

# People Directorate

## Engagement Report: Dementia

February 2019 – March 2019

# 1 Introduction

## 1.1 Purpose:

This report provides an overview of the engagement activities that have taken place between the 11<sup>th</sup> of February and the 22<sup>nd</sup> of March 2019 with people with dementia, their families and carers as well as the general public and professionals.

The purpose of this engagement exercise was to understand what is important to people and what needs to improve in relation to dementia care and support in Warwickshire. This feedback will be used to help re-refresh Warwickshire's current Dementia Strategy 'Living Well with Dementia in Warwickshire 2016-2019' and will help inform the future commissioning of dementia services as both the Dementia Navigator Service, and Dementia Day Opportunities services, are required to be recommissioned by the 1<sup>st</sup> of April 2020.

This engagement exercise is also being driven by the Better Health, Better Care, Better Value partnership; this is Coventry and Warwickshire's Sustainability and Transformation Partnership (STP) involving local NHS organisations and councils working together to improve health and care in the areas they serve, with a focus on supporting people to be healthier, provide high-quality care and make services more sustainable. There is a particular priority around Mental Health and Emotional Wellbeing, which includes dementia.

## 1.2 Context:

It is currently estimated that there are 8,500<sup>1</sup> people living with dementia in Warwickshire; of these an average of 59.5%<sup>2</sup> of people suspected to have dementia have received a diagnosis of their condition. There are substantial efforts being made locally to increase the rate of diagnosis in Warwickshire to reach the national target of 67.9%.

**Warwickshire's 'Living Well with Dementia' Strategy 2016-2019**: is a plan which outlines local priorities and needs of people living with dementia, their families or carers, and how health and care organisations will work together to support people to live well with dementia. Some of the key aims of the current strategy are that people;

- Know where to get advice and information about their condition;
- Know how to reduce their risk of developing dementia;
- Receive a diagnosis in a timely manner and are provided with support tailored to their individual needs;
- Live in a community where they feel confident to access this community free from stigma and discrimination;
- Receive care and support from skilled and knowledgeable staff;
- Are confident that they can get help if things suddenly change;
- Carers are supported to balance caring responsibilities alongside having a life of their own.

The current strategy can be found here: [www.warwickshire.gov.uk/dementiastrategy](http://www.warwickshire.gov.uk/dementiastrategy)

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<sup>1</sup> Poppi and Pansi Dementia prevalence projections

<sup>2</sup> Average percentage of people suspected to have dementia with a diagnosis of dementia across Coventry and Rugby CCG, Warwickshire North CCG and South Warwickshire CCG as of February 2019.

**NHS Well Pathway for Dementia:** this was put forward as part of central government's Challenge on Dementia 2020<sup>3</sup>. The pathway identifies the key stages where health and care services, as well as the wider community, should focus to improve the journey through assessment, support and services that a person with dementia and their carers/families experience. The pathway is as follows;

- ✓ **Preventing well:** ensuring that the risks of people developing dementia is minimised.
- ✓ **Diagnosing well:** timely and accurate diagnosis, care plan and review within the first year.
- ✓ **Supporting Well:** Access to safe, high quality health and social care for people with dementia and carers.
- ✓ **Living Well:** people with dementia can live normally in safe and accepting communities.
- ✓ **Dying Well:** people living with dementia die well in the place of their choosing.

The areas of the pathway are reflected in the survey questions used as part of the engagement exercise.

## 2 Engagement

### 2.1 Approach:

To capture a wide range of views, a mixed approach to engagement was pursued. A survey was designed and made available online and in paper format. In addition to this, WCC and health officers visited a range of community based and commissioned directly hear the views of people with dementia, their carers and people that support these services (both paid staff and volunteers). The paper based survey was distributed using a targeted approach (via community groups and service providers) and was distributed during the face to face visits. The link to the online survey was extensively promoted in both internal and external communications such as newsletters and emails.

Throughout the report comments in *italics* are comments made directly by participants to this engagement e.g. people with dementia, their carers, staff, volunteers or other professionals

### 2.2 Survey:

The survey questions sought to gain an insight into the views of people with dementia, their carers and professionals about their knowledge of and access to local dementia services and support as well as asking questions linked to the main areas of the current dementia strategy. Survey participants were given the opportunity to share their views about what is working well about current dementia support and what could be improved.

A total of **116** survey responses were received.

