

Coventry and Warwickshire's Living Well with Dementia Strategy 2021 – 2026

DRAFT

Please note: Communications will professionally design and format the strategy before publication.

Foreword

The vision for Coventry and Warwickshire's Living Well with Dementia Strategy 2021 - 2026 is that

'everyone affected by dementia is enabled to live well'.

Coventry and Warwickshire's Living Well with Dementia Strategy 2021-2026 details the priorities that will help ensure that people with dementia, as well as their carers, receive the appropriate support, information, and advice along their journey with dementia. The strategy will be supported by a delivery plan which will set out exactly what we will do over the next five years, to ensure that **'everyone affected by dementia is enabled to live well'**.

The impact of the Covid-19 pandemic outbreak has been very challenging for people with dementia and their carers. People with dementia were an extremely vulnerable group during the pandemic and whilst we know that there have been many examples of excellent care and support, we also know that many people have experienced significant challenges including social isolation, lack of engagement in meaningful and enjoyable activities and concerns about accessing services. This has further increased the health inequalities that existed before the pandemic.

Although dementia diagnosis rates were improving prior to the Covid-19 pandemic, we still need to do more to encourage and support people to come forward for a memory assessment if they have concerns about their memory. There are many benefits of receiving a timely diagnosis, including access to treatment, support, and services. Many local organisations, groups and individuals are working to become dementia friendly, which has done a great deal to reduce the stigma that used to be associated with dementia. We are confident that by progressing our vision and priority areas we will be able to ensure more people receive support following a diagnosis of dementia which will help them to live well, remain at home and independent for longer.

The strategy also shows a strong commitment to supporting family and friends who provide care and support for a loved one with dementia. It is essential that those people who are providing many hours of unpaid support to their loved ones are supported in their role. This is important because, without support, informal carers are at risk of isolation and experiencing poor health outcomes. The strong links between the Dementia strategy and Strategies that focus on Carers will help to ensure carers of people living with dementia are well supported.

The strategy closely links with, and supports other local strategic ambitions and priorities, in particular Coventry and Warwickshire's Health and Care Partnership (HCP), the local Health & Wellbeing Strategies, and Coventry and Warwickshire's Council Plans.

Cllr Margaret Bell

Portfolio Holder for Adult Social Care and Health

Warwickshire County Council

Portfolio Holder for Adult Social Care and Health

Coventry City Council

Background (infographics to be formatted by communications)

Key data about people living with dementia in Coventry and Warwickshire:

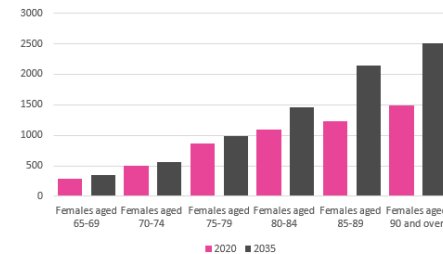
This page will include infographics on:

- Number of people estimated to be living with Dementia.
- Number of people with a diagnosis of Dementia. Approximately 55% of people living with dementia have a diagnosis.
- Number of people receiving a diagnosis of dementia each year.
- Projected number of people living with dementia in 2030, 2040, 2050
- Diagrams showing those with a dementia diagnosis in different age groups, sex, ethnicity. For example:

Figure 8 Predicted dementia prevalence for males by age between 2020 and 2035



Figure 7 Predicted dementia prevalence for females by age between 2020 and 2035



Source POPPI, August 2020

- Number of people living with dementia living in each District / Borough of Warwickshire, and in Coventry.
- Number of people with early onset dementia (under the age of 65).
- Number of informal carers of people with dementia
- Other key data will be added.

Approach

This strategy is underpinned by engagement with a wide range of key stakeholders, including people living with dementia, carers, and practitioners to understand the issues facing those living with dementia and the barriers to overcoming these challenges.

The development of this Dementia Strategy is also shaped by the national policy framework and local strategies, delivery plans and work programmes, many of which have involved significant engagement with practitioners, people living with dementia and carers.

