Report title and challenge question(s):

(Q) Do we have whole system pathways for users and how does it differ from a standard way of managing? Please provide illustrative case studies to support the report

Priority report relates to (where applicable):

Dementia

Report to: Health and Wellbeing Board

Report author(s):

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-Please limit your report to a maximum of five pages.
-At the Board, it is assumed that members have read all papers. Unless your paper is for information, you will have 3 minutes to outline your paper before a Board discussion.
1. Introduction

1.1 What is the ‘wicked issue’?

(Q) Do we have whole system pathways for users and how does it differ from a standard way of managing? Please provide illustrative case studies to support the report

1.2 What are the existing mechanisms/projects to address this issue?

In 2017 it was identified in NHS Right Care that Waltham Forest was an outlier in terms of non-elective admissions to hospital for people aged over 65 with dementia. It was agreed to look at how we might improve this and as a result improve the quality of life for people with Dementia as we know hospital admissions shorten their lives and they deteriorate when in hospital.

The most common reasons for admission to hospital for people living with dementia are Urinary Tract Infection (UTI), Pneumonia and falls. People with dementia should not be admitted to hospital with urinary tract infections. An improvement in the support of people with dementia who have been diagnosed for a while and are in the moderate to advanced stages of dementia should reduce their likelihood of emergency hospital admission. Better links with current clinical pathways for falls as well as contractual changes for domiciliary care and care planning would achieve this. Better coordination of support for people with dementia in Waltham Forest will bring together better carers support with an understanding of how to support someone with dementia as well as tools to provide better health care and checks and access to technology that will improve their support.

A project was agreed with Alzheimer’s Society, who is commissioned by Waltham Forest CCG to provide post diagnostic support. The project covers prevention, escalation and treatment in the community of UTIs, falls and sepsis in people living with dementia. This will include ensuring the monitoring of people with dementia by formal and informal carers, education and training on dementia care and development of peer networks for carers of people with dementia. Prevention of pneumonia will also be undertaken but as these are also end stage conditions it will be necessary to ensure those who are approaching end of life care are on the correct pathway. In addition, carers will be encouraged to ensure the person living with Dementia receives the pneumococcal vaccination. Community pharmacists and practice nurses have also been targeted to promote this.

It was agreed that the Alzheimer’s Society would continue to provide immediate post diagnostic support but would increase the level of follow up of people who have been diagnosed a while before. They additionally introduced risk assessment tools to determine whether the people with dementia they were working with had a clinical as well as social risk; providing preventative advice as well as clarifying what to do if the person living with dementia’s health deteriorated.
This work has been whole system including the development of the clinical tool which was developed in a workshop with Local Authority, Barts Health NELFT and Alzheimer’s Society. The tool is for non-clinicians and explains what to do to prevent UTIs, sepsis, falls and pneumonia as well as when to escalate to if the person living with dementia’s health starts to deteriorate.

The CCG has worked alongside the local authority to develop this work, which has included introducing contractual changes to ensure hydration is managed through formal and informal carers and in care homes: simple effective personalised care practices are clearly part of the solution.

1.3 What more can the partnership do? / What is your ask of the board today?
The first step is that the Health and Wellbeing Board will become Dementia Friends on 20 March 2019. This is however just a first step. There needs to be challenge at all levels in development of buildings and services, both in health and social care but also with corporate bodies. The aim is for a positive, dementia friendly approach to be included in all contracts as a minimum to ensure people living with dementia are included and welcomed. When services reports etc. are reviewed they must ensure they do not indirectly discriminate against this small but growing group who are over-represented in emergency hospital admissions because we are, in part, failing to provide appropriate, responsive services.

2. Context
Many UTIs are avoidable or can be managed with prompt access to medical care. However, they are extremely common amongst people with dementia. A UK study found that UTIs, as well as pneumonia, were the main causes of hospital admission for 41.3% of people with dementia. UTIs in people living with dementia can often be prevented by the application of preventative care practices, which can be applied in their own home, nursing home or medical settings. UTIs are often caused by dehydration, urine retention and poor hygiene, which can be prevented by proper care practices. People with dementia can become dehydrated because they do not recognise the vessel being used to administer water, which can lead to them not drinking even when thirsty. Therefore it is important that routines are created and familiar objects used as part of individuals’ care plans. In addition, carers can find out the person preferences and make drinks readily available and visible.

3. Issue(s)
Untreated comorbidities in people with dementia may be increasing health and care costs significantly by causing deterioration in the dementia. Assuming cognitive function in patients with both dementia and comorbidity declines 2 years faster than patients with dementia only. Significant savings could therefore be made to health
and social care by developing policies and strategies that effectively address how to prevent, diagnose and manage comorbid conditions in people with Dementia.

The Post Diagnostic Support Guidance from the London Strategic Clinical Network advises management of comorbidities for people with dementia and monitoring of the red flags such as UTIs, Constipation and Chest Infections leading to Delirium. Prior to this project our post diagnostic support was limited to development of a support plan and signposting to services. Some people who had been diagnosed over a year attended the Dementia Café and other peer group activities run by Alzheimer’s Society but in the main received no other support. Alzheimer’s Society had no information regarding the care of people they were supporting.

