

Dementia Support Review Engagement Pack

Thank you for requesting this Dementia Support Engagement Pack.

Introduction

There are currently 850,000 people living with dementia in the UK and the number is set to rise. The NHS, local government and voluntary organisations are working with people affected by dementia living in Norfolk and Waveney to help shape support services that are fit for the future. Our vision is to develop high quality dementia support across Norfolk and Waveney, providing the right support at the right time wherever you live. In parts we have got this right and in others there is more work to do.

Using this Engagement Pack

We have tried to design this Pack so that it is as easy as possible to follow and to feedback. We also hope that this material may be helpful for small groups who wish to respond.

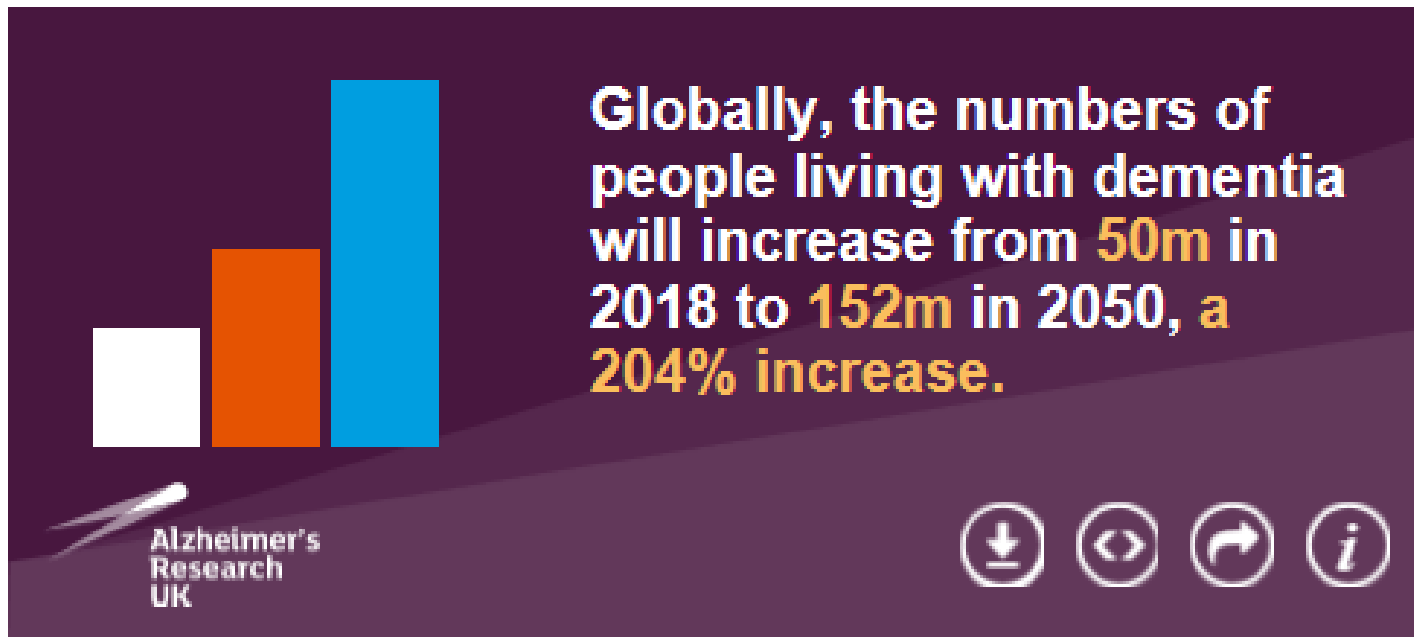
After the introductory slides, which follow, you are invited to answer a total of ten questions. These questions relate to different aspects of dementia support. For example, question one and two ask you to think about things that might help prevent or slow, the onset of dementia, and slides seven and eight are concerned with carer support.

Please use the attached Microsoft Word document *Answer Sheet* to provide your feedback to each of the ten questions. You can either print this sheet off and complete it by hand, or type your responses directly into the form. The completed form should then be returned by email to dementareview@nhs.net, or posted to STP Dementia Review Feedback, c/o Mental Health Commissioning Team, South Norfolk Clinical Commissioning Group, Lakeside 400, Old Chapel Way, Broadland Business Park, Norwich, NR7 0WG.

