under the age of 65, because of the way data is currently collected. Only those still under the age of 65 are recorded as 'young onset'.
- In the UK, in 2014 there were over 40,000 people aged 64 and under recorded as living with dementia. Around 4% of people with Alzheimer's disease are under 65.
- In North Yorkshire, based on these figures it is currently estimated that 173 people are living with early onset dementia¹.

¹ www.pansi.org.uk/index.php?pageNo=408&arealD=8640&loc=8640



Specific issues for people with young onset dementia include:

- Having to leave work due to illness or to be a carer for a loved one, people of working age can lose their income.
- Benefits are different to those over 65 years and may affect income.
- Younger adults may have children who still need support, so any loss of income may be difficult and may lead to challenges for childcare.

People with Learning disabilities

- People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia.
- Studies indicate one in ten people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia.
- It is estimated that one in fifty people with Down's syndrome develop dementia

in their 30s, this rises to more than half by age 60+. It is likely to develop at a younger age than the general population.

- People with learning disabilities often show different symptoms in the early stages of dementia and are more likely to have other physical health conditions which are not always well managed.
- People with a learning disability are less likely to receive a correct or early diagnosis of dementia.
- People with learning disabilities may experience a more rapid progression of dementia and will need specific support to understand the changes they are experiencing and to access appropriate services.
- People with Down's syndrome are at increased risk of developing Alzheimer's and it is more likely to develop at an earlier age.

Living with dementia and other health conditions

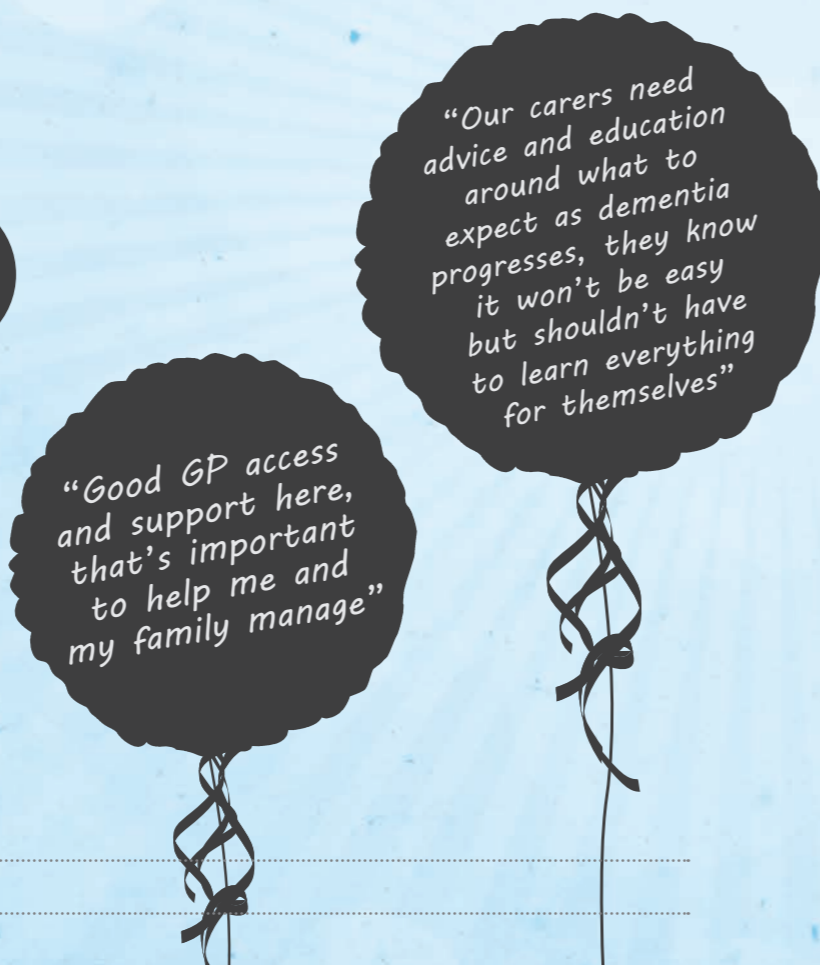
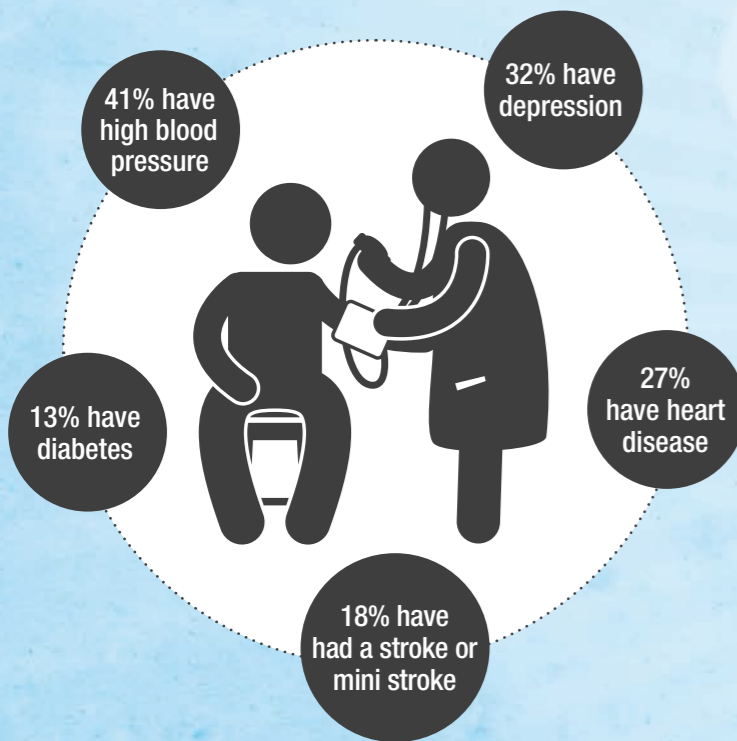
- 70% of people with dementia are living with at least one other long-term health condition.¹
- Poor management of dementia associated with diabetes, depression and urinary tract infections costs the health and social care system almost £1 billion a year.
- People with dementia are less likely to receive a diagnosis for other health conditions and get the care and support they need to manage them.
- Untreated long term health conditions, such as diabetes, can cause dementia to progress on average one to two years faster.
- Studies have shown that of the 850,000 people living with dementia in the UK they are also likely to have:²

Prevention

Support should always begin with prevention of the illness not diagnosis. Vascular dementia is the second most common type of dementia. However there is evidence that individual cases of dementia are often a mixture of Alzheimer's disease and vascular dementia. Vascular dementia has the same risk factors for us as heart disease and stroke therefore the same preventative measures are likely to reduce our risk.

Risk factors for us include getting older, smoking, lack of physical activity along with an inactive lifestyle, drinking too much alcohol, eating a poor diet which has a lot of fat, sugar and salt and for us to be overweight in midlife. Smoking doubles our risk of dementia.

NHS Health checks for adults aged 40 - 74 are an ideal opportunity for GPs and other health care professionals to offer advice and to talk to us about a healthier lifestyle.

