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

Executive Summary

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Norfolk Public Health
Improving health and wellbeing,
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Dementia currently affects 800,000 people in the UK (equivalent to the population of Newcastle and Sunderland) and it will rise to 1 million by 2021. It costs the UK society an estimated £23 billion per year. However the statistics miss the unique life stories of individuals, carers, family and friends. Each with their own journey, challenges, good times and bad. Over the past 10 years in Norfolk, dementia has come a long way but there is still much to be done. The momentum that has been built from the many achievements to-date now needs concrete progress as Norfolk strives to become a Dementia Friendly county.

This report describes the needs of people with dementia and their carers in Norfolk and makes recommendations to further improve services. The aim is to systematically review the health issues facing individuals with dementia and their wider social network, leading to actions that will improve diagnosis and care for individuals with dementia and their carers. It is aimed at commissioners, providers, voluntary organisations, strategic bodies, people with dementia and their carers.

The report has been produced by 1) reviewing data, 2) evaluating research, strategies, national documents and examples from other areas and 3) speaking to people with dementia, carers and professionals, in addition to visiting a number of different organisations along the dementia pathway.

Key facts include

- An estimated 16,400 people in Norfolk have dementia (either diagnosed or undiagnosed). Equivalent to 1 in every 53 people in Norfolk or the populations of Cromer, Hunstanton and Holt combined.
- Great Yarmouth and Waveney Clinical Commissioning Group (CCG) has the highest number of people with dementia reflecting its larger population.
- North Norfolk CCG has the highest proportion of people with dementia.
- There are about 26 new cases of dementia per year per 1000 population of over 65s in Norfolk (diagnosed or undiagnosed). That equivalent to about 78 new people getting dementia in Wymondham per year.
- The incidence of dementia increases as age increases, but is not a natural part of ageing.
- Just over half of people with dementia have mild dementia and remaining have moderate or severe disease.
- About two thirds of people with dementia live in the community compared to long term care.
- Over the next 20 years there will be an estimated additional 9,000 people with dementia. That is equivalent to the whole population of Downham Market. The greatest growth will be in people over 90 years old.

Community Development

People with dementia find it hard to feel part of, and participate in, their community. In Norfolk, the first town to take part in the Dementia Friendly Communities programme was Wymondham followed by Swaffham and Diss with plans developing for other towns. Other important communities were identified including social networks (e.g. friends and family), support groups (e.g. day services and dementia cafes), community groups or clubs, workplaces and ethnic, cultural or faith communities. The community of carers is equally important.

People with dementia and their carers identified several attributes they wanted from their community which included awareness, support groups, clearer information, a supportive physical environment, activities at the right level, good transport and local amenities. A mapping exercise showed where services are distributed throughout Norfolk.

Timely diagnosis

Feedback from people with dementia and carers suggest that they would like to know their diagnosis. Diagnosis is not an end in itself, but a gateway to allow people with dementia and their carers to make informed decisions about the future. Nationally the average person waits three years from the onset of symptoms to receiving a diagnosis.

The diagnosis rate in Norfolk and Waveney 2012/13 was 43.2%, meaning that 56.8% of people with dementia remained undiagnosed. Great Yarmouth and Waveney CCG has the highest diagnosis rate (49.6%) and West Norfolk CCG has the lowest (35.3%). Across the county diagnosis rates vary from 13% to 123% (23% more diagnoses than estimated cases). Only 6% of practices diagnose more than two thirds of people with dementia and 30% of practices diagnose less than one third. There needs to be a step change in the diagnosis rate if the national NHS England target of 67% is to be reached.

There appears to be no relationship between living in a rural area or being deprived and having a diagnosis of dementia.

Barriers to diagnosis include a perceived lack of support, the absence of a cure, lack of understanding among GPs about the diagnostic pathway and a lack of an accepted diagnostic tool.