### 2.3 Demographic profile of survey respondents:

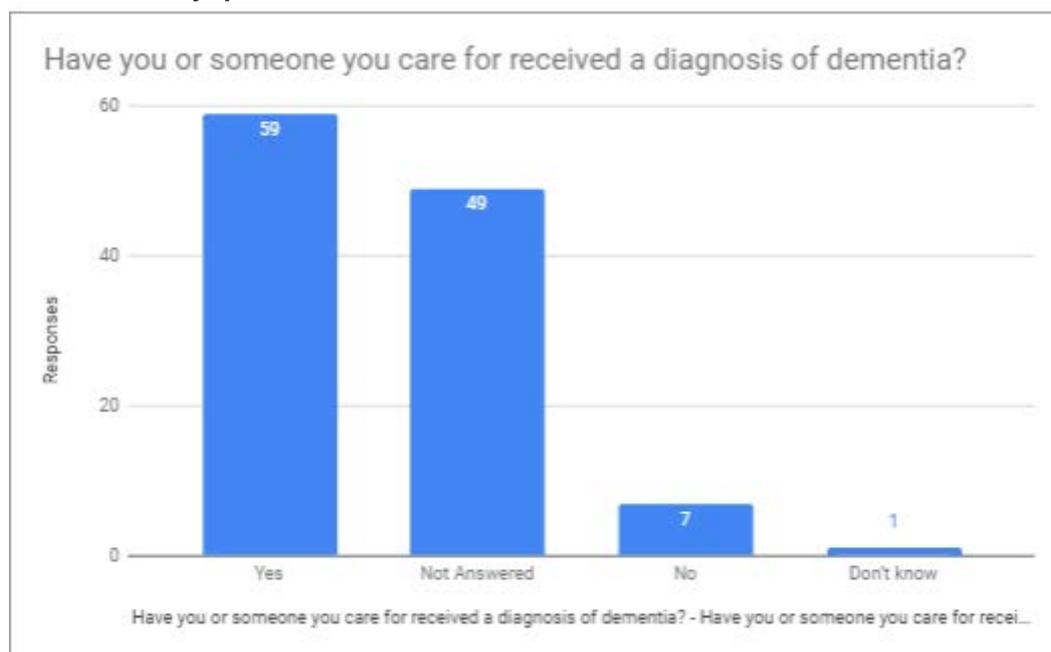
59% of respondents to the survey were from South Warwickshire.

53% of respondents identified themselves as having dementia or supporting someone who has dementia.

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<sup>3</sup> Prime Minister's Challenge on Dementia 2020, Department of Health, published 2015.

**Chart 1: Survey question**



81 out of 116 respondents were female; 69% of total respondents. A female dominance in responses is expected. National statistics around dementia prevalence highlight the female prevalence of dementia. 65% of people living with dementia nationally are women<sup>4</sup> and 60-70% of informal carers of people with dementia are women<sup>5</sup>. Therefore it is reasonable to expect that locally more women than men have contributed to the engagement survey.

## 2.4 Face to face groups:

WCC and Health officers aimed to get out to a broad range of dementia groups and services during the engagement period to talk directly with people that use these groups which includes people with dementia, their carers, staff and volunteers.

In total **18** groups were visited these included;

- ✓ Dementia day opportunities
- ✓ Dementia cafes
- ✓ Dementia community groups
- ✓ Dementia singing for the brain groups.

Groups in all areas of the county were visited; 5 visited in Warwick District, 5 visited in Stratford District, 4 visited in Nuneaton and Bedworth Borough, 2 visited in North Warwickshire Borough and 2 visited in Rugby.

A total of **275** people were engaged as part of face to face groups.

A presentation to a meeting of GP's about the dementia strategy also took place during this engagement period.

Dementia support groups in the community are well supported by informal volunteers. In total, **49** volunteers were supporting across the **18** community groups that were visited during this period of engagement.

<sup>4</sup> Dementia UK: Update Second Edition, Prince M et al, 2014.

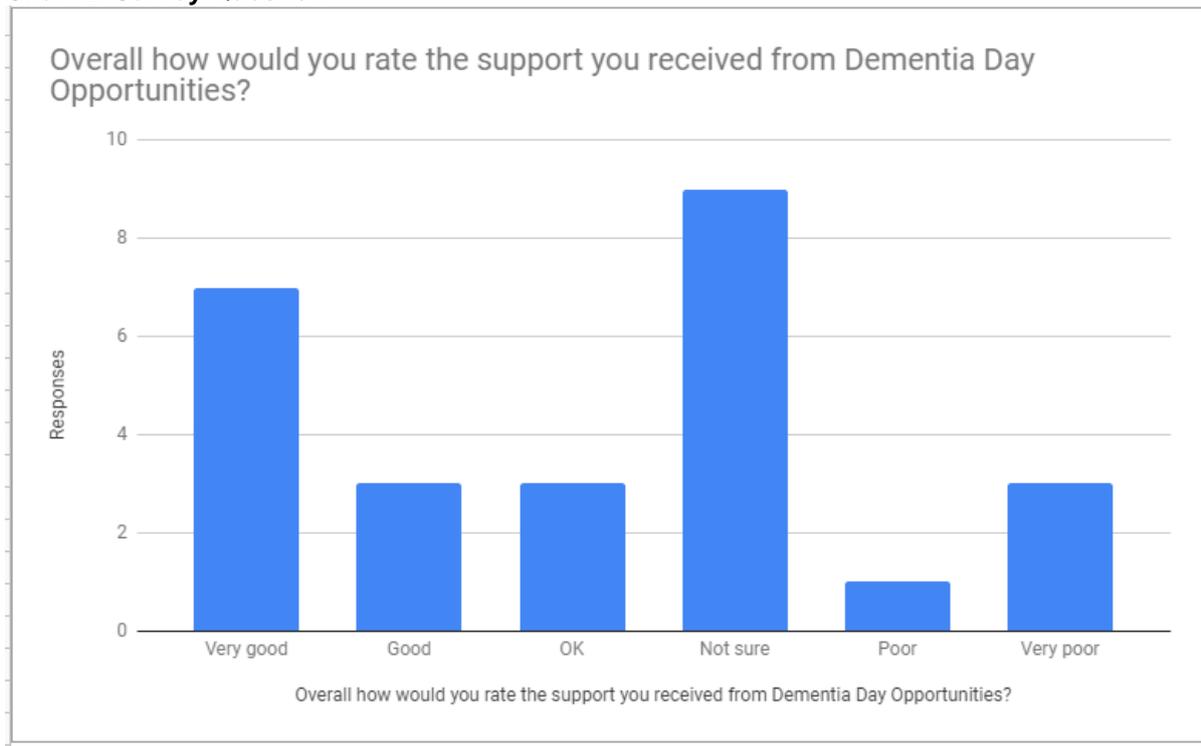
<sup>5</sup> Women and Dementia: A marginalised Majority by Alzheimer's Research UK, 2015.