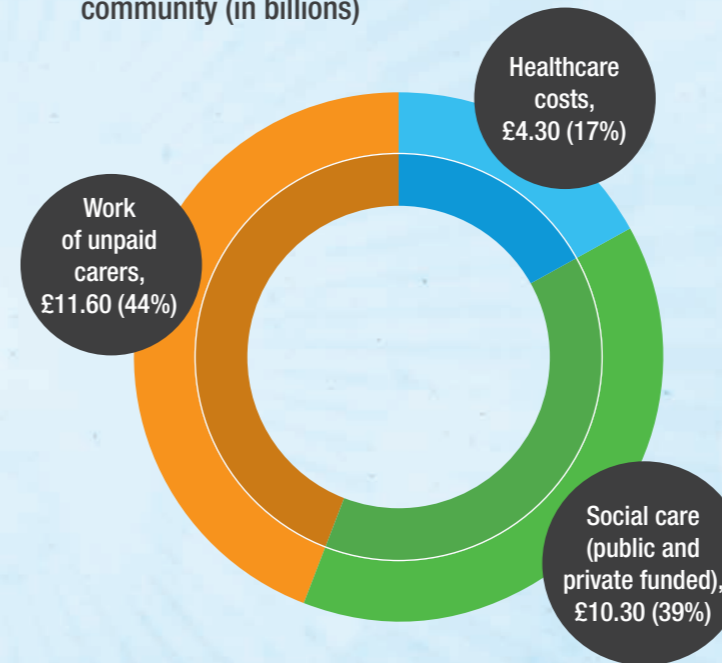


Financial Impact - the national picture

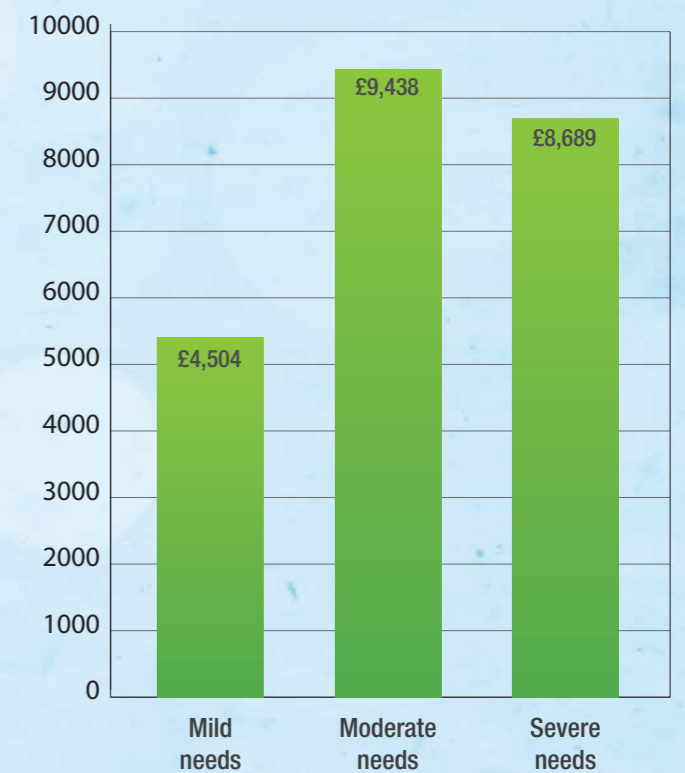
- Approximately three quarters of the total costs for people with dementia is provided as unpaid care by our family and friends.³
- In 2014 the estimated annual cost of dementia was over £26 billion, at £32,250 per person annually.
- For people living with dementia in the community the average health costs are:
 - £2,751 per year for those with mild dementia.
 - £2,695 for those with moderate dementia.
 - £11,258 for those with severe dementia.
- The pattern of healthcare costs is different for people in residential care.
- For people with early-onset dementia, around 10% of residential social care costs and around 5% of community-based social care costs are met by the person living with dementia.
- Of 17,000 missing persons enquiries it is estimated that one in fifteen are for people with dementia. Police costs for looking for missing persons due to dementia are £22 to £40 million per year.

³ www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Dementia costs to the community (in billions)



Healthcare costs by level of need



¹ Alzheimer's Society, People with dementia and comorbidities are receiving disjointed substandard care, April 2016, https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2591, last accessed 20/07/16

² All Party Parliamentary Group on Dementia, Dementia rarely travels alone: Living with dementia and other conditions, April 2016, p.5

What else do we know?

National Strategies

The National Dementia Strategy for England

'Living Well with Dementia' 2009¹ identified 17 key objectives to progress improvement in the quality of services for us, including:

- Improving public and professional awareness and understanding of dementia.
- Good-quality early diagnosis and intervention for all.
- Good-quality information for those with diagnosed dementia and their carers.
- Enabling easy access to care, support and advice following diagnosis.
- Improved end of life care for people with dementia.

The Prime Ministers Challenge², launched in March 2012, set out a programme of action to deliver improvements in health and care, create dementia friendly communities, and boost dementia research. They worked with people living with dementia and their carers and created a series of 'I' statements describing a vision of how people living with dementia wish to be supported by society. These were:

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carer's needs.
- I have support that helps me live my life.
- I have the knowledge to get what I need.

- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.

Public Health England aims to reduce the numbers of people with dementia in midlife. It expects partners in our communities such as health, local authorities, voluntary sector, leisure services, and emergency services, should:

- use routine appointments and contacts to identify those of us at risk of dementia by making every contact count;
- talk to us about being healthy during our lives; and
- give advice on how to reduce our risk factors for dementia.

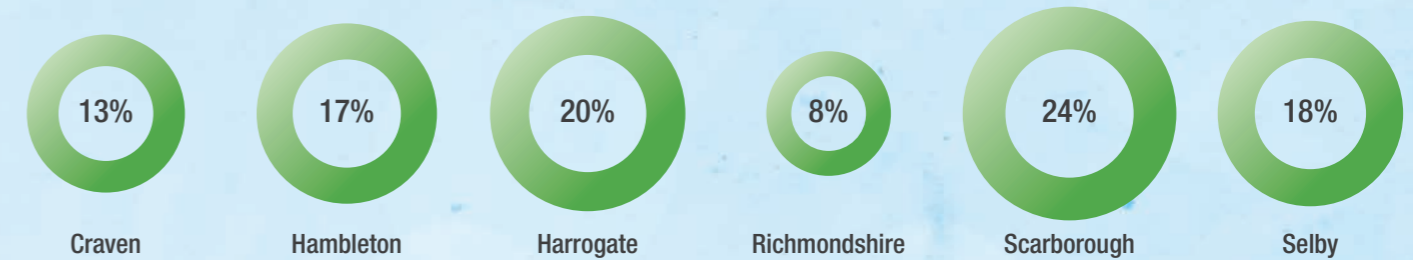
The Alzheimer's Society Dementia Friends

programme encourages greater awareness and supports people of all ages to think about how they can support those of us living with dementia in our communities. It includes the training for children and young people to create a 'dementia friendly generation'. As of February 2017 there are 22,614 Dementia Friends across North Yorkshire.

The Alzheimer's Society Dementia Friendly Communities is a programme which helps to

Dementia Friends in North Yorkshire by District

As of February 2017 there are 22,614 Dementia Friends across North Yorkshire.



create dementia-friendly communities across the UK. Everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

National Dementia Atlas is an interactive map that plots data about dementia care and support, and allows people to compare the quality of dementia care across the country and in our own communities.

The data is grouped in themes based on NHS England's well dementia pathway which is a framework to ensure people with dementia have a better experience of health and social care support from diagnosis through to end of life.

Dementia Action Alliance launched the National Dementia Declaration. This brings together organisations in our communities to do activities that will make a difference to those of us living with dementia. Members engage in awareness raising, education and encourage organisations to see dementia as their business by work together to use their knowledge to influence change and how our community views dementia.

SCIE Guidance to support people with dementia and their carers sets out how to identify, treat and care for people living

with dementia and the support that should be provided for carers by GP practices, hospitals and social care. Examples are:

- People living with dementia not be excluded from any services because of diagnosis, age or other disabilities.
- The rights of carers to have an assessment of needs are upheld.
- Health and social care managers coordinate the treatment and delivery of health and social care services for people with dementia and their carers.
- Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.
- Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training that is consistent with their roles and responsibilities.

NHS Well Pathway for Dementia³ - describes five-year plan which covers:

- preventing well - I am given information about reducing my personal risk of getting dementia,

¹ <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

² <https://shapeatlas.net/dementia/#6/52.955/-2.164/1-p65>

³ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

- diagnosing well - I am given a timely diagnosis, an integrated care plan and a review with the first year
- supporting well - I have access to safe high quality health and social care for people with dementia and carers,
- living well - those around me and looking after me are supported and I feel included as part of my community
- dying well - I am given choice and control to die with dignity in the place of my choosing

Local Strategies

North Yorkshire Community Plan sets out its ambitions to support our communities to be able to develop and deliver the services we need and to enhance their ability to support us in a changing world.

2020 North Yorkshire sets out the County Councils' corporate vision and plan for Health and Adult services, with an overall objective for people to live longer, healthier, independent lives:

- Investing in local services and activities to support people to live independently in their communities, close to family and friends.
- Offering advice information and support to help people resolve concerns at an early stage.
- More choice and control for people, over the support to meet social care needs.
- Developing services with providers to improve the support available to people.

North Yorkshire Joint Health and Wellbeing Strategy has five themes: Connected Communities; Start Well; Live Well; Age Well and Dying Well.

The strategy sets out ambitions for:

- Vibrant and self-reliant communities in all parts of North Yorkshire.
- More dementia friendly communities.
- A stronger link across health and social care.
- More people receiving personal budgets for their care.
- A range of options in place that help people to keep their independence for longer with fewer older people entering nursing or residential homes for long term care and more Extra Care housing available.
- More support options for people in their last years of life.
- More people receiving support for themselves and their families at the end of life.
- More carers feeling that they can have a life outside caring.

NHS Services in North Yorkshire

The NHS in North Yorkshire is a complex network of organisations all of whom have some degree of responsibility for supporting people living with dementia and their carers.

There are two main types of organisation responsible for health services in North Yorkshire, Commissioners who determine what services are needed in which areas and providers who are paid to deliver the services.

All health organisations across the county recognise the importance of prevention and engagement with Communities - Clinical Commissioning Groups and GP Surgeries are actively involved in the work of dementia collaboratives and in the development of dementia friendly communities across the county. These groups work to raise

the profile of dementia, including the early warning signs, and reduce the stigma of dementia in local communities.