A literature search found a lack of evidence based solutions to improving diagnosis. One study found that improving quality of coding in GP practices resulted in dementia recorded diagnosis increasing by 8.8% and it took practices on average 4.7 hours.

Support for people with dementia and their carers

Support is necessary for both the person with dementia and their carer to prepare for a diagnosis, come to terms with the condition and manage the progression of symptoms. With good support a person with dementia is able to maintain their unique sense of identity and self-worth.

A recent evaluation of the Admiral Nurses pilot in mid-Norfolk showed positive results with potential benefits to health and social care.

The National Institute of Health and Care Excellence recommend cognitive stimulation for all people with dementia. However there are only a limited number of groups in Norfolk.

In general slightly less than one in eight people in Norfolk provided unpaid care for someone else in 2012/13. North Norfolk is the area with the highest proportion of unpaid carers. Only one in 16 of these carers undergo a carer's assessment.

End of life care is an important part of someone's dementia journey. A number of community health services provide end of life care. Discussion with hospital staff revealed a lack of capacity within community services to allow expedited discharge for people with dementia to allow them to die at home.

Discussion with people with dementia and their carers suggests a lack of knowledge and information about legal support.

Generally people with dementia and their carers felt the quality of services when received was good, but that there remain capacity issues. Gaps identified were in relation to accessible information, services targeted to specific stages of dementia, variation in provision, care needs of the carer, respite, support from GPs, personal care services, home carers, Accident and Emergency (A+E) services, out of hours services, support for people who are employed and lack of a central point of contact.

People with dementia often have other medical problems or a dual diagnosis (e.g. dementia in Parkinson's disease). These need to be incorporated into the service delivery of person centre care.

Data from Norfolk Constabulary suggest that the number of victims of crime and non-crime events relating to domestic abuse is increasing in over 65 year olds. Anecdotal evidence suggests that this may be due to dementia; either a true increase or an increase in reporting.

Primary and community healthcare services

There has been a change in community mental health services over the past few years. The establishment of the Dementia Intensive Support Teams (DIST) has aimed to provide community health care closer to a person's home. The formation of the DIST has resulted in more episodes of patient management compared to mental health hospital admissions. However there remain questions about whether the DIST currently have sufficient capacity, is consistently delivered across the county and if the current number of dementia assessment beds is right.

Staff identified the following issues with current service provision; lack of age and stage specific services, more proactive services, lack of information, lack of continuity of care, lack of understanding around the diagnostic pathway, lack of overnight services and more training for GPs.

Focus group discussions revealed high satisfaction with the quality of service received from the ambulance service.

The number of people over 65 years old who have been reported missing has increased in the past 2 years. The estimated cost of missing people because of dementia is £136,000 in 2012/13 and £176,800 in 2013/14. A number of assistive technologies have come to market to help prevent missing persons.

People with dementia and their carers expressed a desire to have a single point of contact, rather than contacting multiple different agencies. A dementia adviser, dementia support worker or Admiral Nurse, or similar, may be able to provide this single point of contact and help to provide a joined up integrated service

Secondary healthcare services

About 1 in 3 to 1 in 5 people in hospital have dementia. The proportion of emergency admissions for those aged 65 years and older with dementia recorded as a co-morbidity has increased over the past decade. West Norfolk CCG has a significantly higher rate of such hospital admissions compared with other CCGs.

Some people with dementia stay in hospital for longer than they should. Possible reasons for delayed discharges include delays in organising social care, Continuing Health Care Assessments, cancelled home care, lack of community services and lack of service provision over the weekend. There were positive and negative themes about hospital admission. Areas for improvement included reducing frequent moves between wards, inappropriate admissions, access to specialist support and Accident and Emergency departments. The FAIR CQUIN (also known as memory matters) was generally felt to be a good scheme.

