



# Improving the Care Experience for People With Dementia

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# Welcome to the Watch!

We are the independent champion for people who use health and social care services.

Healthwatch England works nationally and there is a local Healthwatch in every area to support you in your work. Together we:

- + Find out what people like about services and what could be better
- + Share these views with those who plan and deliver care
- + Provide advice and information to help people access services.
- + Have the power to make sure that those in charge of services hear people's voices.

# Session outline

- + **Presentation (10 mins):** What we were are hearing from people's about their experiences of dementia care
- + **Breakout discussion 1 (15 mins)**
- + **Breakout discussion 2 (15 mins)**
- + **Feedback (10 mins)**

# Findings on Dementia - 2016/17

52 local Healthwatch visited 120 care homes and attended local support groups to gather evidence from over 1,000 people living with dementia.

The care being provided was found to be compassionate, with people affected by dementia grateful for the support they receive. Areas for improvement included:

- + The availability and type of information at point of diagnosis sets the tone, with support not always well signposted.
- + Services can be inconsistent, with a feeling that GPs and care staff don't have specialist knowledge
- + Community services like dementia cafes are very good but not always accessible to those who need the help most

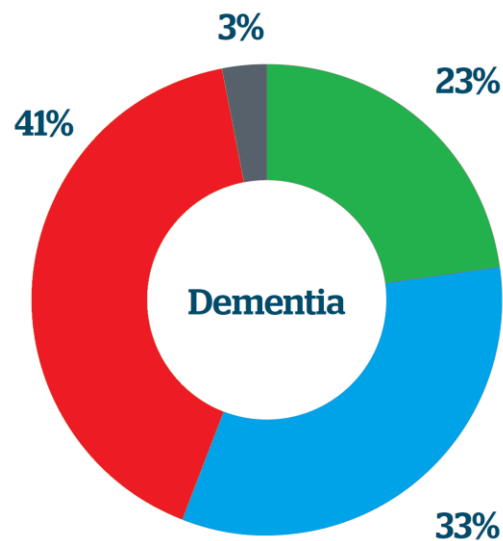
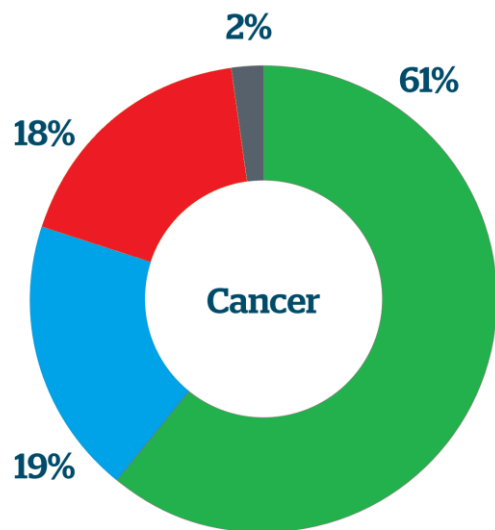
# Findings on Dementia - 2018/19

Dementia is a degenerative condition, and in many cases people's needs can change significantly in a very short space of time.

Following concerns raised with local Healthwatch by families and carers, we conducted a review to see how well services were staying on top of these changing needs.

- + Only half of social care users are receiving their Care Act mandated annual reviews – with the rate even lower (45%) among people with dementia.
- + A quarter of people with Dementia were subject to an unplanned review due to an emergency or sudden change in circumstances.
- + Some received both a planned and unplanned review, but 1 in 3 got nothing at all.
- + 65% of people with dementia who did have a care review were put forward for a full reassessment of their needs – however, half of these led to no change.
- + Carers are typically waiting up to 2 months for support after requesting an assessment

# NHS Long Term Plan



- Net positive responses
- Net neutral responses
- Net negative responses
- Net 'unknown' responses

## Case Study

Healthwatch Wiltshire with their local Alzheimer's Support and Wiltshire Care Partnership to find out from over 1,600 people living with dementia, and their carers, how to improve local services.

- + Built evidence to secure extra local investment in specialist dementia training
- + Showed how improvements in the care home environment were driving improvements in care – eg. lighting and contrasting colours helping to reduce falls
- + Highlighted improvements residents wanted such as buffet meal options.
- + Helped make the case for more community support – such as dementia support groups in underserved areas of the county + provided greater variety of activities
- + Created dementia friendly survey to support continual feedback on care.

We have produced an engagement toolkit with Healthwatch Wiltshire which you can access [here](#).

# Impact of the pandemic

Government and NHS communications about the pandemic have been particularly confusing for those with learning disabilities and dementia.

- **Healthwatch Bradford**

Daughter of dementia care home resident fears mother 'won't recognise her' after months apart due to Covid.

- **Healthwatch East Sussex**

The rapid roll out of digital and telephone appointments has had mixed responses, with positives and negatives for people with dementia.

- **Healthwatch England**



# Discussion One - 15 Mins

Think about the systems you have in place locally for ensuring people with dementia are identified and then provided with the support that meets their changing needs.

In your groups please do the following:

- + Share examples where you think things are working well at the moment
- + Explain why you think these approaches are working
- + Think about how these initiatives came about and how you might replicate this in other areas

Nominate one person to give feedback when we return.

## Discussion Two - 15 mins

The pandemic has changed so much of the way we deliver care and support, often with limited opportunity to involve services users in the design.

In your groups please do the following:

- + Share examples of how you have been delivering care differently during the pandemic
- + Discuss what elements of this you are looking to keep
- + Discuss how you are planning to make sure service users have had a chance to shape any permanent changes.


Nominate a different person to give feedback when we return.

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# Feedback

**Discussion one** – How can we best identify people with dementia and then provided them with support that meets their changing needs?

**Discussion two** – What have you done differently during the pandemic and how are you going to ensure service users have their say on any long term changes to care?

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# Please get in touch:

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