Thank you in advance for taking the time to share your views with us. If we can provide any assistance or help in relation to this work, please contact dementareview@nhs.net, or telephone 01603 595855.

Please note that completed Answer Sheets need to be returned to the address above by the 12th December.

By way of introduction, please read the statements and dementia related information that follows on the next four pages.



Source: Dementia fact sheet December 2017; World Health Organisation



Source: Lakey, L (2009) Counting the cost: Caring for people with dementia on hospital wards published by the Alzheimer's Society

Dementia in Norfolk and Waveney

- There are an estimated 16,256 people (age 65+) with dementia in Norfolk and Waveney*
- Across Norfolk and Waveney there are also 353 people aged 0-64 with a recorded dementia diagnosis**
- Our ageing population has driven dementia rates above the national average

*Recorded Dementia Diagnoses, NHS Digital, October 2018

**Recorded Dementia Diagnoses by Age; Care Plans, Referrals and Assessments, NHS Digital, October 2018

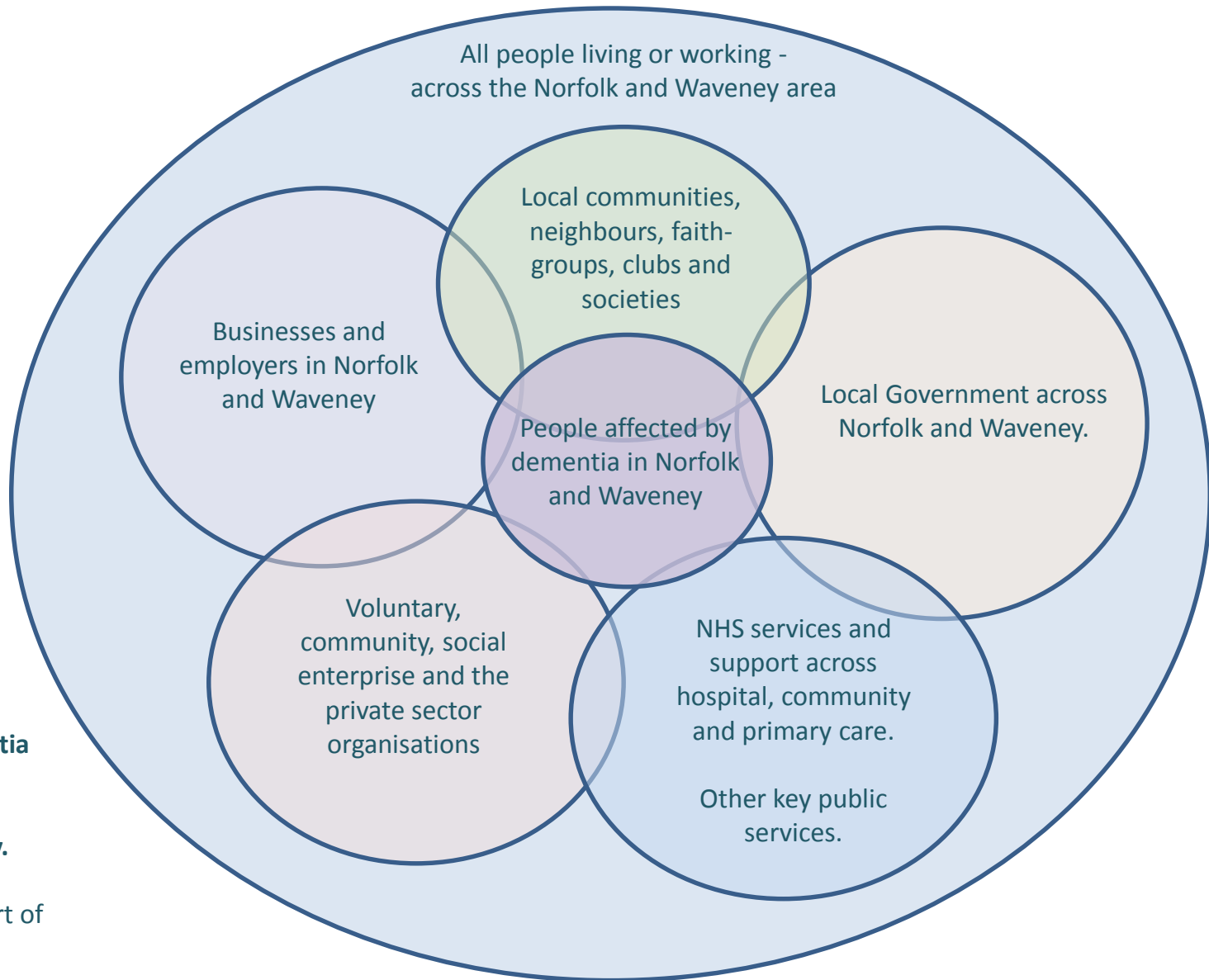
Dementia in Norfolk and Waveney

- In North Norfolk 1.2% of the population lives with dementia compared to 0.8% across the UK
- Two thirds of people living with dementia in Norfolk and Waveney are living at home

The next page outlines the different organisations and groups who are part of the wider Norfolk and Waveney community.

All of these organisations and groups will play a part in helping to get dementia support right.

Making Good Dementia Support Real in Norfolk and Waveney.



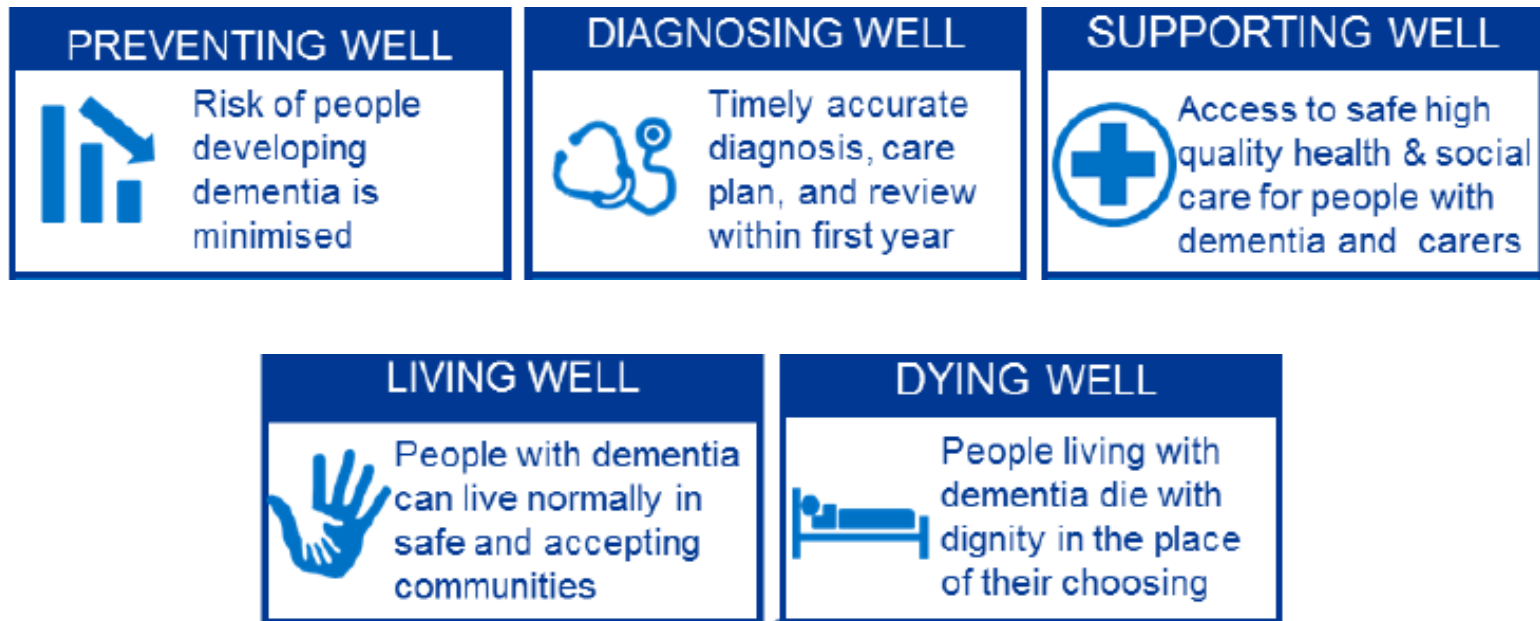
Good Dementia Support is everyone's responsibility.

We are all part of the solution.

The *Well Pathway* described on the next two pages is a way of breaking down good dementia support into its different parts.

