#### Agenda Item No: 7

# CAMBRIDGESHIRE AND PETERBOROUGH DEMENTIA STRATEGIC PLAN

To: Adults Committee

Meeting Date: 24 May 2018

From: Executive Director: People and Communities

Electoral division(s): ALL

Forward Plan ref: Key decision: No

Purpose: To outline the strategic plan for improving outcomes,

experience and the cost effectiveness of services for people living with dementia and their carers as a national and local

priority.

Recommendation: The Committee is asked to approve the Strategic Plan so that

the improvement in outcomes, experience and cost

effectiveness in dementia care across Cambridgeshire and

Peterborough can be delivered.

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#### 1. BACKGROUND

1.1 Using the national Well Pathway for Dementia, the Dementia Strategic Plan presents a vision for dementia care in Cambridgeshire and Peterborough and the key outcomes to be delivered. It summarises the current status of dementia care, identifying strengths and opportunities for improvement and likely future demand and the actions known to be required to improve outcomes over the two years from 2018/19. It aims to ensure that the best use of resources is made and to identify significant gaps in services and any investment required. The work on cost effectiveness will be undertaken in the context of the current pressure on public sector resources with the aim being to identify opportunities for service redesign and reinvestment to deliver the required improvements.

#### 2. THE STRATEGIC PLAN

- 2.1 Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance which can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement i.e. cognitive impairment. However, not all cognitive impairment is caused by one of the dementias i.e. they are not all progressive. The scope of the Strategic Plan is confined to progressive cognitive impairment/dementias. Therefore, it includes Alzheimer's disease, dementia with Lewy Bodies and cardio-vascular dementias and Mild Cognitive Impairment (MCI).
- The Strategic Plan was developed by the Older People's Mental Health (OPMH) Delivery Board, which is made up of representatives of the voluntary sector including carer representatives and representatives of people living with dementia, Cambridgeshire County Council (CCC), Peterborough City Council (PCC), Peterborough and Cambridgeshire Clinical Commissioning Group (CCG) commissioners, and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) who work primarily with older people living with dementia and their carers. However, they also care for people with early onset dementia i.e. those under age 65 years.
- 2.3 The Plan is based on the outcomes of engagement with a variety of individuals employed by both statutory and voluntary sector organisations across the Cambridgeshire and Peterborough health and social care system during 2016 and 2017. It was finalised following engagement on the draft Strategic Plan from September to October 2017. This included a Survey Monkey Questionnaire that was circulated using existing networks and engagement events with representative groups including:
  - The Older People's Partnership Boards: Cambridgeshire and Peterborough
  - The Ageing Well Strategy Board
  - The Carers' Trust: Carers' Group
  - The STP: Clinical Advisory Group
  - The Peterborough Living Well Partnership

- 2.4 The Plan aims to achieve equity of access, assessment, treatment, support and outcomes across the area. It also aims to prevent or delay the onset of dementia. Overall, the aim is to ensure the cost effectiveness of dementia care and to maximise the use of resources available to meet health and social care needs in relation to dementia and other conditions across the area. It describes how the Older People Mental Health (OPMH) Delivery Board plans to work with its partners to achieve the vision for dementia. These are summarised in action plans for each of the Pillars and Cross Cutting Themes of the Well Pathway for Dementia (see Appendix 1). The Executive Summary is attached for reference (Appendix 2). The full Strategy document is attached as Appendix 5.
- 2.5 The work that will be done to develop the business case requested by the Sustainability and Transformation Partnership (STP) is also described within the Plan. This will be completed during the Autumn 2018 with implementation of the agreed improvements to take place from 1 April 2019.
- 2.6 Gaps and improvements that can be made across the dementia pathway in Cambridgeshire and Peterborough have been identified. The most significant gaps have been identified as:
  - Early intervention and support including information, advice and guidance and advance care planning primarily provided by the voluntary sector.
  - The infrastructure required to support the development of dementia friendly communities and environments – primarily provided by the voluntary sector/also in primary care
  - Support to maximise quality of life whilst living with dementia for individuals living with dementia and their carers.
  - Capacity to support people intensively to remain at home at times of crisis and/or enhanced need (service provided by Dementia Intensive Support Team (DIST)).
  - Psychological treatment for people following diagnosis and in specialist dementia inpatient care.
  - The seamlessness and co-ordination of care across both mental and physical health clinicians, teams and organisations.
  - Management of dementia and quality of care in care homes.
  - Personalised care planning and support.
  - Specialist assessment, treatment and support for people diagnosed with early onset dementia<sup>1</sup>.
- 2.7 Gaps in non-progressive dementias such as those that are caused by substance misuse or brain damage have been identified. However, responsibility for delivery of services for these groups rests with a variety of individuals, teams and organisations which are beyond the usual networks of those working with the progressive dementias. Having given the matter considerable thought, the OPMH Delivery Board decided to highlight these gaps but to recommend that other networks address the issues with their support and advice if required.

<sup>&</sup>lt;sup>1</sup> This document contains key issues identified within the needs assessment undertaken to inform the Strategic Plan. The detail is contained in 'Early Onset Dementia, Needs Assessment', October 2017.

