



**“Bring Me Sunshine” – North Yorkshire Dementia Strategy**

**Presented by: Mike Rudd**

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**Summary:** This is the final draft for approval, after formal consultation, of “Bring Me Sunshine” which outlines the themes and actions for Health and Wellbeing Board members to support people living with dementia and their carers from 2017-2022.

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**Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?**

Themes	✓
Connected Communities	✓
Start Well	
Live Well	✓
Age Well	✓
Dying Well	✓
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	
Economic Prosperity	✓

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**How does this paper fit with other strategies and plans in place in North Yorkshire?**

- The strategy links with North Yorkshire’s Mental Health Strategy “Hope, Choice and Control”
  - The strategy links with North Yorkshire’s Carer’s Strategy, “Caring for Carers”
  - The strategy links with North Yorkshire’s draft Learning disability strategy, “Live Well, Live Longer”
- 

**What do you want the Health & Wellbeing Board to do as a result of this paper?**

- The Health and Wellbeing Board to approve the final draft of the strategy to be launched and agree to receive a report on progress in implementing the strategy annually starting in October 2018.



North Yorkshire County Council

Health and Adult Services Directorate

Report Prepared for North Yorkshire Health and Wellbeing Board

### **North Yorkshire Dementia Strategy**

#### **1.0 Purpose of Report**

- 1.1 To present the final draft for approval, after formal consultation, of “Bring Me Sunshine” which outlines the themes and actions for Health and Wellbeing Board members to support people living with dementia and their carers from 2017-2022.

#### **2.0 Context**

- 2.1 The previous North Yorkshire Dementia Strategy expired in 2013. This draft strategy looks to define the future strategic direction for all partners when supporting people living with dementia and their carers.
- 2.2 It is estimated that 10,000 people in North Yorkshire are living with dementia, whilst only 5,800 of these have a formal diagnosis. The number of people living with dementia is set to almost double by 2030.
- 2.3 With this expected increase it is vital that health, social care and other statutory and voluntary organisations work together to develop solutions that support people to live well and stay independent for as long as possible, whilst also developing the more specialist and acute services that people will need as their dementia progresses.
- 2.4 The draft strategy aims to bring together thinking across health and social care to agree a joint set of principles and priorities for action in the coming years.

#### **3.0 Content and Style**

- 3.1 The strategy is written for people living with dementia and their carers whilst also being useful and informative for professionals. The style is intended to be clear, concise and free from jargon wherever possible.
- 3.2 The importance of portraying the genuine voice of people living with dementia has been recognised throughout the development of the strategy, each section is introduced in the first person by a person living with dementia, this style will be reinforced through the graphic design of the strategy.
- 3.3 The strategy looks to set out the context of dementia across North Yorkshire, drawing in relevant facts and figures along with descriptions of services and need from across the county.
- 3.4 It is important to stress that whilst we can and must do better, dementia support is well developed in North Yorkshire and the strategy takes the time to acknowledge some of the excellent work being done across health, social care and the voluntary and community sectors.
- 3.5 The final section of the strategy sets out the 4 key principles and 5 priorities with associated actions which will form the basis of work for the strategy partners and others through the lifetime of the strategy.

- 3.6 Part of the 2016 Dementia Congress was an artwork exhibition at which people living with dementia could submit pieces of artwork they had created. It is intended that some of this artwork will be used as part of the graphic design for the final strategy document to bring it to life and again place people living with dementia at the heart of the document.
- 3.7 Following feedback from Health and Wellbeing Board additional content regarding community best practice and specific examples of changes made within acute hospitals has been included in the final draft.

#### **4.0 Engagement**

- 4.1 Initial engagement in early 2017 led to over 1300 responses from members of the public, often in the form of rich personal stories.
- 4.2 Following approval by Health and Wellbeing Board the draft strategy was released for public consultation in May 2017, this yielded a further 36 responses.
- 4.3 The response to the strategy was positive with the tone and style being identified as particular strengths. The positive nature of the consultation meant that no substantive changes to the nature or structure of the strategy document were required.
- 4.4 The Principles and Priorities set out in the strategy were widely supported by all respondents.
- 4.5 The consultation did raise the issue of supporting LGBT people living with dementia which was not included in the original draft. This is an emerging area of practice which is now referenced within the body of the strategy.
- 4.6 A full report on the consultation responses is attached as Appendix A, with the final draft of the Strategy at Appendix B.

#### **5.0 NEXT STEPS**

- 5.1 The final design be completed including images from people living with dementia in North Yorkshire.
- 5.2 A joint launch to take place with “Caring for Carers” in October 2017.
- 5.3 Strategy Partners to draw up implementation plans and report progress to Health and Wellbeing Board annually.

#### **6.0 RECOMMENDATIONS**

- 6.1 The Health and Wellbeing Board to approve the final draft of the strategy to be launched and agree to receive a report on progress in implementing the strategy annually starting in October 2018.

**Mike Rudd, Head of Commissioning, Services for Older People, NYCC**

**County Hall, Northallerton**

Report compiled by:

Adrienne Lucas – Commissioning Manager

Stacey Annandale – Commissioning Officer

**‘Bring me sunshine’ multi-agency dementia Strategy consultation**

The draft dementia strategy ‘Bring me sunshine’ brings together the experiences of people from North Yorkshire who are living with dementia and their carers. It describes what people have said they would like dementia support services in the county to look like over the next five years.

The strategy has been developed by talking to nearly 1300 people who live with dementia every day of their lives. They have described the things that are important to them.

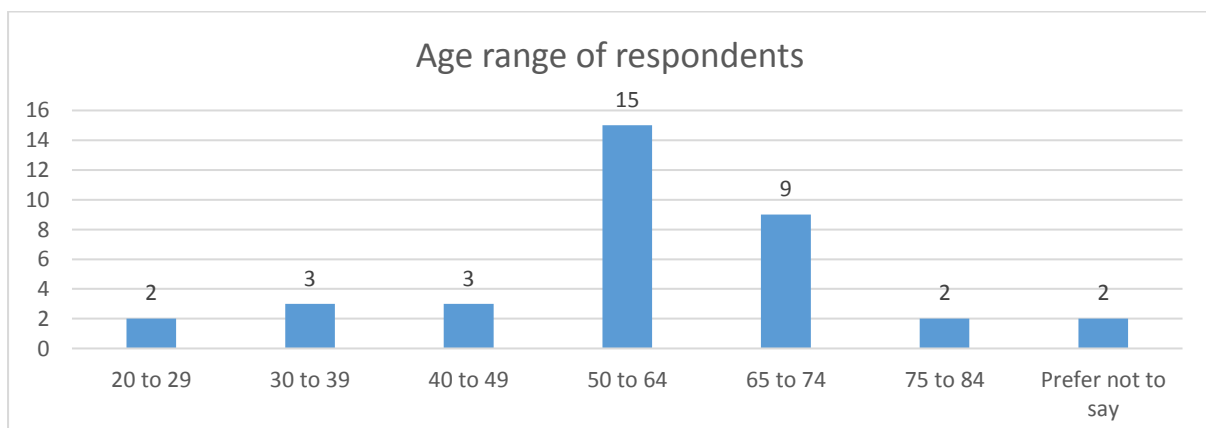
This information has informed a set of themes, now incorporated into the dementia strategy, which will shape how dementia support will be provided by organisations and people in North Yorkshire working together.

