

Date: Thursday, 8 December 2016

Time: 9.00 am

Venue: Council Chamber, Shirehall, Abbey Foregate, Shrewsbury, SY2 6ND

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HEALTH AND WELLBEING BOARD

TO FOLLOW REPORT (S)

8b DRAFT DEMENTIA STRATEGY (25 Mins) (Pages 1 - 38)

- a. Healthwatch Dementia Report – A report is attached. Contact: Jane Randall-Smith, Shropshire Healthwatch Chief Officer (10 minutes).
- b. Draft Dementia Strategy – Peter Downer, Dementia Commissioner (15 minutes) – a report will follow – IS ATTACHED

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**Health and Wellbeing Board
8 December 2016**

DEMENTIA STRATEGY 2017/2020

Responsible Officer

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1. Summary

- 1.1. The dementia journey is distressing for those involved, the costs associated with dementia are significant and age is the biggest risk factor in developing the condition. Shropshire has a rapidly aging population and there is insufficient infrastructure to enable people to *live* with the condition as they otherwise may be able. Failure to pro-actively address this issue will likely result in significant systemic failure demand with an associated drastic systemic increase in disease management costs. This collaboratively produced strategy sets out aims that will help address this situation.

2. Recommendations

It is recommended that the Health and Wellbeing Board endorse this Strategy

REPORT

3. Risk Assessment and Opportunities Appraisal

(NB This will include the following: Risk Management, Human Rights, Equalities, Community, Environmental consequences and other Consultation)

- 3.1. The implications of refraining from taking any pro-active action towards enabling people to live better with dementia will have negative consequences. People with dementia will continue to require higher levels of support than may otherwise be the case, and as demand grows, this will have major ramifications for the health economy. Dementia-driven demand is difficult to detect, present NHS payment and performance monitoring systems collect information on primary reasons for acute care, whilst existing systems within adult social care are not able to identify the numbers of people with dementia absorbing local resources. This means that data can mislead decision makers as to the perceived magnitude of the condition.

4. Financial Implications

- 4.1. There may be some funding issues surrounding the ability to implement some of these aims, although the consequences of refraining from attempting to achieve them are thought to be grave.

5. Background

- 5.1. Dementia is a condition that impacts not only on the person diagnosed, but the people with whom they share their lives. Age, the biggest associated risk factor for people developing the condition, means that for Shropshire, dementia is likely to have a huge impact upon the people living in our county over the coming years. It is a condition that is reported to cost the health economy significantly more than any other illness group with an estimated 53% of that cost being absorbed by family carers. Shropshire has an ageing population; it is thought that by 2031, South Shropshire will be among the three oldest populations across England and Wales. This means that by this time, should current prevalence apply, we will have around 5,900 people over the age of 65 living with the condition within the county. Current prevalence for this age group is around 4,300, there are currently around 3,000 people diagnosed, with a further 80 people below that age of 65 diagnosed with dementia.
- 5.2. A number of innovations to promote a positive lived experience of dementia have been established over recent years, an overview of these can be seen on page 17 of the strategy document. However recent engagement work has shown a paucity of support for people living with dementia during the early stages of the journey. It is thought that this has led to reluctance among primary care physicians to diagnose people with the condition. Having a diagnosis early is thought to be important in enabling people to develop strategies that can promote independence, in effect enabling them to *live* with the condition for longer. This strategy document sets out ways in which we as a county can promote early diagnosis, provide better support post diagnosis, support community based treatment, and promote early discharge for when acute admission cannot be avoided. It is not a complete answer to the issues faced by people living with the condition, although we believe that achieving these aims would represent the correct direction of travel.
- 5.3. If we are able to achieve the following, we are likely to reduce the demand placed upon adult social care relative to prevalence, this will in turn have a positive impact upon NHS spend:
- Diagnose people with dementia earlier.
 - Provide guidance that is person centred to extend the time they are able to *live* with the condition.
 - Support carers better in their caring role.
 - Cultivate communities to enable them to be accessible for people with dementia, growing locally available community-grown support options.

If we are able to do the following we are likely to reduce the demand seen in terms of unplanned admissions for people with dementia:

- Provide community support options that address both physical illness, and the complex behaviours that can emerge as a consequence of being physically unwell for people with dementia.
- Provide an enhanced level of discharge planning for people with dementia admitted to hospital which commences at the point of admission.

6. Additional Information

- 6.1. This document has been produced in collaboration; stakeholder buy-in is assured through the joint ownership that this document represents.

7. Conclusions

- 7.1. This document represents a collaboratively produced solution to a collaboratively identified problem. We (The Health Economy Dementia Steering Group) believe that the direction of travel outlined within these pages is correct and must be endorsed to enable strategy to be put into action.

List of Background Papers (This MUST be completed for all reports, but does not include items containing exempt or confidential information)

DEPARTMENT OF HEALTH. (2009). Living well with dementia: A National Dementia Strategy. *Department of Health*. [Online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf [Accessed 11th October 2016].

DEPARTMENT OF HEALTH. (2012). Prime Minister's Challenge on Dementia – Delivering major improvements in dementia care and research by 2015. *Department of Health*. [Online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf [Accessed 10th October 2016].

DEPARTMENT OF HEALTH. (2015). Prime Minister's challenge on dementia 2020. *Department of Health*. [Online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf [Accessed 11th October 2016].

HEALTH ECONOMICS RESEARCH CENTRE. (2010). Dementia 2010 – The economic burden of dementia and associated research funding in the United Kingdom. *Alzheimer's Research Trust*. [Online] Available at: <http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/Dementia2010Full.pdf> [Accessed 10th October 2016].

Cabinet Member (Portfolio Holder)

Local Member

Appendices

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Dementia Strategy 2017-2020

NHS
Shropshire
Clinical Commissioning Group



A product of collaboration
Page 5

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1 Foreword

This collaboratively-produced Shropshire strategy document has been written for people who: live with dementia, provide support for people with dementia, are affected by dementia; and anyone interested in learning about what we in Shropshire are planning to do to help improve the lived experience of the condition. This aims set out within this document will not take immediate effect; they will be achieved over a three-year period. We must view this as one of many steps towards improving the lives of people with dementia; this will not solve all of the issues, although we are confident we are moving in the right direction.

The term “dementia journey” is currently the preferred way of describing the lived experience of dementia, and is used throughout this work. The language used here is plain and straightforward; it is a document designed to engage and be understood by as many people as possible.

So people reading this can feel confident the information provided is accurate, where possible, the reference to where it has been collected from will be included within the text (enclosed in brackets). The full reference will be given at the end of the document.

We hope that this is not a chore to read, and that it helps you to understand more about what we want the future to look like for people living with dementia within our beautiful county. As far as Shropshire health conditions go, we believe that dementia is a “sleeping giant”... one that has begun to wake up. This is a foe beyond anything we have seen in our county, and we hope that this document gives you some insight as to how we can work together to tackle it.

“People with dementia are our people... they have always been our people... we must not allow dementia to have us forget that.”



Pete Downer

Commissioner of Dementia Services

2 Executive Summary

2.1 Purpose

This report provides an overview of: what dementia is, the current situation on both a national and local level in relation to dementia, what the anticipated impact is going to be for Shropshire, how the county has responded to the issue and what the county intends to do about the condition. This document is framed as a “call to action” with an overarching intention of raising the reader’s awareness of how local communities must support local people to live with dementia in order to limit the impact that the condition has upon them.