- Hambleton, Richmondshire and Whitby CCG** have developed a Dementia Collaborative which brings together key stakeholders from across the area including the voluntary, community and statutory sectors to agree key areas of work and drive forward awareness and change across the area.
- Scarborough and Ryedale CCG** are actively involved in developing Scarborough into a Dementia Friendly Community where people living with dementia and their carers are at the centre of planning for local development and services.

It is also essential that all mental health services, including those for people living with dementia strive for 'parity of esteem' with physical health services. This means that health conditions which mainly affect a person's mental abilities or wellbeing will be treated with the same sense of urgency and importance as physical health needs.

Primary Care

Primary Care in North Yorkshire is commissioned via the Clinical Commissioning Groups and mostly delivered by GP surgeries across the county. GP surgeries are responsible for the ongoing support of local communities whilst also providing services such as community nursing, pharmacies and a range of clinics. In most instances it is the GP who will be the first point of contact when worries about memory problems begin to emerge.

North Yorkshire's CCGs recognise the importance of delivering effective dementia care in Primary care and there is a lot of work going on across the county to develop and further improve services.

Development focusses on four main areas which all CCGs are working towards, below are just some examples of the work which is currently planned or underway:

- Improving diagnosis rates and speed of diagnosis - too often diagnosis occurs too late for the person to make important choices, this is often at a time of crisis which could have been avoided had the diagnosis been made earlier.**
 - Harrogate and Rural CCG** will develop dementia navigators, support for community teams and increased capacity for memory clinics. Ultimately the services aims to have a fully integrated network model which will improve early detection and diagnosis and improves outcomes and quality for people living with dementia and their carers.
- Developing Capacity within primary care - to ensure that people are able to access the diagnostic tests and skilled professional support that they need, close to home and when they need it. This will include new, more effective screening tools and a focus on ongoing post diagnostic support.**
 - Airedale, Wharfedale and Craven CCG** will expand diagnostic services available in GP surgeries and other community settings, as well as developing a system that supports people

to live safely and with social interaction in their own homes for as long as possible

- b. **Scarborough and Ryedale CCG** have a workforce development programme to increase the knowledge, skills and capacity of primary care staff to ensure more effective early identification, diagnosis and support for people living with dementia.
- 3. **Workforce Development - working with practice staff to increase their knowledge and skills of dementia as well as ensuring that all staff are aware of the availability of dementia navigator services and the importance of offering referrals to people with a diagnosis.**
 - a. **Vale of York CCG** have a workforce development aim to increase the knowledge and skills of practice staff, to improve the efficiency of screening, coding and links to memory and care navigator services.
- 2. **Ongoing support to maintain independence - an initial diagnosis of dementia does not mean a person's life stops. Regardless of age or situation there are techniques and coping strategies as well as regular health checks and medications reviews that can help people living with dementia and their carers manage their condition most effectively in the community.**

it can have a severe negative impact on the person's future outcomes.

The importance of continuity for people living with dementia is recognised by all hospitals routinely accessed by people living in North Yorkshire. All these hospitals are signatories to 'John's Campaign' which operates on the principle that family/carers are able to stay with people when they go into hospital. Access should be easy for family carers and their expert knowledge as carers should be used to support people. John's Campaign applies whether a person with dementia is living in a mental health unit, a nursing home, a rehabilitation unit, supported housing or a care home.

Residents of North Yorkshire access services at hospitals both within and beyond North Yorkshire. These hospitals are managed by a range of NHS providers commissioned by the CCGs.

At any one time it is thought that around one in four people in an acute hospital are living with dementia, and we know that once in hospital people living with dementia have worse outcomes than the general population. It is vitally important that hospitals are dementia friendly places for people to be treated and that people are supported, wherever possible to return home as soon as possible.

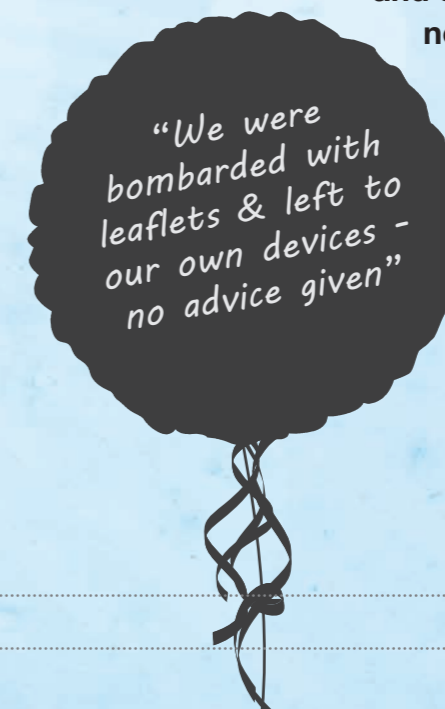
All the CCGs and Hospital Trusts routinely accessed by people living in North Yorkshire have ambitious plans to transform services and improve outcomes for people living with dementia, a flavour of which is set out below, these can be summarised into four key themes:

- 1. **Outreach and Prevention - There is a strong focus on supporting people to live with dementia away from hospital,**

whether this be in the person's home, in a residential or nursing home or an Extra Care housing scheme.

- a. **Airedale, Wharfedale and Craven CCG** are working to further develop their care home liaison service which supports people living residential homes to reduce the need for hospital admissions.
 - b. **Hambleton, Richmondshire and Whitby CCG** are developing a collaborative approach with South Tees Acute Trust to ensure that more people receive appropriate care and support and fewer people with dementia are treated in an acute setting.
2. **Workforce Development - As in Primary Care the experience of a person living with dementia is often dictated by the skills, knowledge and approach of the individual member or members of staff responsible for their care whilst in hospital. Current work focusses on developing knowledge, skills and a broader understanding of the personal impact of dementia beyond the purely practical or medical.**

- a. **Vale of York CCG** are developing a dementia awareness training programme for all clinical and public facing staff with a view to having a more rounded and holistic view of what it's like to live with dementia or care for someone who does.



- 3. **Environment - Hospitals can be disorienting and confusing places for a person living with dementia especially where the dementia is relatively advanced. The change in location, people and routine can be upsetting and lead to an increase in challenging behaviour which in turn may exacerbate the condition and lead to a longer hospital stay than is necessary. There is an understanding that hospitals need to be configured and run in a way that is understanding and supportive of people living with dementia and their carers.**

- a. **Harrogate and Rural District CCG** together with Harrogate Foundation Trust have improved the environment of the Byland ward at Harrogate Hospital to ensure that people with dementia are able to better orientate themselves within the hospital.

- 4. **New or Improved Services - as our understanding of dementia and the needs of people who live with it improve, new services are being developed to ensure that people are supported to retain their independence and that where possible people are not treated in hospital where there is no need for them to be. CCGs and Hospital Trusts are continuing to develop improved ways of supporting people living with dementia as outlined above, this innovation and progress will continue through the lifetime of this strategy.**

Overview of activity by area

Hambleton, Richmondshire and Whitby

Local Strategies

Developed a Dementia Collaborative which brings together key stakeholders from across the area including the voluntary, community and statutory sectors to agree key areas of work and drive forward awareness and change across the area.

Secondary Care

Developing a collaborative approach with South Tees Acute Trust to ensure that more people receive appropriate care and support and fewer people with dementia are treated in an acute setting.

Airedale, Wharfedale and Craven

Primary Care

Will expand diagnostic services available in GP surgeries and other community settings, as well as developing a system that supports people to live safely and with social interaction in their own homes for as long as possible

Secondary Care

Working to further develop their care home liaison service which supports people living residential homes to reduce the need for hospital admissions,

Harrogate and Rural District

Primary Care

Will develop dementia navigators, support for community teams and increased capacity for memory clinics. Ultimately the services aims to have a fully integrated network model which will improve early detection and diagnosis and improves outcomes and quality for people living with dementia and their carers.

Secondary Care

Together with Harrogate Foundation Trust have improved the environment of the Byland ward at Harrogate Hospital to ensure that people with dementia are able to better orientate themselves within the hospital.

Vale of York in North Yorkshire CC

Primary Care

Have a workforce development aim to increase the knowledge and skills of practice staff, to improve the efficiency of screening, coding and links to memory and care navigator services.

Secondary Care

Developing a dementia awareness training programme for all clinical and public facing staff with a view to having a more rounded and holistic view of what it's like to live with dementia or care for someone who does.

Scarborough and Ryedale

Local Strategies

Actively involved in developing Scarborough into a Dementia Friendly Community where people living with dementia and their carers are at the centre of planning for local development and services.

Primary Care

Have a workforce development programme to increase the knowledge, skills and capacity of primary care staff to ensure more effective early identification, diagnosis and support for people living with dementia.