To check that this has been described effectively in the strategy we have consulted with the wider community and an online survey with an easy read, plain English and a full version have been hosted on the NYCC dementia webpage from 15/05/17 to 23/06/17 and received 428 hits.

Online survey results

36 people responded to the online survey, geographically this was distributed as Scarborough 23%, Harrogate 20% Hambleton 17%, Selby 14%, Ryedale 9%, Richmondshire 9%. Craven 6% and 3% preferred not to say.

The median age range of the respondents is 50 – 74

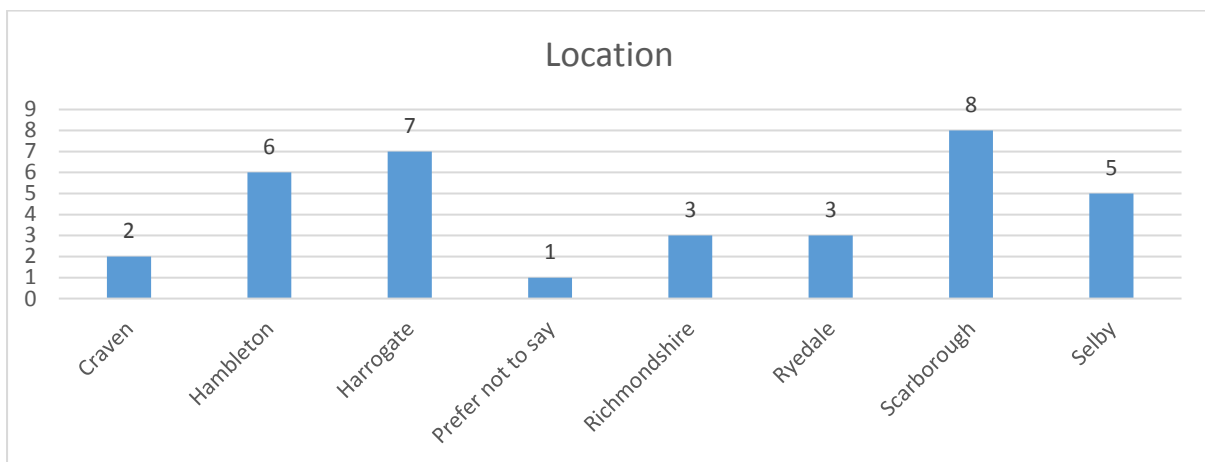


The gender distribution was mostly female 71% and 24% male and 5% preferring not to state their gender.

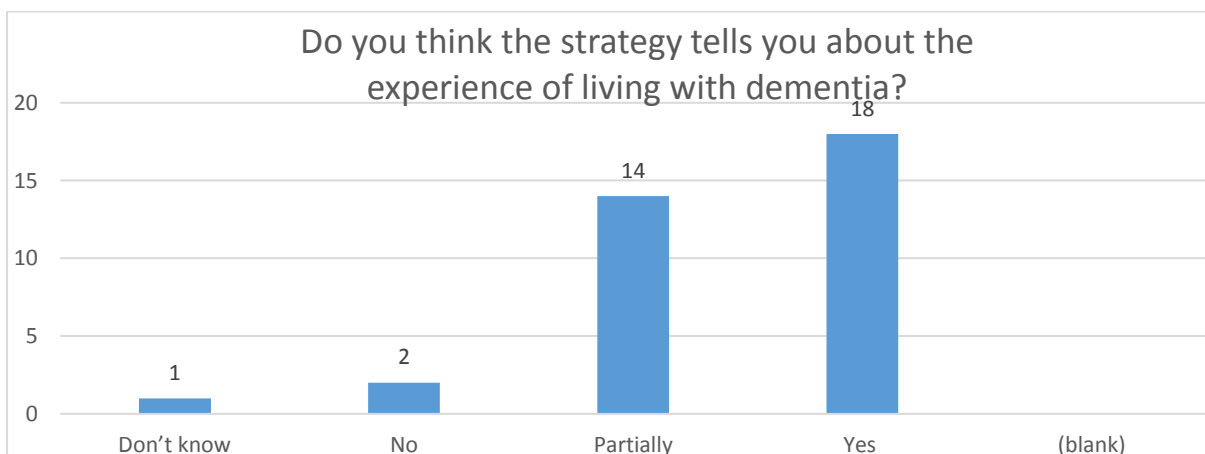
Of those people who responded 57% were carers, 17% were general public, 14% were NHS/social care professionals, 9% were groups i.e. community groups and 3% stated as other.

94% of people stated their ethnicity as White and 6% did not state.

All areas of the county were represented as below.

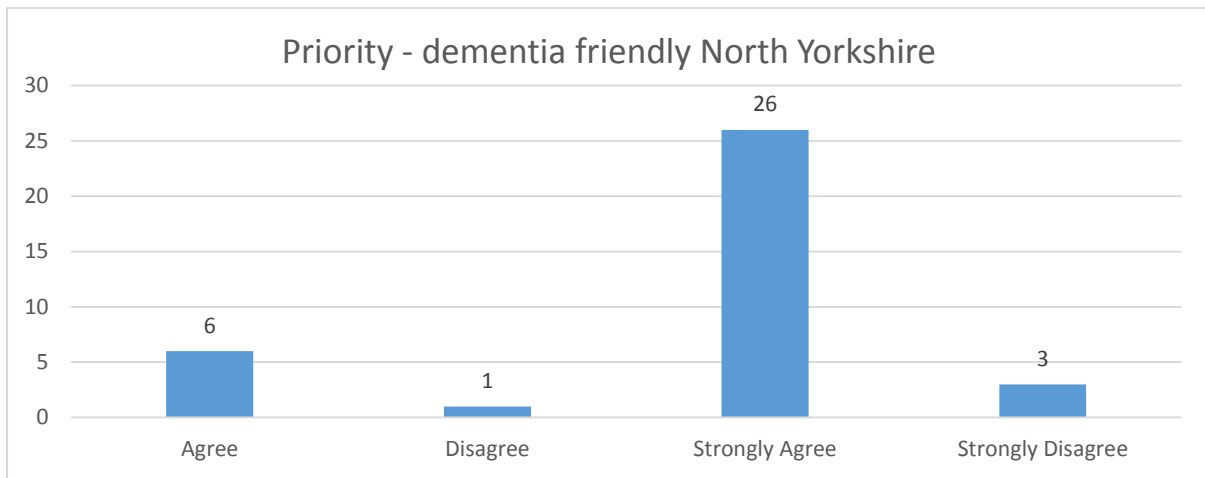


When asked “do you think the strategy tells you about the experience of living with dementia?” 51% (18 people) said yes, 40% (14 people) said partially, with 9% (3 people) saying no or don’t know.