## 3 Dementia Day Opportunities analysis

Dementia Day Opportunities are group, usually building based support, where people with dementia socialise with others, undertake activities, are provided with meals and are supported by dementia trained staff. Access to these services usually requires a social care assessment, and users of these services are a mix of WCC funded and self-funders at countywide locations.

### 3.1 Survey results:

Chart 2: Survey Question



Overall, based responses received about overall rating of support received from dementia day opportunities was that this was good or very good. It is worth noting however, that many survey participants skipped this question as they may not have had personal experience of this service, so the numbers related to this question are lower and not as statistically valid.

### 3.2 Comments from people with dementia about day opportunities:

- *Everyone is very cheery.*
- *It is a tremendous uplift coming here.*
- *Nice to get out of the same four walls.*
- *I get to chat to others and watch what people are doing.*
- *Children came to sing us carols- I love it when the children visit.*
- *The staff are brilliant and so caring, if it wasn't for them I would feel isolated.*

When asked what they would like to improve or change about the day opportunities service the following feedback was provided by people with dementia;

- *It is a lovely room (where day opps is held) I would just like Wi-Fi.*

A member of staff explained that one particular venue has a weak Wi-Fi signal and a lady with dementia would have liked to use her Alexa as she bought this following a staff

members suggestion to look up music and old comedians and she would like to share this with the group.

Further comments about improvements are as follows;

- *I wish we could do more outdoor activities especially as the weather is getting better.*
- *I don't like the meals. They don't arrive on time and are sometimes cold.*

### **3.3 Feedback from Staff and Volunteers:**

There was evidence of very caring and dedicated staff and volunteers supporting day opportunities who often had personal experience of caring for someone with dementia. Staff engaged with people effectively and understood and respected each person's needs, likes and dislikes, providing them with opportunities to undertake activities suited to their personal preferences.

The range of activities available at day opportunities is vast and very much depends on the interests of the particular group or people within that group. Some of the activities observed during engagement were quiz's, art and drawing, dominoes, seated exercise, carpet games, local entertainer visit to sing, group singing, reminiscing, gardening and flower arranging. The groups also organise regular trips out to places of interest.

On a few occasions, it was noted that volunteers had training needs and this was highlighted with Provider service managers where applicable.

Staff take an active approach to noticing change in people both physically and cognitively and liaise closely with informal carers with regards to these changes which could, for instance, prompt a visit to GP or Consultant at Memory support service. Staff were proud that they could help provide people with support that helps them to remain at home for as long as possible, whilst also providing their carers with an opportunity to have a break.

A comment from a day opportunities staff member: *You see a real change in people – one lady that started had not been eating properly, she wasn't able to pick up a small ball in a game, she has quite advanced dementia. She now eats her meals, she sees other people here doing it and she eats too. She has made friends and smiles a lot. She is able to throw a ball during seated activities and is much more active now.*

Day opportunities services are not CQC registered, and do not provide personal care, but services do actively prompt and encourage people to look after their own personal care needs as well as their nutrition and hydration. For example, staff were regularly observed reminding individuals to drink, as they often forget that they have a cup of tea or water next to them and forget the need to drink.

### **3.4 Key themes:**

1. People with all stages of dementia (not just early stage) are benefitting from using day opportunities. This service is providing them with socialisation and stimulation in a supportive and inclusive environment. Although these services were originally commissioned for people with early stage dementia, in practise these services are supporting people with the full spectrum of dementia support needs.
2. The service is not commissioned to provide personal care; some social workers and other providers highlighted this as a gap in service provision as there is a limited supply of dementia day care including personal care in the market.
3. Day opportunities provide holistic and individualised provision to people with dementia taking account of the individuals own interests, background and stage of the dementia journey. People with dementia usually do not cease to use service until they either develop personal care needs or move to residential care.
4. The structure and routine of day opportunities helps carers to benefit from regular breaks, enabling them to have time for themselves to look after their own wellbeing.

5. The communication between the service, individuals with dementia and their carers is robust and strong, and often these discussions help informal carers to identify when the person with dementia might need to see their GP. The service helps informal carers with strategies to try when needs deteriorate.
6. The service helps people with dementia maintain independence and wellbeing. It was clearly visible from visiting all services that people are happy, relaxed and engaged. There have been many case studies provided by the service which indicate that individual's abilities and mood improve as a result of attending day opportunities.