Vale of York outside North Yorkshire CC

Mental Health Services

Tees, Esk and Wear Valleys NHS Foundation Trust (TEWW) provides a range of mental health services across North Yorkshire including supporting people living with dementia.

Ryedale

We have seen the development of a new build "Springwood" specialist Mental Health Unit in Malton which has 14 en-suite bedrooms and a high dependency suite. Springwood offers specialist assessment and care for people living with dementia who have the most complex mental health needs associated with their dementia.

Harrogate

Under the auspices of the Acute Hospital Liaison Service a programme of dementia awareness training was delivered to large numbers of hospital staff, including nurses, support workers, porters, administrative staff, technicians and hospital managers.

Northallerton

The Mental Health Care Home In Reach Service has worked closely with Health and Adult Services in supporting care homes with some training in the care and support of people living with dementia - there have been two planned training events so far.

North Yorkshire Older Peoples Mental Health Services for Older People now deliver dementia care based on a TEWW pathway which recognises not only the clinical presentation of dementia, but also the needs of carers, and focusses on therapeutic interventions and support with some of the side effects of dementia

including falls, behaviour that challenges and the management of pain and delirium.

North Yorkshire

The development of Acute Hospital Liaison Services in Harrogate, Northallerton and Scarborough, based on the acute hospital premises. These teams operate 7 days a week and respond to referrals from the medical, surgical and elderly care wards. Their aim is to support ward staff with the assessment and treatment of people living with dementia, who have been admitted to hospital and their mental well-being is affected. These teams also provide advice and some training to acute hospital staff.

In addition to this, Memory Services have been developed in North Yorkshire, and in Harrogate and Northallerton, for example, offer post diagnostic support, signposting and advice.

TEWW are also supporting dementia research, with designated staff who introduce the scheme to staff working with people living with dementia - this is particularly highlighted within Memory Services. The research advisors will visit interested people and their families - this can be a person already living with dementia who wants to participate in research or any other person who is considering participating.

How services are currently set up

North Yorkshire County Council Public Health commissions health checks and healthy living services for residents to access. There is a campaign called 'One You' targeting people aged 40 - 60 that encourages us to think about how we live. Other ways to improve how we live include:

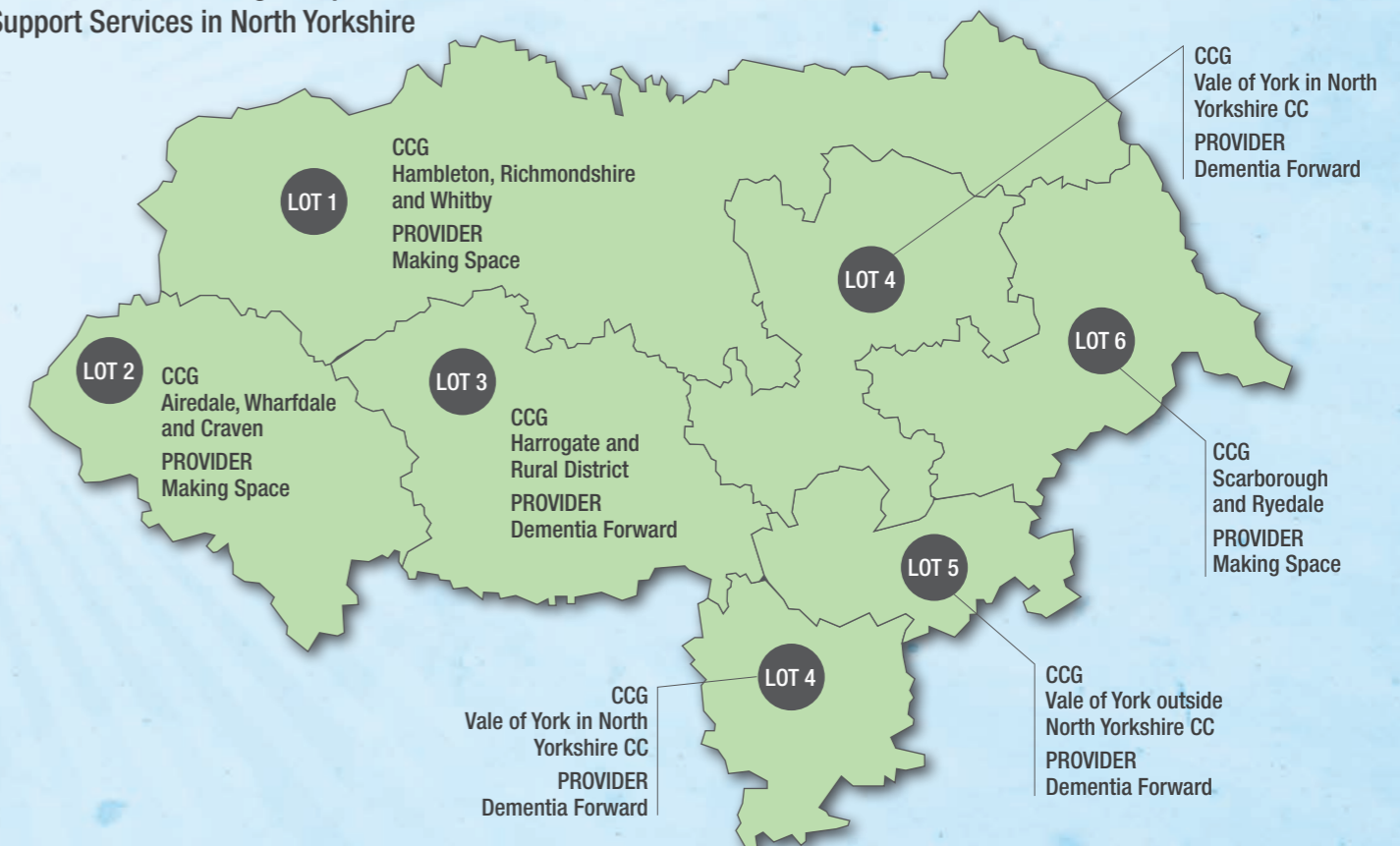
- Developing, delivering and enforcing local tobacco control plans.
- Developing and implementing guidance and policies to reduce alcohol consumption across the population.
- Improving where we live and work to encourage and enable us all to build physical activity into our daily lives.
- Supporting us to eat healthily.
- Addressing loneliness and encouraging us to be socially active and mentally stimulated.
- NYCC Public Health team are working with a range of partners to ensure the above actions are progressed in North Yorkshire.

North Yorkshire County Council also has responsibility for Adult Social Care across the county and has 7 district councils to work with. The County Council is responsible for

assessing the needs of those of us who may need support with daily living tasks, and the needs our carers. It offers personal budgets to those with eligible needs and commissions support for people. This includes support for people living in their own homes, support for carers and where necessary arranges for residential and nursing home care. Anyone receiving support from social care is assessed to establish what they can afford to contribute to the cost of their care and support.

In addition to statutory and commissioned services there is a large range of both formal and informal support groups within our communities, and the Council has invested in a Stronger Communities Team and a Living Well service, both funded by Public Health, to help people to find and access some of the more informal support available in communities.

Clinical Commissioning Groups and Dementia Support Services in North Yorkshire



The National Health Service in North Yorkshire is made up of Clinical Commissioning Groups (CCGs) which are groups of family doctors and other health professionals responsible for the planning and commissioning of health care services for our local areas. NHS England has put together a five year plan for a better NHS. The CCGs in North Yorkshire link to three Sustainability and Transformation Partnerships which between them cover West Yorkshire and Harrogate; Humber Coast and Vale; and Tees Durham and Darlington.

The Tees, Esk and Wear Valleys NHS Foundation Trust delivers Mental Health services across the county.

NYCC and the CCGs jointly commission Dementia Support Services and Carers Resource Centres. The Dementia Support services are delivered by two providers - Making Space who deliver services in Hambleton, Richmondshire, Whitby, Craven, Scarborough and Ryedale and Dementia Forward who deliver services in Harrogate, Vale of York (Selby and South Hambleton / North Ryedale) as well as City of York.

There are many other services which are important particularly in the voluntary sector to support us locally e.g.:

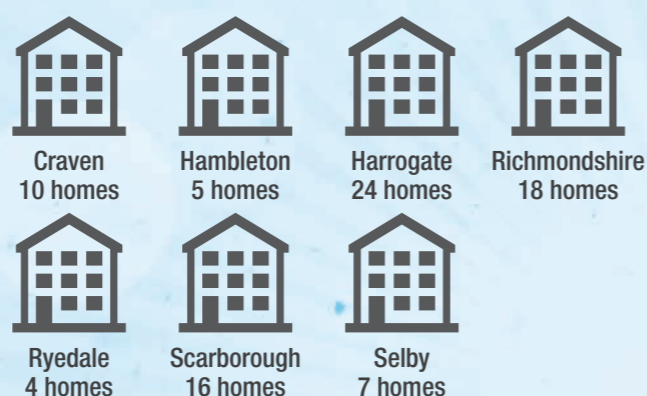
- Practical support.
- Activity based groups.
- Advocacy.
- Befriending.