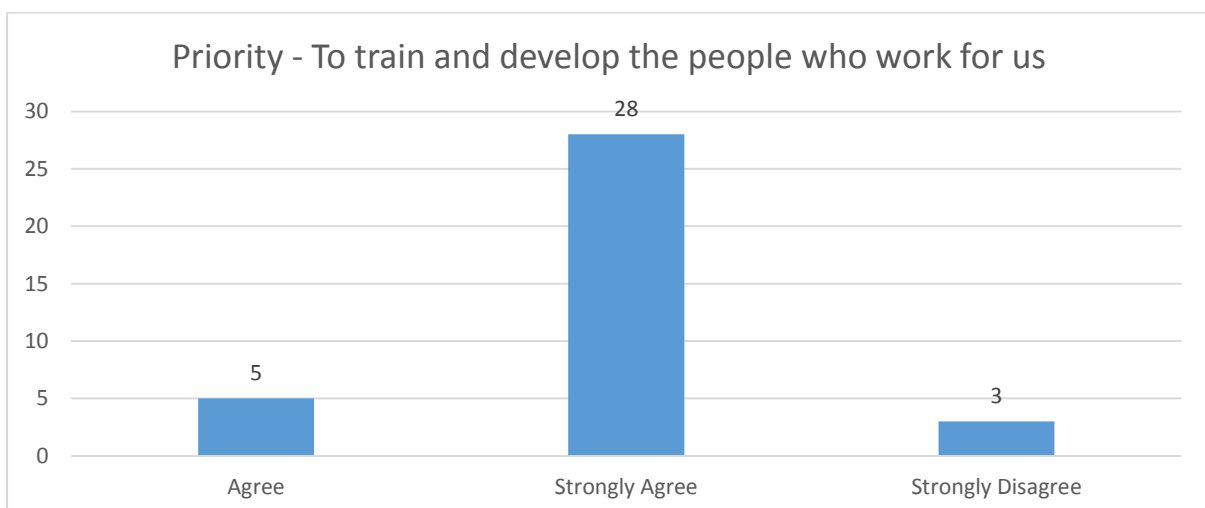
Additionally 92% (33 people) of people agreed with the themed feedback with the strategy from people living with dementia and their carers, with 8% (3 people) partially agreeing.

Consultation about the 5 priorities under which outcomes are described as follows:



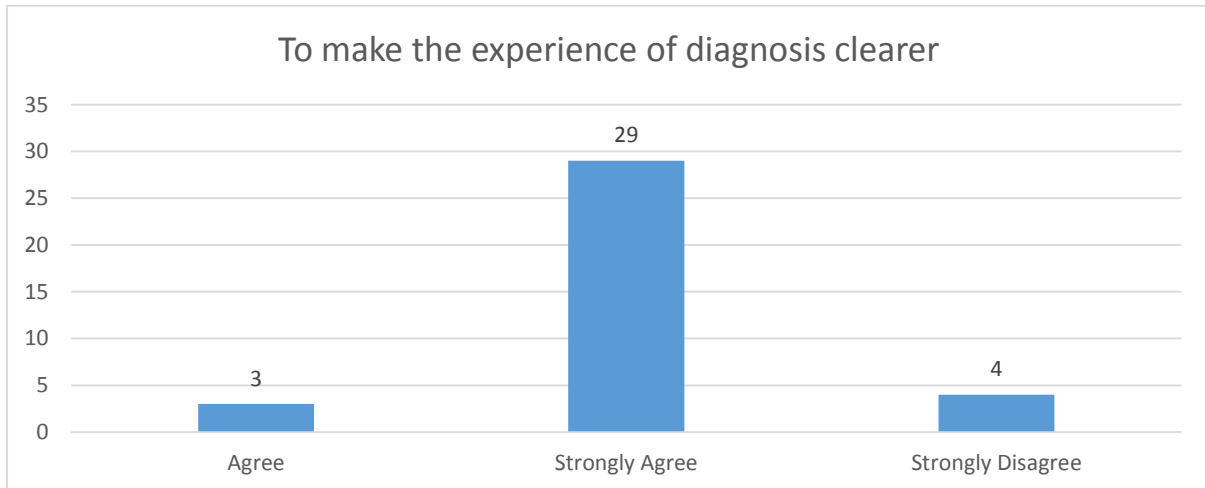
Regarding the ambition to develop the people who work with people living with dementia 92% (33 people) agreed or strongly agreed it was important with 8% (3 people) strongly disagreeing that it was important.

One lady commented *“When my husband was admitted to James cook hospital with loss of mobility, he was not allowed out of bed during his 6 days stay, not even to toilet him!! I also saw dementia patients not being helped to eat - & so going hungry!”* name and contact details provided.



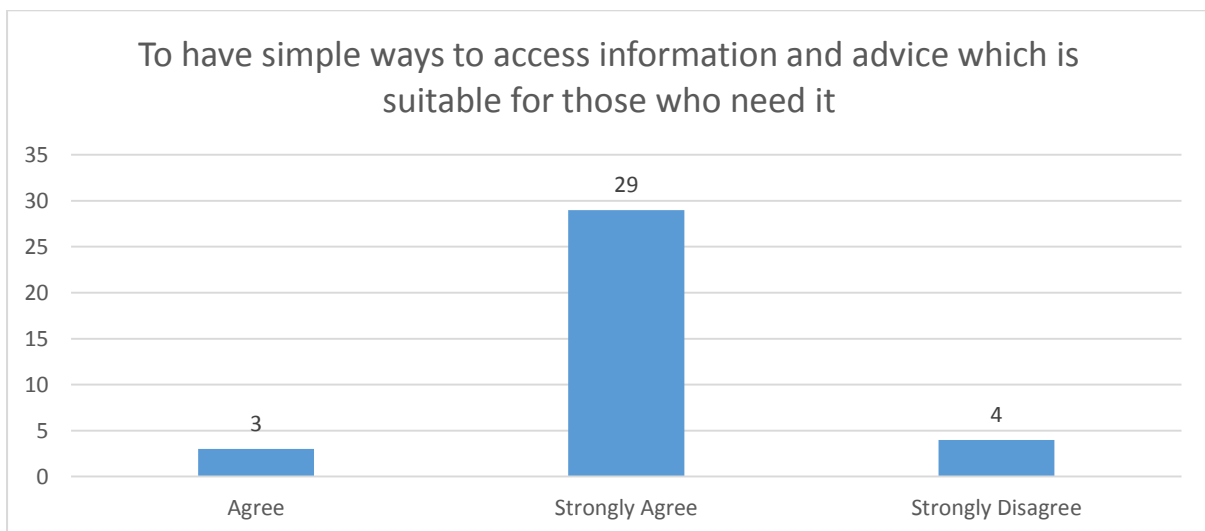
Regarding the ambition to improve the experience of diagnosis 89% (32 people) agreed or strongly agreed it was important with 11% (4 people) strongly disagreeing that it was important.