2.2 Context

- Dementia is a condition that has a significant detrimental impact on those who live alongside it, not just those who have the condition.
- Dementia is considered to have the biggest financial impact of all of the long-term conditions, costing the economy nearly double that of cancer (Health Economics Research Centre, 2010).
- Age is the biggest risk indicator for developing dementia, although dementia is not a result of aging.
- Projections show that by 2031, 45% of the South Shropshire population will be over 65 years of age and will be among the three oldest populations across England and Wales.
- Shropshire presently performs well in relation to the national picture when considering national performance indicators for dementia.

2.3 Methodology

The Shropshire Health Economy Dementia Steering Group (HEDSG) relies on voluntary engagement, consists of local dementia experts, and has been instrumental in developing this document. This group has worked to map existing service provision, identify gaps and set up five task and finish groups to develop ideas for how these gaps can be filled. These groups each met for a total of around 6 hours to undertake the work. Working in this way has enabled a diverse array of contribution towards what we believe is a shared vision of what the future needs to look like for people living with dementia in the county.

2.4 Identified Gaps

It is identified that there are often difficulties in getting a referral to the Memory Service. It is also identified that people are often diagnosed late in their dementia journey. The most significant gap however takes the form of the lack of assistance provided to people living with dementia during the early stages of the condition, with inadequate community infrastructure to allow people to continue to *live* as they choose for as long as possible as opposed to *existing* with the condition. A lack of support for Carers was identified, as was the disproportionately high numbers of people with dementia having unplanned admissions to the acute hospitals. It was also identified that length of stays in hospital for people with dementia tend to be longer than for those without the condition. An overarching issue was that services are disjointed and difficult to navigate.

2.5 Key Aims

Shropshire as a county needs to:

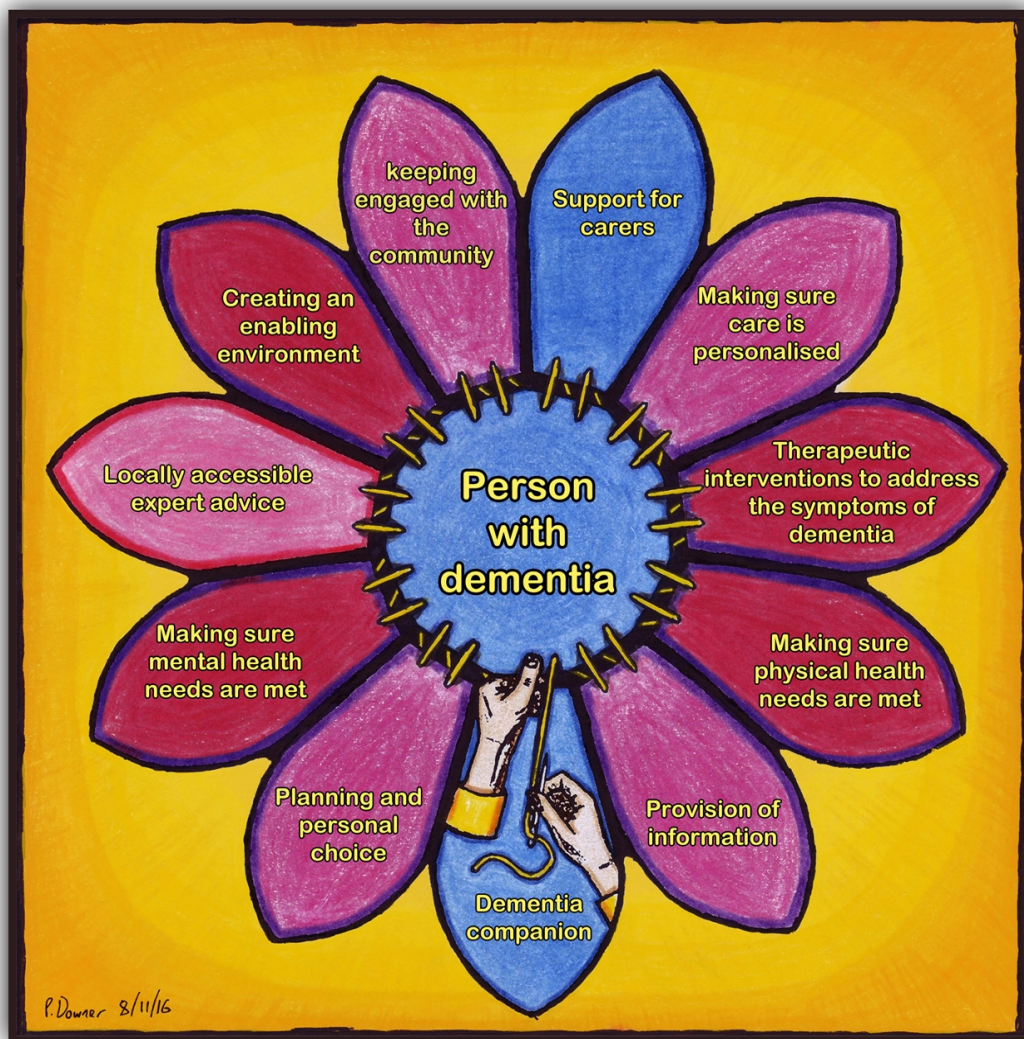
- Increase community-based options available for people with dementia to promote a better quality of life for people living with the condition.
- Reduce the number of people with dementia who experience unplanned admission to the acute hospitals.
- Reduce the amount of time that people with dementia spend in hospital once they are admitted.

2.6 Strategic Goals

To do this Shropshire needs to:

- Diagnose dementia earlier.
- Increase the provision of support during the earlier stages of the dementia journey through implementing the Shropshire Model for living with dementia (figure 1).
- Provide a crisis-resolution team to work collaboratively with community-based physical treatment services, to eventually gate-keep all admissions for people with dementia, ensuring that hospital admission only takes place as a last resort.
- Provide a greater number of dementia support workers in the inpatient setting.

Figure 1 – The Shropshire Model for Living with Dementia



2.7 Challenges

Challenges to achieving the above are mainly related to the financial circumstances that Shropshire is experiencing at present, and existing contractual arrangements. However, we have specialists in these areas who are able to assist with overcoming these barriers. The principle that this strategy is based upon is that if we are able to get things right earlier in the dementia journey, then people will be able to live better for longer and as a result require less intensive, invasive and expensive support later in their journey.

3 Introduction

In England, a lot of work has taken place at a national level to combine quality evidence and research to guide us as to how best to help people live well with dementia. In addition, to this, Shropshire Clinical Commissioning Group (CCG) has been working closely with local dementia specialists to understand what it is like to live locally with the condition. These specialists have included: people with dementia, Carers of people with dementia and people delivering support. More recently, the purpose of our conversations has been to create a shared-vision of how we want the future to look for our people who live with dementia, and how we need to work together to get there.

