

# Warwickshire's Living Well with Dementia Strategy Refresh

2016 - 2019



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# Foreword - Councillor Jose Compton

I am delighted to introduce Warwickshire's Living Well with Dementia Strategy Refresh 2016 - 2019. This strategy refresh details progress and achievements since the launch of Warwickshire County Council's first dementia strategy in 2011 and also provides information on our priorities in relation to dementia in Warwickshire over the next three years.

Although diagnosis rates are improving, there is still room for more to be done to support people to come forward for a memory assessment. People need to understand that with the right support and services, it is possible to live well with dementia. I am confident that by progressing our objectives and priority areas we will be able to support more people to receive support following a diagnosis and in turn support them to live at home, independently for longer.

Also, carers and families of people with dementia are at risk of isolation and experiencing poor health outcomes, this strategy refresh puts forward priorities that, when delivered, will help ensure that people with dementia, as well as their carers, are offered support, information and advice at crucial times along their journey with dementia.

The delivery plan that underpins this strategy will be the mechanism by which we deliver our objectives. As portfolio holder for Adult Social Care, I will take a role in overseeing the progress of this delivery plan. Having had personal experience of caring for someone with dementia myself, I realise the importance of ensuring that Warwickshire County Council delivers excellent dementia care and support for the people of Warwickshire and the county can be regarded as a dementia-friendly place.



**Councillor Jose Compton**

Portfolio Holder/Cabinet Member for Adult Social Care  
Warwickshire County Council



### Foreword - Councillor Les Caborn

Dementia is one of our most significant public health priorities, as it has far reaching effects on people who live with the condition, their carers, family, friends, communities, businesses, health, social care and voluntary services and the economy. It is estimated that by 2025, over 11,000 people aged over 65 will be living with dementia in Warwickshire. By 2020, around one fifth (18%) of those aged over 80 in Warwickshire are projected to have dementia.

We have listened to people who live with dementia and those who care for them about their needs and, although much progress has already occurred, we recognise that there is still a great deal to be done to increase timely diagnosis rates and improve access to co-ordinated but personalised advice, information, care and support.

This strategy outlines Warwickshire County Council's commitment to improving the lives of people living with dementia and how we can work in a more integrated way with our strategic partners across the county to ensure that people regard Warwickshire as a place where they can live well with dementia. For example, we want our communities, organisations and businesses to be more understanding of dementia and so, through the work of the Coventry and Warwickshire Dementia Action Alliance, we will continue to work towards supporting more Dementia-friendly Communities and encouraging more individuals to become Dementia Friends.

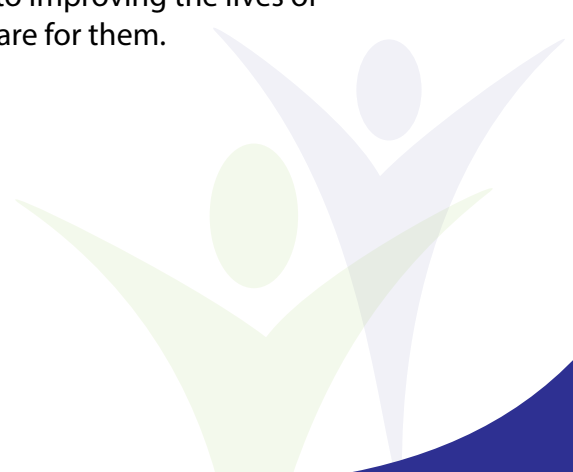
Warwickshire County Council is also committed to ensuring that our local workforce is knowledgeable and skilled in communicating with, supporting and caring for people with dementia. This does not just include those working in health and social care services but also includes people from a range of organisations across Warwickshire such as pharmacies, libraries, leisure centres, and those working for District and Borough Councils, the Fire Service and the Police.

We will continue to raise awareness and develop and commission services that support people with dementia to live well and enjoy a healthy lifestyle as this enhances their physical and emotional wellbeing as well as the wellbeing of their family, friends and carers. We will also continue to promote the benefits of a healthy lifestyle to reduce the risk of developing dementia in the first place and delaying progression of the disease for those who have a diagnosis.

The impact of dementia can be far-reaching, but by increasing awareness and understanding of dementia we can make a real difference to improving the lives of people living with dementia and also support those who care for them.



**Councillor Les Caborn**  
Portfolio Holder for Health  
Warwickshire County Council



# Introduction

In 2011, Warwickshire County Council (WCC) in collaboration with health, voluntary and independent sector partners, published its first Dementia Strategy<sup>1</sup>. This strategy had a vision that by 2014, all people with dementia would have access to high quality integrated services across health and social care from highly skilled staff.

Warwickshire's refreshed Living Well with Dementia Strategy 2016 - 2019, details the extent to which WCC, our partners, people with dementia and their carers feel we have achieved this. This is based on what people with dementia, their carers and professionals working within dementia care in Warwickshire have told us during a public consultation held in 2014. Overall, although much progress has been made to deliver against the original objectives set in 2011 there is still much that needs to be done to fully realise this strategy's vision.

A delivery plan underpins this strategy that outlines key priorities for further commissioning activity and delivery of services and support for people with dementia and their carers between 2016 - 2019. **(Appendix 1)**

This strategy refresh is delivered within a context of significant reform within health and social care including the implementation of the Better Care Fund 2013 (known locally as Warwickshire Cares Better Together) and the Care Act 2014, both of which focus on the delivery of support that is personalised and promotes prevention and wellbeing. It is therefore timely to refresh Warwickshire's Dementia Strategy to ensure that it reflects current national and local priorities, through commissioning intentions, related to dementia care and support.

<sup>1</sup> Warwickshire County Council (2011) Living Well with Dementia in Warwickshire 2011 – 2014.



# Vision

The vision for Warwickshire's Living Well with Dementia Strategy refresh 2016 - 2019 is that **Warwickshire is a place where people can live well with dementia**. This means that people with dementia and their carers:

- Have access to a timely diagnosis of their condition and are offered appropriate post diagnosis support following this;
- Have access to high quality, personalised and integrated services across health and social care;
- Are provided with support that is tailored to their requirements and is delivered by skilled and knowledgeable staff;
- Have access to information and services that focus on early intervention, prevention and the importance of staying healthy at all ages;
- Experience less stigma and discrimination as awareness of dementia and the creation of 'Dementia-friendly' communities increase.



# Principles

The following principles underpin the delivery of this strategy's vision:

- People are provided with information and support to reduce their risk of developing dementia;
- People diagnosed with dementia and their carers will be offered information about support in their local area at the point of diagnosis;
- People with dementia will be able to access multi-disciplinary teams and joined up services;
- Carers will know they are entitled to an assessment of their needs and will have access to the right support at the right time;
- Providers of services for people with dementia will ensure that all their employees are appropriately trained in dementia care according to their roles and responsibilities;
- The provider market, including the voluntary and third sector will be shaped to respond to the dementia challenge locally;
- The environment in which care is delivered in is, or is aspiring to be, 'dementia-friendly';
- WCC Public Health, WCC Strategic Commissioning, Clinical Commissioning Groups and Coventry and Warwickshire Partnership Trust (CWPT) will work together to achieve timely diagnosis rates for dementia, and improve availability of integrated post diagnosis support. In doing so we will also collaboratively work to make best use of available resources;
- GPs will be central to the diagnosis pathway by facilitating access to assessment services and by providing ongoing primary care support;
- WCC will monitor progress and achievements by undertaking co-production with people with dementia and their carers.



# National Context

The development of Warwickshire's Living Well with Dementia Strategy refresh 2016-2019 is shaped by the following national policy framework:

- Prime Ministers Challenge on Dementia 2012, and Prime Ministers Challenge on Dementia 2020
- Better Care Programme 2013
- Care Act 2014
- Dementia 2015 – Aiming Higher to Transform Lives (report by the Alzheimer's Society)
- NHS Outcomes Framework 2015-2016
- NHS 5 year Forward View – NHS England 2015
- Public Health Outcomes framework
- Quality and Outcomes Framework (QOF)
- National Institute for Health and Care Excellence (NICE) Dementia Guidelines

Full details of each are contained within **Appendix 2**





## Local Context

This strategy, and its delivery plan, links closely with a number of other programmes of work, and should be considered in parallel with the following:

- Warwickshire's Extra Care Housing Position Statement 2014
- Warwickshire's Health and Wellbeing Strategy 2014-2018
- Warwickshire's Joint Carers Strategy Refresh 2012-2015 (version being drafted 2016 – 2019)
- Development of Warwickshire's Assistive Technology Statement of Intent
- Coventry and Rugby CCGs Commissioning Intentions 2014-2016
- Warwickshire North CCG Commissioning Intentions 2015-2016
- South Warwickshire CCG Commissioning Intentions 2016-2017
- Warwickshire Cares Better Together work programme 2015-2020



## How will this strategy be delivered?

This strategy details the integrated work that Warwickshire's multi-agency Dementia Strategy Delivery Board and work streams have delivered over the last five years. Members of this board include; WCC Strategic Commissioning and Public Health, South Warwickshire Clinical Commissioning Group (SWCCG), Warwickshire North CCG (WNCCG), Coventry and Rugby CCG (CRCCG), Coventry and Warwickshire Partnership Trust (CWPT), South Warwickshire Foundation Trust (SWFT), George Eliot Hospital (GEH), Rugby St Cross Hospital, University Hospital Coventry and Warwickshire (UHCW), Coventry City Council (CCC), The Alzheimer's Society, AGE UK, (specific details of board members are available on page 33).