A health professional comments *“diagnosis is targeted at 11 weeks from point of referral and happens in most cases - one positive step would be to speed up the neuroimaging which currently is the biggest problem and can halt the process”*



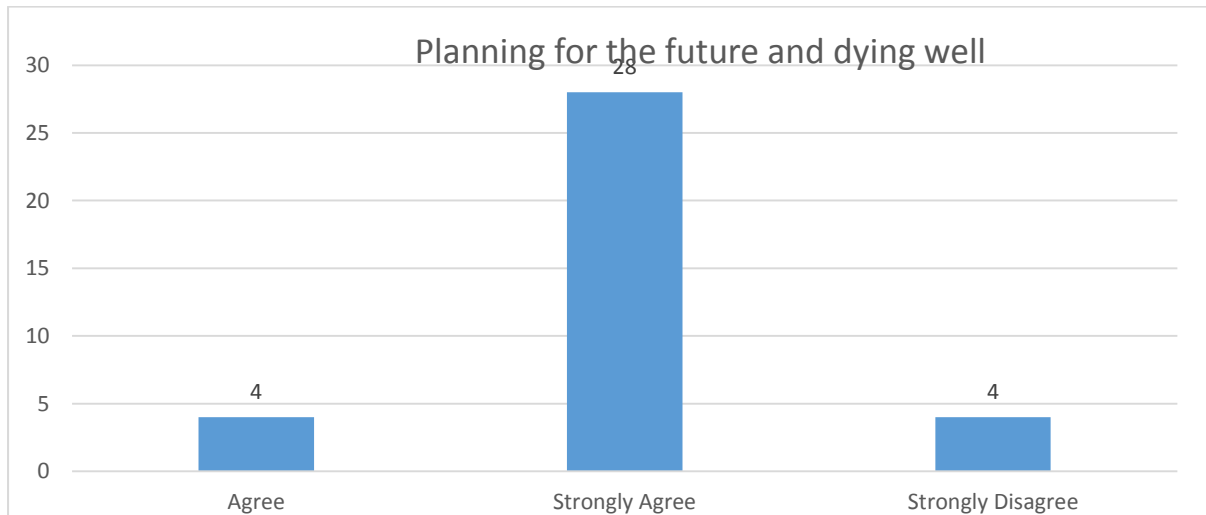
Regarding the ambition to have simple ways to access information and advice suitable for those who need it 89% (32 people) agreed or strongly agreed it was important with 11% (4 people) strongly disagreeing that it was important.

One person comments *“The issues most carers face is a lack of good clear advice on how to deal with this Disease. My experience is that it is too difficult to find the help you need. Too much of a splintered system where different sections of the Care / medical system work without effective communications”*



Regarding the priority to enable planning for the future and dying well 89% (32 people) agreed or strongly agreed with 11% (4 people) strongly disagreeing that it was important.

One person contributes *“I think the same bereavement support should be suitable for people with or without dementia.”* whilst another offers *“I think that at present people often have little influence in later stage care, and this should be looked at.”*



We will take all the contributions into consideration. A number of comments are:

*“Think it tells you what the strategy aims to do but doesn’t fully cover how you are going to make it work”*

*“Would love to see them [outcomes] happen but knowing there's no money and Dementia isn't and hasn't been taken seriously then I have serious doubts about any of this happening. Until dementia is accepted as an illness as cancer and heart disease is then I fear this is just another paper exercise”*

*Need “consultation with LGBT communities”*

*“The lack of and difficulty in finding good respite care to enable carers to take planned breaks. This is especially difficult for self-funders who are reliant on finding a vacancy in a home.”*

*“Until you actually experience it for yourself, it's impossible to equate to the reality of the situation. This is why more respite care in the home is needed on a regular basis.”*



Particularly a number of areas of good practice:

*“a forum to include providers of equipment used around the house such as washing machines and cookers that have dementia friendly controls. Something like that would greatly help someone with dementia keeping their independence.”*

Could be referred to the developing Assistive Technology strategy work stream to promote and find solutions.

The overall response to the survey is positive and supports the progression of the strategy.

DRAFT

# 'Bring Me Sunshine'

Living Well With Dementia in North Yorkshire



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## Introduction/foreword

To be included on completion of final draft document.

Signatory page

## 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 XX 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.

The strategy has only been made possible through the significant input from partner organisations including 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 these organisations 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 our dementia singing groups, as a song 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 those of us living with dementia, the strategy sets 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 those of us 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 of us and the key priorities that have been developed as a result.

These principles and priorities will shape the North Yorkshire approach to how we are supported throughout the lifetime of the strategy. We will aim for a clearer, simpler and more person centred system of support and information for those of us living with dementia and our carers. All partners are committed to the delivery of the 4 Principles and 5 Key Outcomes outlined on Page 39.

### What's the Picture?

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

- Of the 700,000 people believed to be living in England with dementia only 419,000 have received a diagnosis.
- 10,000 people are estimated to be living with dementia in North Yorkshire but only 5,793 people have actually been diagnosed.
- By 2025 13,573 people are expected to be living with dementia, in North Yorkshire
- Public Health England estimates that approximately a third of dementia cases might be in part caused by preventable factors such as diet.

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 1 in 4 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 dementia<sup>1</sup>.

Specific issues for people with young onset dementia include:

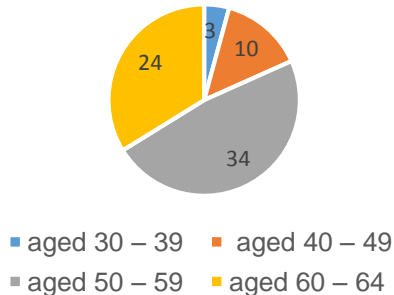
- Having to leave work due to illness or to be a carer for a loved one, people of working age can lose their income,
- Benefits are different to those over 65 years and may affect income
- Younger adults may have children who still need support, so any loss of income may be difficult and may lead to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

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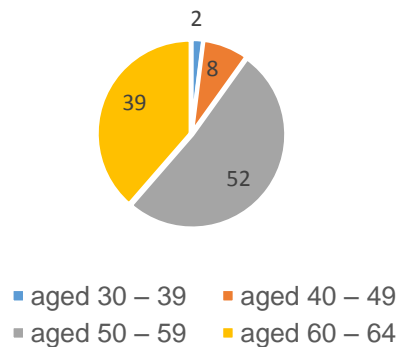
<sup>1</sup> <http://www.pansi.org.uk/index.php?pageNo=408&areaID=8640&loc=8640>



