SHROPSHIRE HEALTH AND WELLBEING BOARD

Meeting Date: 11th November 2021

Paper title: Dementia vision and new model of care

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1. Summary

1.1 Due to the gradual nature of dementia, the mild early-stage symptoms and the low diagnosis rate, it is difficult to know the exact number of people living with the condition. Several studies have been carried out to determine the prevalence of dementia among particular age groups, and these are used to estimate the total numbers of people living with dementia in the UK. It is estimated that across Shropshire Telford and Wrekin there could be over 7000 people living with dementia

1.2 The aim of this project is change service delivery so patients and carers benefit from a more personalised journey which most suits their individual needs. We will do this by understanding the needs of our local population who are living with dementia (or caring for someone who has dementia) and by working in co-production we will develop a vision and a revised service model.

1.3 During the last six months a task and finish group was set up and have met several times via zoom to develop a 'Dementia Vision' for Shropshire Telford and Wrekin. This group is led by a local patient who is living with dementia, who is involved in many dementia groups across the County and has an incredibly good insight to what improvements other people living with dementia and their carers would like and benefit from. The group also is attended by Healthwatch, the Local Authorities, 3rd Sector organisations other people living with dementia and their carers.

1.4 The group has co - produced a document a vision statement and key principles for the new model of support.

'People living with dementia and their unpaid carers are enabled to live the lives that they choose, that enhance and preserve their wellbeing'

1.5 It is proposed that the new revised model will commence delivery by April 2022 with a two year implementation to fully embed the programme. A steering group with people living with dementia and their carers will co-produce an implementation plan and oversee its delivery.

2. Recommendations

2.1 We are asking the Board to:-

- Note the key activities to date and comment on this programme of work and the revised model

3. Report

3.1 Introduction

3.1.1 The purpose of this report is to provide details and to give sight to members of the new revised Dementia model that has been co–produced and co-designed with people living with Dementia and their carer's. It is also an opportunity to gain approval from the Board in relation to this new revised model of care.

3.2 Background

3.2.1 There are currently 850,000 people with dementia in the UK, more than ever before, and this number is projected to increase. The number of people with dementia is increasing because people are living longer. It is estimated that by 2025, the number of people with dementia in the UK will be more than 1 million. Locally we have 4479 patients on the Dementia Register above the age of 65 across Shropshire Telford and Wrekin.

3.2.2 Due to the gradual nature of dementia, the mild early-stage symptoms and the low diagnosis rate, it is difficult to know the exact number of people living with the condition. Several studies have been carried out to determine the prevalence of dementia among particular age groups, and these are used to estimate the total numbers of people living with dementia in the UK. It is estimated that across Shropshire Telford and Wrekin there could be over 7000 people living with dementia

3.2.3 Although there is no cure for dementia at the moment, an early diagnosis means its progress can be slowed down in some cases, so the person may be able to maintain their mental function for longer. A diagnosis helps people with dementia get the right treatment and support. It can also help them, and the people close to them, to prepare for the future.

3.3 The Project:

3.3.1The aim of this project is change service delivery so patients and carers benefit from a more personalised journey which most suits their individual needs. We will do this by understanding the needs of our local population who are living with dementia (or caring for someone who has dementia) and by working in co-production we will develop a vision and a revised service model.

3.4 Evidence for change

3.4.1 Following the publication of the NHS Long Term Plan in 2019, NHS England asked all local Healthwatch's to give people in their community the opportunity to have their say on how the national plan is delivered locally, so that their views can feed into the development of local NHS plans.

3.4.2 Making care better for people with Mental Health and dementia is a key priority in the NHS Long Term Plan. In the Shropshire, Telford & Wrekin STP area, Healthwatch Shropshire and Healthwatch Telford & Wrekin have worked together to complete this work.

3.4.3 A number of Public engagement activities were held between March – May 2019 and a total of 16 focus groups were ran across Shropshire, Telford & Wrekin Healthwatch.