- The County Council has a key role to play in addressing each of the priorities above arising from the Care Act. Qualified Social Workers and Support Workers seconded to CPFT as part of the integrated mental health service are responsible for care planning and support and are for ensuring that this is personalised. These staff, and those employed within Early Help teams are responsible for ensuring that information, advice, guidance and appropriate signposting, including referral for diagnosis, is provided as early in the course of the disease as possible. Social Workers and the Commissioning Teams are responsible for ensuring access to good quality housing and accommodation, including care homes. The County Council also has responsibility for carer assessment and support and for supporting the development of dementia friendly communities and environments. In addition, the Council has a responsibility to work effectively with partners in the NHS, the voluntary sector and with people living with dementia and their carers to deliver care that is co-ordinated and seamless.
- A core data set to monitor quality, outcomes has been developed and will be refined as part of the work to implement the Strategic Plan. These are based upon the Memory Service National Accreditation Programme quality standards and the reporting requirements of NHS and social care organisations. In addition to the need to report on core national and local activity, performance and outcomes this data set will enable the system to monitor the improvements that are of the greatest importance to people living with dementia and their carers. Achievement of this ambition will be supported by the alignment of the Personal Care and Support Planning initiative with the development of the dementia pathway.

#### 3. NEXT STEPS

- 3.1 The Plan has been signed off by all the Boards necessary except for Peterborough Cabinet and the Health and Wellbeing Board. The processes to secure sign off are underway and near completion.
- The Plan draws together work to improve outcomes for people living with dementia and their carers that was already underway and the work needed to address the additional gaps in care and support and opportunities for improvement identified as it was developed. Implementation of both is already underway as implementation is an iterative and evolving process.
- 3.3 A detailed implementation plan has been developed with Task and Finish Workstreams established led by key individuals from across the health and care system. Responsibility for delivery lies with the Dementia Steering Group, the project group established to ensure delivery and ultimately with the OPMH Delivery Board which reports to the Ageing Well Strategy Board and the MH Strategy Group. Cath Mitchell, Director of Integration, Cambridgeshire and Peterborough is the Senior Responsible Officer with overall responsibility for delivery.
- 3.4 The County Council will have a key role in supporting the OPMH Delivery Board to deliver the Strategic Plan. In particular to:
  - Support the proposal to develop Dementia Friendly Communities, working closely with District Councils and leading as a County Council and identifying

Dementia Champions. The possibility that Area Champions could support and help to progress this work is currently being explored.

- ii) Support the proposal to encourage organisations across Cambridgeshire and Peterborough to become Dementia Friendly and lead by example by exploring how and then committing to what would be required for the County Council to become Dementia Friendly. There are 3 key ways in which an organisation can become dementia friendly:
  - 1. Make customer service more dementia-friendly
  - 2. Improve the physical environment
  - 3. Provide practical support and deal with difficult situations effectively
- Two of the key risks to delivery of the Strategic Plan are currently rated amber. Mitigating actions are in place to address them:
  - Risk 1: Insufficient capacity within OPMH commissioning and provider organisations to deliver a complex programme of work with the detailed level of analysis necessary to achieve the outcomes required.
  - Risk 2: The need to for system wide participation in delivery of the strategy.

The third risk relating to resourcing the facilitation of the care pathways workshops has been resolved.

#### 4. ALIGNMENT WITH CORPORATE PRIORITIES

#### 4.1 Developing the local economy for the benefit of all

There are no significant implications for this priority.

#### 4.2 Helping people live healthy and independent lives

See wording under 3.1 above

## 4.3 Supporting and protecting vulnerable people

See wording under 3.1 above

#### 5. SIGNIFICANT IMPLICATIONS

#### 5.1 **Resource Implications**

There are no immediate resource implications within the Strategic Plan. However, the aim is to improve the use of resources and to identify gaps in the current pathway and to address the implications of the inevitable increase in demand for dementia care and support arising from the 86% (n=8,100) increase in the numbers of people living with dementia in Cambridgeshire and Peterborough to 2031. The Plan will identify proposals for service redesign and may lead to the development of business cases for additional investment for consideration by the Cambridgeshire County Council and Peterborough City Council. The CCG/Strategic Transformation Partnership. Proposals for redesign and/or investment will be developed January –

September 2018, with a business case/s developed September to December 2018

It is likely that resources in terms of staff time (primarily time for training) and investment in training and minor adaptations to physical environments will be required in order to progress the proposals relating to making the County Council a Dementia Friendly organisations, if it is agreed that this should be pursued. The current proposal is to explore what would be required and identify the potential cost.

#### 5.2 Procurement/Contractual/Council Contract Procedure Rules Implications

No immediate implications.

#### 5.3 Statutory, Legal and Risk Implications

No immediate implications.

#### 5.4 Equality and Diversity Implications

The Plan will have a positive impact on: age, disability, race, religion/belief, pregnancy and maternity (for those in caring roles), rurality and deprivation. It has a neutral impact on gender reassignment, sex, sexual orientation, and marriage and civil partnership. There are no negative impacts.