### Females with early onset dementia in North Yorkshire 2015



### Males with early onset dementia in North Yorkshire 2015



## People with Learning disabilities

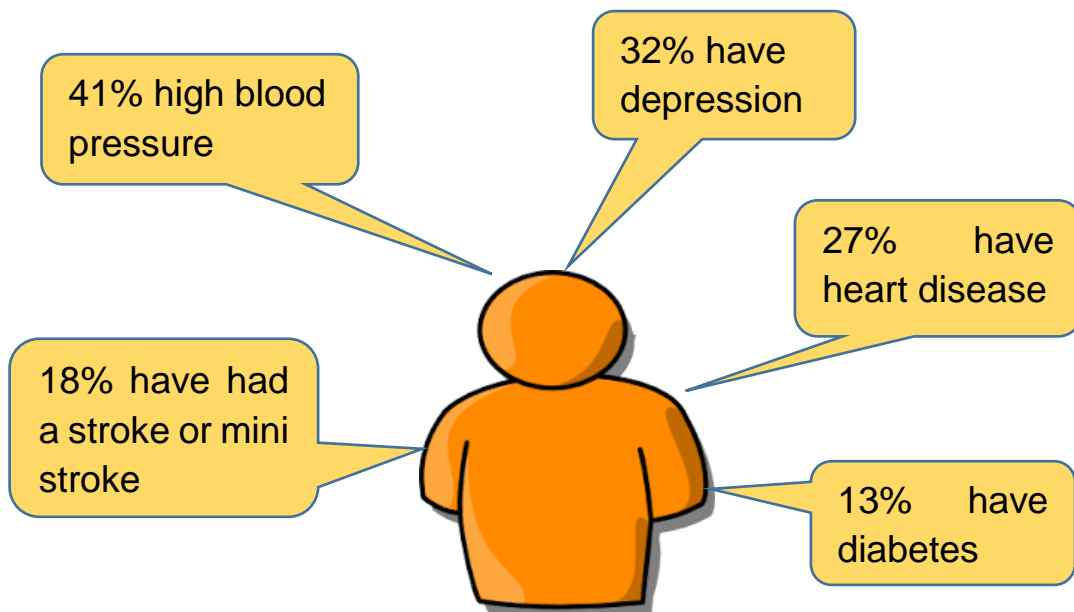
- People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia.
- Studies indicate 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia.
- It is estimated that 1 in 50 people with Down's syndrome develop 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.<sup>2</sup>

<sup>2</sup> 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](https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2591), last accessed 20/07/16

- 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<sup>3</sup>:



### Dementia and LGBT communities

Older LGBT people tend to be more isolated than their heterosexual counterparts, due to social stigma leading to family estrangement and the fact that they are statistically less likely to have children to support them.

The importance of strong social networks to support people living with dementia is identified as vital throughout this strategy, meaning that LGBT people are more at risk of isolation and poorer outcomes.

We will continue to monitor emerging best practice in the support of LGBT people living with dementia, and will develop policy and practical solutions to support this group in line with the evidence base.

<sup>3</sup> All Party Parliamentary Group on Dementia, *Dementia rarely travels alone: Living with dementia and other conditions*, April 2016, p. 5

## Prevention

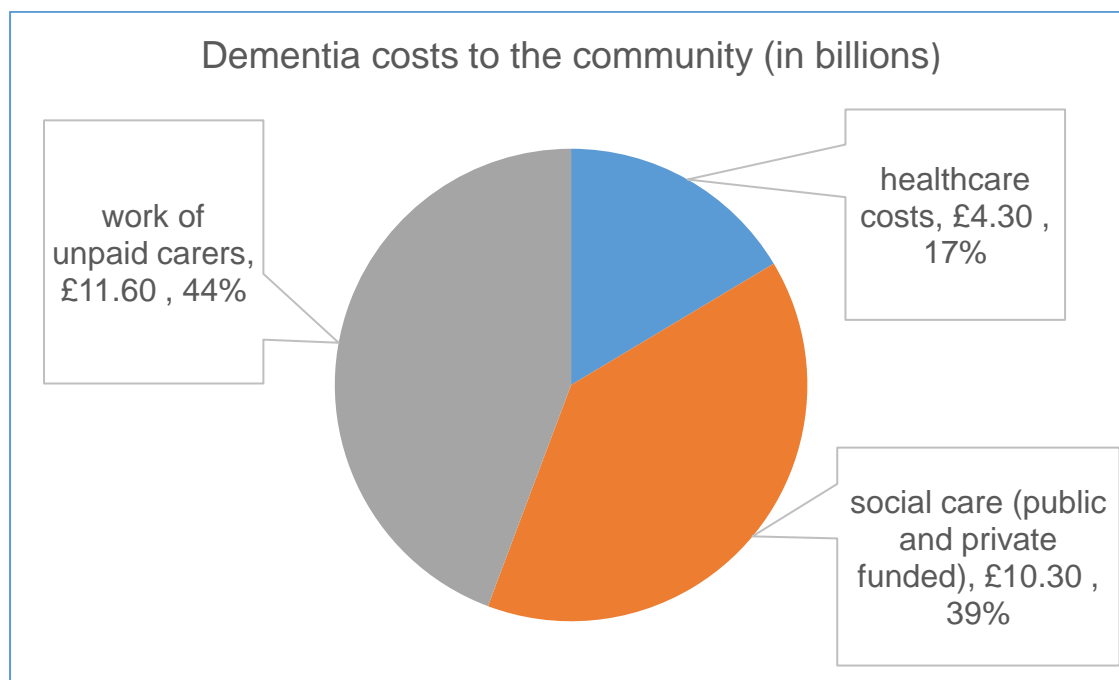
Support should always begin with prevention of the illness not diagnosis. Vascular dementia is the second most common type of dementia. However there is evidence that individual cases of dementia are often a mixture of Alzheimer's disease and vascular dementia. Vascular dementia has the same risk factors 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.