The vision for Coventry and Warwickshire's Living Well with Dementia Strategy 2021 - 2026 is that 'everyone affected by dementia is enabled to live well'.

We aim to achieve our vision by focusing on the following priorities:

Our local priorities align to the national priorities of The Well Pathway for Dementia:



Priority One: Preventing Well

We will promote and support healthy lifestyles, aiming to reduce people's 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: Dying Well

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.

Challenges and response to the Covid-19 pandemic

The Covid-19 pandemic has brought many challenges for people living with dementia, and for their carers and loved ones. This strategy aims to build on some of the positive developments such as the individualised and flexible support offered by services to people with dementia and carer and increased creativity and adaptations to how support is delivered. Many have also benefited from a greater virtual offer including singing for the brain online groups and wellbeing programmes involving arts, music and physical activity. However, we also recognise the challenges that Covid-19 has brought and will seek to overcome these as we move towards life after Covid-19.

" I can get through this as long as I keep getting your support and your calls, I don't trust just anyone coming to my house"

Feedback from person with dementia using Dementia Day Opportunities service during the Covid-19 pandemic

What we are doing already

Warwickshire County Council, Coventry City Council and our partners in the NHS, District and Borough Councils and voluntary sector have been working closely together for many years with the aim of supporting people to live well with dementia. Some of the key developments and highlights in the last four years include:

Priority One: Preventing Well

- Greater awareness that the risk of developing dementia can be reduced through healthy lifestyles, through health awareness campaigns and NHS Health Checks.

‘what’s good for your heart is good for your head’.

Priority Two: Diagnosing Well

- Increasing diagnosis rates from 40% in 2012 to around 60% in 2020.
- Some GPs are able to offer memory assessment for less complex cases, meaning patients can be diagnosed closer to home by staff they already know.
- The introduction of post diagnosis support packs and sessions for people newly diagnosed with dementia, and for their carers.

Priority Three: Supporting Well

- Everyone receiving a dementia diagnosis is offered a “Next Steps” course, and further post-diagnostic support is now available through [Dementia Connect](#) (Alzheimer’s Society) and [Admiral Nurses](#). Both services offer extended support as and when required throughout the dementia journey.
- The Dementia and Memory Assessment Service in Coventry has achieved Memory Service National Accreditation Programme (MSNAP) which recognises high quality memory assessment services.

Priority Four: Living Well

- The development of [Warwickshire’s Living Well with Dementia website](#), with information and details of services and support.
- [Reading Well Books on Prescription](#) – offers a selection of self-help books about dementia in all public libraries in Coventry and Warwickshire.
- There are approximately 90 organisations signed up to the [Coventry and Warwickshire Dementia Action Alliance \(DAA\)](#). These organisations have all committed to raising awareness of dementia and supporting people with dementia in their communities.

Priority Five: Dying Well

- A range of training has been delivered for professionals to support end of life care for people with dementia; this includes
 - Dementia Awareness Training for Palliative Care Teams and Hospices.
 - Training in Advance Care Plans for Community Dementia staff.
 - A workshop on Dying Well with Dementia for multi-agency clinicians from a variety of services.