#### 5.5 Engagement and Communications Implications

The Plan was developed by the OPMH Delivery Board that has wide representation of key organisations involved in the delivery and commissioning of dementia care and support. Individuals within and the organisations represented were consulted. There were monthly consultations and engagement throughout the period when the Plan was developed at the scheduled meetings. Members of the Committee are as follows:

- PCC/CCC MH Commissioning Team
- C&P CCG:
- CPFT
- Alzheimer's Society
- Carers' Trust
- Peterborough LEP
- Councillor Lamb
- Ageing Well Strategy Board
- STP: PCIN
- Older People's Partnership Boards: Peterborough and Cambridgeshire
- Cambridgeshire ASC Teams
- Peterborough ASC Teams

The Plan has now been signed off by:

- The OPMH Delivery Board: 17.01.18
- The Ageing Well Strategy Board: 16.01.18 (subject to approval of the Plan by the OPMH Delivery Board)
- PCC/CCC Joint Commissioning Board: 14.02.18

STP: PCIN:01.03.18STP: CAG: 15.03.18CCG: CEC: 27.03.18

• CPFT: Executive Team: 27.03.18 (approval by the Trust Board is not required)

Sign off by the following is planned April – June 2018:

STP: HCECCG: GB

• CCC: Adults Committee

PCC: Health and Wellbeing BoardCCC: Health and Wellbeing Board

No further consultation needed to finalise the Plan. As the Plan is implemented there will be significant and ongoing engagement and consultation with all stakeholders.

#### 5.6 Localism and Local Member Involvement

The development of Dementia Friendly Communities (DFCs) are key to the national dementia strategy and are also included as a key strand within the Cambridgeshire and Peterborough Dementia Strategic Plan. Increasing the number of DFCs is a key outcome from the pre-and post-diagnostic support workstream. This workstream has been identified as having the biggest gap in terms of what is needed to provide cost effective care and support for people living with dementia and their carers in Cambridgeshire and Peterborough. Support for, and involvement of, Members in the development of DFCs would make a significant contribution to this (see 3.4 above). District Councils are also key to this workstream and plans to engage with and involve them in this work are included in the action plan.

#### 5.7 **Public Health Implications**

Prevention is one of the 5 Dementia Well Pathway Pillars. There is a Prevention workstream and action plan within the plan. These summarise and pull together the components of the Public Health Strategy that relate to dementia. There are therefore no specific implications of the Strategic Plan for Public Health, although the Plan highlights the importance of prioritising and progressing this work.

Implications	Officer Clearance
Have the resource implications been	Yes
cleared by Finance?	Tom Kelly
Have the procurement/contractual/	Yes
Council Contract Procedure Rules	Tom Kelly
implications been cleared by Finance?	-
Has the impact on statutory, legal and	No

risk implications been cleared by LGSS Law?	Name of Legal Officer:
Have the equality and diversity	Yes
implications been cleared by your Service Contact?	Oliver Hayward
Have any engagement and communication implications been cleared by Communications?	Yes
Have any localism and Local Member involvement issues been cleared by your Service Contact?	No
Have any Public Health implications been	Yes
cleared by Public Health	Katie Johnson

Source Documents	Location		
Cambridgeshire Public Health Strategy 2015 – 18	Public Health, Shire Hall, Cambridge		
Apart from the above, the main sources were local activity and finance data (operational) and national strategy documents:			
<ul> <li>Dementia: The NICE/SCIE Guidelines on Supporting People with Dementia and their Carers in Health and Social Care, NICE/SCIE, 2006</li> <li>National Dementia Strategy, DH 2009</li> <li>Prime Minister's Challenge on Dementia: 2020, DH, 2015</li> </ul>	https://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf?res=true  https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategyhttps://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020		
<ul> <li>Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset, NICE, 2015</li> </ul>	https://www.nice.org.uk/guidance/ng16		

#### Appendix 1: The Well Pathway for Dementia<sup>2</sup>

Dementia Pathway. (6) BPSD - Behavioural and Psychological Symptoms of dementia

#### NHS ENGLAND TRANSFORMATION FRAMEWORK - THE WELL PATHWAY FOR DEMENTIA **DIAGNOSING WELL** SUPPORTING WELL LIVING WELL DYING WELL PREVENTING WELL Timely accurate People living with Risk of people Access to safe high People with dementia developing diagnosis, care can live normally in dementia die with quality health & social dementia is plan, and review dignity in the place safe and accepting care for people with minimised within first year dementia and carers communities of their choosing "I was diagnosed in a timely "I am treated with dignity & I know that those around me respect" "I am confident my end of life and looking after me are way" "I was given information about supported" wishes will be respected" reducing my personal risk of "I am able to make decisions "I get treatment and support, getting dementia" and know what to do to help which are best for my "I feel included as part of "I can expect a good death' myself and who else can help' dementia and my life" society' STANDARDS: STANDARDS: STANDARDS: STANDARDS: STANDARDS: Choice(2)(3)(4), BPSD(6)(2) Diagnosis(1)(5) Integrated Services(1)(3)(5) Prevention(1) Palliative care and pain(1)(2) Risk Reduction(5) Memory Assessment(1)(2) Liaison(2), Advocates(3) Supporting Carers<sup>(2)(4)(5)</sup> End of Life(4) Health Information(4) Concerns Discussed(3) Housina (3) Carers Respite(2), Preferred Place of Death(5) Co-ordinated Care(1)(5) Supporting research(5) Investigation (4) Hospital Treatments(4) Provide Information(4) Technology<sup>(5)</sup> Promote independence(1)(4) Integrated & Advanced Health & Social Services (5) Relationships(3), Leisure(3) Care Planning (1)(2)(3)(5) Hard to Reach Groups(3)(5) Safe Communities (3)(5)