The board and work streams have collectively worked to deliver the objectives of the first dementia strategy, published in 2011. This governance mechanism will also take forward the objectives identified within this strategy using the delivery plan as a guide to delivery (Appendix 1)



# Dementia Needs Analysis

## The prevalence of dementia in the UK

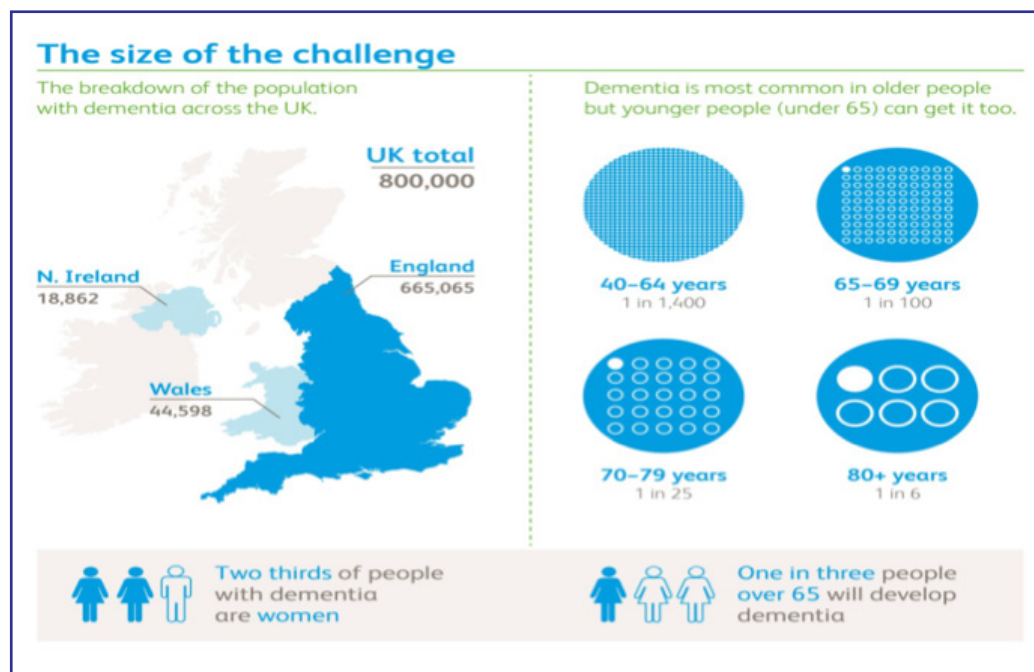
There are 850,000 people living with dementia in the UK currently; this number is projected to increase to over 1.1 million by 2021 and 2 million by 2051.<sup>2</sup>

Early onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK. It is estimated that there are now at least 15,034 people with early onset dementia (i.e. people before the age of 65 years) in the UK. This number is predicted to increase to 17,279 by 2021 and 17,584 by 2051, an increase of just 17% over the next 45 years.<sup>3</sup>

It is estimated that there are 11,392 people from black and minority ethnic (BME) communities who have dementia in the UK. 6.1% of all those are early onset, compared with only 2.2% for the UK population as a whole, reflecting the younger age profile of BME communities.<sup>4</sup>

Figure 1 highlights the size of the challenge and highlights that dementia prevalence grows with age and affects more women than men.<sup>5</sup>

**Figure 1: Size of the dementia challenge nationally**



<sup>2</sup>Dementia UK Second Edition, Alzheimer's Society, 2014

<sup>3</sup>Dementia UK report by Personal Social Services Research Unit (PSSRU), London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society 2007

<sup>4</sup>Projecting Adult Needs and Service Information System (PANSI), Sept 2014

<sup>5</sup>Source: <http://dementiapartnerships.com/recognising-signs-of-dementia/> 2012

It is however worth noting that a recent study<sup>6</sup> has highlighted that dementia levels in some western countries, including the UK, could be stabilising. This study put forward evidence that some of the projections around dementia prevalence that were set some years ago were exaggerated. Throughout the delivery of this strategy the projected numbers and actual prevalence of dementia in Warwickshire will be monitored. There will be a full Joint Strategic Needs Assessment of dementia in Warwickshire during 2016 which will assist with this.

### **The prevalence of dementia in Warwickshire**

It is estimated that there are currently 7,615 people in Warwickshire living with dementia. This number will increase by approximately 34% to just over 11,000 in the next ten years. Of these, two thirds of people with dementia live in the community in their own home.<sup>7</sup>

The percentage of adults (18+) with dementia (2012/13) was 0.63% (England average 0.57%). In Warwickshire this ranges from over 1,800 people in Stratford-on-Avon district to around 700 in North Warwickshire borough.

These demographic pressures will bring increased demand for support services and Warwickshire's Living Well with Dementia Strategy refresh 2016-2019 focuses on how we will tackle these pressures locally.

### **Early onset dementia**

According to the recent projections, there are currently 147 people with early onset dementia in Warwickshire (people under the age of 65); this number is set to rise by 6% to 157 over the next 15 years.<sup>8</sup>

Younger people with dementia have specific needs, which generic dementia services may not be able to address. Warwickshire County Council and partners will plan to ensure age-appropriate services are available to younger people who develop dementia. We will also work with employers to help enhance awareness and understanding of the challenges that dementia presents to organisations and business, including the impact on families and carers.

<sup>6</sup>The Lancet, Neurology, Dementia in western Europe: epidemiological evidence and implications for policy making, August 2015

<sup>7</sup>Warwickshire's Joint strategic needs assessment 2015

<sup>8</sup>Projecting Adult Needs and Service Information System (PANSI), Sept 2014

**Table 1: Early Onset Dementia Projections for Warwickshire**

	2014	2015	2020	2025	2030
Males aged 30-39 predicted to have early onset dementia	2	2	3	3	3
Males aged 40-49 predicted to have early onset dementia	8	8	7	7	7
Males aged 50-59 predicted to have early onset dementia	44	45	49	48	45
Males aged 60-64 predicted to have early onset dementia	32	32	34	40	40
<b>Total males aged 30-64 predicted to have early onset dementia</b>	<b>87</b>	<b>87</b>	<b>94</b>	<b>98</b>	<b>94</b>
Females aged 30-39 predicted to have early onset dementia	3	3	3	3	3
Females aged 40-49 predicted to have early onset dementia	10	9	8	8	8
Females aged 50-59 predicted to have early onset dementia	28	28	31	30	27
Females aged 60-64 predicted to have early onset dementia	20	19	20	24	24
<b>Total females aged 30-64 predicted to have early onset dementia</b>	<b>60</b>	<b>60</b>	<b>63</b>	<b>66</b>	<b>63</b>

Figures may not sum due to rounding.

## Dementia support for minority ethnic communities

Table 2 illustrates the number of people from BME groups using Warwickshire County Council dementia support services compared to other White British groups using the same services.<sup>9</sup>

**Table 2: Number and % proportion of people from white and BME groups using WCC dementia services**

BME	Total	Ethnicity Count	Total	Proportion
BME	39	Caribbean	6	0.4%
		Chinese	2	0.1%
		Indian	17	1.2%
		Other Asian	4	0.3%
		Other Ethnic Group	3	0.2%
		Other Mixed	1	0.1%
		Pakistani	1	0.1%
		White & Asian	2	0.1%
		White & Black Caribbean	3	0.2%
White	1418	Gypsy/Roma	1	0.1%
		Not Recorded	48	3.3%
		Not Stated - Adults only	29	2.0%
		Other White	28	1.9%
		White British	1281	87.9%
		White Irish	31	2.1%
<b>Total</b>	<b>1457</b>	<b>Total</b>	<b>1457</b>	

The statistics within table 2 suggest that there is a significant difference in the numbers of people using services from a White British background compared to non-white BME communities within Warwickshire. Further work needs to be undertaken to understand if these numbers are representative or if low numbers suggests that barriers exist that are preventing people from BME communities accessing sources of care and support. Specific actions in relation to this are detailed in the 'what will we do' sections for each of the objectives.

<sup>9</sup>Warwickshire County Council CareFirst recording system, 2015

### Funding and costs of dementia care

Dementia UK<sup>10</sup> estimates that the total annual cost per person with dementia nationally based on 2012/13 prices are as follows;

- People in the community: £29,298
- People in residential care: £36,738
- People in all settings: £32,242

Dementia costs society an estimated £26 billion a year, more than the costs of cancer, heart disease and stroke. In the next 30 years, predicted costs are likely to treble.<sup>11</sup>

Recent research has estimated that by 2030, dementia will cost businesses more than £3 billion, due to increases in the numbers of people leaving employment to care for people with dementia.<sup>12</sup>

The Council is working with reduced public funding, which will influence the way support services are delivered in the coming years. This strategy refresh has therefore taken place within the context of financial restraints. As a result the delivery of objectives will be by working collaboratively as partners to ensure best value is achieved in commissioned services. There is, and will continue to be, an emphasis on improving services to ensure they meet people's needs, whilst working within reduced public budgets.

### What have we done so far and what do we still need to?

Since the launch of Warwickshire's Living Well with Dementia Strategy in 2011, there has been significant progress in terms of highlighting dementia as a key issue at a local level.