Priority Six: Training Well

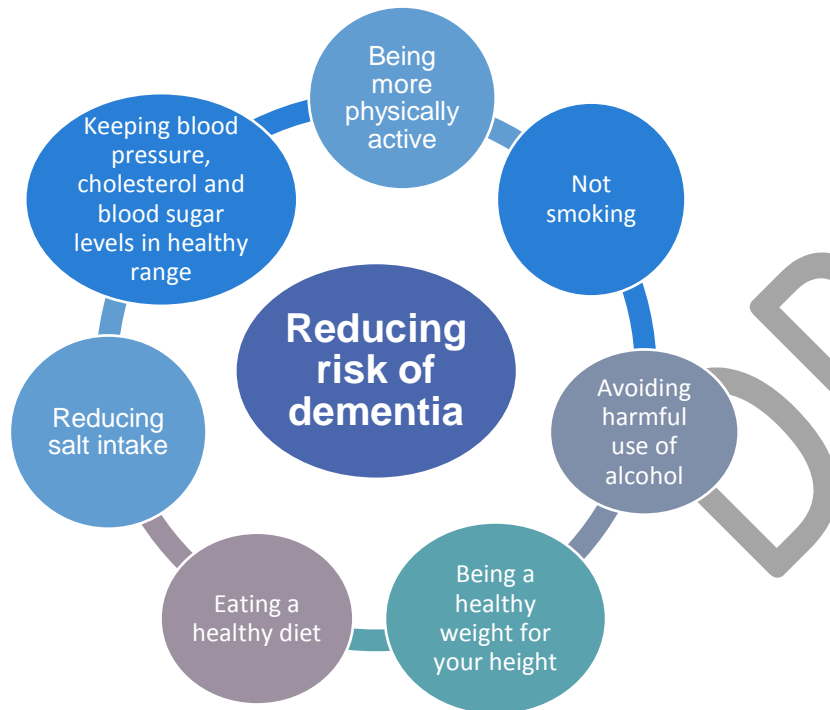
- There are now over 30,000 Dementia Friends in Warwickshire.
- Face to face Dementia Awareness sessions have been delivered to a range of organisations including Local Authorities, library services, voluntary sector, dental practices, general practices, hospice staff, and leisure centre staff.
- Frontline social care staff (including care home staff) can access training via Social Care Information and Learning Service (SCILS)

Priority One: Preventing Well

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

Although some of the risk factors for dementia (such as age, genetics, and ethnicity) cannot be changed, there is strong evidence that you can reduce your chances of getting dementia. Even if someone has dementia, they can take action to lessen the symptoms.

People can reduce their risk of dementia through the following:



“What’s good for the heart is good for the brain”

However, only about a third of people (approximately 33%) think it’s possible to reduce their risk of developing dementia, compared to 81% who think it is possible to reduce their risk of developing diabetes.

What we will do

- We will continue to raise awareness of the benefits of healthy lifestyles to reduce the risk of developing dementia.
- We will encourage greater take up of NHS Health Checks for those aged 40-75.
- We will raise awareness of ways to reduce risk of dementia in at-risk populations (e.g. those with Mild Cognitive Impairment, individuals with learning disabilities and people from Black and Minority Ethnic backgrounds).
- We will continue to support people with Mild Cognitive Impairment to access [Warwickshire’s Physical Activity on Referral Service](#).
- Making Every Contact Counts supports practitioners working across Warwickshire to support their clients, customers, and patients to make positive changes to their physical and mental health and wellbeing. We will continue to promote and support Making Every Contact Counts across Warwickshire: (www.warwickshire.gov.uk/health-improvement/making-every-contact-count/1).

How we will know we have been successful

- Increased number of awareness campaigns delivered each year which include dementia risk reduction messages and how far these campaign messages reach (measured by number of press releases, people visiting websites, views on social media).
- More people attending NHS Health Checks
- More people with Mild Cognitive Impairment referred to [Warwickshire’s Physical Activity on Referral Service](#)

Priority Two: Diagnosing Well

People will receive a timely, accurate diagnosis of dementia.

- An estimated 11,500 people in Coventry and Warwickshire live with dementia, but only around 60% of these have a formal diagnosis.
- When someone is diagnosed with dementia, they can access a wide range of support for themselves and their families.
- Some people who have received a diagnosis have reported that knowing the diagnosis helps them prepare and come to terms with the changes that are happening. It can also help loved ones to understand and support them. See Norman's story.
- Many people live a fulfilling life for years following their diagnosis.
- Although there is not currently a cure for dementia, for some types of dementia it is possible to take medication to slow the progression of the disease.