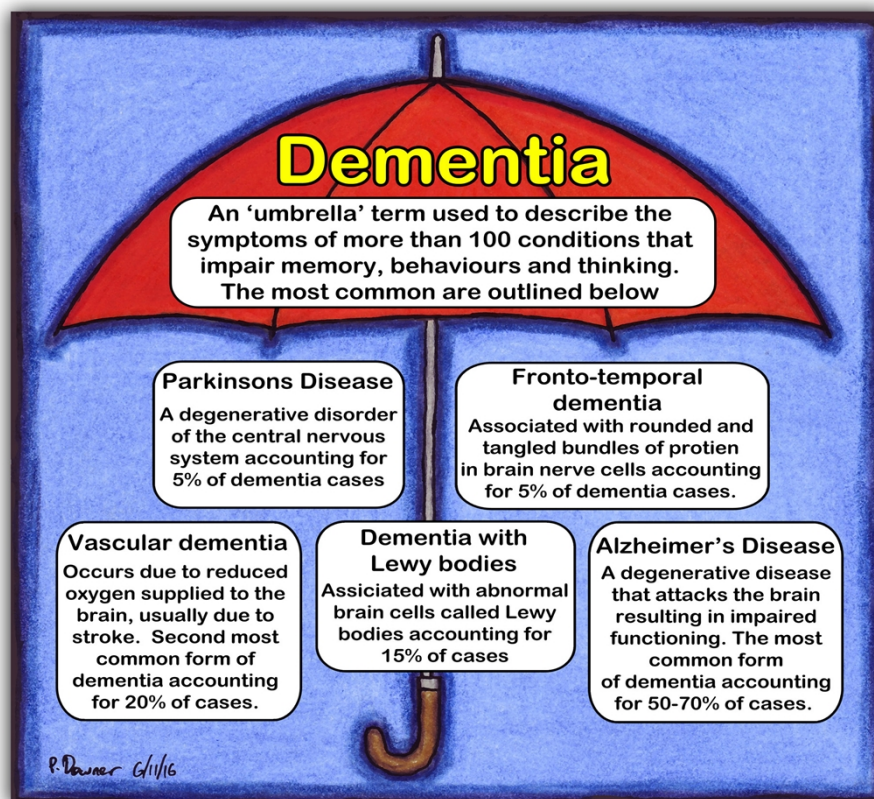
This document provides relevant background information, national and local statistics about the condition, and information gathered from our local engagement. It will illustrate what life is currently like for people living with dementia locally, and how we want the future to look. More importantly, it will outline how we as a county must work together to achieve our aims. We hope that over the next three years, more local businesses will choose to join the dementia action alliance, and more communities will become dementia friendly enabling people living with dementia to remain living within them for longer.

4 Background

4.1 What is dementia?

Dementia is an “umbrella term” (figure 2) used to describe a group of conditions that are characterised by damage occurring to the brain which leads it to stop working as it should. Conditions or behaviour that damages the brain can cause dementia; this can include disease of the brain such as Alzheimer’s disease, oxygen deprivation resulting from strokes, and alcohol abuse. Although the progression of some forms of dementia can be slowed by medicine, and in some cases lifestyle changes, there is currently no cure. It is important to understand that dementia is **not** a natural part of ageing, and that although dementia can change the way a person thinks and acts, they are people, and should be respected as such. This means that we need to involve people with dementia in everyday life, and work as a community to offer them the same opportunities as everyone else (The Alzheimer’s Society, 2016a).

Figure 2.



4.2 Can I reduce my risk of having dementia?

According to the Alzheimer's Society (2016b), there are certain medical conditions that can increase a person's risk of dementia; these include high blood-pressure, diabetes and obesity. It is widely accepted that in terms of keeping our brains healthy, what is good for our hearts, is good for our heads. The Alzheimer's Association (2016) suggests that heart-healthy food, a reduction in fat and cholesterol consumption, regular exercise and not smoking can help reduce the risk of the second most common form of dementia: vascular dementia. However other authors on the subject suggest that these healthy-body tips, combined with keeping socially active, getting good sleep, reducing stress levels and keeping mentally stimulated, can in some cases help to delay the onset of Alzheimer's disease (Smith et al, 2016).

4.3 What are the signs of dementia?

Just as no two people are the same, no two people with dementia are the same either. This means that how dementia presents in each person is also different; some people begin to develop problems with memory whilst others may begin to behave in out-of-character ways, or have difficulty in performing day-to-day tasks.

4.4 What do I do if I suspect that I or a loved one might have dementia?

Regardless of the type of dementia or how it presents, getting a diagnosis early is really important. An early diagnosis gives people living with dementia the opportunity to put things in place to help them live with the condition better for longer and in some cases begin treatment to slow the conditions progression. If you have concerns that you have symptoms of dementia, you really need to see your GP. If it is someone close to you that you are worried about, encourage them to speak to their doctor. The longer someone with dementia remains undiagnosed, the less time they will have be able to learn how to live with the condition before learning becomes difficult. This means they will need more intensive support sooner and lose independence quicker than may otherwise be the case.

It is also important to understand that having an earlier diagnosis means that people with the condition can make advanced decisions about how they want their care to be delivered in the later stages of their journey. Some Carers of people with dementia reach a point whereby they can no longer cope with supporting their loved one at home. If there is a plan in place specifying how the person with dementia wants their care delivered if this happens, Carer guilt and sadness and other negative health-impacts can be reduced (Banerjee and Whittenberg, 2009).

Our engagement has revealed some of the difficulties faced by some Shropshire people approaching their GP for a specialist dementia assessment; this document sets out how we have listened and are aiming to improve this situation. In order to achieve the plans set out within this strategy, GP cooperation will be pivotal. We must engage GPs to win their support; we believe that the GP practice represents a powerful and symbolic community hub... we do not want to change that.

5 The National Picture

5.1 The impact of dementia

Sube Bannerjee, a professor of dementia, and director of the Centre for Dementia Studies at Brighton and Sussex Medical School, states:

“The costs of dementia dwarf those of the illnesses that are currently prioritized at a national and international level such as HIV, cancer, heart disease, stroke and diabetes.”

(Banerjee, 2012; p. 705)

It was estimated that in 2010, the treatment and management of dementia in the UK, cost £23 billion with family Carers saving £12.4 billion to the health economy. As a comparison, in 2010, cancer cost the health economy an estimated £12 billion. Despite this, dementia research received around a twelfth less government and charitable funding per £ spent managing the condition than cancer (Health Economics Research Centre, 2010). With the ageing population that is forecast that by 2026, the cost of dementia in England will be around £35 billion (McCrone et al, 2008).

5.2 What the government are doing about dementia

Dementia has been on the national radar for some time. In 2009 the Department of Health published the first national strategy for improving the lives of people living with dementia called:

Living well with dementia: A National Strategy

(Department of Health, 2009)

This document laid out seventeen key objectives to guide how health services at the local level should be arranged. Shortly after this time, driven by the principle that early diagnosis is important to enabling people to live well with dementia, the first national target for dementia diagnosis rates was set. In 2010/11, it was believed that only 42% of the people living with dementia in England were diagnosed (Department of Health, 2012). This meant that many people were not getting the chance to prepare themselves for their dementia journey properly. The Department of Health expressed dissatisfaction with this situation and set the target that two thirds of the predicted prevalence (66.7%) was to be diagnosed by 2015 was put in place. This target has been achieved, and in some areas; Shropshire being one of them, exceeded. According to the Quality Outcome Framework (QOF) data that is collected from Shropshire GP practices, it is believed that presently 70% of Shropshire's population living with dementia has been diagnosed.