4. Identification of gaps, themes and challenges

The Alzheimer’s Society is just one service working with people living with dementia. We need all contracts to require providers to be dementia-friendly and for their practice to reflect understand of the basic needs of working with this client group. More also needs to be done to ensure services recognise and remove barriers to access for people with dementia across the whole health and social care system, especially in commissioning and service provision.

It will not be enough to simply develop mini versions of services just for people living with dementia; we need to continue to create more targeted support for informal carers to support them to remain in their caring role as well as establishing dementia-friendly communities in the borough. This will need leadership and resources, including a commitment from ‘the top’ of the Health & Social Care economy.

Work has already started by setting up the Dementia Hub. Its development will allow people living with dementia and their carers to find and obtain appropriate advice and support from a dedicated, centralised resource. Additionally, this will enable people to be appropriately signposted to targeted community, health and social care resources to better address and meet their individual care and support needs as their dementia and associated conditions progress.

5. Proposed solutions

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<th>Recommendations</th>
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<th>Evidence base for recommendation</th>
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<tr>
<td>1. Home Care Contracts to include a requirement to monitor hydration in people over 65 and to understand the signs of deterioration from dehydration</td>
<td>Local Authority</td>
<td>Dementia and Comorbidities. Ensuring parity of care. Jonathan Scrutton and Cesira Urzi Brancati. April 2016</td>
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<td>2.</td>
<td>Dementia Action Alliance to be set up to move towards a Dementia Friendly Community in Waltham Forest</td>
<td>Local Authority</td>
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<td>3.</td>
<td>Health and social care to continue to work together to develop joined up services that address the prevention of hospital admission for people living with Dementia and allow them to live well for as long as possible.</td>
<td>Local Authority/Waltham Forest CCG.</td>
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<td>4.</td>
<td>Increase the knowledge and understanding of Dementia within the Health &amp; Social Care workforce</td>
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<td>5.</td>
<td>Contract monitoring across Health &amp; Social Care to proactively monitor improvement in increased skills and knowledge of workforce</td>
<td>Local Authority/Waltham Forest CCG</td>
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6. Appendix: Case studies

**Case Study 1: Mrs A**

Mrs A suffers from dementia, lives at home with her son and receives five visits a day from a care worker as part of her care package. Her son is an unpaid, informal carer and keeps his mother company throughout the day and cares for her throughout the night. During a visit from the care worker Mrs A’s son described as feeling isolated and was finding it increasingly difficult to cope: he said that at times he had felt like walking away from the situation.

The care worker noticed that Mrs A was aggressive towards her son. He told the care worker that his mother was shouting during the night and appeared to be experiencing visual hallucinations. The care worker suspected that a urinary tract infection was causing this behaviour.

The care worker reviewed the plan and asked for the Rapid Response Team to be contacted to carry out a home visit and manage Mrs A’s physical health. The Rapid Response Team is a nurse led team who are able to deliver oral and parenteral treatment in the community and whose role is to work in collaboration with the General Practitioner and Local Authority services with patients who are too complex for the General Practitioner alone to manage in order to avoid hospital admission. The Rapid Response Team diagnosed and treated the urinary tract infection and liaised with the memory service mental health team who were also providing Mrs A with care.

The Rapid Response Team provided Mrs A’s son with information and education about his mother’s condition and because he said that he was finding it difficult to cope he was referred to the local carer support service.
Case Study 2: Mrs B

Mrs B was at the later stage of his dementia journey. She had a care package five times a day and her son is also her carer; he cared for her throughout the night and kept his mother company throughout the day. Mrs B had an initial assessment for continuing health care but had not heard back about the results of this assessment. Her son felt isolated and that he was at breaking point, unable to cope, saying he was thinking about walking out. Mrs B was calling out during the visit, was physically aggressive towards her son, shouting during the night and experiencing hallucinations: it was suspected she had a UTI and potential delirium.

Actions and results

- The son was encouraged to call Rapid response to attend to the UTI, and given information about delirium information about delirium. Result: a hospital admission was prevented and Mrs B was treated at home for UTI
- Liaised with memory service nurse regarding antibiotics. Result: was able to reassure son as to timescale for improvement in mother’s condition, preventing hospital admission.
- Safeguarding alert was raised. Result: the safeguarding team contacted son to assess situation aiming to prevent the son from ‘walking out’.
- Supported carer with phone calls and referral to Carers First. Result: emotional support, son had someone to turn to; ongoing support from Carers First.
- Liaised with continuing health care team to find out about progress of application for nursing home. Encouraged CHC brokerage team to secure nursing home placement as a matter of urgency, negotiated extra care during the night to support the carer. Result: night care put in, nursing home place was secured and Mrs B was moved into care, preventing a crisis hospital admission.