

Coventry and Warwickshire's Living Well with Dementia Strategy (2022-2027)

Presentation to Health and Wellbeing Board, 12th January 2022

The purpose of the presentation is to provide an overview of:

- Summary of the key findings from the Dementia strategy engagement undertaken through September and October 2021
- How these findings will be used to develop the strategy and associated strategy delivery plans
- Overview of Approvals process prior to publication

Background to the refresh of the strategy:

- Strategy will be a Coventry and Warwickshire wide, and system wide strategy, involving health, social care and voluntary sector
- Fully supported by NHS colleagues and voluntary and community sector
- Draft strategy was presented at OSC (Sept 2021) and at Health and Wellbeing Partnership meetings (Rugby) / Place Executives (North and South)
- Also presented to Joint Commissioning Board, Health and Care Partnership Mental Health Strategic Board
- Focus of strategy is on key objectives for 2022-2027; progress on these key objectives will be reviewed and additional objectives may be added at a later date during the lifetime of the strategy
- System partnership approach for delivery of strategy
- Strategy has a 'plan on a page' approach - one page for each of the six priority areas
- Delivery plans will be developed for each Priority – to include Lead organisation with responsibility for delivery, dates and actions to ensure achievement of objectives

Coventry and Warwickshire Dementia Strategy priorities:

Priority One: Reducing risk of developing dementia

We will promote and support healthy lifestyles, aiming to reduce the risk of developing dementia.

Priority Two: Diagnosing Well

People with dementia will receive a timely, accurate diagnosis of dementia.

Priority Three: Supporting Well

People affected by dementia will have access to safe, high quality care.

Priority Four: Living Well

People affected by dementia will be able to live in safe and accepting communities, where they can access a range of support services and enjoyable and meaningful activities.

Priority Five: End of Life

People with dementia will be supported to die with dignity in the place of their choosing. Their families will be supported.

Priority Six: Training Well

Training and awareness opportunities will be offered to support communities to increase their awareness of dementia.

Staff who work with people with dementia and their carers will have access to appropriate training.

The local Dementia strategy priorities are aligned with the NHS Well Pathway for Dementia



Engagement on draft strategy – how it was undertaken:

September and October 2021 – 6 week engagement

- Online survey through Ask Warwickshire. Distributed widely via emails to stakeholders and through other communication channels (Easy read version, hard copies and alternative formats were available to maximise engagement).
- In-person engagement with people with dementia and carers. Making Space (commissioned co-production service) led this engagement in Warwickshire. Offered 1-to-1 sessions, small groups and visits to Dementia cafes etc. Face to face and virtual opportunities offered. Signposted to services and support.
- Responses could be submitted via email.
- Commissioner attendance at various meetings with practitioners took place prior to, and during formal engagement period.

Engagement – survey participants:

Survey: 85 people responded to survey (62 to main survey; 23 to easy read)

Capacity in which person was completing the survey (Number of people/percentage of total)

- Person living with dementia - 3 (3.5%)
- Family member, friend, informal unpaid carer taking care of someone affected by dementia - 37 (43.5%)
- Member of the general public - 8 (9.4%)
- Statutory partner (health/ local authority) - 13 (15.3%)
- Councillor / elected member (WCC, District or Borough, Town Council) - 2 (2.4%)
- Voluntary and/or community sector - 7 (8.2%)
- Business - 7 (8.2%) Other - 8 (9.4%)

Area of Warwickshire / Coventry they live / work in (Number of people/percentage of total)

- North Warwickshire Borough - 11 (12.9%)
- Nuneaton & Bedworth Borough - 7 (8.2%)
- Rugby Borough - 11 (12.9%)
- Stratford-on-Avon District - 16 (18.8%)
- Warwick District - 19 (22.4%)
- Coventry - 6 (7.1%)
- Work / undertake role across all of Warwickshire - 3 (3.5%)
- Work / undertake role across all of Warwickshire and Coventry - 5 (5.9%)
- Live outside of Warwickshire and Coventry - 6 (7.1%) Other - 1 (1.2%)

Engagement (in-person engagement):

In person engagement:

- A total of 223 people with dementia and carers were engaged with through a range of 1-to-1 sessions, small groups and visits to Dementia cafes / groups.
- At least one group session took place in each district and borough of Warwickshire and in Coventry.
- Focus of in-person engagement was on Priority Three: Supporting Well and Priority Four: Living Well, but other priorities were explored.
- The vast scope and significance of this engagement captured feedback relating to all priorities.
- Participants were informed about support services - Dementia Connect and Carer Wellbeing service.
- Little representation from people from ethnically diverse communities
- 4 emails were received with feedback about the draft strategy.

Key findings - summary:

- Overarching message from **in person engagement** – more information on what support is available and how to access it. ‘People don’t know what they don’t know’.
- Participants highlighted a lack of knowledge of available services, with carers often learning about them through word of mouth, emphasising the importance of peer support networks.
- **Survey responses:** Many people in strong agreement or agreement with the objectives (for 5 of the 6 priorities, this was approximately 90% of respondents (range was 87-92%). For priority Three – supporting well – 84% of respondents strongly agreed or agreed with the objectives.
- Key points – more awareness of support available for carers and people with dementia, support needs to be available evenings and weekends, support needs to be in place early after diagnosis, carers should not have to spend time finding out about services.
- Majority of negative comments were in relation to how the strategy will actually be achieved.

