



Living in Norfolk with Dementia: A Health and Wellbeing Needs Assessment

Accessible Summary

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Improving health and wellbeing,
Protecting the population
Preventing ill health

Dementia describes a set of symptoms that usually include memory loss and difficulty thinking. In Public Health we have led a project looking at what it's like to live with dementia in Norfolk. It has looked across all services for people with dementia and their carers, from before a diagnosis to dying. The aim is to identify gaps in the service. This will hopefully help health planners and the council to improve services.

The project involved looking at statistics, research and reports followed by speaking to people with dementia, carers and health and social care staff.

Key facts about dementia include:

- In the UK there are about 800,000 people with dementia. That's equivalent to the population of Newcastle and Sunderland combined.
- In Norfolk there are 16,400. That's equivalent to either 1 in every 53 people in Norfolk or the populations of Cromer, Hunstanton and Holt combined.
- In people over 65s, about 26 people per 1000 get dementia every year which is equivalent to about 78 new people getting dementia in Wymondham per year.
- You are more likely to get dementia as you get older, but is not a natural part of ageing.
- Two thirds of people with dementia live at home and one third live in a care home.
- Over the next 20 years there will be about 9,000 more people with dementia in Norfolk which is equivalent to the whole population of Downham Market. The biggest increase will be in people who are over 90 years old.

The project looked across 10 areas. These were

Communities

Wymondham, Swaffham and Diss have become dementia friendly towns. Friends and families, workplaces, clubs, community groups and faith groups were found to be important communities too. People with dementia and carers said that they wanted people in the community to be more understanding of their condition, specific groups for different ages and levels of dementia, better transport and help to get out and about more easily.

Diagnosis

Less than half of people with dementia have a diagnosis (43%). The number of people with a diagnosis varies a lot across the county. One in three practices have a diagnosis rate of less than 30%. Reasons for not getting a diagnosis include lack of a cure and GPs thinking that there aren't many services available. The computer systems that GPs use may not have recorded everyone with dementia properly and if this was fixed the diagnosis rate might increase.

Support for People with dementia and their carers

Good support for people with dementia and their carers is really important. In some parts of Norfolk specialist nurses, called Admiral Nurses, have been used. A recent

study found that they work well and could potentially save money because they stopped people going into hospital or care homes. A treatment called Cognitive Stimulation is recommended for people with dementia. However there are only a limited number of groups available in Norfolk.

One in eight people in Norfolk look after someone else. These people can have a Carer Assessment which works out if they can get extra help, but not many people do this.

People with dementia felt that services were generally good, but were over-stretched. Gaps were a lack of information, services to match the stage of dementia, respite services and support for people who still work. Feedback suggested people with dementia and other medical problems, such as Parkinson's or Down's syndrome were at risk of a poor service.

Domestic abuse is increasing in people over 65 years old but we don't know if this is related to dementia.

GPs and community health services

Some mental health hospital beds have closed to fund a bigger community service. The increased community service has been able to see more patients but it's unclear if the number of beds is adequate. Feedback from staff showed that early intervention is needed, people with dementia should see the same member of staff when possible, staff were unaware of all the services available and more training for GPs. People with dementia were happy with the service from ambulance staff. They wanted a single person to contact instead of lots of different people.

It was estimated that it costs the police over £176,000 per year to look for people with dementia who go missing. New gadgets might be able to help.

Hospital services

On average 1 in 4 people in hospital have dementia. The number of people being admitted with dementia is increasing. People with dementia often stay in hospital longer than they should. This could be because of delays in organising social care, home carers have been cancelled or a lack of services to help someone at home, especially at the weekend. Areas for improvement include stopping people with dementia moving around different hospital wards, preventing people going into hospital who don't have to and improving A+E services.

Medicines

There are four drugs that doctors can use for some types of dementia. They all seem to work equally well but there is a big difference between the cheapest (£16 per year) and the most expensive (£1,037 per year). The way doctors use these drugs differs across the county. Pharmacists offer a service to help people manage their medicines called a Medicine Use Review. People with dementia and carers are likely to benefit from this service. One area for improvement highlighted was that

sometimes people with dementia are discharged from hospital and their paperwork for the pharmacy is not clear.

Social care and housing

Feedback highlighted the following issues – lack of early information and advice (especially for people who pay for their own care), lack of funding in the system, strict criteria, few respite services, long waiting times, few community service and lack of joined up working.

One in five dementia care homes did not meet all the Care Quality Commission standards. The commonest area of concern was around caring for people safely and protecting them from harm.

Good housing can help people with dementia and prevent them needing to use health and social care. Norwich City Council is trialling a new scheme to help people with dementia to improve their housing.

Staff and training

A survey by the University of East Anglia found that most hospital staff (92%) felt that they had insufficient dementia training. Knowledge around some of the laws of mental health needed improving. Home carers and care home staff were identified as especially needing more training. The organisation responsible for health-related education in England (Health Education England) is likely to start a three tier training programme which will match training with the amount of contact a staff member has.

There are a number of different dementia specialists. Three levels of specialist are needed to provide support for people with dementia and carers. This may include dementia advisers, dementia support workers and Admiral Nurses.

Inequalities

The service someone with dementia gets depends on who they are and where they live. Some groups are at particular risk of a poor service. These include those with other medical problems, people who pay for services themselves, rural residents and those without friends or family. We don't have good data on ethnicity, religion or sexuality to know if these groups have a worse service.

Recommendations

The full report makes 56 recommendations. These recommendations include

- providing good information to people who are diagnosed
- having a web and print directory of services
- more dementia specialists
- helping people to die in their place of choice
- helping school children understand about dementia
- improving GP systems
- encouraging more people with dementia and their carers to get involved in designing services

Dementia needs assessment for Norfolk, 2014

- more services aimed at different stages of dementia
- developing more flexible respite
- increasing cognitive stimulation therapy
- better training, more joined up working
- improving hospital environments
- more support for periods of crisis
- better consistency of staff
- improving quality of care in care homes