

# Leicester, Leicestershire and Rutland Joint Living Well with Dementia Strategy 2024-2028

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## Section 1: Introduction

Supporting and helping those living with dementia and their carers remains a priority for Leicester, Leicestershire and Rutland's (LLR) health and social care organisations. Our strategy sets out Leicester, Leicestershire and Rutland's ambition to support people to live well with dementia. It continues to reflect the national strategic direction outlined in the latest Prime Minister's Challenge on Dementia which details ambitious reforms to be achieved by 2020. The strategy is written for people affected by dementia either directly or as a carer and for the professionals who work to support them.

Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy was developed in 2019 and has since been refreshed to reflect our priorities for 2024-2028. The strategy has been developed in partnership between local health, social care and voluntary sector organisations and informed by people with lived experience of dementia.

An important focus of our strategy is to continue to deliver personalised and integrated care. We have used the NHS England Well Pathway for Dementia to give us a framework that puts the individual and their carer at the centre of service development and implementation across health and social care. We acknowledge that by collaborating in this way, efficiencies across the wider health and social care system will also be realised.

As a partnership, we are committed to minimising the impact of dementia whilst continually improving dementia care and support within the communities of Leicester, Leicestershire and Rutland, not only for the person with dementia but also for the individuals who care for someone with dementia. We will continue to actively encourage a person-centred and strength-based approach. We also aim to improve access to diagnosis and support services for all patients and people drawing upon support especially those from seldom heard groups who currently do not access services.

## Section 2: What is dementia?

[Prime Minister's Challenge on Dementia 2020](#): "Dementia describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's Disease, a series of small strokes or other neurological conditions such as Parkinson's disease."

All types of dementia are progressive. The way that people experience dementia will depend on a variety of factors therefore the progression of the condition will be different.

People of any age can receive a dementia diagnosis, but it is more common in those 65 years old and over. Early onset dementia refers to younger people with dementia whose symptoms commence before the age of 65. Due to the life stage differences amongst

younger people with dementia in comparison to the older population, different social issues are experienced.

No two people with dementia are the same and therefore the symptoms each person experiences will also differ.

### **Section 3: Our approach**

We aim to create a health and social care system that works together so that every person with dementia, their carers and families have access to and receive person-centred compassionate care and support not only prior to diagnosis but post-diagnosis and through to end of life.

This strategy has been guided by principles developed by NHS England in their transformation framework. This 'Well Pathway for Dementia' is based on NICE guidelines, the Organisation for Economic Co-operation and Development framework for Dementia and the Dementia I-statements from The National Dementia Declaration.

Our vision is that Leicester, Leicestershire and Rutland are all places where people with dementia can live well through the following NHS England guiding principles:

- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

Furthermore, following the pathway as part of ongoing business we will focus on: Leading, Integrating, Commissioning Training, and Monitoring Well

### **Section 4: National picture**

There are currently around 900,000 people with dementia in the UK. This is projected to reach 1.6 million people in the UK living with dementia by 2040 (Alzheimer's UK, 2019). The majority of people living with dementia are aged 65 and over, however there is a small portion of people under 65 living with dementia, approx. 40,000 (Alzheimer's Society, 2014). Figures published by the Alzheimer's Society, Alzheimer's Research UK, Public Health England and WHO show that:

there are over 25,000 people with dementia from black and minority ethnic groups in England and Wales, and this is estimated to rise to nearly 50,000 by 2026

- there are 209,600 new cases of dementia in the UK each year
- worldwide, around 50 million people are currently estimated to have dementia and there are 10 million new cases each year
- two thirds of people with dementia are women and over 600,000 women in the UK are now living with dementia. The condition is the leading cause of death in women in the UK

- There are over 700,000 unpaid carers of people with dementia in the UK. Women are more likely to take on unpaid caring roles for people with dementia and are two and a half times more likely than men to provide intensive, 24-hour care.

## Section 5: Local picture

There are currently over 9,000 diagnosed people living with dementia across Leicester, Leicestershire and Rutland.

- As nationally, similar rates of males and females have a diagnosis of dementia across LLR, however this shifts with more females having a diagnosis of dementia in age categories above 80.
- Largest ethnic group to have a diagnosis of dementia across LLR is 'White', this is followed by 'Asian/Asian British', however there is significant gap in the rate of diagnosis between the two groups.

There was a total of over 14,000 people predicted to be living with dementia across Leicester, Leicester and Rutland in 2020 and data projections show that this number is estimated to increase to over 13,000 in county, 3,000, in city and 900 in Rutland by 2030 (POPPI).

1 in 14 of 65s and over in Leicester, Leicestershire and Rutland is thought to have a dementia, which is reflective of the national trend. It is estimated that there are 105,000 carers across Leicester, Leicestershire and Rutland, although specific data for how many people care for those with dementia is not available. For further information relating to carers, please see the Leicester, Leicestershire and Rutland's Joint Carers Strategy 2022-2025 'Recognising, Valuing and Supporting Carers in Leicester, Leicestershire and Rutland'.