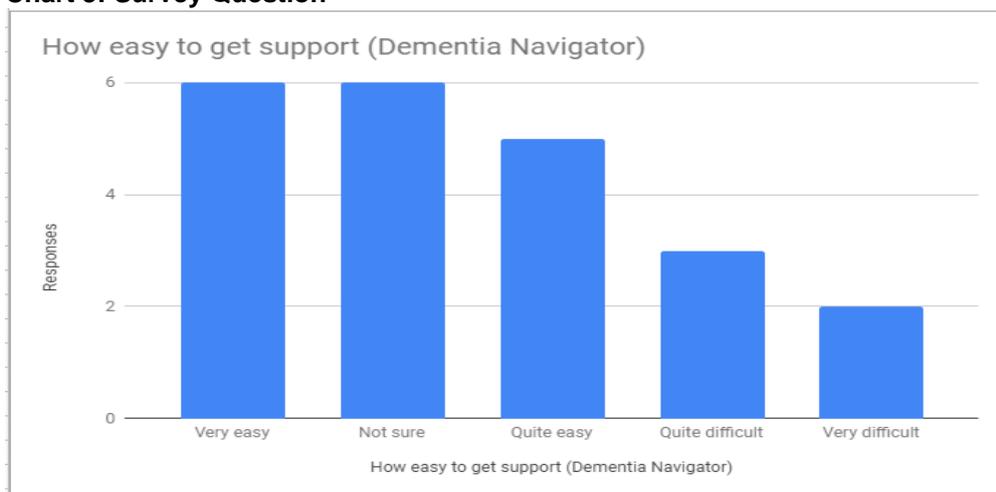
## 4 Dementia Navigator Service analysis

The Dementia Navigator Service provides advice, information and emotional support to people with dementia and their families across all areas of Warwickshire, about dementia specific issues and the things that are affecting them throughout their journey with dementia. Support from this service can be provided over the phone, by email or face to face. An individual can self-refer or can be referred by someone else to the service.

There are 7 FTE equivalent Dementia Navigators that operate countywide. The service receives an average of **55** new referrals per month as well as supporting existing users. Each Navigator holds a case load of between **20-38** people at any one time.

### 4.1 Survey results:

Chart 3: Survey Question



Survey feedback suggests that people find it very easy or quite easy to access the DN service. Some caution does need to be applied when using this stat as this question elicited a fairly low level of responses.

Some respondents have also reported access issues and also commented that they had no knowledge of the service suggesting that work still needs to be done to embed the service across the dementia pathway.

- *No one has told us about this support, I was at the end of my tether with my husband who has dementia; I didn't know which way to turn due to my husband aggressive behaviour.*
- *Dementia Navigators are great but they do have a waiting list.*

- *Able to make an appointment very quickly, and even able to change it due to our health issues. We were given a lot of information as well as received an email with forms/ fact sheets that she didn't have with her. Very knowledgeable and friendly.*

As part of the engagement we have the following responses from DN staff about their view about the impact of the DN service:

*We can offer people time, offer them a listening ear. We validate how they are feeling and the importance of their perspective on something.*

*I think that one of the greatest strengths of the service is its flexibility. ....we can offer such wide ranging ideas and potential solutions, not just dementia specific. If we think something will be of interest to a family we can talk about it.*

*(The service) is easily accessible by phone, text, email and we respond quickly. We keep in good communication with people, even if we haven't been successful in finding something, we let them know and consider alternatives for them.*

#### **4.2 Key themes:**

1. People feel well supported by the Dementia Navigator service with most people finding it accessible, informative and supportive at extremely emotional and destabilising times for them.
2. Case studies and service feedback suggest that Dementia Navigators are supporting people with dementia and their carers with a range of needs – the service has an outcome focused way of working at the heart of its delivery which ensures that support is targeted and meaningful for Individuals.
3. The service uses resources effectively in reaching as many people with dementia and their carers as possible as each navigator holds a case of both people who they are actively supporting to reach their outcomes and those that they have supported to meet their outcomes that may come back to the service again if they need further support or if things have changed.
4. The DN service recognises and values the role of informal carers who are often the primary customer when working with a family. There is evidence that the service helps carers to reduce their stress and maintain their caring role.
5. On several occasions respondents reported that they were in 'crisis' until they reached out to get the support they needed this suggests that further work needs to be done to embed the Dementia Navigator service into care pathways and ensure people are being made aware of the service at an early stage in their journey.
6. People find the terminology of 'navigator' confusing at time, some people indicated that they thought this service was not going to support them, and simply sign post them onto other sources of support. Some respondents got confused with the Dementia Navigator service and other 'navigator' services provided by other services.