What we will do

- Continue to encourage anyone with concerns about their own memory or the memory of a loved one to see their GP as soon as possible. Symptoms of dementia (such as confusion or forgetfulness) may be caused by a range of factors (including infections) which can often be easily treated.
- Continue to increase dementia diagnosis rates so that at least two thirds (67%) of people living with dementia have a diagnosis (this target has been set by the government).
- Review the dementia pathway and publish the key services and support available at all stages of the pathway to practitioners and those with dementia and their carers.
- Support GPs to undertake diagnosis of dementia where appropriate or refer to memory assessment services.
- Ensure that everyone receiving a diagnosis of dementia receives a Care Plan, and information about the minimum support offer (as shown in the diagram on the following page).

Normans story

"An early diagnosis of dementia is so, so important. Once diagnosed, I knew what I was up against. As they say: know your enemy. If I hadn't been diagnosed early and I hadn't been seen by consultants on a regular basis, I wouldn't be as well as I am today. I don't know what my future holds, but at least I'm prepared for it"

Norman diagnosed with dementia at 50. See more at www.scie.org.uk/dementia/symptoms/diagnosis/early-diagnosis.asp

- Ensure that everyone receiving a diagnosis is referred to a post diagnosis dementia support service.

"When someone is diagnosed with dementia you can go when you have problems, but it is so nice to get a call every 6–12 months to ask if everything is alright. I am not good at asking for help". Comment about Dementia Connect in Warwickshire service

- Promote the diagnostic and identification role in acute hospital care pathways and strengthen communication when a diagnosis is made.
- Ensure a high-quality memory assessment pathway by supporting Coventry and Warwickshire Partnership Trust (CWPT) to achieve Memory Services national Accreditation programme (MSNAP) accreditation across Coventry and Warwickshire.

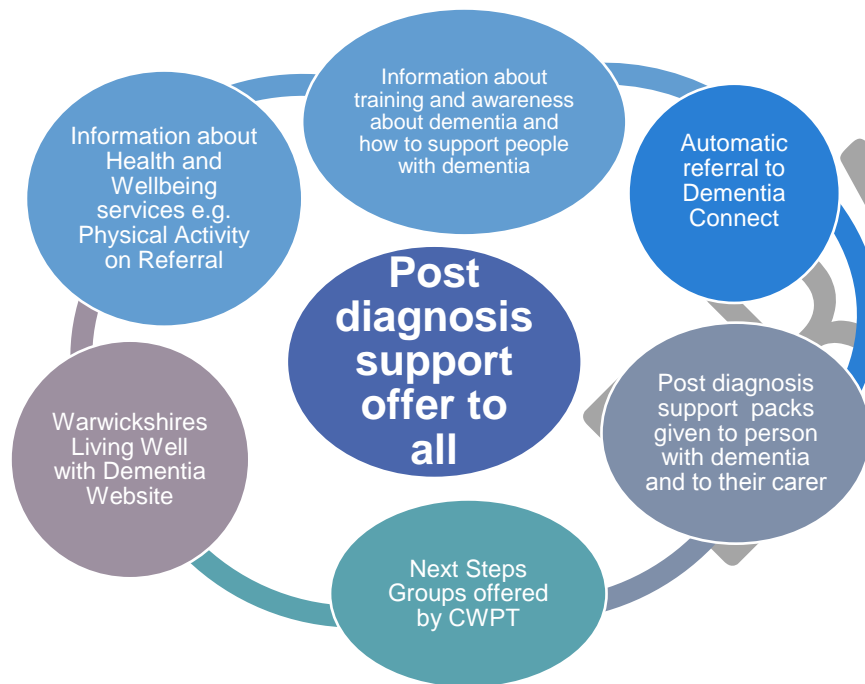
How we will know we have been successful

- Greater number of people diagnosed with dementia (and as a percentage of the people estimated to be living with dementia)
- More people diagnosed with dementia receive a Care Plan following their diagnosis (and as a percentage of all those diagnosed)
- Everyone diagnosed with dementia is offered a referral to a dementia support service (currently Dementia Connect) following their diagnosis.

Priority Three: Supporting Well

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

Post-diagnostic support helps the person living with dementia and their family come to terms with the diagnosis, access information, ask questions, find support and plan for the future. We want to ensure that people access support and are linked in with sources of information as early after diagnosis as possible. The diagram shows the minimum support offer for those receiving a diagnosis of dementia and for carers:



What we will do

Raise awareness of post diagnosis support available for people affected by dementia and ensure that information is easily accessible, available in a range of formats, and easy to understand.