#### RESEARCHING WELL

- · Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

#### INTEGRATING WELL

Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health
England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD)

#### COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

#### TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- · Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

#### MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

<sup>&</sup>lt;sup>2</sup> https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf , online, accessed: 05.07.17

# Cambridgeshire & Peterborough All Age Dementia Strategic Plan 2018 - 2023

Dementia: Everybody's Business: better outcomes for people living with dementia and their carers

**Executive Summary** 

Cambridgeshire and Peterborough Older People's Mental Health Delivery Board January 2018

Cambridgeshire and Peterborough CCG, Cambridgeshire County Council and Peterborough City Council, Cambridgeshire and Peterborough NHS Foundation Trust, Cambridgeshire University Hospitals NHS Foundation Trust, North West Anglia NHS Foundation Trust, The Alzheimer's Organization, The Carers' Trust, Care Network

# **EXECUTIVE SUMMARY**

Improving experience and outcomes for people living with dementia and their carers is a national priority. The Cambridgeshire and Peterborough Sustainability and Transformation Partnership (STP) which brings together leaders of health and social care organisations across the health and social care system to ensure that services are effective and efficient, has identified improving outcomes and experience for people living with dementia and their carers as a key priority for 2018/19 and beyond.

This Strategic Plan has been developed by the Older People's Mental Health (OPMH) Delivery Board to deliver that improvement. The Plan aims to address the needs of people of all ages living with dementia<sup>3</sup> and mild cognitive impairment<sup>4</sup> and their carers living in Cambridgeshire and Peterborough. It also aims to prevent or delay the onset of dementia and to identify ways that individuals and communities can be supported to improve the quality of life of people living with dementia as they go about their lives.

The Plan relates specifically to dementia. A definition of dementia has been agreed by those involved in dementia across the Cambridgeshire and Peterborough health and social care system:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.<sup>5</sup>

It can be caused by a number of progressive neurodegenerative diseases, including Alzheimer's disease, frontotemporal dementia, vascular disease, Parkinson's disease and Huntington's disease. Not all cognitive impairment is due to dementia.

Mild cognitive impairment (MCI) is also included within the scope of the Strategic Plan because, whilst people with MCI are at higher risk of developing dementia, it is not possible or appropriate to make a positive diagnosis of dementia at the point when MCI is identified. It is important that people with MCI are identified, in particular to distinguish them so that they are not misdiagnosed with dementia. To do so would give a large number of people a diagnosis of a progressive terminal neurodegenerative disease which they do not have, and which may never develop. This would be inappropriate and unhelpful, causing unnecessary distress for individuals and their families. MCI can be defined as:

A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities<sup>6</sup>.

<sup>&</sup>lt;sup>3</sup> A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.<sup>3</sup>

<sup>&</sup>lt;sup>4</sup> A condition where an individual has cognitive deficits beyond those expected for their age and education, but which are not significant enough to interfere with their daily activities<sup>4</sup>.

<sup>&</sup>lt;sup>5</sup> The ICD-10 Classification of Mental and behavioural Disorders, clinical descriptions and diagnostic guidelines' World health organisation 1992 ISBN 92 4 154422 <sup>6</sup> Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E (1999). "Mild cognitive impairment: clinical characterization and outcome". Arch. Neurol. 56 (3): 303–8.

Services for people with cognitive impairment that results from brain damage of a non-progressive nature are not included within the scope of the Strategic Plan because responsibility for commissioning and provision lies with a variety of organisations, groups and individuals beyond the boundaries of dementia commissioning and provision. However, it is essential that it is noted that there are gaps in services for people with non-progressive cognitive impairment. This issue has been drawn to the attention of STP leaders and commissioners by the Older People's Mental Health (OPMH) Delivery Board as part of its work to develop the Strategic Plan. Members of the Delivery Board are happy to provide assistance to those addressing these needs.