Care and Support

North Yorkshire County Council commissions care from over 100 domiciliary care providers and 210 residential and / or nursing homes registered with the Care Quality Commission.

Of the 210 residential and nursing homes, 81 (36%) are registered to offer care and support to people living with dementia.

The availability of residential and nursing support for people living with dementia varies by area due to market capacity, as of February 2017 there were the following number of homes registered to provide dementia support in each district:



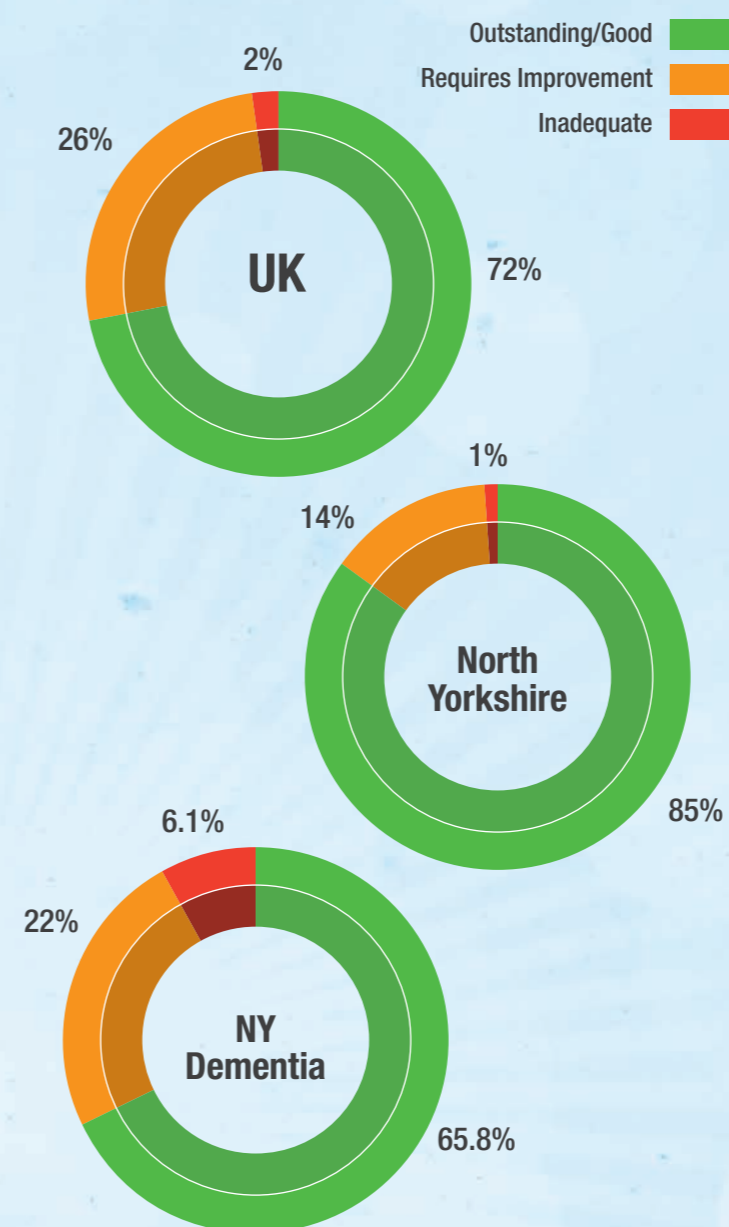
Residential and Nursing Quality

The Care Quality Commission together with NYCC's Quality and Monitoring team have responsibility for the inspection and support of all regulated care providers in North Yorkshire.

CQC rate providers on a scale of 'Inadequate', 'Requires Improvement', 'Good' and 'Outstanding'.

The chart opposite shows a comparison between the UK wide care sector, the wider North Yorkshire sector and homes registered to provide dementia care.

Residential and Nursing Quality



In 2015 NYCC launched a dementia self-assessment tool for residential and nursing homes, which allowed providers to assess their current position in terms of delivering effective dementia care. The results from this self-assessment can then be used to highlight areas of need and development. This process will continue to be developed over the lifetime of the strategy.

Achievements

Dementia Support services commissioned by North Yorkshire County Council and CCGs provides support to people living with dementia and their carers. Within the first six months of the Dementia Support Services being set up in 2014, they had offered support to nearly 750 people living with dementia and almost 700 carers in North Yorkshire. Over 230 people had also benefited from the education and awareness raising sessions provided by this service.

Since April 2016, there have been 2393 new referrals for people living with dementia and 1771 new referrals for carers. Additionally 1154 people have undertaken the education and awareness raising sessions.

A pilot is underway at Kings Road GP Surgery in Harrogate who are working with Dementia Forward to help those of us who are worried about our memory. It helps GPs find out more about us and our families, listens to our carers who know us best and helps those of us who may have problems understanding what is happening such as a learning disability. Support workers will link with GPs, raise any concerns and also collect our experience on what it is like to access support in the health system.

John's Campaign⁴ - all the larger hospitals covering North Yorkshire, James Cook, Friarage, Harrogate, Scarborough, Airedale and most community hospitals have signed up to the national 'John's Campaign' where family/carers are able to stay with us when we go into hospital. Access should be easy for our family carers and their expert knowledge as our carers should be used to support

⁴ <http://johnscampaign.org.uk/#/about>

us. John's Campaign applies whether a person with dementia is living in a mental health unit, a nursing home, a rehabilitation unit, supported housing or a care home.

Alzheimer's Society, Dementia Forward and Making Space are delivering dementia advice clinics in GP practices across North Yorkshire for people diagnosed with dementia or worried about memory loss.

Scarborough hospital, working with the Alzheimer's Society, has reviewed their dementia awareness and led to training for all staff from porters to nursing staff. This has led to changed support and benefits people with dementia during stays. The 'forget me not' logos are used on beds to indicate that we have dementia and for our beds not to be moved which can lead to increased confusion.

Dementia Action Alliances involve all seven District Councils in North Yorkshire. They are at different stages depending upon when they started. All promote dementia activities and events such as Dementia Awareness Week. A number of cross cutting themes for the District Councils linked with Dementia Action Alliance work has emerged this includes:

- Supermarkets reviewing their interior design, black mats which are often seen by people living with dementia as a black hole to fall into are removed. Staff awareness sessions to improve interaction with people who may have dementia. Coin recognition charts at checkouts dementia friendly symbols added to exit, toilet and checkouts.
- Recruitment of banks, Town Halls, hospices and community groups e.g. scouts, theatres, leisure pools, museums. Plans being developed with the wider community.

- The Dales Pharmacy in Hawes completed a dementia friendly refurbishment of shelving, displays, carpeting, décor, lighting and layout to improve orientation and navigation. A safe haven is provided with seating for people with dementia. Its staff became dementia aware with training extended to local care homes where the pharmacist is the registered provider of prescriptions and medication.

- Doctors Surgeries have worked to refurbish practices as Dementia Friendly.

North Yorkshire Police⁵ have implemented the Herbert Protocol which is for when people with dementia go missing. Vital information about the person such as medication, description, photograph, significant places in the person's life and their daily routine are recorded. This information is essential to locate the person quickly, at any time of day or night.

Sporting Memories provide training for carers, relatives and health and social care staff working to use sport as a way to help people living with dementia reminisce. Memories are stimulated giving opportunities for conversations with us and inclusion.

North Yorkshire Sport is a charity which encourages us to take part in sport either by watching or doing it. It is working with Dementia Forward promote sport and its benefits for those of us living with dementia, our families and our carers.

NYCC dementia awareness training is mandatory for all 2010 Health and Adult Services staff and must be refreshed every three years. As the Council's first point of contact all

⁵ <https://northyorkshire.police.uk/content/uploads/2016/01/Herbert-Leaflet-2016.pdf>

38 of the Customer Service Centre's specialist advisors have received the dementia awareness training. As a further first contact point all the library staff have dementia awareness training.

October 2016, North Yorkshire Dementia Congress. This event was attended by 150 people living with dementia and their carers, professionals from health, social care, private and voluntary sector and school pupils. Presentations included a gentleman living with dementia who told his story; a joint presentation from the Alzheimer's Society, Dementia Forward and Making Space about dementia support across North Yorkshire; pupils from St Aidan's High School in Harrogate and Harrogate High School talking about dementia as an intergenerational subject; and Airedale, Wharfedale and Craven CCG and Dyneley House GP surgery in Skipton talking about health approaches to dementia. There was a market place, art exhibition and songs from the Harrogate Singing for the Brain group and workshops which have contributed to the collective themes identified by surveys and the priorities and actions outlined in this strategy.