## **5 Feedback on Dementia Strategy and pathway**

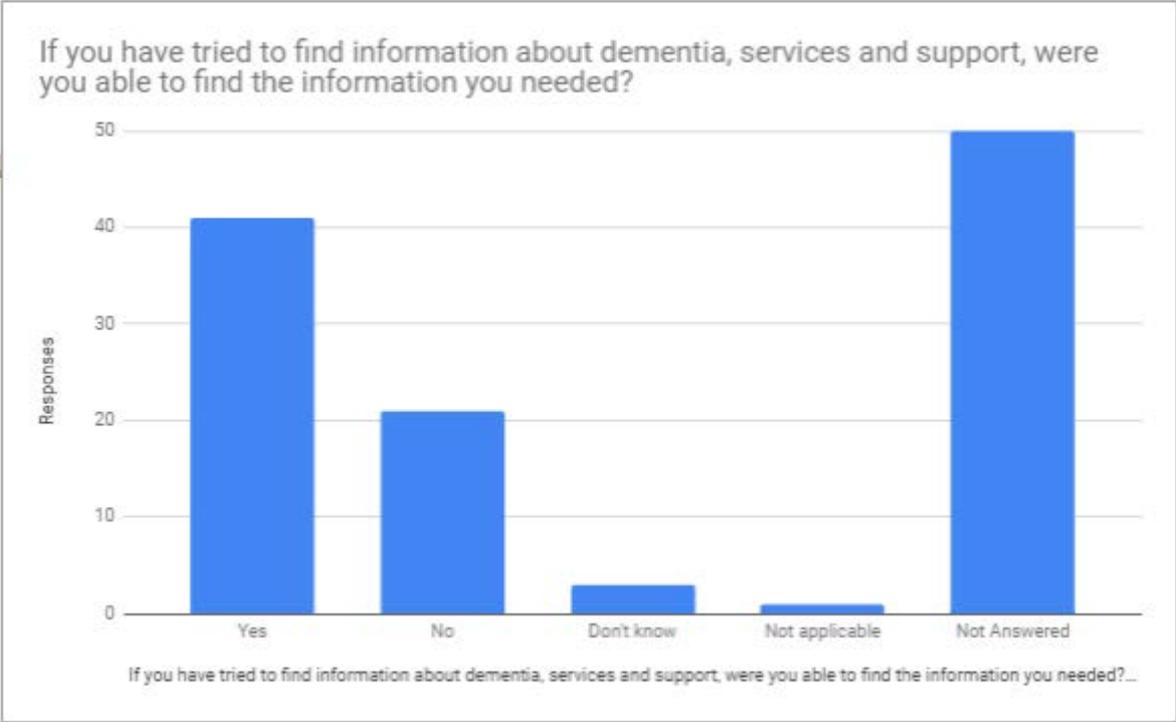
### **5.1 Survey comments:**

Survey participants identified gaps and areas of importance to them about the wider dementia pathway. The comments below have been put forward by the survey and group feedback and have been grouped around key themes.

### **5.2 Information and advice:**

The provision of clear and easy to understand information about support available was highlighted as a key requirement:

**Chart 4: Survey Question**

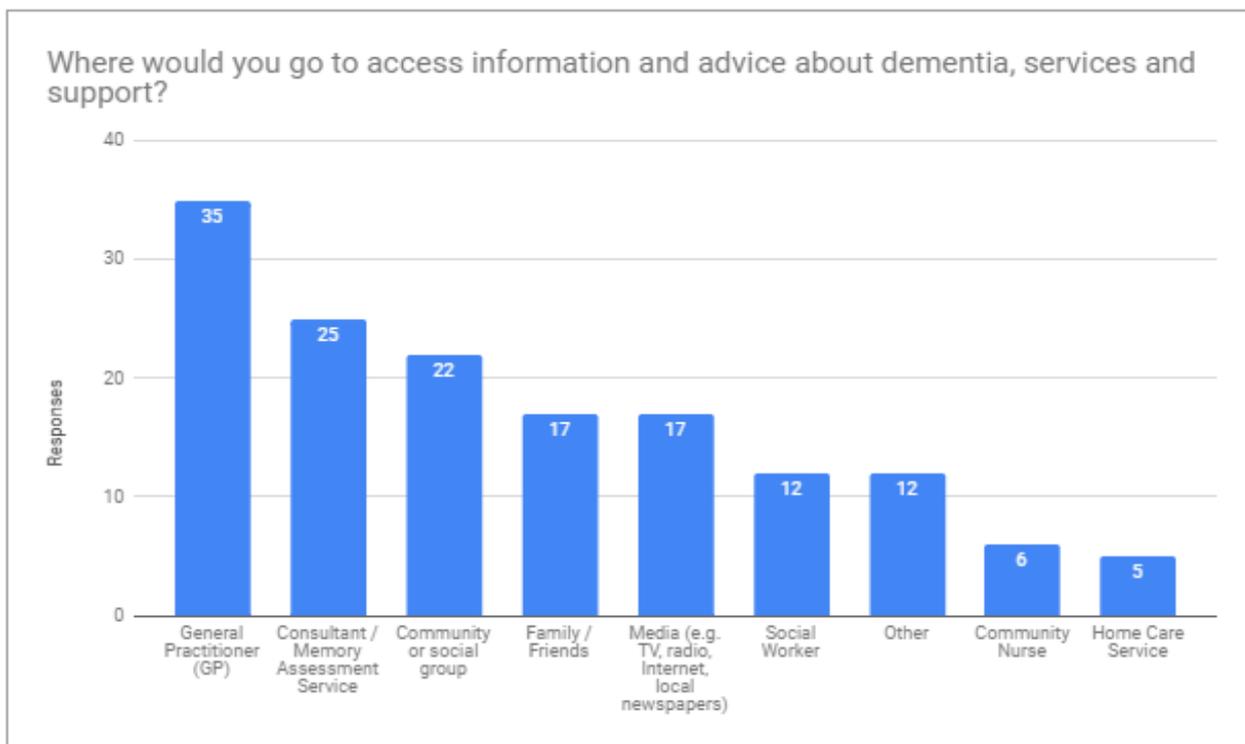


*My Grandma had dementia for a long time before she had an official diagnosis. Whoever we asked for help just told us it was to be expected at her age.*

- *Information is given at point of diagnosis but it's quite overwhelming. Takes a lot of courage and confidence to go to new services for the first time so would be good for someone to check back in with you a few weeks after diagnosis. Would be good to have people who can encourage you to go to services and try them out. People all seemed to think there were plenty of services, it's just knowing about them and having the courage and ability to get to them.*
- *Having a 'one stop shop' for information and support. Social Worker should be aware of all options available with regards to funding of care home placement.*
- *Would be good to have a cover-all help-line, specifically to Warwickshire local areas.*

The living well with dementia website was mentioned many times as a valuable and useful resource for local information and dementia support and services. However, most respondents identified their GP (23%) as the key place they would seek to find information or advice about dementia services and support. This highlights the key and vital role that primary care play in providing locally specific information and advice about dementia.

**Chart 5: Survey Question**



### 5.3 Dementia friendly communities:

The issues of the wider community's perceptions around dementia was recognised as an area of importance. Warwickshire now has 88 individual business or organisations signed up to be the Dementia action alliance, efforts to create more dementia friendly communities will be increased during the next strategy period.

- *Encouraging communities to become Dementia Friendly so we didn't feel worried about taking dad to places where his needs couldn't be met or where we felt people wouldn't understand.*

### 5.4 Post diagnostic support:

The need for a timely diagnosis and appropriate follow on support was highlighted with some feedback centring around people feeling supported immediately post diagnosis and when at crisis points but a feeling of being 'left to it' for the majority/middle part of the journey.

- *Named coordinator allocated at diagnosis to assist patient in navigating support would be helpful.*
- *Excessively long wait time for a memory assessment.*
- *It was really difficult to get advice outside of routine appointments and the methods of contacting the service were unclear.*

### 5.5 Community based peer support:

Peer support and stimulation was identified as being support and vital to carers and people with dementia's wellbeing. Warwickshire is fortunate to currently have 33 dementia support peer groups across the county which are entirely voluntary and independent sector led that people with dementia and their carers/families can access.

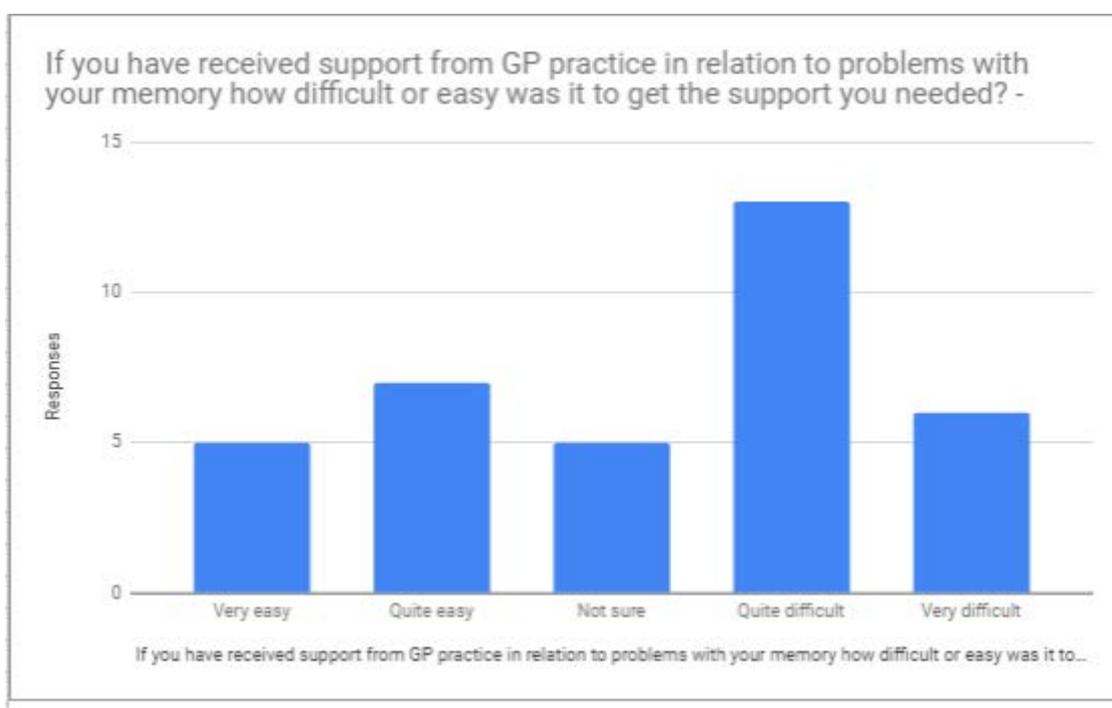
- *Without meeting other carers and cared for would not have information and knowledge I have now. They are very useful for stimulation for my cared for as find it difficult at home.*