Our latest national guidance for improving lives for people with dementia is called:

The Prime Minister's Challenge on Dementia 2020

(Department of Health, 2015)

The key drivers from this document relate to support Carers better in their caring role and enabling people with dementia to retain their sense of self for longer. These national drivers will help us in Shropshire drive forward the change that is needed to improve the lives of local people living with the condition. However it is also important to recognise, that many people do not want a diagnosis of dementia, or are not ready to face this. The decision to be assessed for dementia needs to be an informed decision, and people's wishes must be respected.

5.3 How the government keeps track of what is happening

Currently there are a number of statistics that are used by the government to indicate how well each part of the country is managing dementia. These relate to things like: the number of people living in care homes, the length of time that people with dementia stay in hospital, and whether or not people with dementia die in their usual place of residence (Public Health England, 2016). These not only help us to understand how we in Shropshire are doing compared to the rest of the country, but are also useful for giving us part of the picture for what needs to happen in our county to make things better for our people.

6 The local picture

6.1 How much of an issue dementia poses to Shropshire

In Shropshire a large proportion of the population is elderly, which is significant given that old-age is the biggest factor in developing dementia (The Alzheimer's Society, 2016). Presently there are around 70,000 people living in Shropshire over the age of 65 and around 3,000 of them are diagnosed with dementia. Considering this only represents around 70% of the expected prevalence within this age group, there are likely to be around 1,300 people over the age of 65 living with dementia in the county without a diagnosis.

However, it is not just older people who can have dementia; younger people can have it too. Although there are around 80 people under the age of 65 diagnosed with dementia in Shropshire, recent work completed by the Alzheimer's society suggests prevalence rates of over 240. This means that there may be as many as 175 people under the age of 65 who are living with dementia without a diagnosis, and without any support to help them live better with the condition.

6.2 What the future will be like for Shropshire

It is estimated that by 2031 South Shropshire will be among the top three most elderly populations across England and Wales with around 45% of the population over the age of 65 (Rutherford, 2012). Locally provided Public Health data estimates that by 2032 there will be 96,500 people over the age of 65 living in Shropshire. If current prevalence estimates are applied to this figure, by 2032 there will be around 5,900 people over 65 and around 410 people below this age living with the condition.

Given the age of our population, it is likely that dementia will impact upon Shropshire more so than almost any other part of the country. In order to meet this challenge, we need to enable our communities to better accommodate people living with dementia and deliver services to help enable people to live better with dementia for longer.

6.3 What the CCG and Local Authority are doing about it

In collaboration with Shropshire Council, Shropshire CCG made the decision to employ a health commissioner to specifically look at dementia. A health commissioner's job is to find out as much as they can about the health needs of a population and make plans for how to address those needs. The goal of every good health commissioner is to find ways of improving how services are able to meet their population's needs, whilst reducing overall cost to the tax-payer. The key to this is ensuring that the services provided are fit for purpose, of a good quality and that people are using them at the right time. If we are unable to ensure this is the case, then we not only let our people down, but we also waste their money.

By employing a commissioner to specifically focus upon dementia, Shropshire CCG and Shropshire Council are taking positive steps to ensure that high-quality, high-value support for Shropshire people living with dementia is provided. In response to criticism regarding the low levels of consultation that went into the current dementia strategy, as part of this new strategy, Healthwatch Shropshire was commissioned to undertake a significant piece of engagement work across the county. The report produced as a result of this work has made a valuable contribution to understanding the local picture in terms of where things need to improve for our population living with dementia.

6.4 What we have achieved in Shropshire for people living with dementia

Some of the developments made towards enabling people with dementia to live better in Shropshire are listed below:

- Peer support groups being run across the county by the Alzheimer's Society and Age UK, although only have capacity to support around 3% of people diagnosed countywide.
- Dementia-support workers from the Alzheimer's society are offering one-to-one support to carers of people with dementia, although have limited capacity.
- Training has been provided to some Carers of people with dementia to help them with their caring role; however the places are limited to around 24 per year.
- Dementia awareness training is now offered to public-facing staff in our hospitals.
- The Butterfly Scheme is helping to identify people with dementia visiting our hospitals, ensuring that a recognised dementia-specific approach to providing care called REACH is offered.
- Dementia lead nurse at Shrewsbury and Telford Hospitals who enables the inpatient experience for people with dementia to be better understood whilst offering guidance on how best to work with them.
- Care homes being given the opportunity to undertake training to enable their lead staff to promote Dementia Friendly ways of working.
- Development of an online resource (<http://dementiaroadmap.info/shropshire/>) to highlight local opportunities for Shropshire people living with the condition.
- Libraries now offer opportunities for people to live better with dementia.
- The Diocese of Litchfield has developed and expanded provision of it's "forget me not teas".
- The memory service has achieved a rating of "outstanding" following their most recent CQC inspection.

However, there are a significant number of people in the county living with undiagnosed dementia, and a large number of people who feel unsupported following diagnosis. This document sets out what we plan to do about this.

7 Working towards a local solution

7.1 The people involved

In addition to gathering statistical information and the Healthwatch Shropshire report, the dementia commissioner has adopted a collaborative approach towards finding out what it is like to live with dementia in Shropshire. Below is a list of the different people that have contributed to this process:

- Local dementia support groups.
- People with dementia and their Carers.
- Health professionals who provide support to people living with dementia.
- Healthwatch Shropshire – an organisation set up to give people receiving services a voice among the people planning and delivering them.
- Charitable organisations like the Alzheimer’s society and Age UK.
- GP’s.
- Social workers.
- Support workers.
- Social action groups.
- Shropshire Partners in Care

7.2 What we have learned

The statistics used by the government to decide how well an area is working with people living with dementia are split into five key areas:

- Preventing Well
- Diagnosing Well
- Living Well
- Supporting Well
- Dying Well

These key areas, derived from the NHS England Well Pathway for Dementia (Figure 3), inform the layout of Public Health England’s (2016) Dementia Profile performance indicators. These have formed the framework around which our collaborative work has taken place.

Figure 3.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

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

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

<p>RESEARCHING WELL</p> <ul style="list-style-type: none"> • 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.
<p>INTEGRATING WELL</p> <ul style="list-style-type: none"> • 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.
<p>COMMISSIONING WELL</p> <ul style="list-style-type: none"> • 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.
<p>TRAINING WELL</p> <ul style="list-style-type: none"> • 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.
<p>MONITORING WELL</p> <ul style="list-style-type: none"> • 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.

7.2.1 Preventing Well

The indicators of "Preventing Well" include levels of smoking, obesity, physical inactivity and diabetes. Shropshire performs better than a lot of places in England in this regard, although more could be done to improve this situation, particularly in terms of obesity, diabetes, and admissions for alcohol related conditions within the 40-64 age range. Other than the need to raise awareness surrounding dementia, the Healthwatch Shropshire report does not make any recommendations for prevention. However, the collaborative work that has been undertaken in this area has led to the realisation that dementia needs to feature as part of the Local Authority's public health prevention strategy. A commitment from the Local Authority has been made to act upon this, and work is now being undertaken to establish a methodical approach to dementia-prevention in Shropshire.

