

HOPSC/01/18

Committee Health Overview Policy and Scrutiny

Date 7 February 2018

Purpose

To provide a background briefing to members of HOSC on the progress of the Greater Essex *Let's Talk Dementia* Strategy

Background

In October 2017 Essex partners (covering the local authorities and CCGs across Essex, Southend and Thurrock) launched the Greater Essex dementia strategy.

It sets out a vision:

People living with dementia are recognised as unique individuals who are actively shaping their lives and their care whilst being able to remain as physically and emotionally healthy for as long as possible.

“Dementia” is a term that covers a range of symptoms that result from damage to the brain that can affect memory, attention, communication, problem-solving and behaviour. Every individual’s “dementia journey” is very different.

Dementia has become one of the most important health and care issues facing the world. In the UK it is estimated that 850,000 people have Dementia. Without any change to risk factors, this is forecast to increase to over 1 million by 2025. People are now more likely to die from Dementia related conditions than they are from heart disease.

There are around seven million carers in the UK – that is one in ten people. Of all the UK’s carers, 11% care for people with dementia; these unpaid carers supporting someone with dementia save the economy £11 billion a year.

National Picture

The 2010 Prime Minister’s Challenge for Dementia sets out a national aspiration to be the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and to be the best place in the world to undertake research into dementia and other neurodegenerative diseases.

NHS England, in response to the above challenge, has set CCGs a target for two thirds of people (66.7%) with dementia to be formally diagnosed. Since 2012, the NHS has been seeking to ensure that patients living with dementia are given a formal diagnosis so they can receive appropriate care and support. ECC, through the partnership board, is supporting CCGs to increase their diagnosis rates.

Local Picture

In Essex alone, 18,970 people currently have a diagnosis of Dementia, and this is projected to increase by 34% in the next 10 years. The estimate is that by 2039 there will be an 37,140 people with dementia in Essex, a 96% increase

Currently, 10% of total Adult Social Care spend is on dementia diagnosis (which includes primary and secondary records of dementia). Given prevalence trends the expectation is that the total spend will increase significantly going forward.

Approach – Let's Talk Dementia

Dementia is progressive and currently there is no cure. The condition not only impacts on the person diagnosed but their family, friends and wider networks.

Extensive engagement, research and analysis was carried out to better understand the challenges people face, and the subsequent pressures on the system as a result of these challenges. The findings showed that support for people with dementia is fragmented; people often get lost trying to navigate an intricate web of information and services and as a result end up in crisis.

Equally people living with dementia and the wider system identified opportunities for change and innovation; to enable people living with dementia to live a life they want to live, in the community for as long as possible. We developed the following vision:

Our vision for the future is one in which: People living with dementia are recognised as unique individuals who are actively shaping their lives and their care whilst being able to remain as physically and emotionally healthy for as long as possible.

To achieve this vision there was system wide recognition that partners need to collaborate, co-produce and integrate, not only with each other but the voluntary sector, local communities and the wider Greater Essex network. This is why Essex County Council, Southend Borough Council, Thurrock Council and all Essex based CCGs signed up to Let's Talk Dementia. (Appendix 1 – Let's Talk Dementia Strategy).

The earlier discovery work identified multiple challenges across the system for people living with dementia. It was recognised that to really transform the approach to how we support people living with dementia, we needed to look at these challenges as a whole and not in isolation. As a result nine priority areas were mapped as being central to the experience of dementia:

- Prevention
- Finding Information and Advice
- Diagnosis and Support
- Living well with Dementia in the community
- Supporting Carers
- Reducing the risk of crisis
- Living well in long term care
- End of Life
- A Knowledgeable and Skilled Workforce

Let's Talk Dementia Overview

In October 2017 the partnership formally launched the Dementia strategy with an event held for 150 people from across the Dementia system. Attendees included professionals, people living with Dementia, their families and carers as well as providers offering support. The keynote speech was delivered by Professor Alistair Burns, National Clinical Director for Dementia and Older Peoples' Mental Health, NHS England.

Let's Talk Dementia sets out an ambition to improve the lives of people living with dementia. The four key changes from this strategy will be:

1. **Integrated approach to dementia in Essex** – The strategy will lead to partners working together to approach the challenge of dementia collectively, which will not only ensure a better experience for people living with dementia, but avoid duplication across organisations and ensure a far more effective use of resources
2. **Family Navigation, Information and Support** – providing more co-ordinated access to information and support that enables people to adapt to a life with dementia will ensure individuals and families have the knowledge, confidence and support networks to live independently.
3. **Community programme** – strengthening the response of the entire community to dementia by developing the entire community - including retailers and service providers – to ensure that their businesses and services are inclusive to people living with the condition; supporting people to remain as physically and emotionally active for as long as possible.
4. **Market development** – by working together with partners across the Essex economy, this strategy aims to raise awareness of dementia and challenge the stigma associated with the condition. The development of skilled and competent workforce across the entire economy of Essex with awareness and understanding of dementia strives to change how care is delivered to people living with the condition, and in turn improve the quality of delivery and subsequent capacity across the system.