Warwickshire's Living Well with Dementia Strategy refresh 2016-19 puts forward the following five strategic objectives;

1. Raising awareness and understanding of dementia
2. Timely diagnosis and support
3. Living Well with Dementia through the provision of a wide range of community support services including support to carers
4. Living Well with Dementia in acute/residential/housing with care settings
5. An informed and effective workforce across all services

These are linked to eight outcomes or 'I' statements that were identified by undertaking consultation with people with dementia and their carers;

1. I know where to get information and advice
2. I know how to reduce my risk of developing dementia

<sup>10</sup> Dementia UK: second edition. Alzheimer's Society, 2014.

<sup>11</sup> Department of Health, 'Prime Minister's Challenge on Dementia 2020' Feb 2015.

<sup>12</sup> Centre for Economic and Business research, 'Cost of dementia to business', 2014

3. I receive a diagnosis in a timely manner and am provided with support tailored to my individual needs following this
4. I live in a community where I feel confident to access community resources and services free from stigma or discrimination
5. My individual needs and how I want to live my life are respected
6. I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia
7. I am confident that I can get help when and if things suddenly change
8. As a carer, I am supported to balance my caring responsibilities with having a life of my own.

A summary of the results of the consultation for this strategy, including direct comments put forward by people with dementia, their carers, professionals and providers is included as **Appendix 3**.

**Table 3: Objective area and corresponding 'I' Statements**

Objective area	Outcome or 'I' statement
1. Raising awareness and understanding of dementia and ways of reducing the risk of developing dementia	<ul style="list-style-type: none"> <li>• I know where to get information and advice</li> <li>• I know how to reduce my risk of developing dementia</li> <li>• I live in a community where I feel confident to access community resources and services free from stigma or discrimination</li> <li>• I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia.</li> </ul>
2. Timely diagnosis and support	<ul style="list-style-type: none"> <li>• I receive a diagnosis in a timely manner and am provided with support tailored to my individual needs following this</li> <li>• I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia</li> <li>• As a carer, I am supported to balance my caring responsibilities with having a life of my own.</li> </ul>
3. Living Well with Dementia through the provision of a wide range of community support services including support to carers	<ul style="list-style-type: none"> <li>• My individual needs and how I want to live my life are respected</li> <li>• I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia</li> <li>• As a carer, I am supported to balance my caring responsibilities with having a life of my own.</li> </ul>
4. Living Well with Dementia in acute/residential/housing with care settings	<ul style="list-style-type: none"> <li>• I am confident that I can get help when and if things suddenly change</li> <li>• My individual needs and how I want to live my life are respected</li> <li>• I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia</li> <li>• As a carer, I am supported to balance my caring responsibilities with having a life of my own.</li> </ul>
5. An informed and effective workforce across all services	<ul style="list-style-type: none"> <li>• I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia.</li> </ul>



The following sections provide information on progress against each of the five strategic objectives and 'I' statements since 2011 and provides details of what still needs to be done/priorities for 2016 -19.

### **Objective 1: Raising awareness and understanding of Dementia and ways of reducing the risk of dementia**

#### **'I' Statements;**

- *I know how to reduce my risk of developing dementia*
- *I know where to get information and advice*
- *I live in a community where I feel confident to access community resources and services free from stigma or discrimination*
- *I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia*

Warwickshire's first Living Well with Dementia Strategy 2011-2014 highlighted the need to increase public awareness and understanding about dementia. This is because greater awareness and understanding of dementia helps inform and encourage those worried about potential dementia symptoms (memory, confusion or other dementia symptoms), or their carers, to seek advice and assessment if required. This in turn contributes to improving overall diagnosis rates and timely support provision. Linked to this it is also important to raise awareness of the risk factors for dementia and the actions people can take to reduce these risks such as healthy eating, not smoking, increasing physical activity and reducing alcohol consumption.

In addition, greater awareness and understanding of dementia helps reduce stigma and misconceptions surrounding the condition and helps create a more inclusive society where people with dementia are supported to remain independent for longer.

National government has fully embraced raising awareness and understanding of dementia with the development of the Dementia Friends and Dementia-friendly Communities<sup>13</sup> (DFCs) initiatives and by investing £2.4 million in creating 1 million Dementia Friends by March 2015 nationally. The Alzheimer's Society now fully funds the Dementia Friends initiative and the target is 4 million Dementia Friends nationally by 2020.

<sup>13</sup>Centre for Economic and Business research, 'Cost of dementia to business', 2014.

Below are some examples of work WCC and partners have undertaken to help raise awareness and understanding of dementia over the past three years:

### **Progress/achievements since 2011;**

#### **1a. Coventry and Warwickshire's Living Well with Dementia Portal: [www.livingwellwithdementia.org](http://www.livingwellwithdementia.org)**

People with dementia, their carers and practitioners working with people with dementia told us they wanted a one stop place to go to get information about dementia and to find out about local sources of support.

As a result, WCC worked with a range of stakeholders, including people with dementia, their carers, professionals working within dementia care, CCGs and voluntary and independent service providers to create Coventry and Warwickshire's Living Well with Dementia Portal.

The portal includes a vast range of information about dementia including; services available locally, how to understand and manage the diagnosis and how carers can support and look after themselves. In addition, there is information on Dementia-friendly Communities and reducing the risk of developing dementia. A range of resources (i.e. bookmarks, leaflets, posters and wristbands) have been developed to support access to the portal and raise awareness of dementia. People can also get the latest news from the Living Well with Dementia Partnership blog and can also follow the partnership on Twitter:@DementiaCandW

Between October 2013, when the portal was launched, and July 2015 the portal has been used by over 7,300 individual users.



#### **1b. Dementia-friendly Communities**

WCC has pledged their commitment to become a Dementia-friendly Community by signing up to the National Dementia Declaration<sup>14</sup>. In January 2014,

Coventry and Warwickshire's Dementia Action Alliance (DAA) was created through a partnership between WCC, Coventry City Council, the Alzheimer's Society and organisations across Coventry and Warwickshire who submitted action plans outlining how they will work to improve the lives of people with dementia and their carers.

The DAA acts as the formal partnership to progress the Dementia-friendly Communities (DFC) agenda and has the authority to approve organisations as 'working to become dementia-friendly' as it is recognised by the national DFC programme.

<sup>14</sup> <http://www.dementiaaction.org.uk/nationaldementiadeclaration>

A person living with dementia and their carer are active members of the DAA. They have also participated in the creation of a Dementia-friendly Warwickshire short video which highlights how local businesses and organisations can become dementia-friendly. The video can be viewed by visiting the Dementia-friendly Communities page on Coventry and Warwickshire's Living Well with Dementia Portal.

As of November 2015, there were 40 organisations signed up to the DAA in Warwickshire. All those signed up to the DAA are working towards becoming dementia-friendly by actively contributing to the following:

- Raising awareness and understanding of dementia;
- Developing dementia-friendly environments;
- Reducing stigma and developing positive attitudes towards the delivery of services to those most vulnerable in our society.

To view Warwickshire's DAA action plan and to see a full list of organisations signed up to the DAA please visit; Coventry and Warwickshire Dementia Action Alliance.

### **Dementia-friendly case study examples from Coventry and Warwickshire DAA members;**

#### **Everyone Active Sports & Leisure Management Company by Darren Morris, Community Engagement Manager**

Being a leader in the Sports & Leisure Management industry and with leisure centres often being a focal point in the community, we felt that Everyone Active could make changes to ensure our services are more accessible. We currently operate leisure centres in the Nuneaton and Bedworth boroughs of Warwickshire and are aware of the predicted rises in those developing dementia in this area over the coming years.

Specific changes we have made to our services to make them more dementia-friendly include;

- All general managers and front of house staff have attended dementia awareness training;
- We have encouraged all of our staff to become dementia friends via the Dementia Friend's website;
- We offer two dementia-friendly swimming sessions, which allow people with dementia to attend with their carers or carers can wait in the café and have a break. The swimming sessions are staffed by an instructor who has been trained in dementia awareness;
- In the near future we are hoping to have a dementia coffee hour for people with dementia and their carers to coincide with these sessions.

We recognise the importance of people staying physically and mentally active following a diagnosis of dementia and are aware that our business needs to be ready to support people with dementia and their carers. We are committed to further developing our services to ensure they are dementia-friendly and our ambition is to establish Everyone Active in Nuneaton and Bedworth as a Dementia-friendly business.

### 1c. Dementia Friends

Dementia Friends is a national initiative led by central government and the Alzheimer's Society. The Dementia Friends initiative aims to change the way people think, act and speak about dementia and is based on the principle that people with dementia can live well with a little help from other people in their community. There are over 1 million Dementia Friends nationally and just over 10,000 of these are in Warwickshire. WCC has led a number of awareness campaigns and targeted promotional work to help increase the number of Dementia Friends in Warwickshire and we will continue to do this across the lifetime of this strategy.

For more information about how to become a Dementia Friend please see: [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

### 1d. Self-Care Support

In partnership with Public Health Warwickshire, the following self-care support opportunities for people with dementia have been developed:

- **Books on Prescription (BOP) for people with dementia**

Books on Prescription (BOP) Dementia is a service offered through Warwickshire Library Service. BOP dementia is a collection of 25 recommended titles for people who have dementia, are caring for someone with dementia or want to find out more information about the condition. There are four categories; Information and Advice, Living Well with Dementia, Support for relatives and Carers and Personal Stories.

Anyone can borrow the books from their local library. The books are also available for GPs and health professionals to 'prescribe' or recommend.

"Being diagnosed with dementia can be a challenging time for the individual, their family and friends. The new additions to the Books on Prescription scheme are a great source of reliable up to date information along with tips for practical and emotional support for all involved, and are essential reading for all those on the dementia journey" (Dr. Sue Pritchard, Shipston Medical Centre).