The case for prioritising the care and support of people living with dementia and their carers in Cambridgeshire and Peterborough is strong:

- Dementia affects the older population in significant numbers an estimated 670,000 people in England<sup>7</sup> and 8,600<sup>8</sup> in Cambridgeshire and Peterborough.
- There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke<sup>9</sup>.
- An estimated 25% of hospital beds are occupied by people with dementia.
- Hospital stays of people with dementia are approximately 1 week longer than average<sup>10</sup>.
- 75% of people living in care homes have dementia<sup>11</sup>.
- Dementia is the leading cause of death for women<sup>12</sup>.
- It is estimated that the number of people living with dementia in Cambridgeshire and Peterborough will increase from 8,600 to 16,110 (7,510/86%) between 2016 and 2031. Action therefore needs to be taken to:
  - i) Do everything possible to prevent and delay the onset of dementia to slow the growth in numbers of people living with dementia.
  - ii) Ensure that the best use of the resources available is in order to manage the resulting increase in demand.
- Improving awareness and understanding of dementia will enable people living with dementia and their carers to live more comfortably with their families and communities.
- If dementia is diagnosed early in its course, appropriate support can be provided in the present, and
  as the disease progresses, reducing the incidence of avoidable crises and interventions, improving
  experience and outcomes whilst also releasing resources for investment in other health and social
  care interventions.
- Across Cambridgeshire and Peterborough there is a desire to improve experience and outcomes for people who access any health and social care services.

The main thrust of national strategy is to ensure that people living with dementia are supported to live at home with their families for as long as possible. Early diagnosis and intervention including access to information, advice and guidance, advance care planning that is personalised, timely access to specialist assessment and treatment, and effective support for carers are key

<sup>&</sup>lt;sup>7</sup> The Prime Minister's Challenge on Dementia, DH, 2020

<sup>8</sup> Public Health England, 2016

<sup>&</sup>lt;sup>9</sup> Commissioning for Value: Mental health and dementia pack, Public Health England, January 2017

 $<sup>^{10}</sup>$  The Prime Minister's Challenge on Dementia, DH, 2020//5 Year Forward View, DH, 2015

<sup>&</sup>lt;sup>11</sup> The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

 $<sup>^{\</sup>rm 12}$  The Prime Minister's Challenge on Dementia, DH, 2020/5 Year Forward View, DH, 2015

components of the strategy. Promoting better awareness and understanding of dementia amongst communities and businesses is essential if people living with dementia and their carers are to live and participate comfortably in their communities. Based on the work of the Alzheimer's Society, national strategy includes programmes to increase awareness through the development of dementia friendly communities and environments. There is much that can be done to prevent dementia by tackling key risk factors such as smoking, excess weight and physical inactivity. Overall, the aim is:

To enable people living with dementia to live independently for longer and to enjoy being part of their community<sup>13</sup> and to keep them healthier for longer and out of hospital<sup>14</sup>.

A vision for people living with dementia and their carers in Cambridgeshire and Peterborough has been agreed:

We will work hard to prevent people in Cambridgeshire and Peterborough from acquiring dementia and ensure that those living with and affected by dementia receive compassionate, expert care and support, that is right for them to live positive and fulfilling lives .... we will support and empower them to take part in, and contribute to, the families and communities in which they live and work<sup>15</sup>.

Gaps and improvements that can be made to all of the above in Cambridgeshire and Peterborough have been identified through the work to develop the Strategic Plan. However, the biggest gaps identified are in:

- Early intervention and support including information, advice and guidance and advance care planning primarily provided by the voluntary sector.
- The infrastructure required to support the development of dementia friendly communities and environments primarily provided by the voluntary sector.
- Support to maximise quality of life whilst living with dementia for individuals living with dementia and their carers.
- Capacity to support people intensively to remain at home at times of crisis and/or enhanced need (service provided by Dementia Intensive Support Team (DIST)).
- Psychological treatment for people following diagnosis and in specialist dementia inpatient care.
- The seamlessness and co-ordination of care across both mental and physical health clinicians, teams and organisations.
- Personalised care planning and support.
- Specialist assessment, treatment and support for people diagnosed with early onset dementia<sup>16</sup>.

Addressing these gaps has been prioritised within the Strategic Plan. The Plan describes how the OPMH Delivery Board plans to work with its partners to achieve the vision for dementia using the

<sup>&</sup>lt;sup>13</sup> Dementia Implementation Guide, DH, 2017

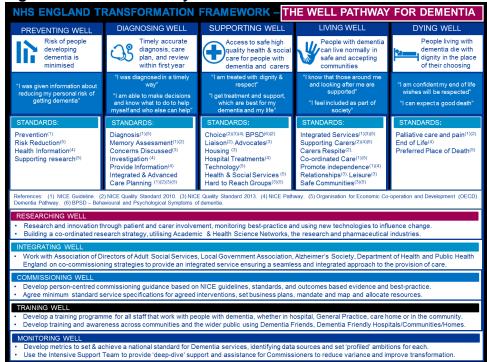
<sup>&</sup>lt;sup>14</sup> The Five Year Forward View Implementation Guide, 2017-19, DH 2017

<sup>15</sup> Adapted from Dementia UK's Strategy

<sup>&</sup>lt;sup>16</sup> This document contains key issues identified within the needs assessment undertaken to inform the Strategic Plan. The detail is contained in 'Early Onset Dementia, Needs Assessment', October 2017.

pillars and cross-cutting themes of the Well Pathway for Dementia which provides a framework for delivery of the national dementia strategy as its basis. (See Figure i below).

