

NORTH YORKSHIRE COUNTY COUNCIL

Care & Independence Overview & Scrutiny Committee

27 October 2016

Dementia Update – October 2016

1.0 Purpose of Report

- 1.1 To update the Committee on the work in relation to the North Yorkshire Dementia Strategy.

2.0 Introduction

- 2.1 Over the past 10 years dementia has risen steadily up the agenda of both health and social care as the numbers of people living with dementia has continued to rise. Present estimates state that approximately 850,000 people are living with dementia in the UK and this figure is set to rise to over 2 million by 2050.
- 2.2 As is often the case the demographics of North Yorkshire mean that the county faces a greater than average challenge in terms of providing the care and support that people with dementia and their carers require. Around 10,000 people are believed to be living with dementia in North Yorkshire which equates to 0.98% of the overall population, significantly higher than the national figure of 0.74%.
- 2.3 It is also important to remember that whilst dementia is usually thought of as affecting older people current estimates suggest that approximately 200 people under the age of 65 are living with dementia in North Yorkshire, with the youngest of these being in their thirties. The accuracy of these estimates is questionable and there is evidence to show that there may in fact be many more people affected.
- 2.4 People with learning disabilities are also far more prone to young onset dementia, specifically people with Down' Syndrome aged 40 or above have a 1 in 2 chance of developing dementia compared to a 1 in 75 chance amongst the general population.
- 2.5 In addition to the human cost of Dementia there is also a huge financial implication. It is estimated that dementia costs local authorities and the health service over £26bn per year. In addition to the more obvious costs it is also estimated that 1 in 15 missing persons cases, totalling over 17,000, involves dementia at a cost of the police of anywhere between £15 and £40 million per year. In addition it is thought that care to the equivalent cost of over £11bn is provided by unpaid carers every year.
- 2.6 Recent research for the King's Fund showed that among people aged over 50 dementia is now the 'most feared' health condition surpassing cancer in this

regard. Whilst there have been great advances in the treatment of cancer in the past few decades, a breakthrough drug or treatment for dementia remains elusive and as such support for people at present involves managing symptoms as they develop and working where possible to limit the risk factors that do exist for some people.

- 2.7 North Yorkshire County Council in partnership with the CCGs currently commission Dementia Forward and Making Space to deliver a Dementia Navigator service across the county. Both organisations provide telephone support, peer support groups, assistance with benefits and services for carers in a service that is highly valued by both statutory organisations and people living with dementia and their carers. We are also fortunate to have close links with the Alzheimer's Society and a range of other local groups who deliver much valued services and support in many small communities.

3.0 The North Yorkshire Dementia Strategy

- 3.1 The previous North Yorkshire Strategy expired in 2014 and work is ongoing to refresh this in order to shape all aspects of our work around dementia over the next few years. The strategy is a joint piece of work between NYCC and the PCU on behalf of the CCGs as well as Airedale, Wharfedale and Craven CCG. In addition to the CCGs we are working closely with Tees, Esk and Wear Valley (TEWV) Mental Health Trust along with Dementia Forward, Making space and the Alzheimer's Society.

- 3.2 Consultation and engagement with people living with dementia and their carers has been a central part of the development of the strategy so far and will continue to be so. A combination of surveys and face to face discussions yielded over 300 responses to the consultation many of which were rich stories, some of which highlight excellent practice whilst others show how far we have to go in many areas.

- 3.3 Analysis of the consultation findings so far have identified a series of key themes for further investigation, below are some direct quotes from people living with dementia and their carers which highlight these issues.

3.4 *Early Recognition and Support*

- 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
- 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
- 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.

3.5 *Consistency*

- The experience of living with dementia is far too varied, some of us receive excellent support but too many of us do not have this experience and are left to fend for ourselves in a disjointed and often bewildering system
- Too many of us wait too long for a diagnosis, there should be a quick and simple process for finding out if we have dementia
- 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

3.6 *Stigma and Awareness Raising*

- 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 should be educating our grandchildren from an early age, kids are great at asking questions and having open minds without any fear or embarrassment
- 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 and how much the little things can help

3.7 *Seeing the Person*

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

3.8 *Advanced Planning and End of Life*

- Professionals need to be sensitive but honest with us on what dementia 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

4.0 Work on the Strategy

- 4.1 An initial draft strategy is in the process of being produced and will be finalised following the 2016 North Yorkshire Dementia Conference to be held on 31st October 2016. This event in itself will bring together over 50 people living with dementia and their carers with health and social care professionals to hear from

a range of speakers and to participate in a series of discussion forums around the key issues emerging from the consultation. (Appendix 1)

5.0 Recommendation

- 5.1 The Committee receive a report when the strategy is finalised by the end of the year and is signed off by Health and Wellbeing Board in February for a formal launch in Spring 2017

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Background Documents Nil

APPENDIX 1

‘Bring Me Sunshine’
Living Well with Dementia in North Yorkshire 2016
Monday 31st October, Harrogate Pavilions
9:30am – 4pm

North Yorkshire County Council and our partners are pleased to invite you to our 2016 dementia conference on the theme of living well with dementia.

The event will offer the opportunity to hear from speakers on a range of topics including Dementia Friendly GP services, intergenerational work and the development of dementia friendly communities, the full programme will be confirmed shortly.

As part of the ongoing work to develop the North Yorkshire Dementia Strategy we will also hold a series of workshops which will mix people living with dementia and carers with health and social care professionals to discuss the key issues arising from the strategy consultation and develop potential solutions.

The day has been carefully planned to ensure it will be accessible and enjoyable for people with dementia and carers. Quiet break rooms will be available throughout the day and dedicated support staff from Making Space, Dementia Forward and the Alzheimer’s society will be on hand to offer support where needed.

Places are extremely limited so book now to avoid disappointment, bookings can be made by emailing dementia@northyorks.gov.uk

‘Bring Me Sunshine’ 2016 North Yorkshire Dementia Conference Provisional Agenda		
‘Welcome	09:45	10:00
Living Well with Dementia	10:00	10:20
Strategy Update	10:20	10:40
Session 1 – Connected communities and Raising Awareness	10:40	11:10
Break AM	11:10	11:30
Intergenerational Work	11:30	12:00
Session 2 – Accessibility	12:00	12:30
Lunch – Art Work Competition	12:30	13:15
Singing for the brain	13:15	13:30
Dementia Friendly GP Surgery	13:30	14:00
Session 3 – Planning for the future and Dying Well	14:00	14:30
Break	14:30	14:45
State of the Nation	14:45	15:15
Session 4 – Living Well	15:15	15:45
Close	15:45	16:00