3.4.4 Full details of the report can be found using the link below:-

https://www.healthwatchshropshire.co.uk/report/2019-07-15/what-would-you-do-nhs-long-term-plan-shropshire-telford-wrekin-report

3.4.5 In addition the health economy steering group, which is co – chaired by a person living with dementia and has service users and carers as part of the group, has also highlighted some of the gaps in services and support.

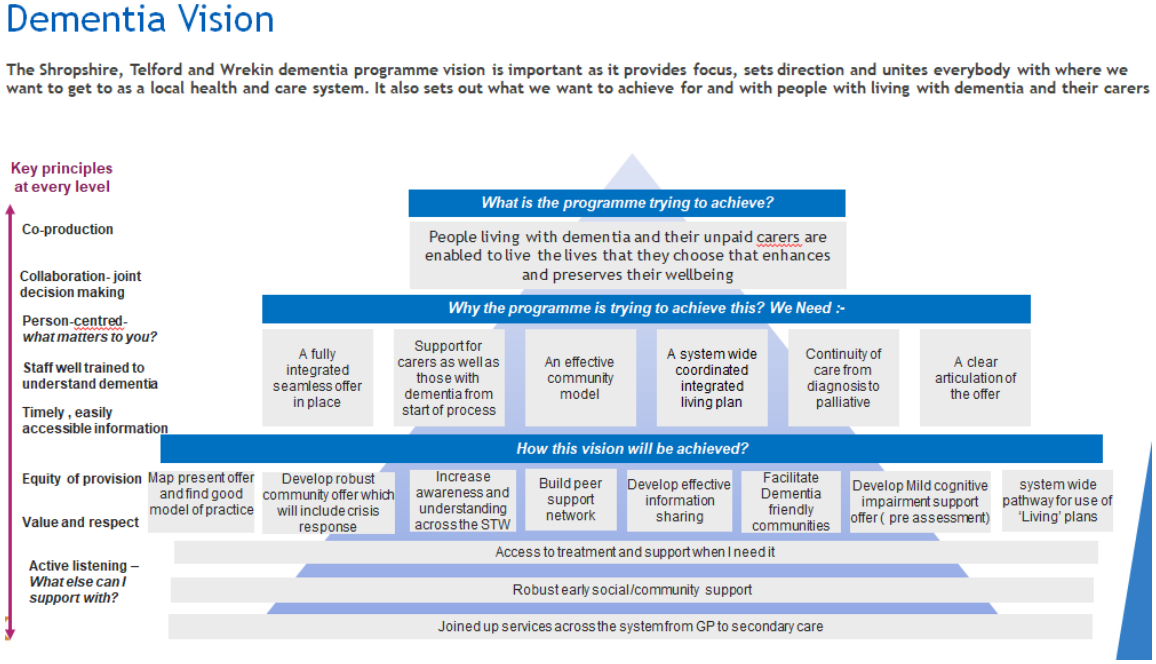
3.5 Project Activities

3.5.1 During the last six months a task and finish group was set up and have met several times via zoom to develop a 'Dementia Vision' for Shropshire Telford and Wrekin. This group is led by a local patient who is living with dementia, who is involved in many dementia groups across the County and has an incredibly good insight to what improvements other people living with dementia and their carers would like and benefit from. The group also is attended by Healthwatch, the Local Authorities, 3rd Sector organisations other people living with dementia and their carers.

3.5.2 The group has co - produced a document a vision statement and key principles for the new model of support.

3.6 STW Dementia Vision Summary

People living with dementia and their unpaid carers are enabled to live the lives that they choose, that enhance and preserve their wellbeing



Our Vision for STW is not so much a pathway as a box of services and support which people affected by dementia can dip into and use as and when they need them. There is no single route for the dementia journey; people can decline quickly or slowly, in steps or gradually, and people can improve for a time during the journey. So support and care

services need to be agile and flexible to allow people affected by dementia to receive what they need, as and when they need it.