Between 1st April 2013 - 31st March 2015, there were over 14,000 loans (including renewals) of BOP books in Warwickshire (this figure includes books on mental health).

[www.warwickshire.gov.uk/booksonprescription](http://www.warwickshire.gov.uk/booksonprescription)

### • **Pictures to Share books**

'Pictures to Share' are a set of twelve illustrated books that can help professionals or informal carers communicate with people with mid to late stage dementia. The books are picture based and use images that are likely to be understood and enjoyed by people with dementia. The pictures are simple, clear and mostly colourful, with no confusing backgrounds or content that is difficult to interpret. Benefits of using the books by a person with dementia include: improved mood, reminiscence, increased engagement and communication, reduced boredom and depression and increased quality of life.

"Pictures to Share' are now available as part of the BOP Dementia collections in Warwickshire Libraries. They have also been used within care settings such as Day Care for people with dementia, and feedback from staff and people with dementia has been very positive. The use of the books helps care staff to understand people's likes, dislikes and personal history, especially with those who have lost the ability to clearly communicate.

### • **Physical Activity on Referral for People with Dementia**

Being active is beneficial for physical and mental health and can improve quality of life for people in all stages of dementia. The benefits of activity may include improved strength and balance, reducing feelings of isolation, increased confidence, increased muscle strength and joint flexibility which can help mobility and maintain independence for longer.

People in the early to mid-stages of dementia can be referred to the Warwickshire Physical Activity on Referral Scheme by their GP, Practice Nurse or another registered healthcare professional.

The scheme offers a 12 week personalised programme of physical activity at a local leisure centre. The activity programme will include gym-based activities and possibly swimming and/or exercise classes. Exercise instructors have all received dementia awareness training.

[www.fitterfutureswarwickshire.co.uk](http://www.fitterfutureswarwickshire.co.uk)

### 1d. Self-Care Support

#### People at risk of dementia

The risk of developing dementia increases with age; the older you are the more likely it will be that dementia could develop. Research<sup>15</sup> has also identified other risk factors and groups of people that may be at an increased risk of developing dementia. These include; people with Down's Syndrome, learning disabilities, Parkinson's or those who have had a stroke.

Raising awareness in the general population that a healthy lifestyle can reduce the risk of developing dementia.

Lifestyle and environmental factors have also been linked to the development of some forms of dementia such as vascular dementia (caused by reduced blood flow to the brain).

The Blackfriars Consensus (2013) reports that the general public, health professionals and policy makers are becoming increasingly aware of the links between behavioural risk factors and non-communicable diseases (such as tobacco and lung cancer or diet and cardiovascular disease). But few people are aware that many of the same risk factors could impact on the risk of dementia. It is therefore important to communicate more clearly the evidence about dementia risks, protective factors and preventive actions to the public and relevant health and care professionals and policy makers. A healthy lifestyle such as eating well, being physically active, reducing alcohol intake and not smoking can reduce the risk of some types of dementia<sup>16</sup>.

<sup>15</sup>Unlocking the Diagnosis, All Parliamentary Group on Dementia, 2012

<sup>16</sup>World Alzheimer's Report, Alzheimer's Disease International 2014

## What we still need to do to deliver Objective 1: priorities for 2016-19

What will we do?	Who	By when?
<b>1.1</b> Work with CCGs, general practice and other commissioners and providers to encourage people who may at increased risk of developing dementia to attend NHS health checks and other health reviews and to ensure they are aware of the ways in which they can reduce their risk of developing dementia.	WCC / CCGs	Start by September 2016 and then ongoing
<b>1.2</b> Work with commissioners and providers of health, social care and community services to ensure that they promote messages on the ways in which people can reduce their risk of developing dementia.	WCC / service providers	2016 and ongoing
<b>1.3</b> Raise awareness of the ways in which people can reduce their risk of developing dementia by improving information accessible through local health and wellbeing websites ( <a href="http://www.warwickshire.gov.uk/healthandwellbeing">www.warwickshire.gov.uk/healthandwellbeing</a> ) and on the Living Well with Dementia Portal ( <a href="http://www.livingwellwithdementia.org">www.livingwellwithdementia.org</a> ).	WCC	May 2016 and ongoing
<b>1.4</b> Source / develop and distribute resources about the ways in which people can reduce their risk of developing dementia. These may be used during national dementia awareness raising campaigns and other associated campaigns such as No Smoking Day and Alcohol Awareness Week.	WCC	May 2016 and ongoing
<b>1.5</b> Work with Dementia Action Alliance Co-ordinator to identify 5 Dementia Champions and equip them with the skills and resources to undertake dementia environment audits	WCC/ Dementia Action Alliance Co-ordinator	September 2016
<b>1.6</b> Complete Dementia-friendly Environmental Audits in (i) 20 public buildings and (ii) 30 care environments during 2016/2017 and (iii) all care environments that WCC commission with by 2019	WCC	(i) (ii) 2016/17, (iii) by 2019
<b>1.7</b> Have at least 120 Warwickshire organisations signed up to Coventry and Warwickshire's DAA	All Partners	2019
<b>1.8</b> Increase the number of Dementia Friends in Warwickshire to at least 30,000 by the end of 2019.	All Partners	2019
<b>1.9</b> Improve utilisation of the Physical Activity on Referral service for people with dementia living in Warwickshire	WCC	September 2016
<b>1.10</b> The number of loans of Books on Prescription dementia books increases by 1,000 loans per year	WCC	2016, 2017, 2018, 2019
<b>1.11</b> Hold an event/s to specifically engage the BME community about the issues affecting them with regards to understanding of dementia, use of services and priorities for the future – add results to this strategy's delivery plan	WCC / WREP	Sep 2016
<b>1.12</b> Increase the level of interactivity of the Living Well with Dementia Portal, to include a search for services function and the development of an online Consultation and Co-production Forum.	WCC	May 2016
<b>1.13</b> Produce and distribute Dementia Portal marketing materials and make them available to all GP surgeries, pharmacies and libraries in Warwickshire	WCC	Sep 2016
<b>1.14</b> Develop and maintain the Living Well with Dementia Portal over the lifetime of this strategy refresh 2016-2019	WCC / CCC	2019
<b>1.15</b> Increase the number of individual users of the portal from 7,300 in 2015 to 15,000 in 2019	WCC / CCC	2019

## Objective 2: Timely Diagnosis and Support

### 'I' Statements;

- *I receive a diagnosis in a timely manner and am provided with support tailored to my individual needs following this*
- *I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia*
- *As a carer, I am supported to balance my caring responsibilities with having a life of my own*

## Progress/achievements since 2011;

### 2a. Increasing Diagnosis Rates

WCC Strategic Commissioning and Public Health continue to work closely with the three local CCGs and CWPT to increase diagnosis rates in Warwickshire. Diagnosis rates in Warwickshire are improving and a strategic intention of this strategy will be to continue to build on this through close engagement and a joined up approach with all partners.

**Table 4: West Midlands Dementia Diagnosis Rates by CCG area** <sup>17</sup>

	<b>Aug 14</b>	<b>March 15</b>	<b>% increase</b>
<b>Coventry &amp; Rugby</b>	50.6%	55.6%	9.8%
<b>South Warwickshire</b>	46.0%	53.4%	16%
<b>Warwickshire North</b>	48.8%	55.5%	13%

WCC Strategic Commissioning and Public Health continue to work closely with the three local CCGs and CWPT to increase diagnosis rates in Warwickshire. Diagnosis rates in Warwickshire are improving and a strategic intention of this strategy will be to continue to build on this through close engagement and a joined up approach with all partners.

As demonstrated by Table 4 each CCG area has seen increases in the rate of diagnosis of dementia. The highest level of increase is within SWCCG; this is because a greater proportion of the population are over 65 in this area. There has also been a project for the over 75s in the south which provides specific support, via a care navigator for this group which has helped to drive diagnosis rates up. This area also had most scope to increase their diagnosis rates as their 2014 levels were the lowest amongst all CCG areas.

<sup>17</sup>NHS England HSCIC 2015



This strategy refresh has redefined its previous terminology of 'early diagnosis and support' to 'timely diagnosis and support'. This is because it is not always possible to diagnose early. If symptoms of dementia are not advanced enough a diagnosis of Mild Cognitive Impairment (MCI) may occur. This is where there is a noticeable cognitive change present but it is not severe enough to interfere with daily life or independent function.

Best practise states that a diagnosis of dementia should take place at a time that is right for the individual and their family. The benefits of early diagnosis cannot be assumed and need to be worked through on an individual case by case basis.