- *Dementia cafes are very helpful. Would be even better if District Council was more proactive in ensuring different organisations do not arrange events on the same days.*
- *I supported someone who became housebound and there was no support specific to dementia that could visit her at home such as music therapy or a therapeutic dog.*
- *A carer describing her experience of using a peer support group; you come in with the weight on your shoulders and go out with the weight lifted.*
- *The (peer support) group acts as a break, respite even as they have opportunities to talk to others with shared experience*

## 5.6 The role of Primary Care:

As highlighted above with the response to the place where people would go to get information and advice about dementia, GP's are a crucial part of the support and assessment process for families. There were comments and survey feedback that suggests that support at a primary care level could improve;

**Chart 6: Survey Question**



- *More support from GP Surgeries in pointing people to opportunities in their area.*
- *More GP's trained in Dementia as they are usually the first point of contact once you are diagnosed. More help and support to inform and prepare the carer for the journey ahead. More consistency in support from different GP practices.*

## 5.7 Valuing informal carers and supporting their needs:

The crucially important role of informal carers and the stress of caring for someone with a dementia came through as a very clear message in both the survey and face to face feedback. Carers needs to be respected as expert care partners and be provided with adequate opportunity for support and breaks in their own right.

- *An acknowledgment that dementia exists and that people are not just "forgetful" or "a bit confused". Carers need proper support, it's an incredibly hard and isolating role and so*

often we have felt that those agencies we asked for help did not take our concerns seriously until an emergency hospital admission led to a diagnosis of vascular dementia. Carers know the person they are caring for better than anyone else so if they raise concerns it's vital they should be listened to.

- Compulsory training for paid carers in dementia care as knowledge is still lacking.
- When caring for someone with dementia things can suddenly hit a crisis point. There needs to be access to immediate help and advice especially for the elderly making it easy and simple to use.

### 5.8 Practical support at home:

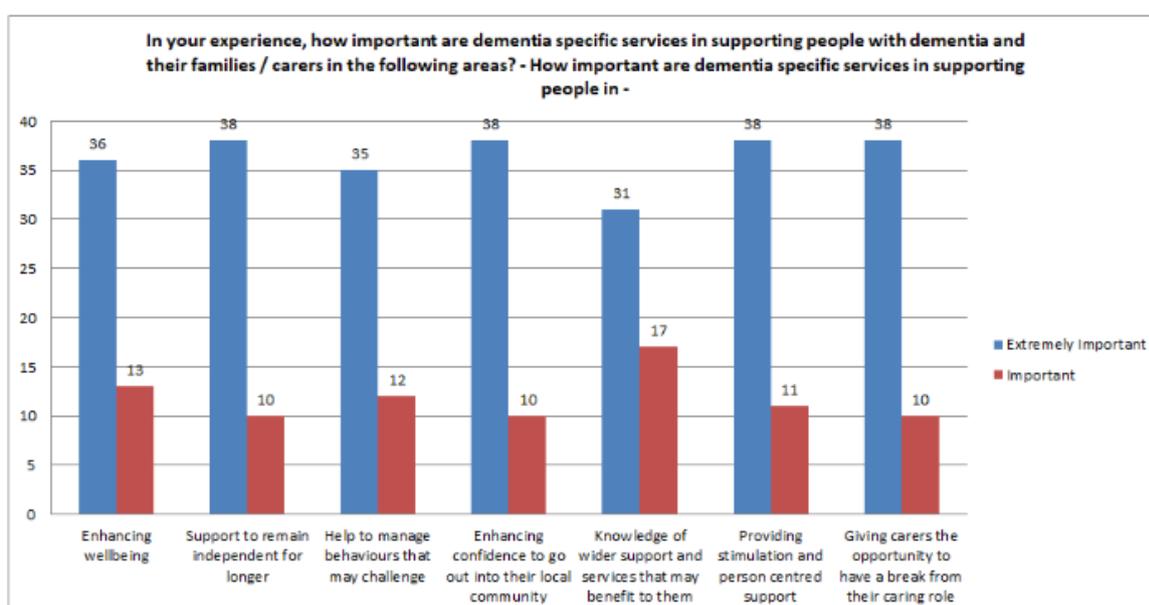
Feedback was provided about the practical support at home that would help assist people with dementia and their carers to live well;

- Greater knowledge and access to assistive technology to enable the person living with dementia to remain living at home more safely.
- Provision of support services to families in the evenings and at weekends to support them in their carers roles.
- All services should be available in all localities such as access to admiral nurse support /side by side and ongoing resources such as an NHS support worker role. This is a postcode lottery currently.
- Provision of support services to families in the evenings and at weekends to support them in their carer's roles.

The importance of physical activity was highlighted in feedback this needs to be accessible to people with dementia and the benefits of this needs to widely publicised to professionals and the public.

