

# Coventry and Warwickshire’s Living Well with Dementia Strategy 2022 - 2027 Customer Feedback

## Introduction

The overarching purpose of this engagement was to understand the experiences of dementia patients and their carers, about the proposed Coventry and Warwickshire’s Living Well with Dementia strategy, its visions and priorities and proposed ways of working.

Making Space Co-production service were tasked to focus engagement on *Priority Three: Supporting Well and Priority Four: Living Well*. However, the vast scope and significance of this engagement captured feedback relating to other priorities.

The engagement events were structured with handouts of discussion points and a choice of in-person 1:1 sessions and group sessions. The aim was to collate and analyse feedback from engagement activities to ensure that the strategy is focusing on the right aspects.

### **Please Note**

People living with dementia - people with a diagnosis of dementia

Carers – refers to informal/unpaid carers

## Participants Profile

### **Numbers of cafes / groups attended and names of cafes / groups attended**

The Pam Britton Trust for Dementia (Oct) <i>Kenilworth</i>	Group work 12 participants (carers) 1x 1:1 (carer)
The Pam Britton Trust for Dementia (Nov) <i>Kenilworth</i>	Group work 10 participants (Carers) 1x written feedback (Carers) 1x 1:1 (Carer)
Focus Dementia Network group	Group work

Coventry	9 participants (8 people living with dementia & 1 Carer) 1x 1:1 (1 Person living with dementia)
Bidford on Avon Dementia Café South Warwickshire	Group work 29 participants (Mixed group) 5x written feedback (Carers) 5x 1:1 (Carers)
Dementia Friends Lunch Group Warwick	Group work 8 participants (people living with dementia)
Phoenix Group (Nov) Wood-end	Group work 35 Participants (Mixed group) 6x 1:1 (people living with dementia) 9x 1:1 (Carers)
Alcester Café (Nov) Alcester	Group work 51 Participants (Mixed Group) 4x 1:1 (carers)
Nuneaton Dementia Café (Nov) Nuneaton	Group work 16 Participants (Mixed Group) 1x 1:1 (Carer)
Wellesbourne Dementia Café (Nov) South Warwickshire	Group work 14 Carers 3x 1:1 (Carers) 3x 1:1 (people living with dementia)

### **Number of people who took part in focus groups (not at cafes / groups)**

Coventry	4 participants (2 carers, 2 people living with dementia)
Coventry	5 participants (3 carers, 2 people living with dementia)
Coventry	4 participants (2 carers, 2 people living with dementia)
Rugby	4 Participants (3 carers, 1 person living with dementia )

### **1:1 sessions**

05/10/21 Nuneaton	1 Carer, 1 person living with dementia
07/10/21 Leamington Spa	1 Carer
12/10/21 Warwick	1 Carer
14/10/21 Coventry	1 Carer, 1 person living with dementia

19/10/21 Atherstone	1 Carer
26/10/21 Leamington Spa	1 Carer
11/11/21 Rugby	1 Carer, 1 person living with dementia
11/11/21 Coventry	2 people living with dementia

## Overview

### Total number of engagements so far

<b>Total number of 1:1 sessions</b>	<b>7</b>
<b>Total Number of group sessions</b>	<b>4</b>
<b>Total number of cafes and support groups attended</b>	<b>9</b>
<b>Total number of people living with dementia engaged with</b>	<b>38</b>
<b>Total number of carers engaged with</b>	<b>84</b>
<b>Total number of mixed groups participants</b>	<b>131</b>
<b>Total number of participants</b>	<b>253</b>

## Findings

### Priority One: Preventing Well (reducing risk)

Many of the participants echoed the same message as the strategy, emphasizing on the need to raise more awareness of the benefits of healthy lifestyles to reduce the risk of developing dementia.

#### Key issues raised

- More information about exercising the brain, and a healthy diet.
- More awareness of impact some sports have, such as football and boxing.
- Make dementia health checks mandatory for older adults

### Priority Two: Diagnosing Well

Participants had mixed experiences of the diagnosis process, while the majority of the participants we engaged with expressed a positive experience with the diagnosis process, some identified areas of improvement. A small number of participants stated that dementia diagnosis can take a long time and the carers' concerns had

not been taken into account. This has led to delays in accessing treatment as well as causing stress and tension for families.

### Key issues raised

- There were a lot of discussions on how to enhance the diagnosis process and the initial diagnostic tests. Other symptoms, behavioural changes and the effects of medicine should also be taken into account when diagnosing individuals.
- A more person-centred approach is necessary, participants suggested using a range of assessment methods, over a certain period, to acquire a comprehensive picture of a patient's behaviour. Participants also agreed that doing evaluations in the patient's home, where he or she feels most comfortable, would alleviate some of the strain of having to travel long distances.
- A better understanding of the resources available to people living with dementia among medical professionals (GPs). It is important that individuals are provided with further support following diagnosis.
- Some suggested that it would have been useful to have a volunteer service of people who have been in this situation to offer support to others soon after diagnosis (a buddy system).