- Continue to develop the Living Well with Dementia website, including map of services: www.warwickshire.gov.uk/dementia
- Redesign the dementia day opportunities support service to offer a blended service offer with greater choice and flexibility.
- Support carers of people living with dementia to maintain and build their community connections, by ensuring that accessible respite support is available to them.
- Support the voluntary sector to restore local support services following the Covid-19 pandemic, e.g. Dementia Cafes.
- Develop and promote the use of assistive technology to help people stay independent for longer.
- Work towards reducing the digital divide by supporting people with dementia to use iPads and similar technology to enjoy a range of virtual activities and stay connected to others.
- Ensure equality of access to dementia services, so that people with protected characteristics are equally able to access support.
- Work with providers of care and nursing homes and accommodation with support settings with aim of enhancing training and skills for workforce, maximising places available, reducing unplanned hospital admissions, delayed discharges, and placement breakdowns.
- Work with the market to ensure the continued development of high quality domiciliary care, housing with care, residential and nursing care options to meet growing demand.
- Review and strengthen the dementia pathway for people with dementia entering and leaving hospital.

How we will know we have been successful

- Greater number of people with dementia receiving support from local Dementia Support Service (currently Dementia Connect)
- More carers of people living with dementia supported by Carer Wellbeing Service
- Greater number of unique users of the Living Well with Dementia website.

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.

There are a range of initiatives aimed at helping people with dementia live well in their local communities, such as Dementia Friends, Dementia Friendly Communities and Dementia Action Alliance. These initiatives have the added advantage of increasing accessibility for everyone, and enabling people with dementia to continue playing a full and valuable role in their local communities.

Case Study: Books on Prescription and your local library

Coventry and Warwickshire Library Services have been members of the Coventry and Warwickshire Dementia Action Alliance (DAA) since 2013. Many of the library staff work directly with the public and are keen to be able to recognise and support the different needs of customers who wish to use the library. Libraries can help people to keep learning, stay connected and reduce isolation and loneliness. Many of the library staff have become Dementia Friends, (these are individuals who have taken the time to learn more about what it is like to live with dementia and the small things that they can do to make a difference). Libraries offer [Books on Prescription](#) collections to help people improve their health and wellbeing. All of the books are selected and recommended by healthcare professionals and follow National Institute for Health Care Excellence (NICE) guidance. Books on dementia include personal stories and support for relatives and carers. Visit www.warwickshire.gov.uk/booksonprescription or https://www.coventry.gov.uk/info/126/libraries/3218/libraries_-_core_services/7 to find out more about how to borrow Books on Prescription or ask at your local library.

What we will do

- Develop and promote opportunities for people living with dementia and carers to maintain their mental and physical health and wellbeing.
- Promote dementia friendly events and activities to encourage people living with dementia to continue to engage in a range of interests, hobbies, and activities.
- Continue to offer and promote a range of arts and cultural opportunities (for example, access to singing, music, arts, and crafts activities) to people living with dementia and their carers.
- Promote opportunities for taking part in dementia research and access to research opportunities
- Work closely with social prescribing colleagues to ensure people living with dementia and their carers are encouraged and supported to continue to take part in the activities they enjoy, and to develop new interests.
- Increase the numbers of Dementia Friends in Coventry and Warwickshire by 10% each year.
- Increase the number of organisations signed up to the local Dementia Action Alliance by 10% each year.
- Work with our local Dementia Friendly Communities and Coventry & Warwickshire DAA to encourage more businesses and organisations to work towards becoming dementia friendly.
- Ensure that information about benefits and entitlements are communicated to people living with dementia and that they are supported to apply for these.
- Review how we can deliver accessible and effective support services and activities following the COVID-19 pandemic.