Figure i: The Well Pathway for Dementia<sup>17</sup>



The aim is to ensure that delivery of the services under each pillar of the Well Pathway are effective and efficient and developed in line with national and local good practice. To achieve this, action plans to improve outcomes from the services under each of the Pillars and Cross Cutting Themes has been developed. (See Section 3.2). These are summarised in Table 1 below. The Strategic Plan aims to deliver the following outcomes:

- Prevention of the onset of dementia where this is possible.
- People living with dementia are supported to live safely for longer within the community and with their carers.
- Improved accessibility to, and consistency of, assessment, treatment and support for people living with dementia and their carers across Cambridgeshire and Peterborough.
- Increased choice and control for people living with dementia and their carers at all stages
  of the disease.
- Improved outcomes and experience of services for people living with dementia and their carers at all stages of the disease and wherever they live i.e. at home, in care homes and when admitted to hospital..
- Well co-ordinated care that addresses physical and mental health and social care needs in a seamless way.
- Crises and avoidable admission to inpatient dementia services and acute hospitals are reduced.
- Better understanding and awareness of dementia within communities
- Better use of resources/value for money.

 $^{17}\ https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf\ ,\ online,\ accessed:\ 05.07.17$ 

A key objective of the Strategic Plan is to reduce costs where possible, releasing resources for investment in new/improved services and/or for investment in other key areas of need.

Investment, capacity, activity and performance across the health and social care system in dementia diagnosis, assessment, treatment and support is not fully understood. The Plan aims to develop this understanding in order to identify opportunities for improved performance, outcomes and reduced cost in order to enable investment to address gaps in services and support. Improvement will be achieved primarily by ensuring early diagnosing, intervention and effective community based, reducing expenditure on more expensive specialist interventions in line with national guidance for CCGs<sup>18</sup> and Local Authorities on cost effectiveness. Finally, the gap between current investment, improvements required and the increase in capacity necessary to match the likely increase in the numbers of people living with dementia will be identified. All of this will be brought together in a business case to the STP and to Peterborough City Council (PCC) and Cambridgeshire County Council (CCC).

A core data set to monitor quality, outcomes and activity based on the Memory Service National Accreditation Programme (MSNAP) quality standards, the reporting requirements of NHS and social care organisations has been developed and will be refined as part of the work to implement the Strategic Plan. Notwithstanding the need to report on core national and local activity, performance and outcomes, the key driver for the development of these outcomes will be to monitor the things that are of the greatest importance to people living with dementia and their carers.

Delivery of the Strategic Plan constitutes a major programme of work. A high level timeline for delivery of the actions/milestones required 2017 – 2019 has been developed to support delivery (See Figure ii below). An assessment of the risks to delivery of the Strategic Plan has been made with the following risks being identified:

- Risk 1: Insufficient capacity within OPMH commissioning and provider organisations to deliver a complex programme of work with the detailed level of analysis necessary to achieve the outcomes required
- Risk 2: Insufficient resources available across the system to support the analysis required
- Risk 3: Lack of resources to support external facilitation for the development of the care pathway

At the time of completion of the Strategic Plan (January 2018), these are rated amber with mitigating actions in place to address them.

 $<sup>^{\</sup>rm 18}$  Next Steps on the NHS Five Year Forward View, DH, 2017

Table i: Summary of the Cambridgeshire and Peterborough Dementia Well Pathway Action Plans

Strategic Plan: Section	Pillar/Cross Cutting Theme and Standard	Key Objective 1	Key Objective 2	Key Objective 3	Key Objective 4
3.2.1	Preventing Well  The risk of people developing dementia is minimised: "I was given information about my personal risk of getting dementia"	To build strategy to include evidence-based and equitable primary, secondary and tertiary prevention efforts across the life course.	To incorporate dementia risk reduction into current long-term disease approaches and unique messaging.		
3.2.2	Diagnosing Well  Timely accurate diagnosis, care plan, and review within first year. "I am diagnosed in a timely way. I am able to make decisions and know what to do to help myself and who else can help".	To increase the dementia diagnosis rate.	To develop a robust pathway that meets the standards within NICE guidelines and MSNAP with protocols agreed between the Memory Assessment Service, GPs, older people's services and the voluntary sector, including protocols that ensure that advance planning is established consistently across Cambridgeshire and Peterborough (includes assessing the feasibility of commissioning a Memory Assessment Service that meets the standards required to achieve MSNAP accreditation).		
3.2.3	Supporting Well  Access to safe high quality health and social care for people with dementia and their carers. "I am treated with dignity and respect. I get treatment and support which are best for my dementia and my life."	To develop a robust dementia pathway within which there is an action plan that supports improvement/achievement of the standards within NICE guidelines and MSNAP consistently across Cambridgeshire and Peterborough that relate to Living Well (includes assessing the feasibility of commissioning	To work with Acute providers to develop a plan for ongoing improvement in the quality of care for people with dementia when in hospital.	To improve awareness of and access to dementia care for hard to reach groups	To ensure that the quality of care of people living with dementia in care homes meets the Care Quality Commission requirements and best practice.