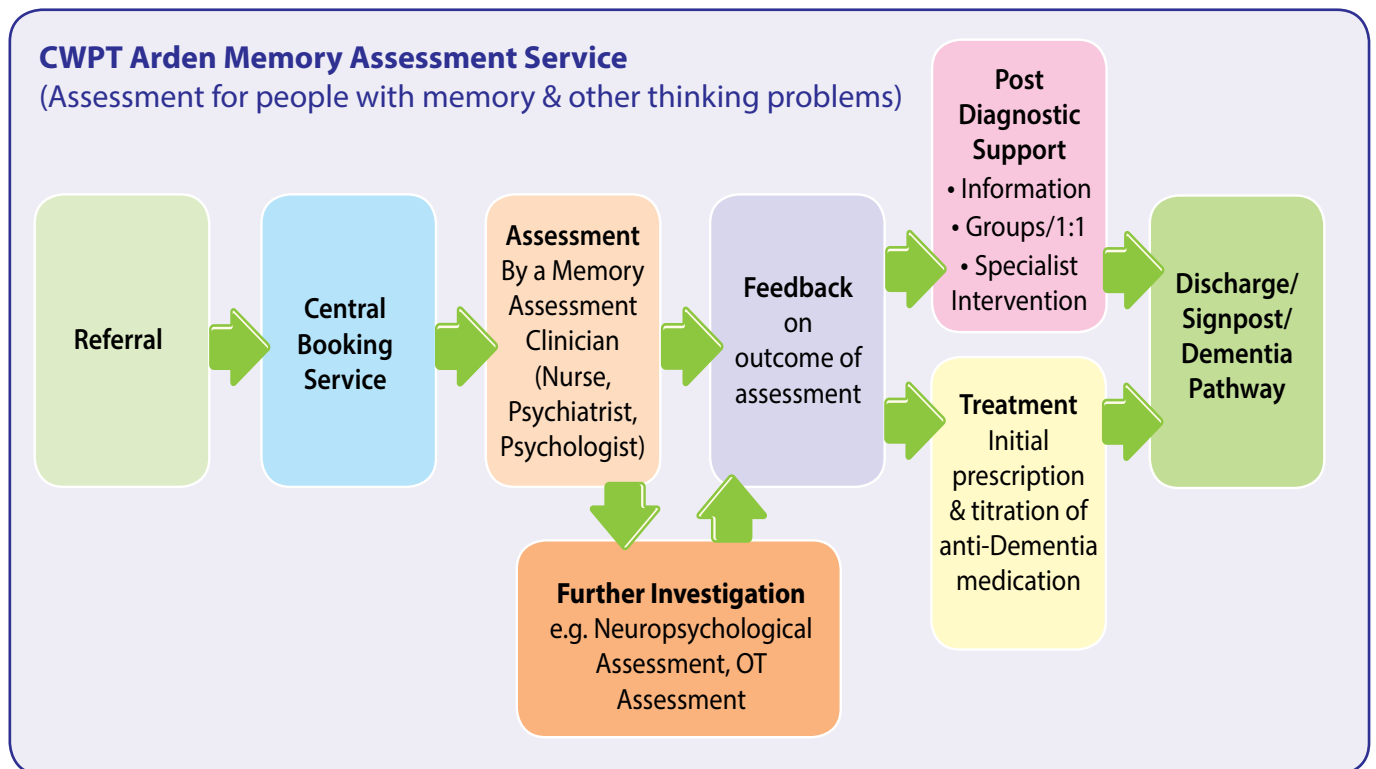
### **2b. Arden Memory Service**

The Arden Memory Service provides dementia diagnostic services and post diagnostic support for those with suspected dementia. The service is provided by CWPT and commissioned by the three local CCGs. The service has been redesigned earlier this year and is now standardised across Coventry and Warwickshire. This pathway has a focus on ensuring that timely and accurate diagnoses occur for individuals and that appropriate follow on support is offered.

### **2c. Standardised Diagnostic Pathway**

An individual may present at their GP, hospital or other place with symptoms of dementia which require further investigation and assessment by secondary mental health services. The individual will be referred to have an assessment by a memory service clinician (usually a specialist nurse, psychiatrist or psychologist) who will undertake a standardised memory assessment. It can take some time, sometimes up to three months, to undertake the investigations and tests required in order that the assessment and subsequent diagnosis is accurate. The most likely outcomes of the assessment are; diagnosis of dementia, Mild Cognitive Impairment (MCI) or another physical or mental health issue which may require further assessment or no evidence of dementia.

**Figure 2: Coventry and Warwickshire Partnership Trusts Memory Assessment Service Pathway**



## 2d. Post Diagnosis Support

It is crucially important to get the appropriate information to people at the point of diagnosis so that they have clear information about their condition and know where to go to get further support. This includes ensuring that carers are provided with support and information on managing their caring role.

WCC was involved in the development of a post-diagnosis information pack that is provided to people at the point of diagnosis by the Arden Memory Service. These packs contain a range of awareness raising and signposting resources.

At the point of diagnosis, people with dementia will also be offered the opportunity to attend a post diagnosis support group. If necessary they may be referred onto a specialist service such as Psychology, Psychiatry or Occupational Therapy. This offer will depend on the individual's level and type of dementia and whether or not they want to engage with this support.

The work of this strategy will support the national joint declaration on post diagnosis dementia care and support<sup>18</sup>. This declaration sets out an ambition to deliver better quality post-diagnostic care and the need to deliver integrated and effective services for people with dementia, their families and carers. The detail of how collectively as partners we will achieve this will be within this strategy's delivery plan (Appendix 1).

<sup>18</sup> <https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support/dementia-post-diagnostic-care-and-support>

### 2e. Dementia Navigators

In April 2015, WCC Strategic Commissioning and Public Health commissioned a new service called the Dementia Navigator Service. This is a countywide service that supports individuals that are going through the process of diagnosis and/or those that are diagnosed with dementia. The service also supports carers and families of those diagnosed.

The aim of service is to help people with dementia and their carers to 'navigate' the health and social care system as well as third sector provision, by providing them with information, advice, emotional support and signposting based on their individual needs and outcomes.

There are four full time equivalent Dementia Navigators in Warwickshire. Dementia Navigators tend to work in specific geographical areas to ensure they have expert knowledge of services and support in the areas, but provision is flexible to ensure that referrals can be managed appropriately and the needs of customers are prioritised. Dementia Navigators work closely with health and social care professionals in their area to ensure that all people newly diagnosed with dementia are referred to the service. People can also 'self-refer' to the service at any stage of their journey with dementia by calling the Alzheimer's Society. The service is promoted widely in GP surgeries, awareness events etc to help ensure that people know the service exists and can self-refer in by calling The Alzheimer's Society main office.

Between April - September 2015 the Dementia Navigator Service has supported approximately 280 customers. The majority of referrals each quarter are self-referrals (30 %) but we are seeing increasing numbers of GP and Memory Service referrals to the service (13%) and (19%) respectively.

#### **Warwickshire's Dementia Navigators service**

## What we still need to do to deliver Objective 2: priorities for 2016-19

What will we do?	Who	By when?
<b>2.1</b> Dementia diagnosis rates in Warwickshire to reach the national target of 66.7% (new targets to be set for 2017/18 when/ if new national target released)	CCGs CWPT	2016
<b>2.2</b> Explore the role of primary care in the diagnostic journey with CCG partners – SWCCG has a 'diagnosing in primary care' pilot planned to commence for 12 months beginning Spring 2016 which has an aim to increase diagnosis rates in the South of the county	CCGs	April 2016
<b>2.3</b> 100% of people diagnosed with dementia are offered a post diagnosis information pack	CWPT	June 2016
<b>2.4</b> Review equity of post diagnostic support to all groups and understand if those from BME backgrounds are equitably taking up post diagnostic support and services	WCC	October 2016
<b>2.5</b> Review the Dementia Navigator Service, with a focus on current and future capacity and produce a clear plan with recommendations for future commissioning of this service	WCC	October 2016
<b>2.6</b> Explore potential joint commissioning opportunities with CCGs for the Dementia Navigator Service demonstrating the service's benefits to the whole health and social care economy	WCC / CCGs	October 2016
<b>2.7</b> Ensure Dementia Navigators are linked into Warwickshire North CCG primary care hubs, social prescribing and Multi-Disciplinary care co-ordination for frail and vulnerable adults	WNCCG / Service providers	September 2016
<b>2.8</b> Explore the potential benefits and feasibility of Dementia Navigators undertaking basic memory tests to screen for dementia	WCC / CWPT / CCGs	March 2017
<b>2.9</b> Over 50% of people referred to the Dementia Navigator Service to have received a diagnosis of dementia in the last three months	CWPT / Service provider	March 2017
<b>2.10</b> Evidence-based psychological group interventions available to people with dementia and their carers as part of the post diagnostic process	CWPT	2016, 2017, 2018, 2019
<b>2.11</b> Post-diagnostic support tailored to those with Young Onset to be available countywide	CWPT	2019
<b>2.12</b> Scope feasibility of funding a support group for those with young onset dementia in Warwickshire until alternative voluntary sources of funding can be secured and outcomes and benefits of this groups can be understood	WCC	June 2016

### **Objective 3: Living Well with Dementia through the provision of a wide range of community support services including support to carers**

#### **'I' Statements;**

- *My individual needs and how I want to live my life are respected*
- *I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia*
- *As a carer, I am supported to balance my caring responsibilities with having a life of my own*

Two thirds of people with dementia live at home in the community. Although dementia is a progressive condition, with deteriorating function, it does not mean that people with dementia immediately lose their independence or quality of life. As the drive to diagnose earlier continues and as people's expectations about the quality of care and support increases, there will be a greater number of people with dementia being supported to remain at home for longer.

Not only does supporting people to live at home for longer help increase their health and wellbeing, it also reduces costs and pressures on health and social care. For instance, within our commissioned services such as domiciliary care we will be encouraging providers to enable customers to make and sustain community links. This will help people have access to a support network within their local community that can help them to remain at home safely for longer.

Support to carers of people with dementia as expert partners in care is essential to prevent carer breakdown or the need for further services. Local authorities have enhanced duties towards carers since the introduction of the Care Act 2015. Carers now meet eligibility criteria for assessment and support if they have needs arising from providing care to another adult which poses risk to their own health or wellbeing. Carers should be supported to:

- Carry out their caring responsibilities;
- Maintain a habitable environment;
- Develop and maintain relationships;
- Engage in work training or volunteering;
- Make use of facilities or services in their local community.

