

# Dementia Support Review

ACT Centre, Aylsham

Tuesday 4<sup>th</sup> December, 2018

# Welcome

William Snagge  
South Norfolk NHS Clinical Commissioning Group

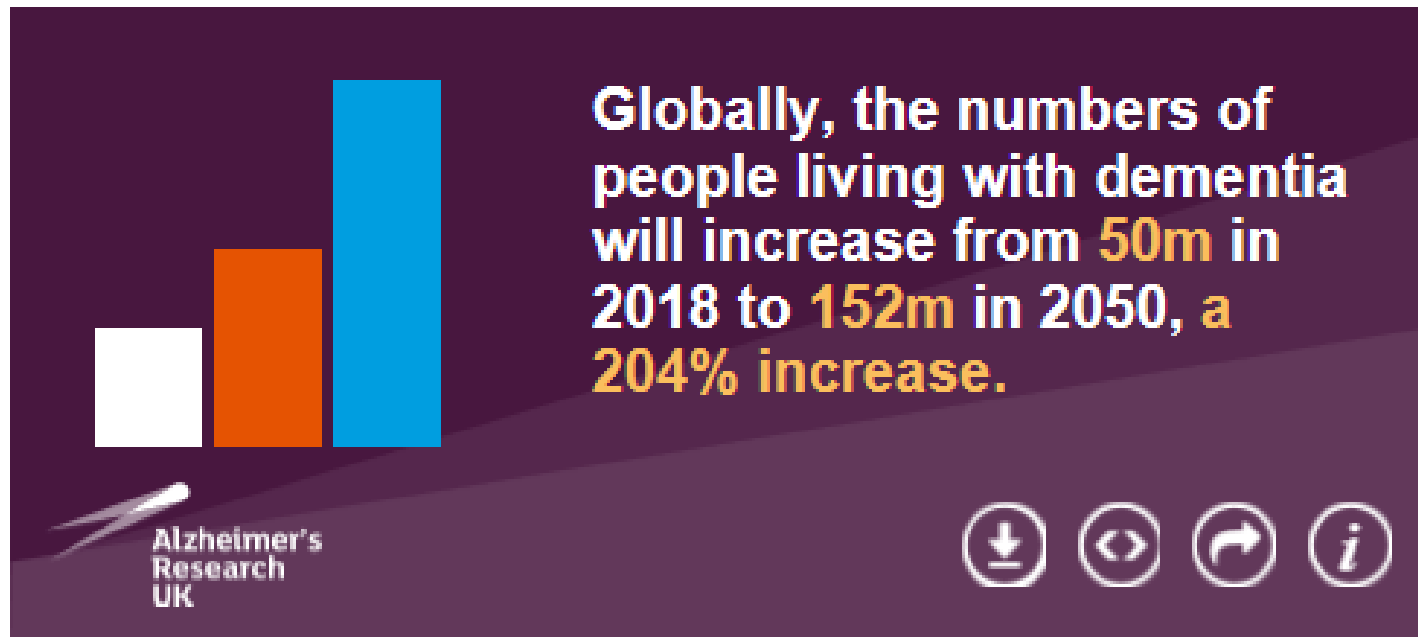
Other Review Group members present

## Plan for today

2pm	Welcome and introductions
2.05pm	Why are we here?
2.10pm	The Norfolk and Waveney Sustainability and Transformation Partnership, and the Mental Health Review
2.15pm	Introducing working together
2.20pm	Working together - Session 1 - three subjects
3.10pm	Break
3.20pm	Working together - Session 2 - two subjects
3.50pm	Next steps
3.55pm	Closing remarks and keeping in touch
4pm	Meeting ends