Key elements of the model:-

3.6.1 General Practice

General Practices are the keystone in this model. We will have General Practices in which all staff understand the diseases that cause dementia, and the realities of living with dementia. General Practices will be Dementia Friendly and provide easy access for those with cognitive difficulties.

3.6.2 Assessment

Following referral to the Assessment Service, assessment will be completed within 4 weeks. The diagnosis will be delivered face to face, in a relaxed, friendly setting, with plenty of time for reflection and discussion. There will be a place provided with tea and coffee where those receiving diagnosis can stop, take it in, and where they can discuss things with a person living with dementia who is suitably trained and willing.
We wish to rename the assessment service, to remove the implication that dementia is just about memory. A new name has not been discussed in detail yet.

3.6.3 Dementia Navigator

This will also be the opportunity to introduce those receiving diagnosis to the role of a Dementia Navigator, and, if possible, to the Navigator in person.

Every person diagnosed will be offered and will meet a Dementia Navigator. This new role will be suitably trained person who takes on supporting those assigned to them. They will:

a) provide local and national information at the right times that is appropriate to each individual;
b) meet or speak to the person living with dementia (and their carer) regularly, or periodically, as the person with dementia wishes;
c) accompany or support in other ways the person with dementia to access professionals, benefits, social activities, work, or whatever else is appropriate;
d) liaise with other professionals in the dementia care system on behalf of the person living with dementia.

3.6.4 Admiral Nurses

An Admiral Nurse service will be provided right across STW, and Admiral Nurses will work within PCN MDT teams.
Admiral Nurses provide psychosocial and practical support for family or friend support ‘groups’ when they are facing difficulties and/or nearing crisis point. They also work integrally with local MDT teams and GPs, and Dementia Navigators, to provide specialised knowledge and experience in dementia.

3.6.5 Peer Support Groups

For many people living with dementia in early to middle stages, peer groups provide the ideal and possibly only support which they need. Therefore Peer Support Groups for People living with dementia and unpaid carers (separately) will be facilitated across STW. This facilitation will be purely to enable meetings to happen and inform people of meetings. Peer Groups will follow the DEEP model where people living with dementia (or carers separately) decide what they want to do, where they want to meet, now they wish to run their group, and everything else. Members of the groups will thereby provide the support and social interaction that almost all highly value.

There will be peer groups in at least every market town or locality across STW. Funding will be found to support access transport for those (many in rural areas) who cannot otherwise attend. Facilitators will organise this.

There may well be groups for different age ranges, i.e. young onset and later onset, but people can attend whichever group suits them.

3.6.6 Annual Dementia Reviews in general practice.

Every person living with a diagnosis of dementia will have an annual review with one or more appropriately qualified/trained staff in their general practice. This will be a meaningful face to face discussion, the aim of which is to ensure that the person with dementia can live as meaningful a life as they can, to plan future care needs and 'advance care planning', and to develop a 'Living and Care Plan' for the person, which will be given to, and 'owned' by, the person with dementia.

The annual review may be comprised of several meetings with different appropriate staff, of necessary.

3.6.7 Information and data sharing

The STW Vision requires information sharing across the whole system in order to provide a joined up system for people. We commit to developing this.

3.6.8 A Crisis Team

This team will provide crisis support in order to keep people at home whenever this is possible, including when that home is a Care or Nursing Home. The prime aim is to avoid moving the person either into hospital or some other care setting.

3.6.9 Care Homes

Recognising that the support provided to residents in care homes is currently unsatisfactory, we will aim to provide the same levels of appropriate care and support whatever the setting in which a person lives. Work is needed to model what this would look like and how it would be provided.

Whether or not a person with dementia pays for their own home or for a place in a care home, they are entitled to receive good, timely and appropriate support and care relating to their living with dementia.

3.6.10 Respite for unpaid carers and social care

Family or friend carers (note that a third of people living with dementia live on their own) need timely and appropriate support in order to preserve their own health and wellbeing.