Strategic Plan: Section	Pillar/Cross Cutting Theme and Standard	Key Objective 1	Key Objective 2	Key Objective 3	Key Objective 4
		a Memory Assessment Service that meets the standards contained within NICE guidelines and MSNAP; as a minimum, standards relating to advance planning must be achieved).			
3.2.4	Living Well  People with dementia can live normally in safe and accepting communities. "I know that those around me and looking after me are supported. I feel included as part of society."	To ensure geographical consistency in relation to Dementia Friendly Communities and Dementia Friendly Environments across Cambridgeshire and Peterborough	To ensure that people living with dementia have access to community based support that is robust and consistent across Cambridgeshire and Peterborough	To establish a robust infrastructure of support for carers that is consistent across Cambridgeshire and Peterborough	
3.2.5	Dying Well  People living with dementia die with dignity in the place of their choosing. "I am confident my end of life wishes will be respected. I can expect a good death."	To improve the quality of care and support and outcomes at end of life for people living with dementia and their carers			
3.2.6	Early Onset Dementia	To ensure that people living with early onset dementia and their carers have access to robust assessment, treatment and support.			
3.2.7	Researching Well	To ensure that every patient with a diagnosis of dementia is given the opportunity to participate in dementia research.	To evaluate the impact of the Dementia Strategic Plan		

Strategic Plan: Section	Pillar/Cross Cutting Theme and Standard	Key Objective 1	Key Objective 2	Key Objective 3	Key Objective 4
3.2.8	Integrating Well	To ensure that care is seamless, addressing physical and mental health and social care needs in an holistic and cost effective way			
3.2.9	Commissioning Well	To improve the commissioning and leadership for health and social care commissioning.	To ensure that best use of resources is made.	To ensure that services are effectively commissioned.	
3.2.10	Training Well	To ensure that staff across the Cambridgeshire and Peterborough health and social care system are involved in and inform the development of and are trained in the operation of the integrated dementia pathway.			
3.2.11	Monitoring Well	To improve understanding of activity, performance and outcomes for people living with dementia and their carers in Cambridgeshire and Peterborough.	To develop a set of indicators of quality that include experience of services and support and outcomes for people living with dementia and their carers related to dementia across the Cambridgeshire and Peterborough health and social care system		

# **Dementia Friendly Communities: Briefing Note**<sup>1920</sup>

A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported.

In a dementia-friendly community people will be aware of and understand dementia, so that people with dementia can continue to live in the way they want to and in the community they choose.

### Why are dementia-friendly communities important?

Dementia-friendly communities are vital in helping people live well with dementia and remain a part of their community.

Too many people affected by dementia feel society fails to understand the condition they live with, its impact or how to interact with them. That's why people with dementia sometimes feel they need to withdraw from their community as the condition progresses.

In fact, over a third of people with dementia told us that they have felt lonely recently. More than a quarter of carers we surveyed said they felt 'cut off from society' too.

This isn't okay. People affected by dementia still have an incredible amount to offer to their community. If appropriately supported, they can continue to play an active and valuable role even years after diagnosis.

#### Who can help make their community dementia-friendly?

Everyone. From governments and local shops, to book clubs and churches, we all have a part to play in creating communities where people with dementia feel active, engaged and valued.

People affected by dementia have the most important role in any dementia-friendly community. By sharing their experiences and connecting with others, they ensure that communities keep the needs of people affected by dementia at the heart of everything they do.

<sup>&</sup>lt;sup>19</sup> https://www.alzheimers.org.uk/info/20115/making\_your\_community\_more\_dementia-friendly/341/how\_to\_become\_a\_recognised\_dementia-friendly\_community, accessed: 04.04.18

<sup>&</sup>lt;sup>20</sup> https://www.alzheimers.org.uk/info/20115/making\_your\_community\_more\_dementia-friendly/337/what\_is\_a\_dementia-friendly\_community, accessed: 04.04.18

# How to become a recognised dementia-friendly community

Our Dementia Friendly Communities recognition scheme celebrates the work of dementiafriendly communities across the country.

Many communities have received formal recognition for being dementia-friendly<sup>21</sup>.

If you'd like to get involved, here's what you'll need to do.

#### Step one: Get a group together

Dementia-friendly communities work best when they're led by local people. Join with other interested people locally to form your 'steering group.' Some communities choose to form a Local Dementia Action Alliance.

#### Step two: Agree a leader

This person will oversee the group and make sure the community is making progress. They aren't expected to do everything themselves, but can coordinate the group's activity.

They'll also be Alzheimer's Society's key contact for the community, receiving support from our Dementia Friendly Communities Officers.

#### **Step three: Raise awareness**

People in your community need to understand dementia before they can take dementia-friendly actions. There are lots of ways you can raise awareness, such as:

- Becoming Dementia Friends
- Accessing Alzheimer's Society training
- Running lessons in schools

#### Step four: Involve people affected by dementia

Before you can start taking action, you'll need to hear the experiences of people affected by dementia where you live. You could do this by:

- Inviting people with dementia to join your group
- Visiting services, such as Memory Cafés
- Hosting a community event

#### Step five: Tell the world

You're doing something amazing, so make sure your community knows about it. It's a great way to get more people on board and to celebrate your successes.