How we will know we have been successful

- Increase in number of Dementia Friends
- More organisations joining the Dementia Action Alliance
- Local Leisure Centres, Libraries and Community Centres working towards and awarded Dementia Friendly status.

Priority Five: Dying Well

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

A third of people over the age of 65 will die with some form of dementia. In care homes, around two thirds of people will have dementia as a factor in their death. Each person with dementia is different; staff involved should understand individual wishes and preferences to ensure people are able to die with dignity and respect, free from pain and in a place they have chosen. Where possible, the person with dementia should be encouraged to plan for the future, including care options, while they are able. This can help to reassure their loved ones they are doing what's best for the person with dementia.

What we will do

- Roll out “Let’s Get Talking” days to all those working with people with dementia and their families to improve skills in talking about end of life. Virtual options will make this training more accessible.
- Develop one consistent advanced care plan and approach to promoting and completing advanced care plans.
- Train a range of professionals to support people with dementia to complete advanced care plans.
- Promote availability of Admiral Nurses, as experienced dementia nurses, who can provide support to people living with dementia and their families in complex situations, including end of life.
- Introduce a flag on NHS systems that identifies patients with an advanced care plan. This will ensure consistency and means clinicians and other professionals know what patient’s wishes are.
- Increase awareness and use of the Care and Support Towards Life’s End (CASTLE) register by health and social care professionals.
- Develop a bereavement support offer for families of people with dementia after the death of their loved one.

Case Study: Dying well with dementia

A gentleman with young onset dementia was being cared for by Coventry and Warwickshire Partnership Trust (CWPT) on a Dementia Ward. He became very unwell and was at the end of his life. With his family’s agreement a DNR (Do Not Resuscitate) was granted and a best interest meeting took place which confirmed the family’s wishes not to send him to a general hospital for further treatment.

Wards at CWPT settings where the gentleman was being cared for are not set up to provide end of life care so the staff needed support, guidance and medical intervention to ensure that this gentleman was allowed to die with respect, dignity and comfort.

The Deputy Ward Manager had attended an End of Life workshop for Dementia that had been delivered as part of the Coventry and Warwickshire Dementia Strategy Board. She contacted the person who had organised the workshop to ask for signposting to contacts and services that might be able to support them to manage their patient’s care in the best way possible. Through conversations with various specialist staff working for CWPT and other local organisations, the staff team were supported to ensure that the gentleman could be cared for and allowed to die with dignity and respect. This also provided huge comfort to his family.

How we will know we have been successful

- Increased number of people on Care and Support Towards Life’s End (CASTLE) Register
- More people with dementia with advanced care plans.
- Roll out of “Let’s Get Talking” days to people working across the dementia pathway.
- Increased availability of bereavement support offer for families of people with dementia after the death of their loved one.

Priority Six: Training Well

Training and awareness opportunities will be offered to support people affected by dementia, carers, and communities to increase their awareness of dementia.

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

Dementia Friends is a national initiative, led by Alzheimer's Society that aims to raise awareness of dementia and the things that can help people living with dementia. Anyone can become a [Dementia Friend](#).

The national Department of Health and Social Care [Dementia Training Standards Framework](#) aims to ensure quality and consistency in dementia education and training. It details the essential skills and knowledge necessary for workers in health, social care, and housing.

There is a range of excellent training available in a variety of formats (such as e-Learning and face-to-face), from a range of providers. It is important that practitioners are made aware of these training opportunities and encouraged to undertake relevant courses.

The Care Certificate is the minimum training induction requirement for anyone entering health and social care, including staff across all commissioned services. The Care Quality Commission (CQC) require evidence of compliance with the Care Certificate for all providers registered with CQC. For other providers it is regarded as best practice and should be a minimum requirement. Care Certificate can be accessed through the Social Care Information and Learning Service (SCILS).

What we will do

- We will promote training and dementia awareness opportunities to informal carers and communities to increase their awareness of dementia. For example, encouraging everyone to become a Dementia Friend.

- We will develop a tiered learning platform on the Living Well with Dementia website to ensure access to learning opportunities is as easy as possible.