We need to think about all these stages when designing good support.

The Well Pathway



Norfolk and Waveney Dementia Support



Norfolk and Waveney Dementia Support

The *We Statements* on the next page were developed by people with dementia and their carers. They represent everyone living with any type of dementia regardless of age, stage or severity.

The “we” used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia. These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law.

www.dementiaaction.org.uk

The *We Statements*:

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

Getting started..

It now time to make a start on the questions we would like to ask you.

The ten questions, which follow relate to different aspects of dementia support.

For example, questions one and two ask you to think about things that might help prevent or slow, the onset of dementia, and slides seven and eight are concerned with carer support.

Please use the attached Microsoft Word document *Answer Sheet* to provide your feedback to each of the ten questions. You can either print this sheet off and complete it by hand, or type your responses directly into the form

Please think about healthy living and reducing the risk of developing dementia in Norfolk and Waveney

Healthy living and reducing your risk of developing dementia

Good information on healthy living and how this may reduce onset of dementia for some.

Access to community resources that promote wellbeing and support everyone to experience a good quality of life.

Specialist support around smoking cessation, alcohol depending and mental health difficulties

National guidance and people with Dementia want:

Risk of people developing dementia is minimised.

‘We have the right to be recognised as who we are, to make choices about our lives including taking risks’

Question1.

What do you feel doing this well looks like?

Question 2.

What does not doing this well look like?

Please think about Diagnosing Dementia well in Norfolk and Waveney

Diagnose well

Speedy initial assessment
close to home

Timely
Diagnosis in
setting that
suits my
needs

Information
about
diagnosis
and consent
to share

National guidance and people with Dementia want:

Timely, accurate diagnosis, care plan and review.

‘We have the right to an early and accurate diagnosis’

Question 3.

What do you feel doing this well looks like?

Question 4.

What does not doing this well look like?

Please think about Support to Live Well and Support to Prevent Crisis in Norfolk and Waveney

Support to live well

Help available for care and support planning - for everyone and regularly reviewed.

Help to manage for agitation, stress and anxiety about my dementia

Timely access to the right pharmacological support when needed - and information on this.

Support to prevent crisis

Support to maintain good physical health

Psychological and social support

Help with sleep problems, pain management and falls prevention

National guidance and people with Dementia want:

Access to safe high quality health and social care for people affected by dementia

‘We have the right to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.’

Question 5.

What do you feel doing this well looks like?

Question 6.

What does not doing this well look like?

Please think about Carer Support in Norfolk and Waveney



National guidance and people with Dementia want:

People with dementia - and people affected by dementia - feel included and accepted within their local communities

‘We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.’

Question 7.

What do you feel doing this well looks like?

Question 8.

What does not doing this well look like?

Please think about Dying Well in Norfolk and Waveney

Dying well

Good palliative
care.

Supported to
at end of life in
the right place
- with the right
people.

National guidance and people with Dementia want:

People living with dementia die with dignity in the place of their choosing.

‘We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.’

Question 9.

What do you feel doing this well looks like?

Question 10.

What does not doing this well look like?

That's all our questions

Thank you very much for taking the time to share your responses.

Completed *Answer Sheets* should be returned by email to dementiareview@nhs.net, or posted to STP Dementia Review Feedback, c/o Mental Health Commissioning Team, South Norfolk Clinical Commissioning Group, Lakeside 400, Old Chapel Way, Broadland Business Park, Norwich, NR7 0WG.

Please note that completed Answer Sheets need to be returned to the address above by the 12th December.

Please see overleaf for what happens next.

What is Happening Next

Using your feedback, and feedback others have contributed, we will develop a set of draft Dementia Support Recommendations, early in 2019.

The draft Dementia Support Recommendations will also take on board good practice beyond Norfolk and Waveney, and guidance from the recent Mental Health Review.

We will share the draft Dementia Support Recommendations and ask for further feedback. Please tell us if you would like the opportunity to review the draft Recommendations early in 2019.

After further feedback, a final set of Dementia Support Recommendations will be developed. These will be used to inform the commissioning of Dementia Support across Norfolk and Waveney from the Spring of 2019, onwards.

Thank you

Thank you once again for contributing to this Dementia Support Review.

If we can provide any assistance or help in relation to this work, now or in the future please contact dementareview@nhs.net, or telephone 01603 595855.