<sup>&</sup>lt;sup>21</sup> There are currently 328 DFCs in England and Wales

You could consider:

- Sharing news on social media
- Writing a press release for your local newspaper
- Taking part in community events and fayres

#### Step six: Identify areas for local action

Taking action is the most important part of any dementia-friendly community. You don't have to tackle everything at once. Speaking to local people with dementia can help you identify what your priorities should be.

We suggest using the <u>BSI PAS1365</u>: A code of practice for dementia-friendly communities to help you. This guide offers eight key areas for action and some suggested actions for communities:

- arts, culture, leisure and recreation
- businesses and shops
- children, young people and students
- community, voluntary, faith groups and organisations
- emergency services
- health and social care
- housing
- transport

#### **Step seven: Monitor your progress**

Now you've got the ball rolling, you'll need to plan how you'll measure your progress. Many communities host regular meetings to share their updates on their actions, but you can choose what's right for you.

As a recognised community, we'll want to know how you're getting on 6 months after your application. You'll then keep us up-to-date with a yearly assessment. However you can update your progress as much as you want over the year.

#### Step eight: Apply for recognition

Your community is ready to apply to our Dementia Friendly Communities recognition scheme. We want to hear how you've achieved the steps above and, more importantly, what your future plans are. Apply now:

- Communities in England and Wales
- Communities in Northern Ireland

# Need more help?

- Read more about the <u>recognition process and our criteria online.</u>
- Email our Dementia Friendly Communities team at <a href="mailto:DementiaFriendlyCommunities@alzheimers.org.uk">DementiaFriendlyCommunities@alzheimers.org.uk</a>

#### Appendix 4

# **Becoming a Dementia Friendly Organisation: Briefing Note**<sup>22</sup>

## Three ways your organisation can help people affected by dementia

- 1. Make your customer service more dementia-friendly
- 2. Improve the physical environment
- 3. Provide practical support and deal with difficult situations effectively

#### 1. Make your customer service more dementia-friendly

Good customer service can be key to helping somebody to live well with dementia. Here are a few tips to help your organisation deliver a more dementia-friendly service.

#### Offering understanding and reassurance

Someone with dementia may find it difficult to process information. They may feel disorientated and struggle to answer simple questions or take in what you are saying. In the later stages, they may be confused about what they are doing and make mistakes.

You can assist a person with dementia by:

- Allowing the person to take their time.
- Understanding how they might be feeling.
- Being friendly and smiley.
- Considering their feelings and responding to the emotions they are expressing.
- Asking direct questions. For example, 'Is there someone you would like me to call?' rather than 'What would you like me to do?'

#### **Communicating clearly**

A person with dementia may not understand what you are doing or remember what you have said. Treat them respectfully by addressing them in conversation, as well as any partner or carer they may be with.

The below guidance is vital when communicating with someone who is experiencing difficulties associated with dementia.

#### Body language and physical contact

https://www.alzheimers.org.uk/info/20116/making organisations more dementiafriendly/355/three ways your organisation can help people affected by dementia, accessed, 04.04.18

- Make eye contact.
- Make sure that your body language and facial expressions match what you are saying.
- Never stand too close or stand over someone to communicate.
- Do not cover your mouth. The person should be able to see your face clearly.

#### **Talking**

- Speak clearly and calmly.
- Use short, simple sentences.
- Speak at a slightly slower pace.
- Avoid speaking sharply or raising your voice.
- Don't talk about people with dementia as if they are not there or talk to them as you would to a young child.

#### Listening

- Listen carefully to what the person is saying, and give them plenty of encouragement.
- If you haven't understood fully, tell the person what you have understood and check with them to see if you are right.
- If possible, use visual clues write your message down if the person is able to read and use objects or pictures to help the person understand. For example, show the person photographs of meals they can choose from.

For more information, please see page 20 of our <u>Dementia-friendly business guide</u>, which gives detailed advice on how you can help people affected by dementia.

#### 2. Improve the physical environment

Places that are noisy, busy or that have sounds that might be distracting can make people with dementia uneasy. They may not recognise colours, faces or objects or have problems with spatial awareness.

- Objects that are shiny, patterned or reflective can cause people with dementia to mistake what they are seeing.
- Features such as lighting, mirrors, shadows, steps and patterned walls and floors might cause problems for some people with dementia.
- Be aware of environments that are noisy or dark, and if you can, provide a quiet place where it is easier to offer one-to-one assistance.
- What is obvious to you may not be so to them.

For more information, please see our Physical environments checklist on page 81 of our Dementia-friendly business guide.

#### 3. Provide practical support and deal with difficult situations effectively

Whatever sector your organisation is in, you should be providing appropriate practical support for people affected by dementia. A small action may make a significant difference to someone and help them to continue living safely and comfortably in the community.

The following actions are just some of the steps you can take.

- If someone can't remember how to do something, offer to show them how to do it. As much as possible, do the task with them and not for them. Break down tasks into smaller tasks, supporting them along the way.
- Be patient, especially if you are asked to repeat yourself.
- If someone cannot remember significant information, for example their address or PIN, make sure you are aware of your organisation's alternative procedures that will help them access the service or information they require (E.g. Being able to sign for purchases). If your organisation doesn't have these processes in place perhaps you could suggest developing them (E.g. A 'no hurry check-out').