Dyneley house Surgery have undertaken significant work to refurbish the practice as Dementia Friendly, colour schemes, signs, staff training have led to this GP Practice winning a national award recently.

Accommodation

North Yorkshire County Council is engaged in an ambitious project to develop accommodation with care to meet the needs of our current and future communities.

This includes the development of extra care housing schemes and other specialist housing and supported accommodation to meet the needs of vulnerable people in the county, including those living with dementia.

North Yorkshire County Council's Design and Good Practice Guide, Dementia Care and Support in Extra Care Housing, focuses on design principles and supporting people living with dementia in extra care housing.

There are currently two schemes where we have already achieved this, Limestone View in Settle (below), and Kirkwood Hall in Leyburn.

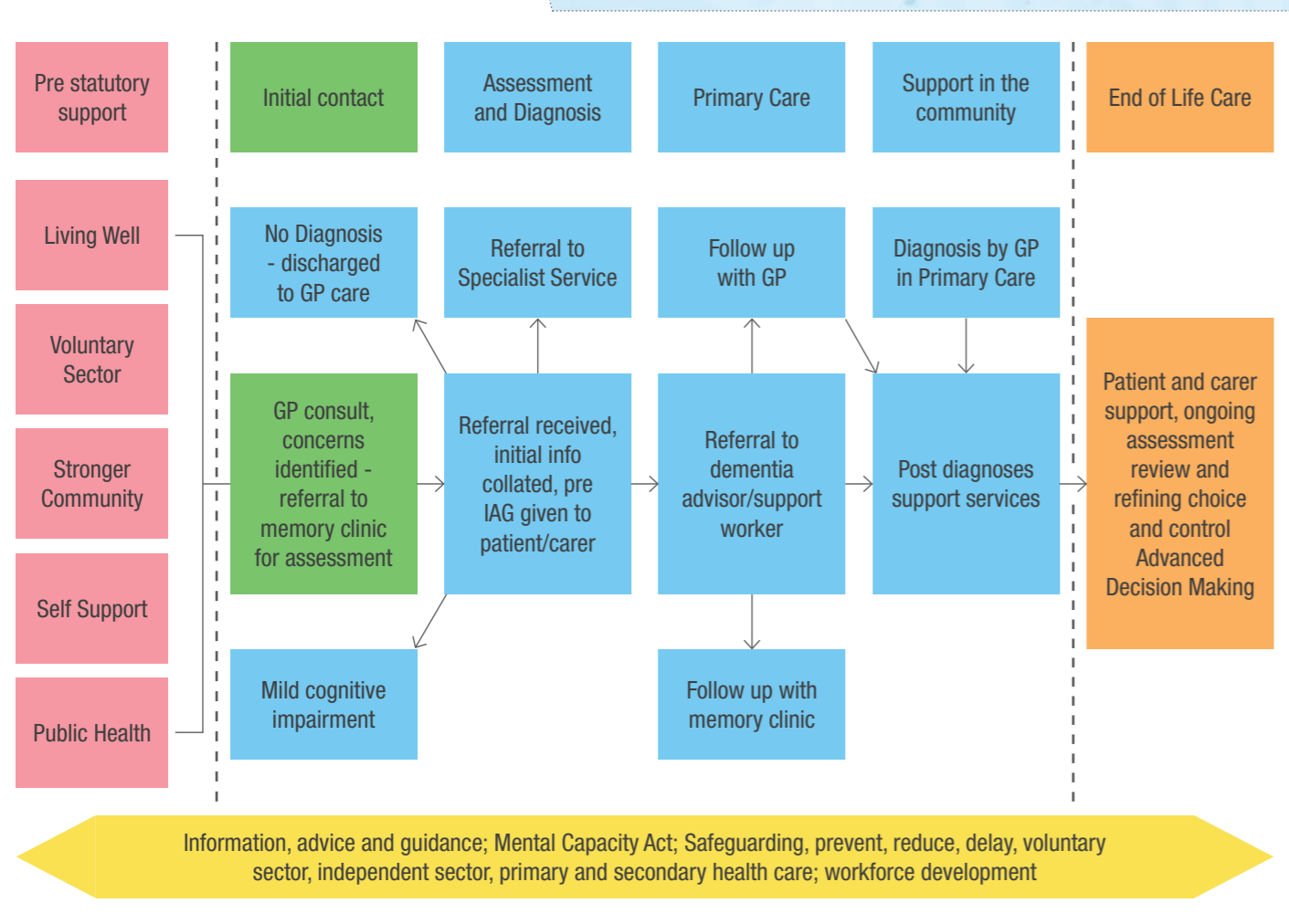


Pathway

The pathway below describes how support should 'wrap around us' when we need it and is dependent upon how much we need at each point in time. Sometimes close and intense and sometimes more distant but there if we need it. This includes prevention in the community with information, advice and guidance to enable us to make informed choices and potentially prevent, delay or reduce the impact of dementia on our lives; through to respecting our wishes at the end of our lives.

This pathway has been identified by the organisations contributing to the development of the strategy to illustrate what needs to happen for those of us worried about or living with dementia. We are aware that currently this pathway is far from consistent across North Yorkshire, with peoples experience dependent on the level of knowledge and capacity in different parts of the county. For example we have heard great things about the one stop shop approach to diagnosis taken in both Scarborough and Northallerton, but this is not available in all parts of the County.

Community pathway for dementia awareness, diagnosis and support



End of Life Care and Support

It has been recognised that for people with dementia the 'end of life' period may be longer and less well-defined than for those with other conditions such as cancer. Similarly, the Care Quality Commission has identified people with dementia as a group at particular risk of receiving poor end of life care.

This strategy aims to ensure 'access for all' to early advance care planning, the same quality of end of life care and the importance of providing support for carers, both before and after the death of a loved one is made available for everyone regardless of their condition or location.

What matters most to people living with dementia - Consultation and engagement across North Yorkshire

Overview

The most important part of developing this strategy has been talking to those of us who live with dementia and our carers in order to fully understand the day to day challenges we faced. We have asked what is already done well, where people living with dementia feel supported and effectively helped to live healthy and independent lives, but we are even more interested in where support falls short and the lessons that can be learned for the future.

The development of this section has also been greatly helped by face to face conversations with individuals and groups across the whole of North Yorkshire, on line surveys, workshops and a dementia congress attended by people living with dementia and their carers.

During the engagement process over 1300 people assisted us with their responses, the following themes and recommendations have been identified as below.

We would like to thank those people living with dementia and their carers who have illustrated key points of emphasis. These contributions more than any statistic or policy are at the core of what this strategy is all about and the document is richer and more meaningful for their inclusion.

Key themes

Challenging the stigma and raising awareness

21% of responses to the survey said that awareness of dementia was the most important issue for them. Places we live and places we go to such as GP Practices, Dentists, shops, Hospitals, Local Authorities, Housing, Police, residential homes, voluntary groups need to be dementia aware and dementia friendly.

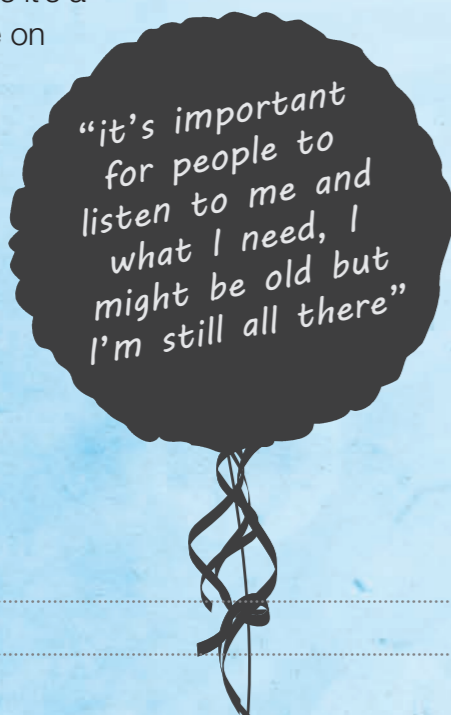
- "Educate children to have knowledge around younger people with dementia and family members. There is still a social stigma around dementia and too many of us are too scared or embarrassed to tell even those closest to us".
- "Modern society is very fast paced, we need a space where we can take a little more time whether it's in shops, on the bus or just going about our day to day lives".
- "We need people to understand what dementia is all about and what it means for us, we don't want pity but more understanding of what it's like to live with dementia and how much the little things can help".

- “We should be educating our grandchildren from an early age, kids are great at asking questions and having open minds without any fear or embarrassment”.