There are between 400 and 550 referrals each month for the DIST and Community Mental Health Teams. About half of referrals are in the central Norfolk region, a quarter in west and a quarter in east. Approximately 73% of people who attend a memory assessment centre in Norfolk received a positive diagnosis. There are currently 15 dementia assessment beds located in Norwich for the whole county. Roughly three are reserved for west Norfolk patients, three for east Norfolk and nine for central Norfolk.

Medicines management and prescribing

There are currently four drugs which are recommended as options for managing Alzheimer's disease. All four drugs are used across Norfolk. There is over £1000 difference in 1 year's treatment cost between the cheapest (donepezil tablets) and the most expensive (galantamine modified release capsules). There appears to be a larger use of rivastigmine in West Norfolk CCG compared to other CCGs. West Norfolk CCG spends the most per patient (£204 per patient) compared. North Norfolk CCG spends the least (£125 per patient). Improvements appear to have been made in the prescribing of antipsychotics.

The Medicines Use Review service is under-utilised and often not accessed by those who need it the most. Reports from pharmacists suggest that people with dementia are often discharged by acute hospitals without enough information. Another issue highlighted was the lack of information and processes for pharmacists to signpost to other services.

Social care and housing, including care homes

Often unpaid caring is a 24 hours a day, seven days a week, 356 days a year job with little respite. It is estimated that unpaid carers of people with dementia save the UK government £8 billion every year.

Discussions with professionals identified a number of issues with current social care system. These include lack of information and advice at an early enough stage (especially for self-funders), lack of funding, strict eligibility criteria, lack of appropriate respite, long waiting times, lack of community services and lack of integration.

North Norfolk CCG has the highest number of people with dementia in care homes. Many people with dementia do not have an opportunity to visit the care home before admission. 40.8% of people self-fund nursing or residential care.

A fifth of care homes in Norfolk which cater for people with dementia did not meet the Care Quality Commission standards from March 2013 to July 2014. Common areas of concern for dementia care homes in Norfolk were 1) caring for people safely and protecting them from harm, 2) staffing, 3) quality and suitability of management and 4) providing care, treatment and support that meets people's needs. Feedback from professionals highlighted the following areas for improvement include stigma, variation in quality, involvement of community mental health teams, activities, quality of staff and respite.

Housing reports suggest that good housing for people with dementia can reduce or delay demand for health and social care services, can improve diagnosis rates and can improve health and social care outcomes. Norwich City Council is considering a Dementia Adaptations Scheme which would improve housing for people with dementia.

Workforce

There are multiple different levels of specialist dementia staff including, Dementia Care Coaches, Admiral Nurses, dementia advisers, dementia support workers and dementia leads.

A survey by the University of East Anglia found that 92% of hospital staff felt that they had insufficient training overall in relation to dementia. Particular deficiencies were reported in appropriate communication skills, assessing cognition, dealing with aggressive behaviours and recognising pain. Knowledge of the Mental Capacity Act (2005) was identified as a gap by the majority of respondents.

Discussion with professionals identified the following issues, workforce development is key, care home staff and domiciliary carers need more training, recruitment is important, there is a need to get the timing of training sessions correct and there should be a focus on training outcomes rather than numbers.

Health Education England is likely to commission a 'tiered approach' to training with differential levels of competence achieved. Norfolk and Suffolk Dementia Alliance

have locally developed the Dementia Care Coaches model. The interactive programme trains individuals to a high standard of competence in order for them to train other people in their organisation and their 'sphere of influence'.

A tiered approach to workforce is also required to provide a comprehensive service across Norfolk. This may include a combination of dementia advisers, dementia support workers and Admiral Nurses, or similar.

Inequalities

The quality and extent of services provided to people with dementia depend on who they are and where they live. There are also certain groups who receive a poor service because they have a dual diagnosis. Unfortunately dementia services do not appear to regularly collect ethnicity, sexual identity, disability or religion information.

There does not appear to be an association between having dementia and being deprived.

In Norfolk 1 in 44 over 65 year olds are non-white British. There is some evidence that people from black, Asian and minority ethnic groups (BAME) suffer dementia at a younger age and generally are less likely to access statutory services.