All of the service outcomes linked to current dementia services were identified by survey participants as either 'important' or 'very important' suggesting that any future support or services needs to encompass this broad spectrum of expected outcomes;

**Chart 8: Survey Question (based on 116 responses to each question).**



## 6 Feedback from BME groups

A piece of work was commissioned by WCC localities team for Equip<sup>6</sup> to look at ways in which Dementia Services across Warwickshire can be made more inclusive and accessible by meeting the needs of Black Minority and Ethnic (BME) communities. These communities include (but not exclusive to) Eastern European, new and emerging groups, Gypsy's and Travellers as well as the established BME groups. The project also consulted with Lesbian Gay Bisexual and Transgender (LGBT) communities.

### 6.1 Approach to BME engagement:

Surveys and face to face workshops were undertaken by Equip staff. Dementia resources published in different languages were made available at face to face events. The results of the BME engagement are available in a full report upon request.

### 6.2 BME engagement results:

**34** people responded to the online survey and **268** people were engaged in community workshops. Only 1% of those engaged in face to face workshops described their knowledge about dementia as 'good'. Most feedback from BME groups was that the only symptom they could relate dementia to was 'memory loss'.

### 6.3 Key Themes:

**Awareness:** Feedback from all workshops demonstrates that there is a lack of awareness about dementia and services available. The prevalent belief amongst these groups is that they believe that dementia is a form of 'madness'.

**Embarrassment/stigma:** Many of the participants at workshops felt that dementia was 'shameful' and it was felt that the condition was hidden from the community.

**Cultural and Religious barriers:** One of the main barriers to accessing services or support for BME participants was the belief that dementia services would not understand or be mindful of cultural and religious needs. For example some female participants felt that using dementia cafes would involve sitting at tables with men. This would be culturally and religiously inappropriate for these women and this would be a barrier.

**Language barriers:** All BME groups stated that any literature with information about a service needs to be available in different languages this enables them to be empowered and informed rather than waiting for someone to translate or interpret information for them.

**Barriers for the LGBT community:** There was a consensus that health and social care staff lack the training and awareness around LGBT issues. They felt that there is an assumption in services that people are all heterosexual. This was identified as an issue across health and social care and not a dementia specific issue.

## 7. Conclusion and next steps

Based on the results of the engagement activities the following next steps are recommended;

The key themes from each section of the engagement will be used to inform the re-refresh of the dementia strategy. The feedback will be grouped into the appropriate well pathway headings and used to shape the delivery plan that sits behind the strategy.

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<sup>6</sup> Equality and Inclusion Partnership are a charity providing support, training and advice across Warwickshire to combat discrimination.

Key comments and feedback about individual services and service partners will be shared with service leads so that they are aware of the feedback that people have taken the time to provide. This will include, Clinical Commissioning Groups, Coventry and Warwickshire Partnership Trust, Commissioned service providers and carers and voluntary based community groups. The engagement report will also be shared with Warwickshire's Dementia Strategy Programme Board, and work streams, as well as the local STP Mental Health & Emotional Wellbeing Programme Board.

A broad range of feedback was collected as part of the survey for this engagement exercise however many people skipped the service specific questions. For this reason there will also be two further surveys, one directed at customers of the current Dementia Day Opportunities and one directed at the Dementia Navigator customers, to seek to find out more detailed and service specific information that will be used to help shape future service specifications for these services.

The potential areas for improvement in our current service offer will be addressed by highlighting them as areas to be developed as part of the re-freshed strategy are:

- **Information and advice** – improved information about how or where to access dementia support, information and advice.
- **Support following a diagnosis** – better links between services following a diagnosis and scoping out, with Health partners, the potential development of a care co-ordination role for people living with dementia.
- **Support for carers** – carers to be recognised as expert care partners and supported more fully to undertake their caring role including access to breaks, advice and information, knowing what to do when there is a crisis and training for carers.
- **Recognition and support to the community** – there are many community based support groups and volunteers in Warwickshire helping people with dementia and their carers in the community to stay independent and well. These groups and individuals need support and recognition to ensure they can sustain and that this support does not duplicate each other and continues to be meaningful to those that use it.
- **Improving access / uptake among those from BME backgrounds and people with other vulnerabilities** – ensuring that people from BME backgrounds have access to the support they need and that due care and attention is taken to appreciate cultural differences that can affect access to services. In addition, the needs of people with other vulnerabilities, such as people with learning disabilities and people from an LGBT background, will be taken into account when commissioning future services and support.

The re-fresh of the Dementia Strategy will also be used as an opportunity to celebrate and highlight the things that are going well in Warwickshire in terms of dementia support including;

- Dementia services and support are well utilised and these services are routinely referred to throughout care pathways.
- There is a vibrant and wide range of community based dementia support services available in Warwickshire.
- Dementia services across Warwickshire are supported by very committed staff and volunteers who are proud to provide personalised and holistic support to people with dementia and their carers.
- People with dementia and their carers value the support they receive from dementia specific services and this helps them to feel confident and well supported in their communities.

Finally, The Council and partners thanks the many participants to this engagement for their honest and thorough feedback. Further updates on service and strategy development will be available at; <https://dementia.warwickshire.gov.uk/>