Respite should be provided quickly when needed, and regularly throughout so that carers can have fixed and expected time off/away. We believe there should be an entitlement to 20 days (equivalent) of respite each year. Many will not need or use this in the early days, but it will become essential at some time later.

3.6.11 Carer Support

Every person providing unpaid care for a person living with dementia should be registered as a care with their general practice. And every contact by GP clinical staff will include an enquiry about their caring role and their health related to that role.

There are a number of important matters to decide, including:

a) in which organisation staff are hosted
b) how Primary Care Networks will organise MDTs to include Admiral Nurses and Dementia Navigators as and when appropriate
c) training required for the Dementia Navigator role
d) training required for first point of contact LA staff to ensure they have correct up to date knowledge
e) training required for general practice staff to upskill re dementia
f) requirements to be accredited as a Dementia Friendly General Practice

3.6.12 Evaluation and Measuring Success

We have started work to produce evaluation methods, and these will focus on both quality and quantity. Self-reporting at the time of contacts will be key to quality.

To view more information around the new model please see below:-

STW Dementia Programme Vision FI

3.7 Impact of the new revised Dementia model

3.7.1 The implementation of the Dementia Vision will improve quality of life and daily functioning for both the diagnosed individual and their carer/family and will deliver person-centred dementia care. It is important to recognise that each individual's experience is unique and therefore each individual requires care which is tailored to their needs.

3.7.2 Ensuring adequate support for people with dementia requires an understanding of the disease and its impact on the person and their family members. The implementation of Admiral Nurses will address this as they are specialised in Dementia and can offer that expertise, especially in the later stages, as people often have complex needs and a high level of dependency, which can present significant challenges. When care practitioners have an understanding of the dementia disease processes, along with the social influences affecting the individual, a person-centred approach can support people with dementia to engage in meaningful activity and motivate and encourage people with dementia to have more independence. In this way, people with dementia can have their personal, social and emotional needs met alongside their medical needs.

3.7.3 There is also a need to recognise the diverse needs of people with dementia, such as those living in remote areas and people from Black, Asian and minority ethnic groups, as well as the dissimilar experiences of people with different types of dementia. The new model will also influence and improve the care and support these cohorts of people receive.

High-quality dementia care depends on care practitioners having the appropriate skills and expertise and the aim of the revised model will certainly influence and hopefully address this.

3.8 Summary of Activities

- Created a task and finish which will now develop into the Steering Group and be expanded to include a more diverse cohort of people
- Mapped current services
- Confirmed financial envelope and funding requirements
- Co-produced a Dementia Vision/Strategy
- Undertaken wider engagement to gain feedback on the Dementia Vision
- Engaged with PCN's around the implementation of Admiral Nurses
- Presented the new model to PCN's
- Liaised with Providers of present services and gained commitment around the delivery of the model as

3.9 Next Steps

3.9.1 The agreed vision has been presented to the following committees:-

- SHIPP & TWIPP
- PCN Network meeting
- Strategic commissioning Committee- CCG internal governance
- Mental Health LDA Programme Board

3.9.2 Expand the steering group which will meet monthly and be responsible for the implementation of the new model.

3.9.3 Agree a new funding pathway for the Admiral Nurses

3.9.4 Develop service specifications and job descriptions

3.9.5 Recruit Admiral Nurses

3.9.6 It is proposed that the new revised model will commence delivery by April 2022 with a two year implementation to fully embed the programme.

3.10 Recommendations

We are asking the Board to:-

- Note the key activities to date and comment on this programme of work and the revised model

3.11 Risk assessment and opportunities appraisal

Please see Appendix 1 to view the Equality Impact Assessment.

4 Financial implications

n/a

5 Climate Change Appraisal

List of Background Papers (This MUST be completed for all reports, but does not include items containing exempt or confidential information)
Cabinet Member (Portfolio Holder) or your organisational lead e.g. Exec lead or Non-Exec/Clinical Lead
Appendices **Appendix 1**    EQIA dementia 20210913 V2.docx