Just under 6,000 carers in Warwickshire are caring for someone with dementia<sup>19</sup>. This means that over two thirds of people with dementia in Warwickshire are supported by an informal carer. It is recognised that carers of people with dementia face a unique set of challenges, primarily due to the degenerative and progressive nature of the condition which has a wide reaching effect on the lives of those with the condition and those that care for them. The way in which a person's dementia affects them will vary, as will carers' capacity to cope, both physically and emotionally.

During 2014/15 WCC supported 178 carers of people with a primary support reason of memory and cognition or dementia to access respite or community short breaks. This represents 33% of the total number of people who accessed respite and short breaks during 2014/15.

The following work has been delivered over the lifetime of the current strategy to support people with dementia to live at home.

### **Progress/achievements since 2011;**

#### **3a. Dementia Cafés**

At a community level, Dementia Cafés provide a safe and supportive environment for people with dementia and their carers to socialise with peers. They give both people with dementia and their carers a chance to access information and advice and talk to others in a similar situation. They also run a programme of activities and informative discussions at each café which the users of the café help determine.

There are now 19 Dementia Cafés held in various locations across Warwickshire all of which are voluntary funded. Details can be found on Coventry and Warwickshire's Living Well with Dementia Portal and Warwickshire's Directory of Services; [www.warwickshire.gov.uk/directory](http://www.warwickshire.gov.uk/directory)

#### **3b. Countywide Carers Support Service**

WCC commissions a countywide carer's support service for informal carers of all client groups across Warwickshire and this is currently provided by Guideposts Trust. This service provides information, advice and support to carers. During 2015 the countywide carers support service was re-designed to more effectively and efficiently meet the outcomes of informal carers. This re-design created a hub and spoke model for carers support; this means that the carers support service ensures they link with their local community so that carers are being identified, supported and signposted onto other relevant information at key points of their caring journey.

<sup>19</sup> Warwickshire Joint Strategic Needs Assessment, carers assessment 2015

The service links in with relevant voluntary organisations, GPs or diagnosing practitioner (e.g. the memory assessment service) in order to identify and support carers at an earlier stage in their caring journey. This is positive as it means that those caring for people with dementia are now more likely to be identified by the service and offered support at an earlier stage, potentially at the point of diagnosis of the person they care for and will therefore be at less risk of emotional stress. This service re-design has also resulted in the service receiving a greater number, and quality, of referrals for carers support. This support service will be retendered during 2016 with the intention of continuing with this model of support over the next few years.

### **3c. Dementia Day Opportunities**

In Warwickshire, there are a range of specialist Day Opportunity services available for people with dementia. These services are commissioned by WCC and are provided by Age UK in the North of the county and Rugby, and by the Alzheimer's Society in the South of the county. These services aim to maintain the health, wellbeing and independence of people with dementia, whilst providing an opportunity for informal carers to have a break from their role.

Dementia Day Opportunities are available to people with dementia who are independent enough to access their local community with support and who would benefit from the social interaction and stimulation that the group environment provides. The services are personalised to individuals in terms of their likes, dislikes and expectations in order to provide a stimulating environment to maintain wellbeing and independence. So far, since the service was launched in April 2015, there has been an average of 78 users per month across all services.

WCC also offer generic older peoples' day opportunities that people with mid-later stage dementia and who are less independent could benefit from.

## What we still need to do to deliver Objective 3: priorities for 2016-19

What will we do?	Who	By when?
<b>3.1</b> Explore best practise in supporting people with dementia to remain independent at home for longer by using Assistive Technology (AT) and equipment solutions. With a particular focus on interventions that help manage; purposeful walking, challenging behaviour and complex needs	WCC	April 2017
<b>3.2</b> Work with the residential and nursing market and ECH to put a plan in place to ensure use of AT is maximised for people with dementia	WCC / Service providers	April 2017
<b>3.3</b> Ensure that WCC in house re-ablement service is able to accept and meet the needs of people with dementia for example, not just those with early stage dementia also working with informal carers to ensure they are able to effectively support the reablement journey	WCC	September 2016
<b>3.4</b> Increase the marketing of preventative and community-based initiatives such as dementia cafes via Warwickshire's Living Well with Dementia Portal	WCC / Vol and Ind Sector	September 2016
<b>3.5</b> Domiciliary Care (homecare) services are re-designed and re-commissioned with a focus on quality support for people with dementia	WCC	October 2016
<b>3.6</b> Understand the feasibility of running an Expert Carer pilot in spotting the signs of infection in a person with dementia	WCC / CWPT	December 2016
<b>3.7</b> 100% of people with dementia and/ or their carers using the Dementia Day Opportunity and Dementia Navigators services will report improved outcomes, wellbeing and independence	W Service providers CC /	March 2017
<b>3.8</b> Quarterly monitoring of both Dementia Day Opportunities and Dementia Navigator Services to take place to ensure individual service outcomes and targets are met	WCC / Service providers	2016, 2017, 2018, 2019
<b>3.9</b> Review and understand current day opportunities and day care provision in respect of capacity and future demand	WCC	Sep 2016
<b>3.10</b> Carers support services will be re-commissioned and this support service will reflect the needs and outcomes of carers of people with dementia	WCC	2016
<b>3.11</b> % of dementia carers accessing a carers assessment of needs or carers specific services increases by 10% each year until 2019	WCC	2016, 2017, 2018, 2019
<b>3.12</b> Review respite/short breaks usage by dementia carers and seek to understand if this is representative and if this is meeting carers requirements	WCC	April 2017
<b>3.13</b> Increased use of personal budgets and personal health budgets by people with dementia to help them to live well	WCC/ CCGs	April 2017
<b>3.14</b> A range of evidence-based assistive technology and Telecare solutions are made available and are marketed to people with dementia and their carers; usage by this group increases by 20% each year up until 2019	WCC	2016, 2017, 2018, 2019
<b>3.15</b> All local Housing Associations will be signed up to the Dementia Action Alliance and delivering on their action plans	Housing Providers / WCC	2019



### **Objective 4: Living well with dementia in acute/residential/housing with care settings**

#### **'I' Statements;**

- *I am confident that I can get help when and if things suddenly change*
- *My individual needs and how I want to live my life are respected*
- *I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia*
- *As a carer, I am supported to balance my caring responsibilities with having a life of my own*

As the needs of a person with dementia progress, an increased amount of support at home and/or in acute, residential, nursing or housing with care services, is likely to be required. If any of these services or support is required, it is important that people with dementia are still supported to live well with their condition. At the mid to later stages of dementia, people are likely to be experiencing diminished communication or comprehension, they may be agitated, confused or disorientated and/or they may also be frail with deteriorating physical health. For these reasons, the needs of people with dementia can challenge health and care services, it is therefore essential that acute, residential, nursing and housing with care services are well equipped to meet the needs of the growing number of people with dementia using their services.

### **Progress/achievements since 2011;**

#### **4a. Acute Hospitals**

Within Acute Hospitals research has shown that people with dementia are likely to experience markedly poorer outcomes compared to those without dementia<sup>20</sup>.

Key facts:

- Currently, 1 in 4 beds in an acute general hospital is estimated to be occupied by someone with dementia<sup>21</sup>.
- People with dementia will be admitted to hospital and will stay in for longer than other older people.
- The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and their physical health.
- People with dementia in hospital are much more likely to be discharged to a care home and/or be prescribed antipsychotic medication than older people in hospital<sup>22</sup>.

<sup>20</sup> The Journal of Quality Research in Dementia Issue 8, The care of people with dementia in general hospital, Bart Sheehan, Chris Stinton and Kate Mitchell, 2013

<sup>21</sup> Acute Awareness: improving hospital care for people with dementia, The NHS Confederation, 2010

<sup>22</sup> Counting the Cost: caring for people with dementia on hospital wards Alz Society 2009

The following work to respond to the challenge of dementia has been undertaken in Warwickshire's acute hospitals over the last four years:

### South Warwickshire Foundation Trust (SWFT):



- Delivery of 'Excellence in Dementia Care bundle in Acute Hospitals' (implementing a set of evidence based interventions to improve clinical practice, whilst also providing patients with dementia with respect, dignity and compassion)
- South Warwickshire NHS Foundation Trust (SWFT) Anti-Psychotic medicine prescribing – remaining focussed on improving prescribing practices and ensuring patient safety;
- Majority of SWFT staff have become Dementia Friends;
- Implementation of the Butterfly Scheme©;
- Partnership working with volunteer organisations, local schools and colleges to improve patient experience and provide therapeutic interventions;
- Mandatory annual dementia awareness training for all SWFT staff;
- Signposting and promotion of common core services, resources and literature;

### George Eliot Hospital (GEH):

- Implementation of ROSE scheme (Respect, Orientation, Support and Empathy); within the ward areas at GEH;
- Monthly dementia awareness training sessions available for all staff within the hospital;
- Encouraging staff to become Dementia Friends;
- Volunteer programme underway to train and support volunteers in dementia care;
- Monthly Dementia Link Nurse meeting to share best practice in dementia care and disseminate feedback to ward areas;
- Use of MyLife Software<sup>23</sup> to support therapeutic reminiscence;
- Links with the George Eliot Medicines Management group to support best practice with prescribing and monitoring medications.