7.2.2 Diagnosing Well

On a general level, Shropshire performs well against other parts of the country when considering indicators of “Diagnosing Well”. However more focused scrutiny of local practice performance suggests that not all GP practices perform as they should in terms of prevalence rates, and from the stand-point of referral into the Memory Service, South Shropshire GP’s have almost every person they refer to the Memory Service accepted as having dementia. This suggests that they tend not to refer people early on in their journey, since if this was the case, there would be higher numbers of people deemed not suitable for the Memory Service. The findings within the Healthwatch Shropshire report suggest that it can be problematic for people to get their GP to agree to refer them to the Memory Service. The Healthwatch Shropshire report recommends that GP’s receive regular dementia specific updates to enable a more pro-active approach towards diagnosis. Work taking place within the collaborative work groups suggests that the diagnostic element of the Memory Service needs to be located in GP practices.

7.2.3 Living Well

Despite the focus of the Prime Minister’s 2020 dementia challenge being geared towards “Living Well” with dementia, there are only two measures of this element of the dementia journey at the national level. These relate to Carers of people with dementia and the quality of life they report to be experiencing, and on this measure Shropshire performs well. However, the Healthwatch Shropshire report highlights the following:

- Facing a system that is complicated and disjointed, many people report feeling unsupported following diagnosis.
- People living with dementia are often not sure of whom to speak to when they need help.
- Communities are not set-up to enable people with dementia to live well within them.
- Assistive technology is difficult to access and as such is under used.
- Not enough is done to enable existing social networks to remain part of a person with dementia’s life, including some family members.

7.2.4 Supporting Well

On a national level, Supporting Well is measured through the numbers of people with dementia admitted to acute hospitals. Compared to the national figures, Shropshire does well in relation to this. However local emergency-admission statistics for the over 65's, suggest that people with dementia were admitted to the acute hospital three times more than people without the condition, the most common cause of which was urinary tract infection. Findings within the Healthwatch Shropshire report suggest that more needs to be done in terms of improving the experience of people with dementia being admitted to the acute hospital to enable a more efficient, less distressing experience for the person admitted. The collaborative group work undertaken identified that in addition to ensuring that people with dementia have a more effective and efficient hospital experience, more needs to be done to prevent admission from taking place in the first instance.

7.2.5 Dying Well

The national statistics suggest that people in Shropshire do tend to die in their usual place, of residence more so than is typical for the rest of the country, although this is more commonly a care home than is typically seen at the national level. However, the Healthwatch Shropshire report identified that many people living with dementia felt that insufficient opportunity to address end-of-life issues where assistance is offered to people living with dementia in Shropshire. Additionally it was identified that there is no dementia-specific consideration in terms of palliative care. The collaborative group work has yielded a similar picture to this, and has prompted engagement with local end-of-life specialists.

7.3 What the learning has produced

This learning has enabled the production of a vision statement that is shared with Telford and Wrekin CCG and Local Authority, and has guided all of the subsequent planning work:

7.4 The Vision

We want to:

“Enable you to remain you, to live well in your community, to feel secure and with those around you, to feel confident and informed, knowing where to go when you need help.”

To help us reach this vision we have adopted some key principles that will underpin all the work we do.

We will:

- Creatively build on your strengths, skills and your independence.
- Support you to plan for your future.
- Be honest about what we can and can't do.
- When we can't offer what you need, we will support you to try to find someone who can help you.
- Ensure you can make timely and informed choices.
- Promote Dementia Friendly communities in Shropshire Telford and Wrekin.
- Work as one team to support you and your family.
- With your consent, share your story so you don't have to.
- Reduce barriers to ensure you are able to get the help you need.
- Work with you to find solutions to prevent a crisis.
- Learn from what works well and what doesn't to improve the help we provide.

8 Achieving the Vision

Below is an outline of what we would like to achieve for all people living with dementia in Shropshire by 2020. It is a blue-print for the future and is the intended outcome of the plans we will put in place between now and then.

8.1 Reducing the Risk of Dementia

Reducing the risk of dementia is not a core feature of this model, although raising awareness will inevitably take place as a result of its implementation. The Local Authority is developing a separate dementia-risk reduction strategy.

8.2 Diagnosing Dementia

At present, a person who is suspected of having dementia is referred to the Memory Service by their GP. This often means that they have to travel to the Memory Service for assessment. In the future, we would like to see the diagnosis-element of the Memory Service provided in GP practices. We would like to see this role facilitated by a Memory and Dementia Nurse Specialist, who would carry out assessment in the primary care setting. Where a positive diagnosis is made, we would like this specialist nurse to be able to initiate treatment.

It is expected that by having a stronger presence in the primary care setting, relationships based upon trust and professional respect can be cultivated between GP's and the Memory Service. It is also anticipated that this Nurse Specialist will be able to raise awareness surrounding dementia within the primary care setting, and encourage GP practices to become more Dementia Friendly. It is hoped that working in this way can encourage GPs to recognise the benefits of an early diagnosis and in doing so begin to challenge some of the negative stereotypes, especially surrounding the futility of diagnosing early. Evidence suggests that in some cases this deters GPs from timely referral to Memory Services (Rimmer, 2016).

Figures 4 and 5 demonstrate the principle of how an early diagnosis enables people to learn how to live with their condition whilst they still have the capacity to do so, extending their ability to retain a level of independence.

Figure 4 demonstrates how diagnosing later in the journey means that there is less time for the person with dementia and the people close to them to learn how to live with the condition, thus requiring higher levels of support sooner:

Figure 4.

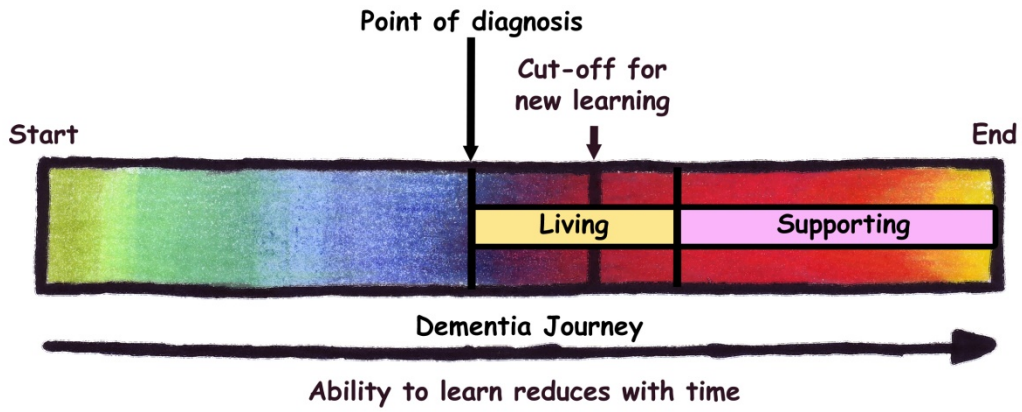
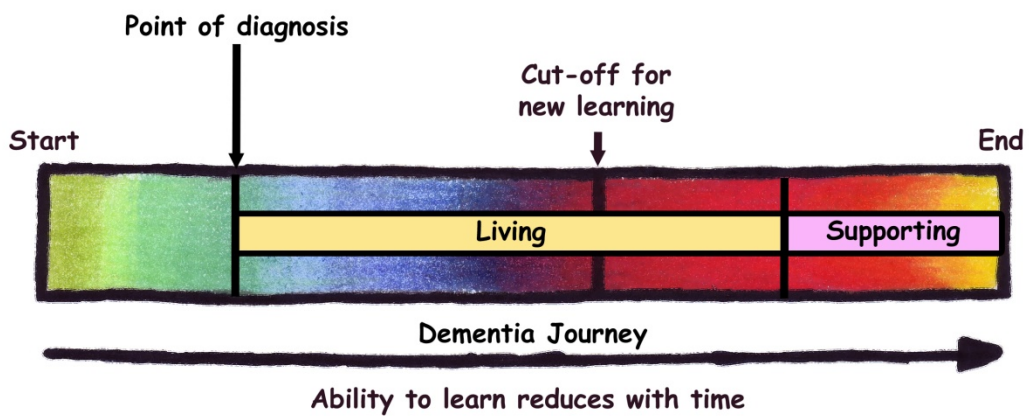