Progress on implementation

Integration and joint working

To implement Let's Talk Dementia an Implementation Forum has been set up that brings together lead representatives across the health and social care network and monitors how they are collectively implementing the priorities set out within it.

One of the challenges has been engagement in this board – some CCGs, at an operational level, have more of a focus on Dementia than others, despite signing up to Let's Talk Dementia Strategy.

Although the 9 priorities that were developed attempted to make the challenge of Dementia more manageable, it has been decided in this board that more progress will be made if there is a focus on 3 of these initially. The Three areas of focus the partnership will concentration on until autumn 2018 are:

- Finding Information and Advice
- Diagnosis and Support
- Living well with Dementia in the community

➤ Information and Guidance (IAG)

The current programme of activity is focused on understanding what information is currently available to people in different parts of Essex, where information is stored and who takes the role of providing/updating information that is available. As with other elements of the Dementia service the offer is inconsistent across Essex. A piece of work to understand the sorts of information people need is currently being scoped, to ensure the right information is available to them in the right place.

➤ Diagnosis and Support

As of 31st December 2017 only one of the CCGs in Essex is meeting the national target of 66.7% diagnosis rate:

- 60.6% Mid Essex CCG
- 68.9% West Essex CCG
- 63.9% South West Essex CCG
- 61.3% South East Essex CCG
- 56.9% North East Essex CCG

There are significant plans in place to address this deficit (additional information is required if needed), through this years IBCF.

Family Navigation, Information and Support

➤ Community Dementia Support Services contract

Alongside the implementation of the Let's Talk Dementia Strategy, Essex County Council has recently gone out to tender for Community Dementia Support. Using insight from the extensive discovery phase of the programme, key partners collaborative designed a new approach to how we support a person, and or family, adapt to a life with dementia. The new approach is outcomes focused, and is built around navigating the system for people living with dementia, their families and carers. The two elements of this new model are; family, information, navigation and support and community support.

➤ Community programme

The community element of the Dementia programme is one of its great successes and is made up of the following:

Pan Essex Dementia Action Alliances (DAA) and Dementia Friendly Network

The Pan Essex DAA is part of a National programme of alliances for organisations across England to connect, share best practise and take action on Dementia. The Pan Essex DAA was launched on the 1st Essex Dementia Day in 2016 and now has representatives from over 65 members from across various sectors (Police, Fire, Ambulance, NHS, Public Health England, Retail, Leisure, Housing, Transport, Charities etc.). This group aims to support Local DAAs (we are the first county to have a DAAs in every locality in Essex) to raise awareness and reduce stigma, promote a community wide response and encourage resilient communities and to action change.

Dementia Ambassadors Programme

Working in partnership with This Girl Can campaign, Essex County Council, Active Essex and Dementia Adventure to want to challenge the stigma associated with dementia and support more people living with the condition to be active, and continue engage with the outdoor environment. The ambassadors sit within a 3 tier programme which focuses on Dementia friends, Dementia champions and the Ambassadors; our ambassadors will help raise awareness, influence changes and create opportunities in local communities, to inspire women, living with dementia in Essex to take part in physical activity and in doing so help breakdown the stigma associated with dementia and the primary barrier to why women don't take part in sport and physical activity.

Challenge Prize

Following on from early discussions with the Leader of the Council, a challenge prize has been developed to address the issue of Dementia. This work has been informed by engagement with a range of experts on the issue of dementia including those living with a diagnosis, carers and those involved in the commissioning and delivery of Dementia services. The opportunity to apply ends in April 2018. The Challenge Statement is:

We are looking for ambitious and innovative products, technologies and services that enable people living with Dementia to remain connected to the people and places around them and to maintain their identity. Ideas should recognise that everybody is an individual with unique past experiences, interests and abilities. We are particularly interested in solutions that will work now and for future generations, incorporating technology as part of everyday living.

Travel Task Group

The Pan Essex DAA identified Travel as a key challenge faced by people living with Dementia, their families and carers. The Team have recently completed a survey to understand this further and are currently reviewing the findings to inform some additional activity in this area.

Market development

Multiple schemes have been developed across Essex to improve the quality of care for people living with dementia. These schemes are funded by the Improved Better Care Fund and therefore jointly agreed across health and social care; including an

extensive quality improvement programme that includes a rollout of the Virtual Dementia Tour to Residential and Nursing Home Providers.

Conclusion

Dementia is one of the biggest challenges facing Essex today and the Dementia programme is well positioned to ensure there is support available to enable people to live well and improve outcomes. One of the key changes of the strategy is to integrate and develop joint working across the Greater Essex footprint. This will not only create efficiencies, ensure we have a sustainable offer but equally improve the lives of people living with dementia and enable them to live independently, as part of their community for as long as possible.