Accessibility

20% of responses said that accessibility was important e.g. Signage, Dementia Friendly Communities, Transport, Inclusivity and Equalities.

- Transport - taxis, buses, aware of dementia and “Extra space in parking bays for people with dementia using a logo such as the forget me not”. “I can’t get my husband into the car in usual spaces and if I stand him by the car he runs away”.
- Being able to get around my community with “signage simple and clear, shops thinking about what it means when they change layout/offer”.
- Systems not working together e.g. health, social care, district councils, voluntary sector - duplicate information activities, partnership working, planning, lack of funding, cost implication for clients.
- Simple English/easy read - we need more information and the right sort of advice, sometimes it’s a lot to take on board all at once.



Early diagnosis and support

5% of responses said that diagnosis and support was important. There was a real appreciation of the support provided by the two Dementia support services and other organisations, but still a number of issues that could be improved:

- “GPs are separated from the problem. Because of confidentiality they won’t share with carers not present at consultations what was said”.
- “District nurses from the surgery are fantastic, I don’t know what I would do without them. It’s important to know they are there and will come out. They do more than just put a plaster on”.
- “When I was first worried that my husband had memory problems, our GP did not listen. They did a very simple diagnostic test but was too low functioning and we had to go back to 3 different GPs before they listened and referred to memory clinic”.
- “Good GP access and support here, that’s important to help me and my family manage”.
- “It can be hard to know what the real symptoms of dementia are - there is not enough general awareness or information”.
- “Whilst many of us receive a timely diagnosis this is not always the case, often we are passed between doctors and clinics with no-one taking responsibility for making a final decision”.
- “Doctors need to understand the impact of saying ‘you have dementia’, they might say it a lot but hearing it is life changing and often terrifying”.

- “We need clear, concise and relevant information at the right time - simple things like ‘am I still allowed to drive’ as well as the longer term health and social care information”. Evidence indicates people want different types of support, small amounts of information and directions in the early weeks of having received a dementia diagnosis and then on-going in small amounts at the right time.
- “Booklets and leaflets were given, but in large amounts at a time of crisis or when a ‘shattering’ diagnosis had just been given and we could not take it in.”
- “We were bombarded with leaflets and left to our own devices - no advice given”.

Ensuring consistent care and support

13% of responses said that experience of living with dementia is far too varied, whether in the individual’s residence, care home or hospital setting the some of us receive excellent support, a quick diagnosis and manage to make connections with groups and professionals who are knowledgeable and supportive. Too many of us do not have this experience and are left to fend for ourselves in a disjointed and often bewildering system.

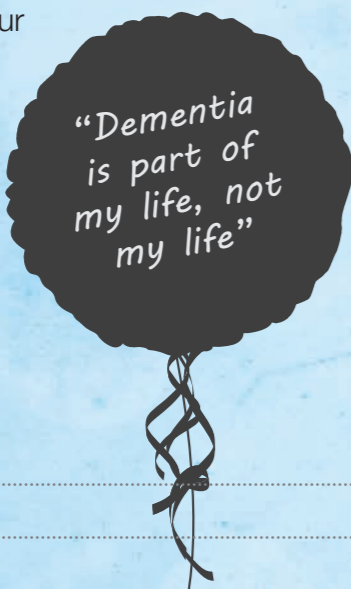
- “This goes wrong in hospitals” evidence of lack of dementia awareness in hospitals by all staff from consultants to nurses.
- “different response depending on the GP and resources”.
- “it’s important for people to listen to me and what I need, I might be old but I’m still all there”.

- “People living with dementia should be identified easily for staff to support them on wards e.g. butterfly/forget me not scheme”.
- “Regardless of the type of dementia I have I am still offered treatment and support and this is reviewed”.
- “Too many of us wait too long for a diagnosis or receive conflicting messages from healthcare professionals, there should be a quick and simple process for finding out if we have dementia”.
- “Once we receive a diagnosis there should be a consistent process that offers advice, support and lets us know what to do next, too many of us feel lost or abandoned with the life changing news of a diagnosis”.
- “Those of us living in residential or nursing home shouldn’t be written off and forgotten about”.
- “Health and social care professionals need to work together more effectively, we don’t care about your organisational boundaries, we care about getting the support and help we need at the right time”.
- “We should be able to consent to our information being shared between organisations when it would benefit our care, especially as our dementia progresses”.
- “Co-ordination and continuity of care planning for people living with Dementia to live well, this should include GPs playing a leading role in ensuring co-ordination.”

Planning for the future and dying well

17% of responses said that planning for the future and dying well was important e.g. "having control as far as possible", advanced care planning, decision making and end of life care for people living with dementia.

- "You only die once, let's get it right please".
- "Making sure carers are supported after death of loved one".
- "Acceptance of having a 'dying plan' as you would have a 'birth plan' before the delivery of a child".
- "Parallel approach to Macmillan nurses for people diagnosed with dementia.... it's hard to know who to approach for what".
- "Power of Attorney, Wills.... wishes met, choice, it's hard to know what all the options are or mean".
- "Professionals need to be sensitive but honest with us on what the diagnosis means in the long term".
- "We should be supported to put our affairs in order at an early stage".
- "We need the opportunity to discuss our wishes for the end of our lives and for how we wish to be treated once our dementia has developed to a stage where we will no longer be able to fully express ourselves".
- "Don't forget about our loved ones as soon as we are gone".



Communities and networks - seeing the person, not the dementia

10% of responses said that networks were important to use local facilities more to spread info e.g. libraries/churches, drop-in facilities.

- "I want to continue the things that I have always done but with support".
- "Dementia is part of my life, not my life".
- "I am a person not an illness. I can live positively with my illness that I can continue my interests e.g. gardening, thinking about my house/home and my memories so I can stay there in familiar surroundings where possible".
- "People living with dementia are not separate, but part of the community".
- "Local community networks are our strongest asset if we can motivate and educate them".
- "As dementia progresses we are seen less and less as ourselves and more as a 'dementia', we have names and we expect them to be used".
- "Professionals need to understand the emotional toll of our diagnosis, we won't always be happy or polite, sometimes we may be upset, angry or rude - this doesn't mean we don't want or need help".
- "We are not defined by dementia, we want to live active lives for as long as we can and not be treated any differently to our friends and families".
- "We want to live in our homes and communities for as long as possible".



The value and importance of carers support

7% of responses said that carers support was important:

- "All carers given opportunity to attend a carers course, essential!".
- "Ensure carers are equipped with knowledge, aware of rights, carers assessment and support to cope".
- "Listen to carers/don't let confidentiality get in the way".
- "Carers need to be more involved in planning and care prior to and during their stay [hospital]".
- "The people who care for us are vital to our health and independence, they need to be recognised and supported properly and given the rest they deserve from what is a 24 hour a day job".
- "Those of us who live alone should be properly supported and recognised as having additional needs to people with active support networks".
- "Our carers need advice and education around what to expect as dementia progresses, they know it won't be easy but shouldn't have to learn everything for themselves".
- "Our carers should also have early access to emotional support to help them cope with the diagnosis".
- "When things get too much there should be someone with the power to make decisions available for our carers to speak to at all times of the day or night".

Workforce Development

7% of responses said that workforce development was important e.g. people have told us of their experiences with GPs, hospitals, communities and whilst some comments were positive there is room for improvement.

- “Where does the business person go to get information about being more dementia friendly?”.
- “Hospital should have nurse specialist in dementia care all wards should be dementia friendly”.
- “Sometimes we may be upset, angry or rude - this doesn't mean we don't want or need help”.

In addition we have heard specific issues that affect people with young onset, and with a Learning Disability.

Young onset dementia

- Diagnosis is taking too long and young onset is too often misdiagnosed.
- Diagnosis rate is improving but still needs to get better.
- Memory services could be better if they had a specialist lead.
- GPs need to be better at recognising and understanding young onset dementia.
- Specific services, in particular residential care is rare and often people are placed out of area.
- Traditional day services and respite are not appropriate for young people with dementia - they are not age appropriate and do not support those more physically able.