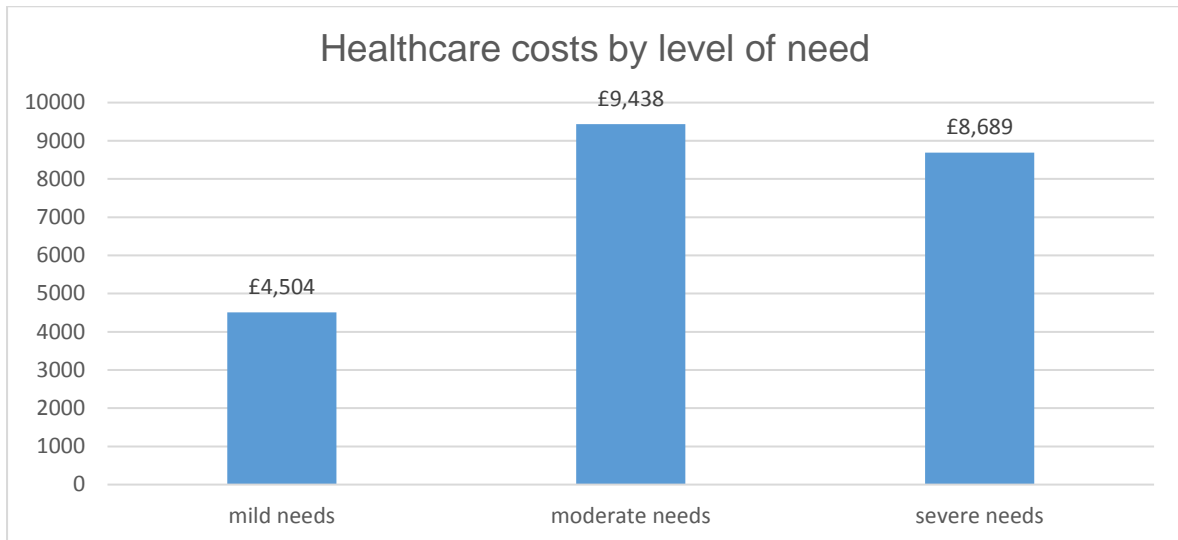
## Financial Impact - the national picture

- Approximately three quarters of the total costs for people with dementia is provided as unpaid care by our family and friends.<sup>4</sup>
- 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.

### What else do we know?

#### National Strategies

**The National Dementia Strategy for England** 'Living Well with Dementia' 2009<sup>5</sup> 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.

<sup>5</sup> <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

- Enabling easy access to care, support and advice following diagnosis.
- Improved end of life care for people with dementia.

**The Prime Ministers Challenge**<sup>6</sup>, 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.

**NHS Well Pathway for Dementia**<sup>7</sup> – describes 5-year plan which covers:

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

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<sup>7</sup> <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

## **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.

**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
- give advice on how to reduce our risk factors for dementia

## North Yorkshire Strategies

**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.

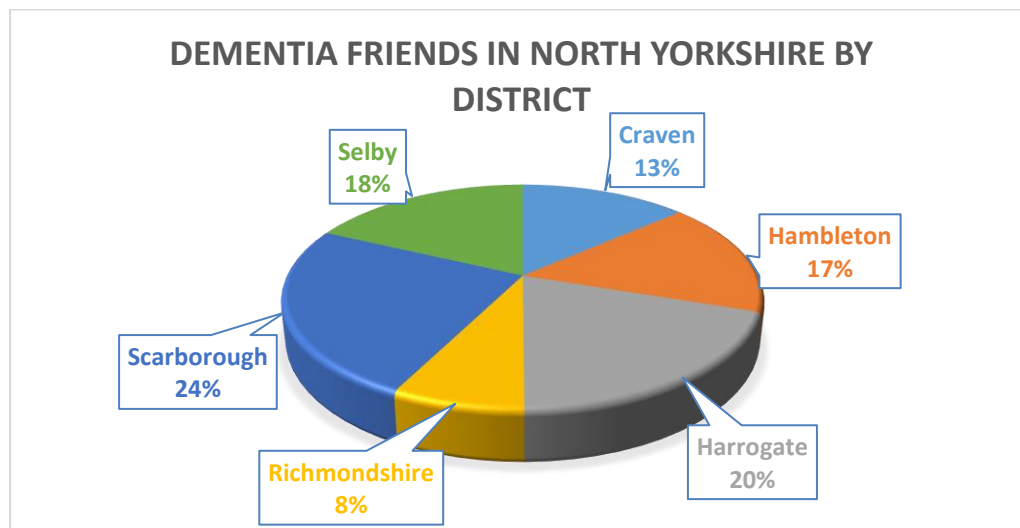
**North Yorkshire Community Plan** sets out its ambitions to support our communities to be able to develop and deliver the services we need and to enhance their ability to support us in a changing world.

**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

Community action

**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** aims to create dementia-friendly communities across the UK. Ensuring that people with dementia feel understood, valued and able to contribute to their community.

**Dementia Action Alliance** launched the [National Dementia Declaration](#). Members engage in awareness raising, education and encourage organisations to see dementia as their business.

### How services are currently set up

North Yorkshire County Council has responsibility to deliver Adult Social Care across the county and works with our 7 district councils. The County Council is responsible for assessing the needs of those of us who may need support with daily living. Support can include where we are living in our own homes, support for our carers and where necessary can arrange residential and nursing home care. Anyone receiving support from social care is assessed to establish what personal contributions can be made to the cost of 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 to help people to find and access informal support available in communities.

**North Yorkshire County Council Public Health** commissions health checks and healthy living services. The campaign 'One You' targets 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.

### **NHS 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 5 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.

Health organisations across the county recognise how important prevention and engagement with our communities is. Clinical Commissioning Groups and GP Surgeries are involved with dementia collaboratives and dementia friendly communities. These groups work to raise the profile of dementia, including the early warning signs and reduce the stigma of dementia in local communities. The NHS in North

Yorkshire is a complex network of organisations all of whom have responsibility for supporting those of us living with dementia and our carers.

There are two main types of organisation responsible for our health services in North Yorkshire:

Commissioners who determine what services are needed in which areas  
providers who are paid to deliver the services

- a. **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.
- b. **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.

Some examples of the work which is currently planned or underway:

1. **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
  - a. **Harrogate and Rural CCG** will develop dementia navigators, support for community teams and increased capacity for memory clinics. This joined up approach will improve early detection, diagnosis, outcomes and quality for people living with dementia and their carers.
  - b. Scarborough and Ryedale CCG are 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.
  
2. **Developing Capacity within primary care** - to ensure access to diagnostic tests and skilled professional support that they need, close to home and when it is needed. This will include new, more effective screening tools and a focus on ongoing support.
  - c. **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
  - d. **Scarborough and Ryedale CCG** have a training and skills programme to increase the knowledge 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 in supporting people living with dementia
  - being aware of the availability of the range of dementia services and the importance of timely referrals
  - a. **Vale of York CCG** 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.
  
4. **Ongoing support to maintain independence** – an initial diagnosis of dementia does not automatically have to stop people

enjoying life. Coping strategies and regular health checks and medication reviews can help people living with dementia and their carers live the life they want to live.

## **Secondary (hospital) Care**

Admission to hospital can be a challenging and upsetting time for those of us living with dementia and our carers and we know that if this time is not handled correctly it can have a severe negative impact on our future health and wellbeing. - The importance of continuity 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 our families or carers are able to stay with us when we go into hospital. Access should be easy and their expert knowledge as carers should be used to support us.

At any one time it is thought that round 1 in 4 people in hospital are living with dementia, and that once in hospital those of us living with dementia have worse outcomes than the general population. It is vitally important that hospitals are dementia friendly places for us to be treated and that we 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 plans to transform services and improve outcomes for those of us living with dementia, some of which are set out below, these can be summarised into 4 key themes:

1. **Outreach and Prevention** – As part of the NHS 5 Year Plan there is a strong focus on supporting people in the community, 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 developing their care home liaison service which supports people living residential homes to reduce hospital admissions.
  - b. **Hambleton, Richmondshire and Whitby CCG** are developing a collaborative approach with South Tees Acute Trust so that people receive appropriate care and support and fewer people with dementia are admitted to hospital unnecessarily.
  