The number of older people from lesbian, gay, bisexual or transgender (LGBT) communities is likely to increase in the future. Older LGBT people are more likely to be single and live on their own compared to heterosexual people.

Approximately 15,000 people over 65 years attend a church in Norfolk. The 2011 census suggest that the majority of people in Norfolk consider themselves to be either Christian or have no religion. There are examples of dementia friendly faith groups.

Feedback from discussion with professionals and stakeholders identified other groups who are at risk of inequalities including self-funders, people who live in rural areas, those with co-morbidities and those without social support.

Recommendations

Based on the above assessment the following recommendations have been made.

1. Information and support for people with dementia and their carers
    a. Within the first 6 months of diagnosis comprehensive information and advice should be given to people with dementia and carers about current and future services, including likely eligibility thresholds.
    b. Clinical Commissioning Groups should ensure that GPs are aware of available support. For example using a web-based road map or information sheet located in each consultation room.
    c. Web and print directory of dementia services that allows users and providers to contribute should be produced by commissioners. This should be a new partnership county-wide website produced jointly with Norfolk

County Council care directory, Heron database, Norfolk and Suffolk Dementia Alliance and Clinical Commissioning Groups.

d. Norfolk County Council and Clinical Commissioning Groups should ensure that people with dementia and carers who self-fund are able to access the same high quality information and advice as those who are eligible for social care support.

2. Support
    a. Dementia advisors, dementia support workers and Admiral Nurses, or similar, should be jointly commissioned by health and social care. Their scope and case load should be well defined. One of their key roles should be providing integrated comprehensive health and social care information during the first 6 months after diagnosis.
    b. Clinical Commissioning Groups should ensure that GP practices sign up to the GOLD driving scheme and GPs should encourage people with dementia to participate.
    c. The support and services offered by Independence Matters are currently under-utilised and should be promoted by commissioners and providers to people with dementia and their carers.
    d. Commissioners should consider a buddying-type scheme to match newly diagnosed people and carers with those who have been diagnosed for longer and carers.
    e. GPs should be encouraged to refer people with dementia and carers to the Medicines Use Review service.
    f. People with dementia who do not have an advocate should be given additional support from dementia advisors/support workers/Admiral Nurses, or similar.
    g. Carers should be encouraged to undertake carers training after diagnosis
    h. More carers should be encouraged to have a carer's assessment.
    i. Norfolk County Council, Clinical Commissioning Groups, providers and voluntary organisations should work together with Parkinson's Pathway Group to agree a common carer's pathway.
    j. Commissioners and providers should work together to help more people with dementia die in their place of choice.

3. Making Norfolk Dementia Friendly
    a. All pharmacies, libraries and transport providers should become Dementia Friendly.
    b. Dementia Friendly Communities should extend to non-geographical communities.
    c. Efforts should be made to ensure that the Dementia Friendly Communities programme does not increase variation and inequalities.
    d. Norfolk County Council should encourage dementia teaching in schools and identify a local school to be a dementia champion.

4. Timely diagnosis
    a. Clinical Commissioning Groups should assist GP practices to standardise dementia coding and undertaking coding audits.
    b. Clinical Commissioning Groups should use the Dementia Partnership principles to improve timely diagnosis.

c. Clinical Commissioning Groups and mental health providers should explore primary care based assessment clinics.