<sup>23</sup> MyLife Software is a software solution that provides communication, interactive games and builds life stories with and for people with dementia: <http://mylifesoftware.com/>

### University Hospital Coventry and Warwickshire (UHCW):



- Delivery of care in accordance with the UHCW 'Forget Me Not' care bundle whose primary focus is on 'Getting to Know Me' documentation, assistance with nutrition and fluids, effective and regular communication by various means and provision of a dementia-friendly environment. It also promotes the use of blue pillowcases for easy identification of people who have dementia and may need extra assistance;
- Remaining focussed on improving prescribing practices, ensuring the prescribing of anti-psychotic drugs is kept to a minimum and supported by detailed assessment and plans in order to optimise patients, wellbeing at all times;
- Dementia awareness training to medical, nursing, support, administrative, domestic and portering staff;
- Provision of a dementia lounge designed to enhance a homely environment away from the clinical areas;
- Partnership working with volunteer organisations to provide Dementia Friends who offer non-clinical support, social activity and reassurance;
- Encouraging staff to become Dementia Friends;
- Signposting and promotion of common core services, resources and literature;
- Protecting individuals, rights by ensuring the principles of the Mental Capacity Act are adhered to.

#### **4b. Re-design and re-tendering of residential and nursing care**

80% of residents within residential care are suspected to have dementia or significant memory problems. A survey by the Alzheimer's Society<sup>24</sup> revealed that 32% of people with dementia had moved care home more than once; indicating that many care homes are unable to meet the increasing needs of people with dementia. Overall, the survey suggested that there were 'low expectations' about the quality of life of people with dementia in care homes; something that needs to be challenged by commissioning that values the delivery of quality outcomes and person-centred care for people with dementia.

<sup>24</sup> Low Expectations, Alzheimer's Society, 2013

The split between ordinary (or 'higher dependency') residential care and specialist dementia care has shifted considerably over the last few years. In the independent sector, many homes are now dual-registered so that if demand for dementia placements was to increase proportionately then availability could adapt accordingly.

WCC has worked closely with CCGs to create an outcome and quality-focused service specification for the procurement of residential and nursing services. This includes specific requirements around the provision of residential and nursing care for people with dementia. Within this there is also a desire to drive up the skillset of residential and nursing home staff in respect of dementia care.

In Warwickshire, our vision is to have high quality care home services that promote individual wellbeing and ensure a good quality of life for all older people and adults with disabilities. We have worked in partnership with local CCGs to develop an outcomes-based approach to commissioning for residential care. This focuses on;

- Outcomes that reflect what is most important to our residents
- Quality Standards that are clear and measurable, support continuous service improvement and reward innovation
- A Quality Assurance approach that protects the safety of residents and creates the conditions for a service that recognises the individual and their right to dignity, respect and empathy in care.

Dementia requirements in the new service specification include;

- The creation of dementia-friendly environments in care homes;
- The provision of dementia person centred care;
- Standards for;
  - I. Communication
  - II. End of life
  - III. Supporting the health needs of people with dementia

The current expected timeframe for the implementation of the new contract is August 2016.

### **4c. Extra Care Housing**

People who live in Extra Care Housing (ECH) have their own self-contained home, their own front door and a legal right to occupy the property, with varying levels of care and support available on site 24 hours. Extra Care Housing is also known as assisted living or housing with care. Flats / houses can either be purchased outright or on a shared ownership basis or can be rented, depending on people's preference and circumstances.

As well as enabling couples to stay together, extra care can help people with dementia who live alone to remain independent.

Within the delivery plan of the Dementia Strategy Refresh 2016-2019, WCC will be working closely with the provider market and customers and carers to scope out and develop an improved offer of ECH for people with dementia within Warwickshire.

WCC will also be working with current ECH housing providers to ensure that current ECH services are dementia-friendly. The age of people living within current ECH schemes, being 55 plus, means that many will go onto develop dementia or will be living near to people with dementia. It is therefore essential that awareness and understanding of dementia is raised to minimise stigma or misconceptions.

Figure 3 below<sup>25</sup> provides an example of the options we might consider as we undertake work to understand the need for dementia ECH in Warwickshire:

**Figure 3: Potential ECH dementia options/models**

<b>Integrated:</b> People with dementia live in apartments alongside all other residents in the scheme.	<b>Separated:</b> People with dementia are clustered together within a separate self-contained area of the scheme (e.g. a wing or floor).
<b>Specialist /dedicated:</b> A scheme where only people with dementia live.	<b>Hybrid / other:</b> Housing based provision alongside a care home (e.g. specialist residential care and Housing based dedicated scheme).

WCC have been engaging customers on potential models of Dementia Extra Care Housing during 2015 with a view to options being developed by spring 2016. We have consulted the market on these options during January 2016 with a view to tendering a Dementia ECH model by October 2016.

As well as scoping the potential development of dementia specific ECH, WCC will be working with the current providers of ECH to raise awareness and understanding of dementia with the residents of current generic ECH schemes. This includes engaging the current schemes on the potential dementia options, providing dementia resources and information and offering Dementia Awareness sessions to individual ECH schemes. Providers of ECH will also be offered a dementia-friendly environment audit where they can learn how to improve the environment to be more dementia-friendly.

<sup>25</sup> Association of Dementia Studies, University of Worcester; Housing and Dementia Research Consortium, 2014.

### 4d. Dementia-friendly environments

The physical environment can have a major impact on a person's experience of care and support. Research and best practise<sup>26</sup> has found that the lives of people with dementia can be significantly improved by making, often relatively minor, changes to physical environments. Positive changes to physical environments include:

- Making places light and airy
- Careful use of colours and design
- Careful use of floor covering
- The creation of quiet/sensory rooms away from the main activity of the care environment
- Ensuring care environments are easy to navigate
- The creation of dementia-friendly gardens and/or accessible outside spaces.

This is because dementia can impact on a person's sight, perception and ability to navigate within physical environments. It is estimated that 80,000 people with dementia in England also experience significant sensory loss<sup>27</sup>. If thought is not given to the way that a person with dementia interacts with their environment, this can result in increased agitation and behaviours that challenge, falls, confusion and can hinder the delivery of person-centred care.

In April 2014, WCC was able to launch a £100k capital investment initiative to improve the environment within care homes to the benefit of people with dementia. Four Warwickshire care homes were successful in securing funding and developments included creating sensory gardens, tea rooms and conservatories to enhance quality of life for care homes residents. An overview of these projects is contained within **Appendix 4**.

Given that these projects were completed during the summer of 2015, the outcomes and benefits of the developments are yet to be fully known. However, early indications are that residents are experiencing pleasure from using these spaces; they have also had a positive impact on families of residents when they visit their loved one and they can enjoy the spaces together. The developments have also had a positive impact on staff morale. For some of the projects, enhancing the spaces has had an added benefit of encouraging providers to develop other spaces not covered under the funding and at their own expense. For example, one home developed a quiet room for residents and families to use which was previously being used as a storage room as it was close to the garden area which was transformed as part of the project funding.

A full review of outcomes for this project was undertaken April 2016 and will be presented to Warwickshire's Dementia Board.

<sup>26</sup> <http://www.kingsfund.org.uk/projects/enhancing-healing-environment>

<sup>27</sup> <http://www.pocklington-trust.org.uk/researchandknowledge/publications/Dementia>

### 4e. Secondary Mental Health Care

Community dementia service provided by CWPT offers crisis and out of hours responses to situations of need where someone might require secondary mental health assessment and/or in patient services.

At this point carers' needs are also assessed and services offered such as psychological therapy to the carer or a referral to the increased access to psychological therapies (IAPT)<sup>28</sup> service for those carers displaying signs of anxiety and/or depression.

### 4f. End of life care

As dementia is a progressive, terminal condition for which there is currently no cure it is extremely likely that the end of life of person with dementia can be planned for. In addition, given that a person with dementia is likely to have diminishing capacity and clear communication may be difficult for them, it is extremely pertinent to ensure that timely diagnoses occur, so that individuals are given the time to consider and plan their end of life wishes.

Key Facts:

Around 500,000 people die in England each year

- of these 17,177 die of dementia
- the lead cause of death in females over the age of 80 is dementia<sup>29</sup>
- 20% die in care homes
- 56% die in hospital<sup>30</sup>

WCC ensures that contracts with providers for dementia-specific services such as; the Dementia Navigator Service, Day Opportunities, Residential and Nursing and Domiciliary Care, include a focus on discussing end of life care planning with individuals and carers at an early stage of service provision. These contracts also require advice and further signposting to be offered as part of the core offer within this service.

Within the provision of care there should be a focus on quality of life at all stages. This is why WCC is currently investing time in developing clear quality standards for residential and nursing care placements which emphasise the need to respect people's choices at the end of life and to provide dignified care. In addition, within our Dementia Navigator and Day Opportunities contracts, we commission providers to support people to plan for the future and to help them arrange power of attorney and think about setting up advance directives. Within domiciliary care, providers are commissioned to specifically ask customers about their needs, wishes and preferences at the end of life and to consult family and carers as part of this.

<sup>28</sup> IAPT not available to people with dementia only their carers

<sup>29</sup> Office for National Statistics 2014

<sup>30</sup> National Audit office 2010



Coventry and Warwickshire's acute hospitals and hospices have adopted the national best practise of the *Amber Care Bundle*<sup>31</sup>. This is based on advanced care planning and ensuring the patient's wishes are central to end of life care planning and is used for all life-limiting conditions.

WCC and partners will encourage and support the use of the Gold Standards Framework<sup>32</sup> within Health and Care services which is a commitment to support, training, innovations and developments leading to improvements in end of life care delivered by front line staff in a variety of settings. For example within the new residential and nursing contract WCC will require providers to adhere to the principles of the Gold Standards Framework within their training of staff.