2. **Workforce Development** – As in Primary Care the experience of a person living with dementia is often influenced 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 staff working with the public to having a better understanding 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 those of us living with dementia especially where our 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.

- 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 the clinical understanding of dementia and the practical needs of people who live with it improve, new services are being developed. These will support people to retain their independence and ensure that where possible people are not treated in hospital if appropriate. This innovation and progress will continue through the lifetime of this strategy.

### ***Mental Health Services:***

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

#### Ryedale

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

## Harrogate

The Acute Hospital Liaison Service has developed a programme of dementia awareness training.

## Northallerton

The Mental Health Care Home In Reach Service working with North Yorkshire County Council 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.

## Countywide

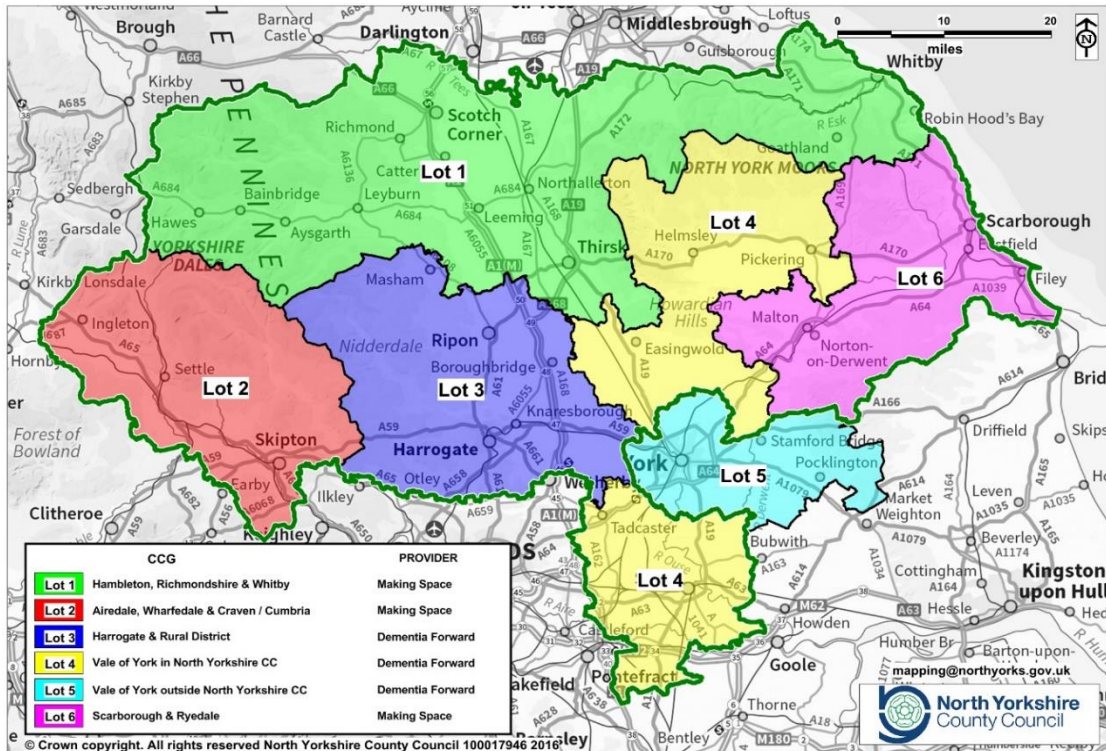
Mental Health Services for Older People deliver dementia care based on the individual's needs, the needs of carers.

Acute Hospital Liaison Services in Harrogate, Northallerton and Scarborough are based at the hospital site. These teams operate 7 days a week and respond to referrals. They support ward staff with the assessment and treatment of people living with dementia, who have been admitted to hospital where their mental well-being is affected.

Memory Services have been developed in Harrogate and Northallerton, offering post diagnostic support, signposting and advice

TEWV support dementia research, with designated staff who will visit interested people and their families who want to participate in research.

NYCC and the CCGs jointly commission Dementia Support Services and Carers Resource Centres. The Dementia Support services are delivered by two providers – Making Space which deliver services in Hambleton, Richmondshire, Whitby, Craven, Scarborough and Ryedale and Dementia Forward which 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 provider dementia support in each district:

Craven – 10 homes  
 Hambleton – 5 homes  
 Harrogate – 24 homes  
 Richmondshire – 18 homes

Ryedale – 0 homes  
 Scarborough – 16 homes  
 Selby – 7 homes

### **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 below shows a comparison between the UK wide care sector, the wider North Yorkshire sector and homes registered to provide dementia care.

Rating / Area	UK	North Yorkshire	NY Dementia
Outstanding / Good	72%	85%	65.8%
Requires Improvement	26%	14%	22%
Inadequate	2%	1%	6.1%

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 Campaign<sup>8</sup>- 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 our 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 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.
- Scarborough Hospital is in the process of developing their own Dementia Strategy 2017-2020. This includes:

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<sup>8</sup> <http://johnscampaign.org.uk/#/about>

- A personalised care plan such as 'All About Me' or the hospitals version 'This is About Me' for use on all elderly care wards.
  - Dementia Friends Training offered to all staff throughout the organisation with additional higher level training offered to those directly involved in caring for people with dementia. We deliver these sessions monthly at Scarborough and Malton Hospitals. These sessions have been taken up by volunteer visitors, security staff, grounds-people, porters, housekeepers, consultants, registrars, matrons, HR and admin staff totalling over 200 in the last 12 months.
  - We are delivering combined Dementia Friends and Awareness Sessions on a bi-monthly basis to Health Care Assistants as part of their inductions. These sessions are very much focussed on their roles and how they can make a difference to a person with dementia during their hospital stay.
  - Twice yearly we are involved in the Staff Nurses Induction Programme (we deliver a Dementia Awareness Session similar to Dementia Friends but with a clinical approach to make the sessions relevant to their roles and the environment).
  - Other actions have been the active promotion and working with the hospital on the promotion and use of the Forget me Not Flower above the beds of those with dementia as an indicator. This has now been launched across the whole organisation.
  - We are also supporting the hospital by undertaking follow up calls to carers of people with dementia (Carers Survey) who have been in hospital to gain feedback on their experience of the care received and feeding this back to the hospital to implement changes and improvements.
- Dementia Action Alliances involve all 7 District Councils in North Yorkshire promoting activities and events such as Dementia Awareness Week. A number of cross cutting themes for the District councils linked with this 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 County Council Police<sup>9</sup> 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 our 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
  - Richmondshire Youth Theatre: Section to be added
  - NYCC dementia awareness training is mandatory for all 2010 Health and Adult Services staff and must be refreshed every 3 years. As the Council's first point of contact all 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.