5. Planning services
    a. Norfolk County Council, Clinical Commissioning Groups and providers should adopt a co-production model of accessible service design and delivery.
    b. Norfolk County Council and Clinical Commissioning Groups, providers and voluntary organisations should use the dementia prevalence map to plan health, social care and transport services.
    c. Norfolk County Council and Clinical Commissioning Groups should ensure that there are services tailored to the age and stage of dementia.
    d. Commissioners and providers should work together to ensure more cognitive stimulation is provided, including continuation groups afterwards.
    e. Commissioners and providers should work together to ensure people with a dual diagnosis do not fall between services.
    f. Norfolk County Council should commission more respite which is flexible, offers choice and includes expansion of domiciliary respite. Commissioners and providers should work together to make respite more affordable.
    g. Norfolk County Council and Clinical Commissioning Groups should commission more activity-based groups for people with dementia.
    h. Commissioners and providers should ensure that current and future services are accessible to service users and carers of different ethnic groups, religions and lesbian, gay, bisexual and transgender communities.
    i. Commissioners and providers should collect information about users in accordance with the Equality Act 2010 to ensure services are equitable.

6. Training
    a. Training provided should focus on the outcome of successfully delivering person-centred care, rather than numbers attending training.
    b. Providers, especially acute hospitals, community healthcare, care homes and domiciliary care organisations, should include essential dementia skills and knowledge in their job specifications when recruiting staff.
    c. Providers and commissioners should work with the Norfolk and Suffolk Dementia Alliance in order to develop their workforce in accordance with the “dementia dozen”.
    d. Providers should use the Dementia Care Coaches model for workforce development.
    e. Providers should ensure that staff are sufficiently knowledgeable about the Mental Capacity Act (2005) and Mental Health Act (1983 amended 2007).
    f. Providers should ensure that frontline health and social care staff are trained in cultural competence.
    g. Commissioners and providers should not consider Dementia Friends training as sufficient for health and social care staff.

7. Integration
    a. Commissioners and all providers throughout the dementia pathway should work together to develop joint referral pathways and where appropriate

agree tools. This approach should be county-wide, but modifiable for local differences. This should include review of the shared care agreements.
   b. Acute trusts should share learning, examples of good practice and expertise in older people's medicine across the county.
   c. Norfolk Constabulary, health services and adult social care should work together to identify people at risk of going missing and intervene early within integrated pathways.

8. Secondary care
   a. In 2015 an independent review should take place of the current provision of dementia assessment beds, including comparison with other comparable areas and localities, to assess if the current provision is adequate.
   b. Acute hospitals should adopt the King's Fund principles for Enhancing the Healing Environment for wards looking after people with dementia and specific areas within A+E and acute assessment units.
   c. People with dementia admitted to an acute hospital as an emergency should receive a comprehensive multi-disciplinary team review including social work and consultant involvement within 24 hours and make every effort to ensure that the patient goes to the right ward first time.
   d. All patients with dementia should have their nutritional needs assessed and immediate action taken where appropriate.
   e. Acute hospitals should ensure that discharge letters of people with dementia accurately reflect medications on discharge and any reasons for medication changes.
   f. People diagnosed in neurology or older people's medicine should be referred to mental health memory services for further support requirements.

9. Personal care and housing
   a. Norfolk County Council should commission a comprehensive Flexible Dementia Support Service for people with dementia who have a crisis which is free at the point of use and also provide more night sitters.
   b. Care First system should have a section to record dementia.
   c. Clinical Commissioning Groups and Norfolk County Council should support the pilot of the Dementia Adaptations Housing Scheme. If successful it should be rolled out throughout the county.
   d. Housing modification information should be given to all people with dementia and their carers as part of a holistic advice and information service.

10. Home carers
   a. The role of paid home carers should not be undervalued. Commissioners and providers should ensure they receive adequate dementia training and information, especially in relation to difficult behaviour.
   b. Providers of home carers should make every effort to ensure consistency of staff.

11. Care homes
    a. Care homes should be encouraged to conduct outreach in the community to de-stigmatise dementia, improve the image of care homes and help make Norfolk a dementia friendly county.
    b. Commissioners and supporting organisations should focus on improving the culture and leadership in care homes that have residents with dementia. Good examples of high quality dementia care and best practice in care homes should be shared.
    c. Care homes should be encouraged to sign the Dementia Pledge.
    d. All care homes with residents with dementia should agree to the Herbert Protocol.