Figure 5 demonstrates how diagnosing earlier in the journey offers people with dementia and the people close to them an increased opportunity to learn how to live with the condition. This means they can *live* as they wish to for longer requiring higher levels of support later than would otherwise be the case.

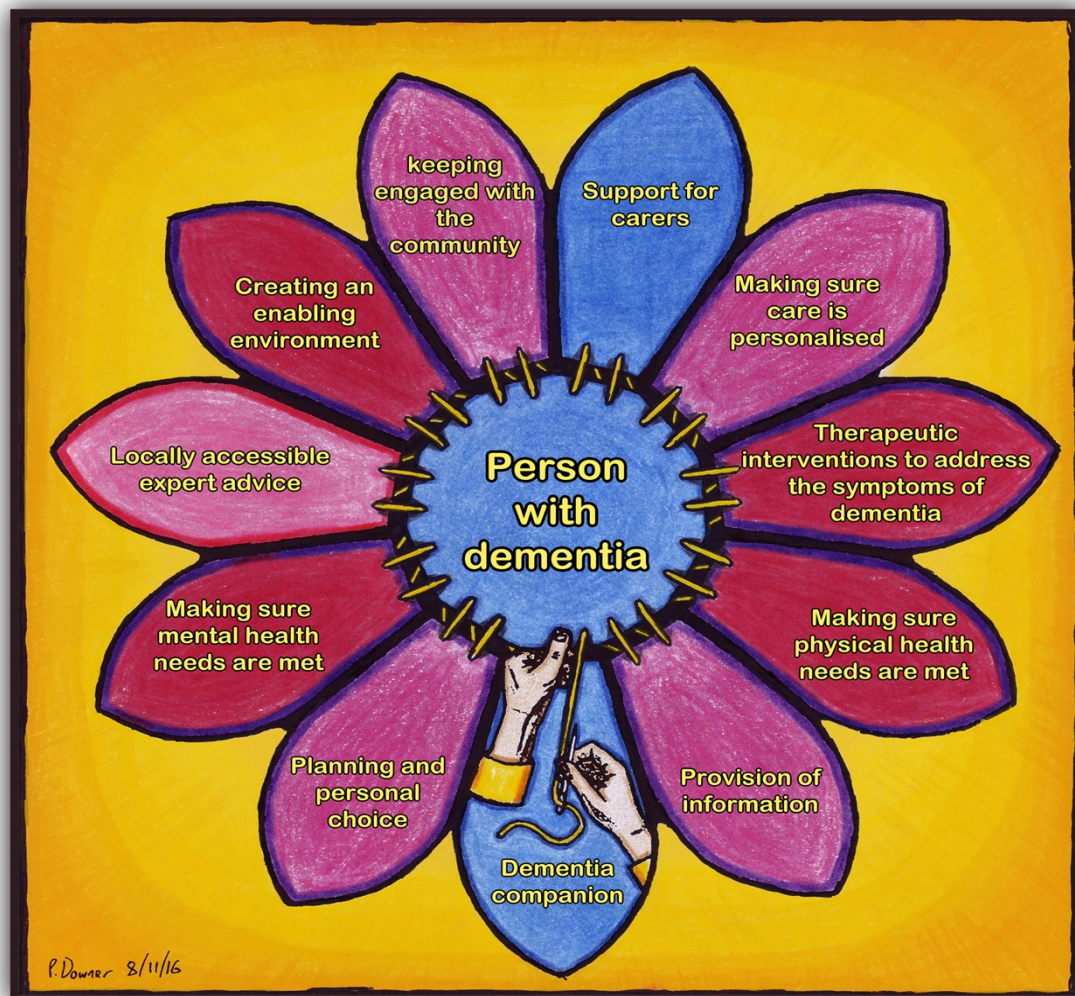
Figure 5.



8.3 Living with dementia

It is essential that once diagnosed people with dementia and their Carers are supported in such a way that enables them to live with the condition better than they otherwise would if they had not been given a diagnosis. Whilst there are models that have been developed to support people to live with dementia, the work that has taken place within the collaborative work groups has led to the emergence of a new model for supporting people with dementia and their Carers to live with dementia (Figure 6). It is believed that if the principles of this model are applied throughout the dementia journey, then not only will people with dementia and their Carers have a more positive experience of living with the condition, but the latter stages of the journey will be less distressing.

Figure 6. The Shropshire Model for Living with Dementia



8.4 How the model works

The Shropshire Model consists of ten segments that contribute to a person's life with dementia. Each person diagnosed with dementia and where possible their carers, will be given the opportunity to be assisted throughout their journey by an individual known as their Dementia Companion. This person will pro-actively engage the person with dementia, and where possible their Carer, to ensure that the elements that making up the model are considered in the development of the living with dementia plan. In some cases a person with dementia or their Carer will be able to access elements of the model

independent of their companion, although should they have any difficulties, their companion will be able to assist. The Dementia Companion is a role that has been developed as a result of the collaborative work that has been undertaken in the development of this strategy; they are “*the golden thread that runs through everything*” and are critical to the model working. It is expected that the Dementia Companion will be a person employed through a third-sector organisation such as the Alzheimer’s Society or Age UK. The next paragraphs will explain in more detail what the segments represent.

8.4.1 Planning and personal choice

This element of the model relates to forward planning in the earlier stages of the dementia journey to ensure that personal choice can steer care decisions in the later stages. Anecdotal evidence suggests that at present there are often scenarios whereby a person with dementia has not made any decisions about how they want their care to be delivered as their condition progresses. This can cause significant feelings of stress and guilt for their Carer. This is a core feature of the pro-active work that the Dementia Companion will facilitate, tying in well with some of the other work that the CCG and Council are completing through the Better Care Fund and Healthy Lives Programme.

8.4.2 Making sure mental health needs are met

This element considers not only the medical needs of the person with dementia in relation to the treatment of their dementia, but also the psychological and emotional needs of the person with dementia, and where applicable, the person’s Carer. This is about ensuring that the services that are available to support people’s psychological wellbeing are accessible where and when required. These services might include access to psychological therapies, input from occupational therapists to promote engagement in meaningful activities and signposting to peer support groups. Again, the Dementia Companion will assist in facilitating access where required, but will also take a pro-active approach towards enquiring about this aspect of a person’s wellbeing during the work that they undertake with people with dementia and their Carers. On occasion it may be that support from mental health services needs to be more intensive, and it is intended that the Dementia Companion will assist the process to ensure additional support can be provided where this is required.