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<sup>9</sup> <https://northyorkshire.police.uk/content/uploads/2016/01/Herbert-Leaflet-2016.pdf>

- October 2016, North Yorkshire Dementia Congress. This event was attended by 150 people living with dementia, 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 people who need support in the county, including those of us 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 how to support people living with dementia in extra care housing.

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

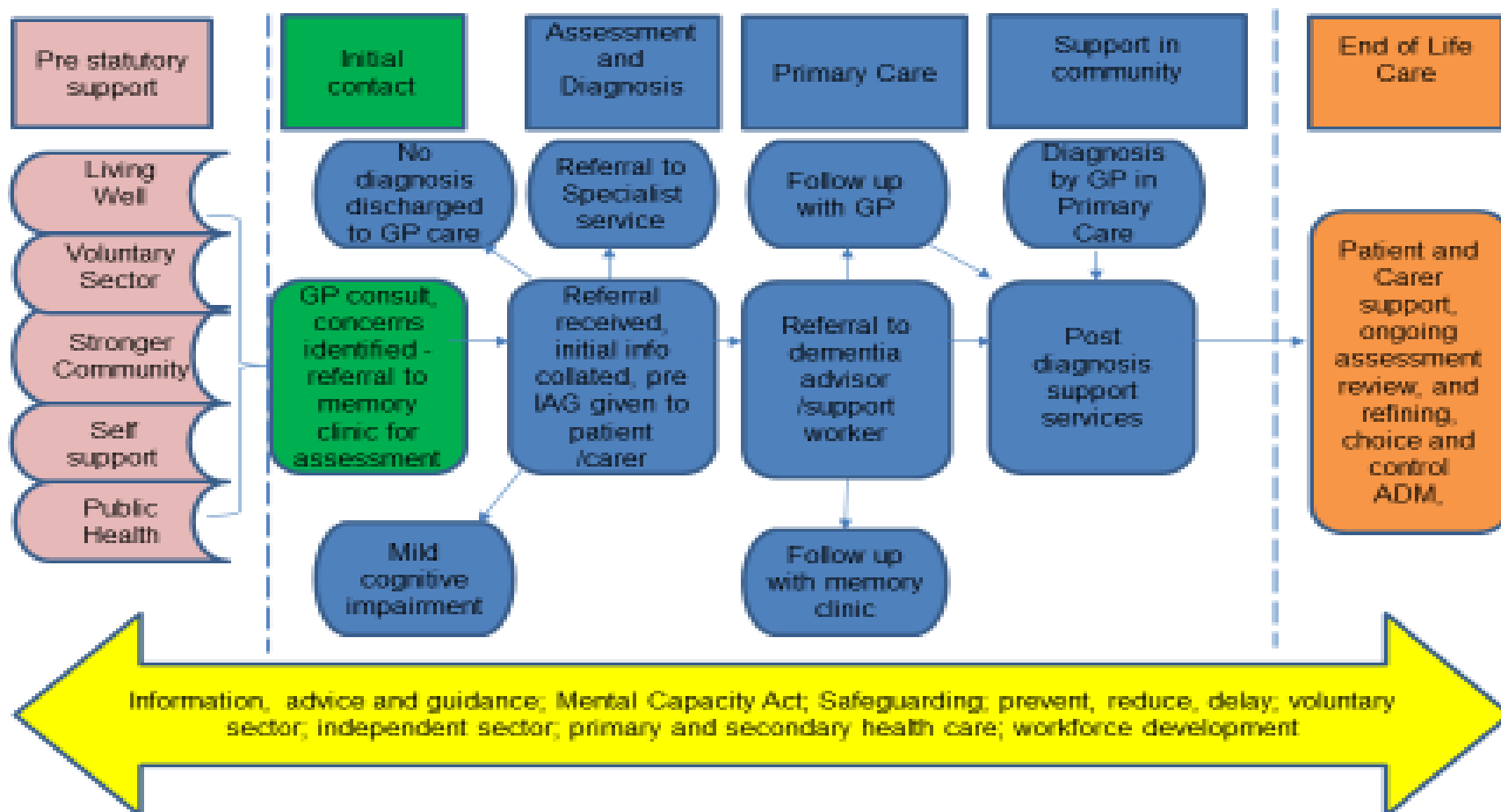


## Dementia Pathway

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 living with dementia the 'end of life' period may be longer and less well-defined than for those of us 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 some of us who are living with dementia and our carers.

During the engagement process over 1200 people assisted us with their responses, the following themes and recommendations have been identified as below.

We would like to thank everyone for their assistance particularly 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 the 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 & 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. As this is an emerging area we will wait for the publication of Social Care Institute for Excellence (SCiE) guidance in 2017 before committing to specific actions.

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

### Delivering the strategy - action plan

The key areas outlined above have allowed us to develop 4 key principles which will run through everything we do and 5 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 principles and priorities are of equal importance and have been identified and agreed in partnership between those of us living with dementia and our carers and health and social care professionals.

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 our carers in employment
  - support local Dementia Action Alliances and Collaboratives to make communities accessible and welcoming to those of us living with dementia and our carers
  - develop and deliver accommodation options for those of us living with dementia and our carers

Priority  
Workforce Development

- We will:**
- work to improve awareness of 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

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 us and our 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

Priority  
Support and Advice

- We will:**
- create simple points of access for information for those of us living with dementia and our carers in North Yorkshire including improved access to peer support
  - review the current information and advice available, 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 those of us living with dementia and our carers
  - ensure dedicated Dementia Support Services for those of us living with dementia and our carers from diagnosis through to bereavement
  - develop support specifically for those of us living with young onset dementia and our families

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 our wishes and fears
  - improve and promote information advice and guidance to enable us to make early and informed decisions when our mental capacity declines, planning for the future and our end of life care wishes
  - work to challenge the social and professional stigma and nervousness around death and dying
  - continue to support our carers through this period and ensure appropriate have the physical, emotional and social support

## Moving Ahead

This chapter highlights the key steps the partners will take to ensure that the immense amount of support, information and goodwill that has been harnessed as part of the development of this strategy is turned into positive action and a visible improvement in the lives of those of us living with dementia and our 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 our carers, this group will oversee the progress of the implementation of the strategy.

The partners recognise that change cannot be imposed from the centre, engaging with those of us living with dementia and our carers has been a central part of the development of the strategy and this approach will continue as implementation of the principles and priorities begins.

Delivery of change in communities will be led by local groups, either already established or specifically developed for this purpose, supported by the partners. In this way local knowledge, skill and experience can be best used to ensure change happens and the words of this strategy are not lost.

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 39, 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 these groups will commit to produce an annual report on progress. In addition NYCC will continue to host an annual Dementia conference in order to highlight best practice and discuss new and emerging issues with those of us living with dementia and our carers and colleagues from health and social care.