# Dementia Support Review

## Introduction



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



# Norfolk and Waveney Sustainability and Transformation Partnership



# Working with the wider Mental Health Review

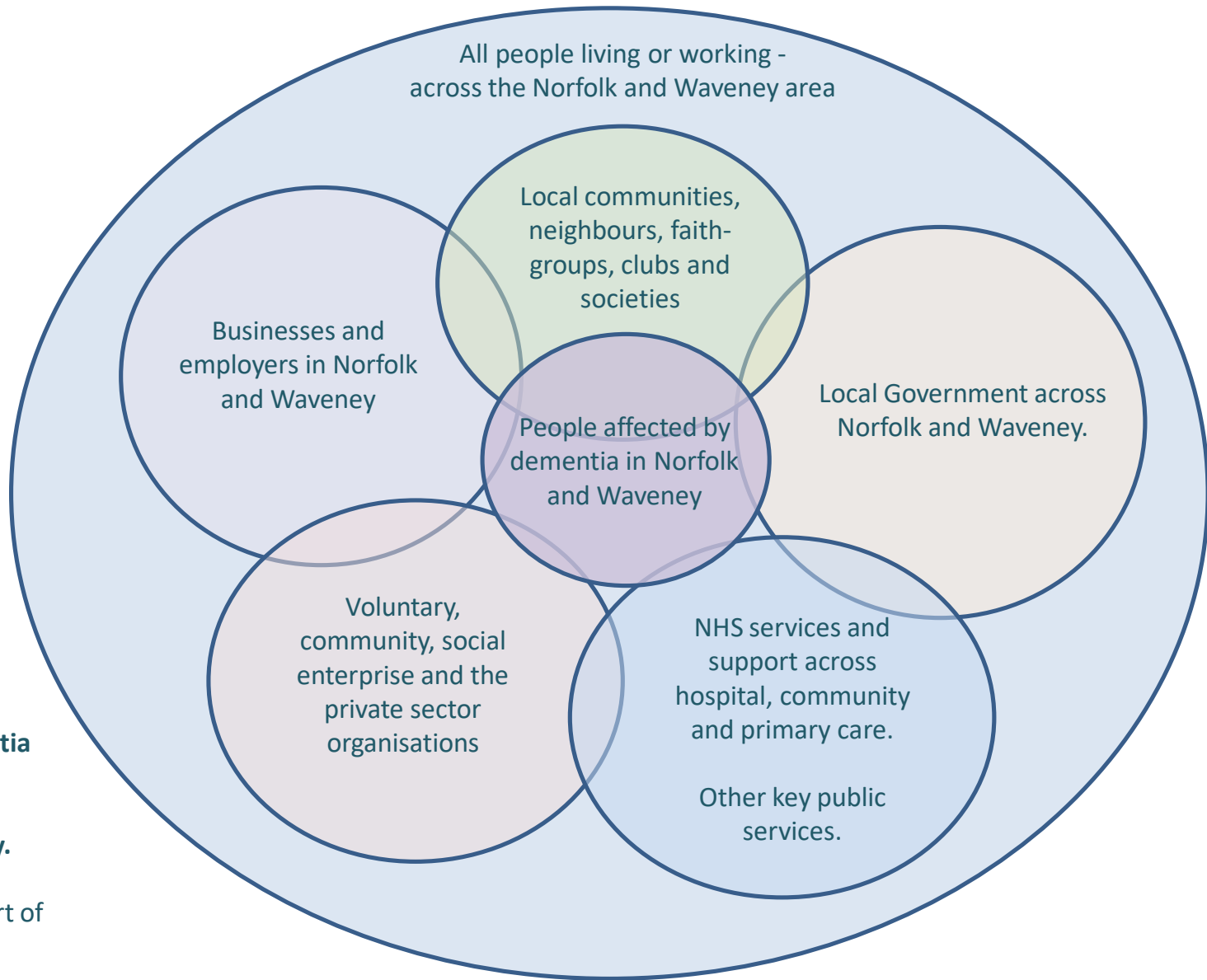
# Getting started

Putting people with experience of dementia at the centre and  
recognising everyone is part of good support

Introducing our table discussions today

Introducing the *Wellbeing pathway* and  
*We Statements*

## 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

## PREVENTING WELL



Risk of people developing dementia is minimised

## DIAGNOSING WELL



Timely accurate diagnosis, care plan, and review within first year

## SUPPORTING WELL



Access to safe high quality health & social care for people with dementia and carers

## LIVING WELL



People with dementia can live normally in safe and accepting communities

## DYING WELL



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

## Norfolk and Waveney Dementia Support

<p><b>Healthy living and reducing your risk of developing dementia</b></p> <p>Good information on healthy living and how this may reduce onset of dementia for some.</p> <p>Access to community resources that promote wellbeing and support everyone to experience a good quality of life.</p> <p>Specialist support around smoking cessation, alcohol depending and mental health difficulties</p>	<p><b>Diagnose well</b></p> <p>Speedy initial assessment close to home</p> <p>Timely Diagnosis in setting that suits my needs</p> <p>Information about diagnosis and consent to share</p> <p>Information about relevant services (including support services and psychological therapies for carers)</p> <p>Advice on planning for the future.</p>	<p><b>Support to live well</b></p> <p>Help available for care and support planning - for everyone and regularly reviewed.</p> <p>Help to manage for agitation, stress and anxiety about my dementia</p> <p>Timely access to the right pharmacological support when needed - and information on this.</p> <p><b>Support to prevent crisis</b></p> <p>Support to maintain good physical health</p> <p>Psychological and social support</p> <p>Help with sleep problems, pain management and falls prevention</p> <p><b>Carer support</b></p> <p>The right advice at the right time, available when needed.</p> <p>Formal Carer Assessment and support as needed</p> <p>Help with dementia education and and skills training</p> <p>Advice on how to look after own physical and mental health, and emotional and spiritual wellbeing</p>	<p><b>Dying well</b></p> <p>Good palliative care.</p> <p>Supported to at end of life in the right place - with the right people.</p> <p>Advice on planning enjoyable and meaningful activities</p>
--	--	--	--

## Norfolk and Waveney Dementia Support

# We Statements

The Dementia Statements 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](http://www.dementiaaction.org.uk)

# We Statements

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

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

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

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

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.



# Table discussions x 3

Two questions for each table discussion

Extra deeper questions available if you would like these

Please feel free to join as many table discussions as you wish over the next 45min. We will then stop for a break before repeating this exercise

# Thinking 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’

Q1. What do you feel doing this well looks like?

Q2. What does not doing this well look like?

# Thinking 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’

Q3. What do you feel doing this well looks like?

Q4. What does not doing this well look like?

# Thinking 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.’

Q5. What do you feel doing this well looks like?

Q6. What does not doing this well look like?

Break

# Table discussions x 2

Two questions for each table discussion

Extra deeper questions available if you would like these

Please feel free to join as many table discussions as you wish over the next 45min. We will then stop for a break before repeating this exercise

## Thinking 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.’

Q7. What do you feel doing this well looks like?

Q8. What does not doing this well look like?

# Thinking 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.’

Q9. What do you feel doing this well looks like?

Q10. What does not doing this well look like?



# What is Happening Next

Using your feedback and ideas and the feedback and ideas others have contributed, we aim to develop a set of draft Dementia Support Recommendations, early in the New Year.

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

We will share these draft Dementia Support Recommendations with everyone and ask for your further feedback. [Please provide table facilitators with your contact details today, to help us to do this efficiently].

Peoples further feedback will be taken on board and reflected in a final set of Dementia Support Recommendations. These will be used to inform the commissioning of Dementia Support across Norfolk and Waveney from the Spring of 2019, onwards.

# Thank You

**Keeping in touch:**

email: [dementiareview@nhs.net](mailto:dementiareview@nhs.net)

Telephone: 01603 595855