*“It would have been great if I had been given a package of information after diagnosis. Most carers do not get time to digest all the information after diagnosis as they have to quickly transition from being husband or wife to being carers. This journey could be made easier if support is offered right at the start”. – Carer (Leamington Spa)*

### **Priority Three: Supporting Well**

Participants identified a number of barriers to accessing support. Participants highlighted a lack of knowledge of available services, with carers often learning

about them through word of mouth, emphasising the necessity of peer support networks.

About 80% of participants did not know about the Dementia Connect service. One of the main reasons that participants identified as a barrier to finding out about this service was because they were older adults who either did not have the skills or resources to access information online about support services.

All participants were informed about the Dementia Connect service and encouraged to contact the service as part of the engagement.

About 90% of carers were aware of the carers support service and knew how to access the service. Most carers said they found out about the service through peer support sessions. They highlighted that without the peer support groups they would not have known about them.

There were several complaints and uncertainty about the dementia service offer from some providers during covid-19. Participants were not clear about what services were in place at various points through the pandemic and currently.

*Ongoing support* - Participants had mixed experiences of ongoing support, with more than half of the participants rating ongoing support as needing improvements.

*Respite for carers* - Carers' respite was identified as an issue that needed to be improved by the participants. Many carers who took part in the activities expressed their frustration with a lack of access to respite or with the fact that they had not received any. Financial arrangements for respite were also identified as a source of worry, with examples being the cost of respite care being too expensive.

### Key issues raised

- A key recommendation was that respite care be person-centred and address the patient's needs, such as the level of dementia they have and the needs of the carers.

- Health professionals leading communication rather than patients and carers; for example, health professionals should call patients and carers on a frequent basis to see how they are doing, rather than patients and carers needing to contact when there is an issue. Often carers are not able to raise concerns until crisis point.
- Another issue raised about access is that professionals and other services like GPs and memory clinics do not tend to signpost to community services. There is a need for a clearer referral pathway with a 'no wrong door policy'.
- People living with dementia and carers suggested that more support is required to help in navigating support services. This might be made easier by providing a single point of contact, such as a phone number where carers can access the appropriate service.

*“I am sure there are many great services out there that we can access but how do you know what you are meant to know if no one tells you about it”. – Carer (Wood-end).*

#### **Priority Four: Living Well**

It quickly became apparent that the peer support groups are so valuable to both people living with dementia and carers. To be able to live well in their communities, participants expressed that they need support with practical solutions. Services like the memory clinic should offer automatic yearly reviews as this is a progressive disease. It would be helpful for families to have that ongoing support.

Participants described the inconsistencies of community support across Coventry and Warwickshire as a 'postcode lottery' situation. With some areas having more than others (particularly rural areas).

#### **Key issues raised**

- Patients and carers highlighted the location of services as being an issue. It was commented that appointments and services can be too far from patients' homes, making it difficult to arrange transport and travel to them.
- Ongoing memory clinic appointments and more Admiral Nurses.
- People living with dementia and their carers suggested that dementia care should be integrated into other services to ensure a holistic approach to individual's cases.
- The availability of support services for people living with dementia and their carers to assist with the practical aspects of care, such as, obtaining a Power of Attorney, claiming carers allowance, blue badges and managing challenging behaviour was also raised as a concern.

*“It is important that volunteers who keep us going in the community are supported to avoid volunteer burn-out. If we were to lose the community services, we wouldn't be able to cope.” – Carer (Atherstone)*

### **Priority Five: Dying Well**

There was a general consensus among participants that end of life healthcare was an uncomfortable subject to discuss, as reflected by the low level of response for this issue in the events. But it was stressed that it is critical to have these talks when patients still have the capacity to do so, and that caregivers should make preparations for their own well-being during this time as well. Additionally, there were concerns raised about the financial impact on carers when their partner dies as some lose benefits and end up living on very little.

The need for better education and understanding of dementia in general was also brought up as a point of discussion.

#### **Key issues raised**

- Support with financial advice for the carers.
- Greater awareness and utilization of ReSPECT form

- **Priority Six: Training Well**

All participants supported the commitments highlighted in the strategy. One couple raised concerns about professionals who have no dementia background or training being allowed to diagnose. The carer expressed that her husband was diagnosed by a district nurse without undertaking tests, this caused panic within the family as they were not offered further support. They felt it was left to the carer to research what to do next.

## **Conclusion**

While participants reported positive experiences with support services such as dementia cafés, they also identified a lack of help for carers, early intervention programmes, and access to crisis support as still lacking. The availability of admiral nurses was a huge discussion point, participants emphasised how crucial it is for more experienced dementia professionals.

People living with dementia and carers expressed how their needs have remained the same over the years, however they have felt forgotten. There is a clear lack of knowledge and information for many of them throughout their dementia journeys. Notably, there was very little representation from people from ethnically diverse groups. It is unclear whether this is due to lack of awareness or other reasons. However, it highlights the key theme raised in all engagement activities which is; **More awareness of what is available and how to get it.**