8.4.3 Locally accessible expert advice

Although we recognise that people with dementia and carers are experts by experience, this element will offer them the opportunity to seek advice from the primary care based Memory and Dementia Nurse Specialist. Where required the Dementia Companion could assist with accessing this resource. This will mean that a more responsive, more localised way of working can be achieved and that resources can be used more effectively and efficiently.

8.4.4 Creating an enabling environment

This element is about enabling existing environments to support the person with dementia to remain functioning effectively within them. This ranges from the domestic setting through to the work environment. The Dementia Companion will be able to assist the person on the dementia journey to involve occupational therapists where required, and take full advantage of assistive technologies during the time within the person with dementia’s journey so that they will be able to learn how to use them. They will where required assist employers of people with dementia to explore ways to enable the person with dementia to continue carrying out their role within the work place. The principles applied within

this segment of the model are the foundations of the Dementia Action Alliance, and underpin other CCG and Council work that is emerging through the Better Care Fund and Health Lives Programme, including housing and future planning.

8.4.5 Keeping engaged with the community

Where agreed, the Dementia Companion will help promote this by working with existing social networks to include the friends and family of the person with dementia. The aim of this will be to enable them to understand more about the condition. They will encourage these groups to see the person and not the dementia. By continuing to involve people with dementia in activities, they will help improve the person's quality of life. Additionally, the Dementia Companion will have local knowledge of Dementia Friendly businesses such as taxi-firms, pubs, hair salons, cafes, shops etc. and will be able to promote their access to the person with dementia and their Carers. This in turn will use market influence to encourage other businesses to become Dementia Friendly.

8.4.6 Support for Carers

One of the key roles of the Dementia Companion will be supporting the Carer of the person with dementia. It has been identified that this is of high importance. Just as the Dementia Companion ensures that the needs of the person with dementia are met, so they will ensure that the same is true for the Carer of the person with dementia. The Dementia Companion will have local knowledge of Carer support opportunities, including peer-support groups and how to access respite options, supporting the process of accessing these. The principles of supporting carers better are a key feature of current research, and form the basis of our local carers strategy.

8.4.7 Making sure care is personalised

This relates to the Dementia Companion promoting the importance of ensuring the personal preferences of individuals are understood and adhered to. This is particularly important in instances whereby people with dementia are admitted to the acute hospital; tools such as the "this is me" passport will help with this. Additionally, medication dispensing considerations, such as whether a dosette pack is needed to enable a person with dementia to manage their medication following discharge will fall under this category.

8.4.8 Therapeutic interventions to address the symptoms of dementia

This element entails the Dementia Companion assisting Carers and others working with people with dementia in developing skills such as approaches to communication, activities of daily living, skill training and activity planning. These techniques can help promote independence for people with dementia, and in an enabling environment that is tailored to the person with dementia's needs, can actively promote a better quality of life for the person with dementia and others who share their lives with them. Where required, the dementia companion may involve occupational therapists, and speech and language therapists.

8.4.9 Making sure physical needs are met

This will include consideration of sensory deterioration, dental needs and physical illness. In the event of a person with dementia being physically unwell, the Dementia Companion can work to assist physical care services, including the ambulance service by sharing critical information (where consent has been provided to do so) that may help a more successful intervention to take place. It is hoped that through working in this way, emergency hospital admissions can be reduced, and people with dementia can be supported in an environment that is familiar to them which will in turn promote recovery from physical health problems more effectively.

8.4.10 Provision of information

Although people diagnosed with dementia and their Carers are given information at the beginning of their journey, this is not always the best time for them to receive this information. The Dementia Companion will be able to provide a flexible solution to this by being readily accessible, and working in a pro-active way, systematically contacting people diagnosed with dementia to provide them with on-going opportunities to learn about their condition.

8.5 Why it is important that this model is delivered

There is a difference between living with dementia and existing, or surviving with dementia. If someone is only able to survive, or exist with dementia, they are missing out on what many people consider to be the most important thing about life, and that is the *living* of life. *Living* includes the sharing of experiences with others, being valued by others and the feelings of acceptance that are so important to validating us as human beings. We want our county to encourage people living with dementia to *live*, to remain part of our lives and to feel no shame for having needs that require our communities to adapt to enable this.

8.6 Become part of the solution – Social Action

If you want to understand more about dementia, the Alzheimer's Society have started a social movement known as the Dementia Friends. A Dementia Friend is someone who has undertaken a dementia awareness session to enable them to develop some insight into what life is like with dementia. Here is a link that can help you find out more: <https://www.dementiafriends.org.uk/>

If you are a business and want to become Dementia Friendly, the Dementia Action Alliance has been set up to help like-minded people achieve just that. Here is a link to the website: <http://www.dementiaaction.org.uk/>

These examples are in no way represent an exhaustive list of ways to become involved with helping communities to support people with dementia, the dementia roadmap (<http://dementiaroadmap.info/shropshire/>) provides a more comprehensive list of opportunities in your area.

8.7 Supporting people with Dementia

This section will explain how we intend to support people with dementia who require a more intensive level of support in order to live with the condition.

8.7.1 Domiciliary care

It is usually case that at some point within a person with dementia's journey, they require additional input at home to help them to take care of some of the essential activities of daily living. It is intended that with permission to do so, the Dementia Companion will be able to share information with the company providing this care to promote the provision of person-centred care.

8.7.2 Home treatment

Home treatment will have two dimensions according to what the person with dementia's need relates to. In some cases, support from both mental health and physical health services will be required. It is intended that the Dementia Companion will be the person who accesses this input on behalf of the person with dementia.

8.7.3 Home treatment from mental health services

Mental health services will provide home treatment interventions to support people with dementia who develop complex unusual behaviour. This may emerge in a number of ways, some people may become aggressive, and others compelled to go for walks, some people may begin to self-neglect. Every person with dementia is different, and every persons needs are also different. The home treatment service will offer involvement from occupational therapists to assist with developing meaningful routines and roles. In some cases it may be that environmental adjustments or advice on communication skills may help. Where it is indicated that there is a need for medication to be reviewed and its impact monitored, mental health nurses can help. The service will embrace a culture of compassion and where needed provide additional emotional support to that which is offered by the Dementia Companion, or existing psychological support services. It is expected that home treatment services will be able to support a person with dementia regardless of their place of residence; this is to include care home environments.

8.7.4 Home treatment from physical health services

Physical health services will provide home treatment interventions where possible for medical conditions including incontinence issues, urinary and respiratory tract infections, and other such medical complaints that often result in hospital admission for people with dementia. If the person with dementia is presenting in such a way that requires interventions from mental health home treatment too, then this should be arranged accordingly.

8.7.5 Crisis resolution mental health services for people with dementia

At present, there is no formal arrangement in place for the provision of out-of-hours support for people with dementia and their carers. In some circumstances this can be crucial to admission avoidance. Currently people over the age of 65 with dementia are around three-times more likely to be admitted to a general hospital for unplanned care. It is understood that this can often be a consequence of the complex behaviour displayed by people with dementia who are physically unwell negating the ability for community treatment of physical illness to be delivered.