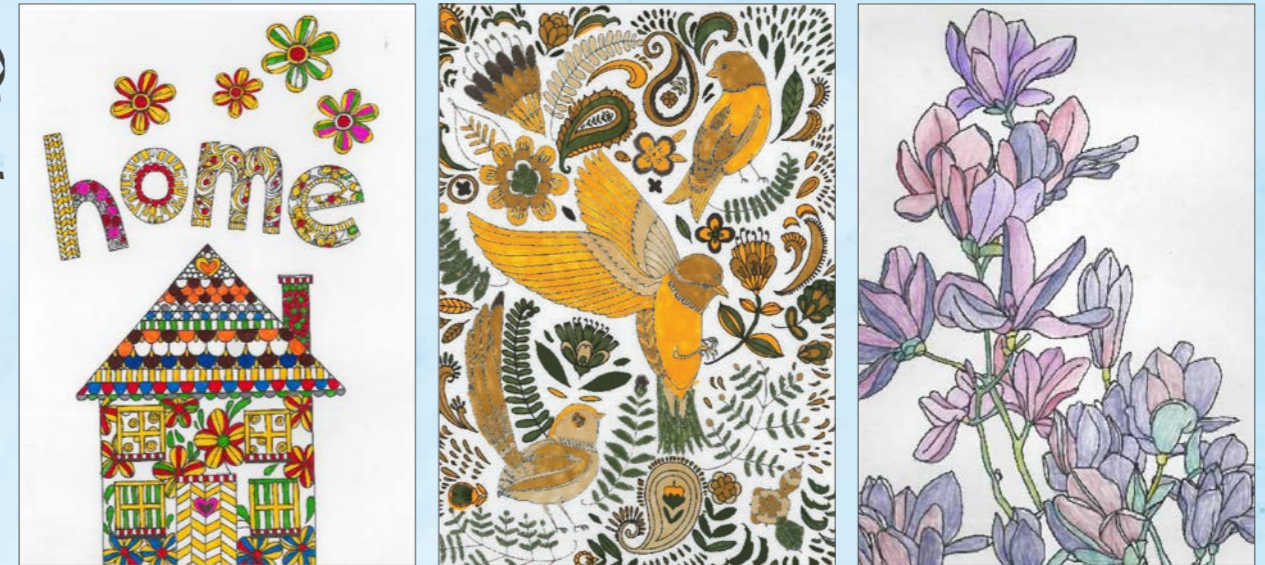
People Living with a Learning Disability and Dementia

As outlined in earlier in this strategy the number of people living with a learning disability and dementia continues to grow and is becoming of increasing importance to health and social care.

It is important that we develop the right support services and mechanisms for people living with a learning disability and dementia that recognise the needs of both long term conditions.

This strategy contains a number of commitments and priorities and these will apply equally to people living with a learning disability and dementia. The overriding principle of seeing the individual, offering suitable and accessible information and allowing the person to make informed decisions will form the core of future work in this area.

Artwork created by people living with dementia



“I want to continue the things that I have always done but with support”

“We want to live in our homes and communities for as long as possible”



Delivering the strategy - action plan

The key areas outlined above have allowed us to develop four key principles which will run through everything we do and five key priorities which will form the focus of the work to be done to improve the support and information we provide for people living with dementia and their carers.

These priorities have been developed and agreed in partnership between health and social care professionals and people living with dementia and their carers.

Strategy action plan

PRINCIPLE
I am Me
I am not dementia
I have a name and I expect it to be used

PRINCIPLE
Carers Matter
Treat them as well as they treat us

PRINCIPLE
The Small Things
Small acts of understanding can make a huge difference

PRINCIPLE
Consistency
Where I live shouldn't determine how I am treated

PRIORITY Dementia Friendly North Yorkshire

WE WILL:

- work with local government, businesses and communities to promote dementia friendly communities across North Yorkshire
- develop a schools' dementia awareness programme to create a 'dementia friendly generation'
- work with employers to emphasise the importance of supporting and valuing carers of people living with dementia in employment
- support local Dementia Action Alliances and Collaboratives to make communities accessible and welcoming to people living with dementia and their carers
- develop and deliver accommodation options for people living with dementia and their carers

OUTCOMES

1. People living with dementia and their carers feel accepted, supported and understood in their communities
2. Support for people living with dementia and their carers is embedded in our communities
3. Improved public understanding of dementia

PRIORITY Workforce Development

WE WILL:

- work to improve the experience and impact of living with dementia amongst health and social care professionals
- review the training and development offer to independent sector care staff and work with providers to assess training and development needs
- ensure that all signatories to this strategy work to become dementia friendly organisations and aspire to all public facing staff undertaking dementia friends training
- support individuals and groups who wish to challenge examples of bad practice
- ensure health and social care professionals are aware of and trained in the importance of carers and the specific challenges carers of people living with dementia can face

OUTCOMES

1. Greater awareness of living with dementia amongst health and social care professionals
2. People are treated as individuals rather than a person with dementia
3. People will experience a more personalised and coordinated health and social care system

PRIORITY Diagnosis

WE WILL:

- work to ensure that the diagnosis process is clear and transparent to people and involves no more professionals or appointments than necessary
- work towards a target of everyone receiving timely formal diagnosis
- work with professionals to ensure that a diagnosis is delivered in a suitable way that recognises the impact on the person and their carer and that full follow up support is offered
- ensure that everyone who wishes to be is referred on to our dementia support services
- ensure that carers are offered support and advice relevant to their needs and are supported through the diagnosis process

OUTCOMES

1. More timely and effective diagnosis routes
2. More effective and consistent post diagnostic referrals
3. A better experience both practically and emotionally of the diagnosis process

PRIORITY Support and Advice

WE WILL:

- create simple points of access for information for people living with dementia and their carers in North Yorkshire including improved access to peer support
- review our current information and advice offer to people, look at ways of improving what already exists and where there is scope for a more innovative approach
- monitor and share the progress of new technology and the ways it could support people living with dementia and their carers
- ensure dedicated Dementia Support Services for people living with dementia and their carers from diagnosis through to bereavement
- develop support specifically for people living with young onset dementia and their families

OUTCOMES

1. Clearer, more accessible information, advice and guidance produced with people living with dementia and their carers
2. Greater access to peer support and learning
3. Adoption of new approaches where technology advances

PRIORITY Planning for the Future and Dying Well

WE WILL:

- develop training and awareness around the importance of planning for the future and having open discussions around people's wishes and fears
- improve and promote information advice and guidance to enable people to make early and informed decisions around mental capacity, planning for the future and end of life care
- work to challenge the social and professional stigma and nervousness around death and dying
- continue to support bereaved carers to ensure they have the physical, emotional and social support they need

OUTCOMES

1. Improved access to knowledgeable professional support
2. Clearer information around what to expect and how to plan
3. Better support for bereaved carers

Moving Ahead

This chapter highlights the key steps we will take to ensure that the immense amount of support, information and goodwill that we have encountered as part of the development of this strategy is turned into positive action and a visible improvement in the lives of people living with dementia and their carers.

Leadership and Governance

The overall leadership for this strategy rests with the North Yorkshire Health and Wellbeing Board which commissioned and approved this document.

Beneath the Health and Wellbeing Board, sits the Commissioner Forum which is made up of NHS and local authority partners and then below that is the Strategy Steering Group made up of the partners involved in the development of this strategy along with representation from people living with dementia and their carers, this group will oversee the progress of the implementation of the strategy.

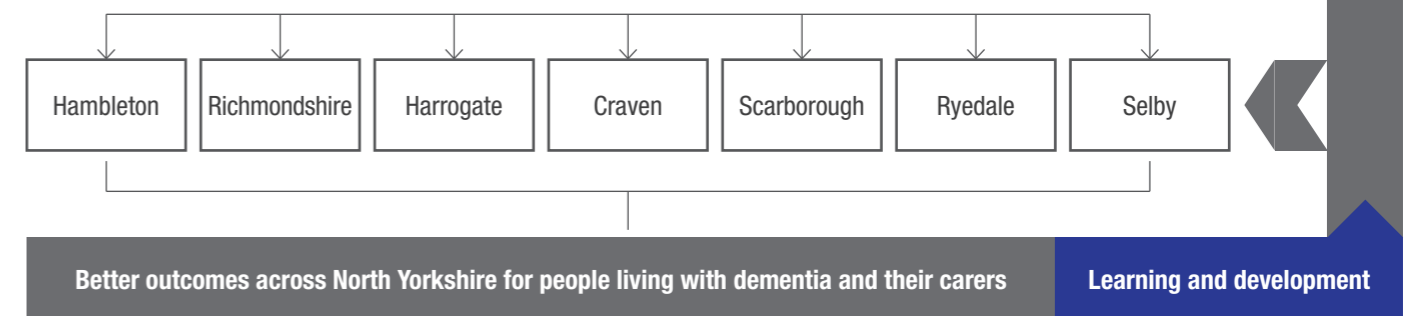
Responsibility for the delivery of change in communities will be delegated to local groups, either already established or specifically developed for this purpose.

The role of these groups will be to develop and deliver local action plans for the implementation of the key priorities set out in Page 32-33, action plans may be variable based on the current position of services and need in each area but all will be co-ordinated to ensure that across North Yorkshire the current inconsistency is minimised.

Working together, see below, these groups will commit to produce an annual report on progress. In addition partners to this strategy will continue to highlight best practice and discuss new and emerging issues with both health and social care professionals and people living with dementia and their carers.



Leadership and Governance





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