We will offer further opportunities for people to participate in the Dementia Bus experience, which offers a sensory experience of what's it's like to live with dementia.



- All Local Authority commissioned service staff will be encouraged to become Dementia Friends.
- Anyone starting work in health and social care, will be required to complete the relevant units of the Care Certificate.
- Local Authority's will aim to ensure that all direct and commissioned service staff who are working with people living with dementia are trained to at least Tier 2 of the Dementia Training Standards Framework.
- We will aim to ensure that all home and residential care staff working with people living with dementia receive mandatory training. This should be equivalent to Tier 3 of the Dementia Training Standards Framework.

How will we know we have been successful

- Increase in number of Dementia Friends created.
- High numbers of staff will have completed relevant training (as appropriate to their role).
- More staff and organisations registered on SCILS.
- We will monitor the numbers of staff who have completed Care Certificate.

How we will deliver this strategy

The Dementia Strategy Board will develop a delivery plan to support achievement of the strategy. The Board will monitor achievement of the delivery plan at regular intervals (between every three to six months). This will ensure we remain on track to achieving the strategy.

The board will include representatives from:

- Warwickshire County Council (WCC)
- Coventry City Council (CCC)
- Coventry and Warwickshire Partnership Trust (CWPT)
- NHS Coventry and Warwickshire Clinical Commissioning Group (CCG)
- South Warwickshire Foundation Trust (SWFT)
- George Eliot Hospital (GEH)
- University Hospitals Coventry and Warwickshire (UHCW)
- Voluntary sector organisations
- People living with dementia and their carers

Working groups will be established which are likely to align to each of the six priority areas. It is expected that each working group will develop an individual action plan for the strategy priority area that they are focussing on.

- Priority One: Preventing Well
- Priority Two: Diagnosing Well
- Priority Three: Supporting Well
- Priority Four: Living Well
- Priority Five: Dying Well
- Priority Six: Training Well

Working groups will include practitioners from a range of organisations and where possible people with dementia and carers will be involved in working groups.

Action plans are likely to include a range of actions to be undertaken across Coventry and Warwickshire as well as actions for Coventry and Warwickshire specifically.

An Equality Impact Assessment has been completed and will be reviewed on a regular basis by each working group to ensure we meet our responsibilities in respect of the Equality Act 2010 and the Public Sector Equality Duty.

There will also be a focus on Health Inequalities, and we will look to address inequalities as part of the action plans for each priority area. Action plans will also focus at a Place level, which will help to consider and address issues that may exist in particular areas across Coventry and Warwickshire.

Projects and / or work programmes to support delivery of the action plans for each priority area will be co-produced people with dementia and those that care for them where possible. This will help to ensure that activities make a real difference to the lives of people with dementia and those that care for them. Please see more detail on this on the following page.

Key measures will be monitored for each priority area (see further details of these measures in each priority area). These will help us to monitor progress towards achieving the strategy. People with dementia and carers will be involved in monitoring progress towards achieving the strategy through a range of methods.

The working groups will report on progress into other appropriate local groups and Boards as appropriate. This may include the Health and Care Partnership Dementia Board, Joint Commissioning Boards, Health and Wellbeing Board and Corporate Boards and Cabinet.

Some of the objectives will need to be achieved through existing funding and partnership working. However, we will also seek additional funding, which would enable us to enhance projects and activities to support achievement of some of the objectives.

Priorities and Dementia Statements

The key priorities described in this strategy will help to achieve the following Dementia Statements which reflect the things people with dementia have said are essential to their quality of life.

- 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.
- 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.
- 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.
- 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.
- 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

Development, delivery and monitoring of the action plans for each priority area will be co-produced people with dementia and those that care for them where possible. This will help to ensure that activities make a real difference to the lives of people with dementia and those that care for them and that the vision for Coventry and Warwickshire's Living Well with Dementia Strategy 2021 - 2026 is achieved

'everyone affected by dementia is enabled to live well'.

Visual image to be added

Find out more about the Dementia Statements [here](#):

Logos of all of the partner agencies will be on this page:

DRAFT