Key findings - response:

To respond to the engagement findings, we propose to develop the strategy in the following ways (subject to approval at the system Dementia Board meeting):

- More detail about it being a system wide strategy and range of partners involved
- Greater detail will be included in the Delivery Plans which will ensure we deliver the strategy. These delivery plans will be published. Some of strategy and all of the Delivery plans need to clarify the organisation(s) responsible for different objectives
- Strategy will be adjusted over time
- Priorities areas need to link together as part of an overall Dementia Pathway
- Statement to be included about funding for the strategy
- Clarify who funds what services, as some misunderstanding about what services the Local Authority commissions and pays for
- Clarify that some of the support, services and work is not starting from scratch. A lot is already underway
- Delivery plans need to ensure equity of service, especially geographically. Should not be a postcode lottery.

Changes to be made to the strategy:

Vision: too broad and doesn't feel realistic.

Will develop the visions to include a Diagnosis of the challenge, **guiding** objectives and **coherent** actions to follow. Why?, What?, How?

People living with dementia and their carers do not always know about the support available and do not always access it at an early stage.

Priorities and Dementia Statements - these have been linked and now show which priorities will help to achieve which Dementia Statements (the statements reflect the things people with dementia have said are essential to their quality of life).

Dementia Statement	Key priority in the strategy that will help achieve the statement
We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.	Diagnosing Well, Supporting Well, Living Well
We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.	Diagnosing Well, Supporting Well, Living Well
We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate, and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.	Diagnosing Well, Supporting Well, Living Well, Training Well
We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.	Diagnosing Well, Supporting Well, Living Well, Dying Well, Training Well
We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.	All priorities

Priority one: Preventing Dementia

- We will change the name of this priority to 'Reducing Risk of Dementia'.
- We will explain more clearly that, although the risk of dementia can be reduced through healthy lifestyles, that factors such as increasing age and genetics are also risk factors for dementia. Unfortunately, even if people lead very healthy lifestyles, they may still develop dementia.
- We will strengthen the health checks objective and make specific reference to the Dementia element of Health Checks.

Priority two: Diagnosis

- We will add a statement about the importance of taking carers perspectives and information regarding their loved one into account.
- We will add a statement that we will work towards ensuring that every practitioner who tells a person they have dementia is appropriately trained and offers post diagnosis support.
- We will explore the use of a range of settings for diagnosis of dementia, to attempt to relieve some of the stress of diagnosis which can impact on the diagnosis
- We will add a statement about ensuring cultural sensitivity during the diagnostic process.

“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

- We will add in an objective about working to raise awareness of available person-centred respite support, appropriate to the needs of the person with dementia.
- We will add in a statement about an annual review of a persons Care Plan with their Care Coordinator (as well as this appearing in Diagnosing Well), which would ensure access to other sources of support and services.
- We will add in a statement about the importance of GPs and other practitioners being aware of Dementia Connect, so that they can ensure everyone is linked in with this service at, or as close as possible, to diagnosis. Dementia Connect can then ensure all people with dementia and carers are linked in with the wider range of community support services.

“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

- We will add in a statement about ensuring equity of provision of services where this is possible (e.g., for commissioned services)
- We will add in statement about ensuring ongoing support from a dementia support service (whether Dementia Connect, Admiral Nurses or another support service) to offer practical and emotional support. Practical support with issues such as obtaining a Power of Attorney, claiming carers allowance, blue badges and managing challenging behaviour.
- We will include reference to having an annual review of the Care Plan in this priority as well as in Diagnosing Well and Supporting Well.
- We will add in a statement about importance of support for volunteers – development of a county wide Dementia Forum in Warwickshire.

“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: End of life care

- We will change name of priority to 'End of Life care'
- We will enhance detail on importance of talking about end of life care while person still has capacity
- We will add to the statement about support for carers after the death of their loved one, that they should be supported as the person approaches end of life
- We will add a statement about support with financial advice after the death of loved one.
- We will add a statement(s) about Palliative care

Priority six: Training

- We will add a statement that we will collate and promote the range of courses for carers, delivered by local and national groups.

Focus on carers

- We will add a statement to each priority area about what specific support will be offered to carers.

Enhancing understanding of the strategy

- Range of colleagues will be asked to read through and ‘sense check’
- WCC Communications will undertake an accessibility check as part of design of strategy before publication

Co-production approach

- We will add a statement to include more detail on the co-production approach. This may include annual focus groups to talk to people with dementia and carers about their experiences of care and support.
- Future commissioning of services will include coproduction throughout the commissioning cycle.

Outcomes from engagement:

- Report of engagement through the survey
- Report of in-person engagement
- Review of all feedback, summarised in a 'You said, we did' report. This will outline the key changes to be made to the strategy, and also include details on how the associated strategic delivery plans will be developed.
- All three above reports will be published on Ask Warwickshire.
- Findings considered and incorporated, where possible, into Dementia Strategy.

Final approvals process, prior to publication

- Discuss strategy at Health and Care Partnership Dementia subgroup - 10th January 2022
- Health and Wellbeing Board on 12th January 2022
- People Group Directorate Leadership Team (date tbc)

For information, discussion and to seek approval to publish (further to any final changes discussed at the meeting):

- Health and Care Partnership Mental Health Strategic Group (date tbc)

For approval to publish:

- Corporate Board (tbc)
- Cabinet (12th April 2022?)
- Health and Wellbeing Board (May 2022)

Coventry City Council are aiming to take the strategy to the April Cabinet meeting for approval to publish.

Aim to publish for Dementia Action Week 16-22 May 2022.

The strategy will be shared with partners, published on the Council's website, and shared through local communication channels.