It is expected that by 2020, arrangements will be in place to ensure that an out-of-hours short-term support service is able to assist with managing complex behaviour to enable community treatment of physical illness for people with dementia through collaborative working. This service will be expected to provide input regardless of a person with dementia's domiciliary arrangements, meaning that even if they are in receipt of support in a nursing or care home, a crisis-resolution service will be available to them.

8.7.6 Respite options

In order to promote a person with dementia remaining in an environment familiar to them, it may be that respite options have to be considered for their Carer. The Dementia Companion will, where requested assist the carer in contacting the relevant people in the local authority, and with permission to do so, will be able to share information with those concerned in order to make things seem as smooth as is possible for the person with dementia and their Carer.

8.7.7 Residential Care

Sometimes, keeping someone with dementia at home is not the right thing to do and it may be that around this time a deprivation of liberty assessment is required if the person with dementia does not have the capacity to recognise this. With the person with dementia's prior agreement, the Dementia Companion can assist the Carer, with sharing information with the residential care provider to enable a more personalised delivery of care. The Dementia Companion will not withdraw once a person is in receipt of residential care; they will remain in place as a point of contact, although they will not be expected to pro-actively engage with the person with dementia to the same degree, as would be the case if the person with dementia were living in their own home.

8.7.8 Hospital admission for mental health needs

Where home treatment has not been successful, it may be that a person with dementia requires a hospital admission in order for their mental-health medicine to be adjusted, or for suitable psychological solutions to be developed. It is expected that the environment to which a person with dementia is admitted is Dementia Friendly, and that Carers are involved to the extent they wish to be. It is expected

that all of the information gathered by the home treatment team is shared with the inpatient staff, and that a plan for discharge is generated at the point of admission. It is important that planning for discharge involves the person with dementia and other relevant people; this might include: the persons Carer, the care home, the domiciliary care agency and, the home treatment team, community based physical treatment teams and the Dementia Companion. Working in this way should promote a successful discharge.

8.7.9 Hospital admission for physical health needs

Where a person with dementia requires admission for physical health needs, it is important that they are engaged with in such a way as to minimise as far as possible the distress caused by being in hospital, and that the admission is as brief as can be managed. It is believed that in order to achieve this a greater number of dementia support workers will be required in the inpatient setting. A key aspect of the ward-based dementia support worker will be “knowledge transfer”; this means that they will educate other staff on the ward about how best to work with people who have dementia. Planning for discharge at the point of admission will need to involve the person with dementia and other relevant people, this might include: the persons Carer, the care home, the domiciliary care agency, the home treatment team, community based physical treatment teams and the Dementia Companion. This will enable personalised care, whilst ensuring that discharge is as seamless as can be managed. This will ensure that the right medication is dispensed in the right format and arrangements are in place in order to promote a successful discharge. It is expected that this will also help reduce the length of time that a person with dementia needs to be in hospital.

8.7.10 Early discharge

Where a person with dementia is well enough not to need to be in a hospital bed, but is not well enough to return to independent living, there is the option for them to be looked after in the more settled surroundings of a care home. The decision to discharge early should be agreed during the discharge planning process. If a person who has dementia does not wish to be discharged to a care home their wishes must be respected, although if it is considered to be in their best interest and the person with dementia lacks capacity to make a decision, it may be that a deprivation of liberty assessment maybe required to ensure that the grounds for depriving the person of their liberty are justifiable.

8.8 Dying with Dementia

It is expected that by 2020 there will be a better provision of support available to people living in Shropshire with dementia, enabling them to die with a greater level of dignity. It is also expected that from 2020 onwards people with dementia will have the opportunity to work with a Dementia Companion. This will promote end-of-life decision making as part of the living with dementia plan. This means that Carers of people with dementia will be less likely to have to make difficult end-of-life decisions on behalf of their loved ones. The Dementia Companion will also be able to provide the Carer of the person with dementia with a level of emotional support, and signpost on to bereavement support. Work to develop a more dementia-specific offer in terms of palliative care services has begun, although this work is in its infancy.

8.9 Key Objectives

To recap the above, there are key objectives required to achieve what we want by 2020. These are as follows:

- A greater understanding of what can be done to reduce the risk of dementia in the county, resulting from a successfully implemented prevention strategy.
- GP based diagnosis, commencement of treatment and specialist advice, resulting from placement of memory and dementia specialist nurses in local practices.
- Good post diagnostic support to promote social inclusion, functional independence and sustainability of role, whilst ensuring care feels more joined up at the point of delivery. The opportunity for assistance from a Dementia Companion will assist in achieving this.
- A service that can respond out of hours, to people living with dementia and their carers who are in crisis. This will result from having a properly specified crisis resolution service for people with dementia.
- Efficient and effective use of inpatient resources. This will result from the provision of sufficient numbers of dementia support workers to enable the needs of people with dementia to be met in a more efficient way, whilst planning for discharge at the point of admission.
- Robust and effective early discharge arrangements. This will result from dementia support workers working together with Dementia Companions, independent sector providers and home treatment services to ensure that adequate community-based support is provided.
- Palliative care arrangements that are more responsive to the needs of people with dementia. This will result from closer working with local palliative care specialists, and development and delivery of strategic intentions towards making this happen.

9 Challenges to Achieving the Vision

9.1 Financial

It is no secret that the financial situation in Shropshire is problematic. We are in a situation whereby our CCG and our Local Authority are both facing significant financial difficulties, meaning that any future development plans must demonstrate that they do not cost the system any more money to provide. It is anticipated that if we are able to realise the ambitions set out within this work, we will be able to get things right for people living with dementia a lot more than we currently do. In so doing, we will reduce not only the demand seen in terms of people requiring support from the local authority, but also the number of emergency admissions taking place at the local hospitals and patient's length of stay.

Another financial challenge is how we are able to prove that we are saving the system money. It is the dementia commissioner's job to think of ways to achieve cost savings without reducing the quality of services provided, although there are finance specialists on-hand to help with this where needed.

9.2 Contractual

Even if it can be evidenced that our plans for the future can save the money whilst improving the lives for Shropshire people living with dementia, it may be that contracting arrangements prevent these savings from being seen. Currently, some of the contractual arrangements that are in place with those who provide the people of Shropshire with services do not allow us to easily re-direct our money.

Additionally, our plans for the future may mean that the people who provide our services may be asked to do things differently. This may mean that contract variations need to be discussed between them and our contracting team who can help to overcome these barriers.

10 Concluding remarks

Although the aims set out within this document may seem ambitious, they have not been created in isolation. This document represents the combined views of many contributors, each of whom has demonstrated commitment to a common cause: to make life better for people who live with dementia. It should be recognised that achieving this strategy represents one of many steps needed to improve the lives of people living with dementia. Achieving this strategy will not solve all of the problems faced by people as a result of the condition, but it is intended to provide a solid foundation from which future work can effectively grow.

Thank you for reading this,

Pete Downer

Commissioner of Dementia Services

(On behalf of the Shropshire Health Economy Dementia Steering Group)



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