### What we still need to do to deliver Objective 4: priorities for 2016-19

What will we do?	Who	By when?
<b>4.1</b> Full outcomes evaluation of Dementia-friendly Environments Capital Projects undertaken with recommended further actions	WCC	April 2016
<b>4.2</b> Co-produce a model of dementia ECH with people with dementia and their carers.	WCC	April 2016
<b>4.3</b> Dementia ECH operational during 2017-2018 resulting in more people being supported to live in the community for longer and reducing care home placements	WCC	2017
<b>4.4</b> 100% of current generic ECH schemes are offered dementia awareness training	WCC/Service providers	Jan 2017
<b>4.5</b> Outcome-focused specification for residential and nursing care, which include dementia specific requirements and focuses on quality, is developed and commissioned	WCC	August 2016
<b>4.6</b> Specifications for residential and nursing care contain enhanced requirements around good end of life care planning for all people including any specific requirements for people with dementia	WCC/CCGs	August 2016
<b>4.7</b> 100% of people with dementia, who use the Dementia Navigator Service, are offered support to plan for the future	Service provider	March 2017
<b>4.8</b> Acute Trusts continue their delivery of dementia specific work as defined within the 'what have we done' section of this strategy	Acute Trusts	2016, 2017, 2018, 2019
<b>4.9</b> Establishing links with Warwickshire's Accommodation with Support market that is affordable, tailored to geographical demand and reflects specific needs.	WCC	2016, 2017, 2018, 2019

<sup>31</sup> The AMBER care bundle provides a systematic approach to manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying in the next one to two months. It is an intervention that can fit within any care pathway or diagnostic group for patients whose recovery is uncertain.

<sup>32</sup> The National End of Life Care Programme, National Gold Standards Framework, 2012



### **Objective 5. An informed and effective workforce across all sectors**

#### **'I' Statements;**

- *I receive care and support from staff who are skilled and knowledgeable in supporting people with dementia*

The quality of the workforce is paramount in ensuring delivery of good dementia care across all areas of the dementia pathway.

WCC Learning and Development team, in partnership with Public Health Warwickshire and a number of external agencies, have undertaken significant development work to help ensure that the health and social care workforce, and people working in front line community services, are skilled and competent in supporting people with dementia.

#### **5a. 2014-15 Workforce Dementia Vision and Pledge**

To maximise the provision of integrated, high quality, compassionate care and support for people living with dementia and their carers, agencies across Coventry and Warwickshire are working in partnership to improve dementia diagnosis rates, health and care services, and the skills and awareness needed to ensure a capable and confident workforce.

To raise the profile of the wider contribution that can be made in care and community settings, a joint Coventry and Warwickshire Vision for Dementia Care was developed and launched in July 2014. It describes what is expected by individuals and organisations, to meet the level and quality of care and support expected.

The Vision is that the health and social care sectors pledge to provide people with dementia and their carers with high quality services, and to take action to drive up the quality of the workforce.

#### **Coventry and Warwickshire Vision for Dementia Care**

### 5b. Care Fit for VIPS Training; online, specialist and leadership

#### • Online

Care Fit for VIPS is a free, online development toolkit for managers of care homes built on the VIPS Framework developed by Professor Dawn Brooker at the University of Worcester's Association for Dementia Studies; it gives care homes the tools to develop person centred care for people with dementia.



As part of the roll out of this tool WCC commissioned 25 half-day briefing sessions for Warwickshire care home managers and senior staff to show them how to use the tool and encourage them to move towards person-centred care.

#### • Dementia Leadership and Specialist Training

Following on from the sessions to introduce the online toolkit a round of specialist and leadership care for VIPS training courses were commissioned from the Association of Dementia Studies. This training was aimed at care home managers and seniors who wanted to develop their dementia-specific leadership skills and who wanted to understand how a person-centred care ethos could be embedded within the culture and values of a residential home. The specialist course was aimed at staff that work directly with people with dementia and have responsibility for the development and delivery of their care plans on a day-to-day basis, again helping them with techniques to embed the delivery of person-centred care. A total of 90 managers or senior care home staff attended this training between 2013-14.

Evaluation of both training courses was positive with care home staff feeling more confident and able to adjust care delivery to ensure it meets the outcomes for residents with dementia. Some feedback from participants includes;

*I plan to encourage a quieter care environment with a richer understanding of dementia.*

*I will be including dementia training in our organisation's induction training as a result of this course.*

*I am aiming to convince our new manager that we have to invest time and resources to improve our standards of dementia care, motivate our staff and improve morale.*

This investment in training for care home staff has helped upskill care home staff and will help providers to work in a more outcome and quality focused way when the new service specification is tendered during 2016.

## 5c Dementia Awareness

WCC, through Public Health Warwickshire, has commissioned a series of half day workshops focused around dementia awareness and dementia-friendly communities.

The workshops have been designed to support organisations and individuals to develop a greater understanding of how people living with dementia may be affected by their condition and how dementia-friendly communities can help people to live well with dementia. This includes communication techniques and how individuals or organisations can work towards becoming dementia-friendly.

The workshops are targeted at staff that are likely to come into contact with people living with dementia or their carers as part of their day to day service provision. Those working in general practices, pharmacies, libraries, leisure centres, environmental health, social care and housing have been among those to have benefitted from the training.

In total, between the autumn of 2013 and September 2015, 788 staff have attended a dementia awareness course commissioned by WCC.

**Workshops can be booked via [www.warwickshire.gov.uk/wilma](http://www.warwickshire.gov.uk/wilma)**

### What we still need to do to deliver Objective 5: priorities for 2016-19

What will we do?	Who	By when?
<b>5.1</b> 30 health and care organisations sign up to Warwickshire's Dementia Workforce Vision and Pledge	Providers / WCC	by 2019
<b>5.2</b> Ensure cultural, spiritual and religious awareness in dementia care is covered within dementia training programmes for front line staff	WCC	April 2017
<b>5.3</b> Continue to train frontline practitioners and staff in organisations signing up to the Coventry and Warwickshire DAA in dementia awareness across Warwickshire. In 2016, we will aim to train a further 300 frontline workers	WCC / All partners	September 2016
<b>5.4</b> Attendance at all awareness training from target groups; care homes, emergency services and housing is increased by 50%	WCC / All partners	2016, 2017, 2018, 2019
<b>5.5</b> A minimum standard of competency for the workforce is agreed with the three local CCGs	CCGs / WCC	June 2016
<b>5.6</b> Dementia Navigators trained in basic Cognitive Behavioural Therapy techniques	WCC / Alz Society / CWPT	April 2016
<b>5.7</b> 10 dementia awareness sessions are delivered to GP practices by end of 2016. All GP practices in Warwickshire have had at least half of their reception staff trained in dementia awareness by end of 2019.	GPs / WCC	December 2016 December 2019

## Conclusion

### Governance

The Delivery Plan of Warwickshire's Living Well with Dementia Strategy refresh 2016-2019 is attached as **Appendix 2** and will be overseen by Warwickshire's Dementia Strategy Delivery Board. Membership of this board is as follows;

- Zoe Mayhew (Chair) Service Manager, Integrated Older People's Commissioning, Warwickshire County Council
- Dr Charlotte Gath, Consultant, Public Health Warwickshire
- Claire Taylor, Health Improvement, Commissioning and Performance Lead: Mental Health, Public Health Warwickshire
- Katherine Herbert, Commissioner, Warwickshire County Council
- Dr Sukhi Dhesi, GP Mental Health Lead, South Warwickshire Clinical Commissioning Group
- Vacancy, Warwickshire North Clinical Commissioning Group
- Sharon Atkins, Joint Commissioning Manager, mental health and dementia, Coventry City Council & Coventry and Rugby Clinical Commissioning Group
- Madeline Curran, Matron, Dementia lead South Warwickshire Foundation Trust
- Sally Wilson, matron for Older Adults, George Eliot Hospital
- Dr Judith Bond, Consultant Clinical Psychologist, Coventry and Warwickshire Partnership Trust
- Debbie Harvey, Coventry and Warwickshire Partnership Trust
- Tony Refson, Service manager, Alzheimer's Society
- Jan Dugdale, Integrated Care Services manager, AGE UK Warwickshire
- Tony Robinson, User and Carer representative
- Jas Dhadli, Service Manager Mental Health, Warwickshire County Council
- Vivien Mershon, Learning and Development Consultant, Warwickshire County Council
- Deborah Harris, Specialist Nurse, University Hospital Coventry and Warwickshire

This board helps ensure that an effective, consistent and collaborative approach is taken to the development of dementia support services and delivery of quality dementia care and support in Warwickshire.

We will also be running 6 monthly on line reviews of strategy delivery progress. This will demonstrate how far we have progressed against each objective this will comprise of 'you said, we did' feedback related to the customer consultation that this strategy is built upon.

Opportunities for people with dementia and their carers to co-produce and co-deliver this strategy refresh will be identified throughout its lifetime.

To keep up to date with delivery progress please see the blog that is hosted on Warwickshire's Living Well with Dementia Portal: [www.livingwellwithdementia.org](http://www.livingwellwithdementia.org)

If you need this information in another format (including easy read) or another language please contact us:

**[dementiapartnership@warwickshire.gov.uk](mailto:dementiapartnership@warwickshire.gov.uk)**

A graphic summary / pathway of this strategy is contained as **Appendix 5**.