## Section 6: National context and background

In February 2015, the Department of Health published the Prime Minister's Challenge on Dementia 2020, to support the National Dementia Strategy of 2009. This detailed why dementia remains a priority and outlined the challenges the United Kingdom continues to face in relation to dementia. The priorities identified within this are to improve health and care, promote awareness and understanding and research. The Challenge continues to promote the Well Pathway for Dementia and therefore this local strategy uses the same structure as a guide.

There are a number of other national drivers that shape and influence the way we can support people affected by dementia. Some are listed below:

- Care Act 2014: sets out a framework of how local authorities should protect and care for adults within their locality.
- Equality Act 2010: protects people from discrimination in the workplace and wider society.

- Health and Care Act: new legislative measures aim to make it easier for health and care organisations to deliver joined-up care for people who rely on multiple different services.
- People at the Heart of Care: adult social care reform White Paper: 10-year vision on how support and care will be transformed
- Living Well with Dementia: a national dementia strategy sets out a vision for transforming dementia services with the aim of achieving a better awareness of dementia, early diagnosis and high-quality treatment at whatever stage of the illness and in whatever setting.
- NHS Adult Social Care Outcomes Framework: measures how well services achieve the outcomes that mean the most to people.

## Section 7: Local Context and Background

### How dementia support currently looks

The Dementia Support Service is the commissioned post diagnostic service, it aids people's understanding of what and where support is available. Anyone affected by dementia can self-refer into the Dementia Support Service and there are also standard referral pathways for professionals. These services are commissioned by the councils and NHS and are subject to competitive tender legislation so the provider may change over time. The commissioned service at point of publication of the strategy is Age UK Leicester Shire and Rutland. Rutland County Council combine this support with their Admiral Nurse service.

There is a range of services and support available for people living with dementia across Leicester, Leicestershire and Rutland. Some of these services are provided by local community groups and the voluntary and independent sector and some is provided or commissioned by NHS and local councils. Some of this support is subject to an assessment of need. The main method of receiving health support for people with dementia is through their general practice and the two NHS Trusts, Leicestershire Partnership Trust and University Hospital Leicester. Different councils have slightly different arrangements for accessing and delivering social care, but work to the same national eligibility criteria. More detailed information including contact details is contained within the online LLR Dementia Friendly Guide and the Dementia Support Service can also help with access. The NHS website also describes services and access to these.

### Local policies that influence our work

Locally, a number of policies and approaches are informing our strategic thinking. This is important to consider as the support offered for people living with dementia and their carers often intersects with other parts of health and social care offers. We are mindful of collaborative working and wider considerations of where our strategy sits. Some areas of specific considerations are:

- [Leicester, Leicestershire and Rutland Joint Carers Strategy Refresh 2022-2025](#) establishes priorities in order to provide better support to carers locally.
- [Joint Health and Wellbeing Strategy](#) 2019-2024 sets out health priorities for Leicester and provides details of objectives for improved health outcomes.

- [Leicestershire Dementia Joint Strategic Needs Assessment 2018-2021](#) explains dementia through focusing on local concordance with other issues and demographics.
- [Rutland Health and Wellbeing Strategy 2022-2024](#) identifies approaches for working in partnership to improve the wellbeing of those in Rutland.
- [City All Age Commissioning Strategy](#) outlines commissioning priorities across the Leicester city social care department.
- [Leicestershire County Council Strategic Plan 2022-2026](#) outlines the county council's vision and priorities.

### **How the strategy is governed**

The Leicester, Leicestershire and Rutland Living Well with Dementia Strategy is managed by the Leicester Leicestershire and Rutland Dementia Programme Board. This is part of the overall systems that are in place to improve health and wellbeing for the citizens of the area. The following shows how specific statutory partnership boards connect.

#### **Leicester, Leicestershire and Rutland Health and Wellbeing Partnership (LLR HWP)**

This is a statutory committee bringing together an alliance of partners who are concerned with improving the care, health and wellbeing of the local population. Each local authority area has a Joint Health and Wellbeing Plan. These feed down to local area Health and Wellbeing Plans. The Dementia Strategy enables these boards to consider activity that specifically addresses the local needs of people living with dementia.

#### **Leicester, Leicestershire and Rutland Mental Health Collaborative Board**

This board ensures a focus on Mental Health and Dementia at a high level particularly with services delivered by Leicestershire Partnership Trust in collaboration with all statutory partners.

#### **Leicester, Leicestershire and Rutland Dementia Programme Board (DPB)**

Sitting under the mental health collaborative is the Dementia Programme Board which has specific responsibility to ensure the implementation and monitoring of the dementia strategy.

##### **Membership**

- Leicester City Council
- Leicestershire County Council
- Rutland County Council
- NHS Leicester, Leicestershire and Rutland Integrated Commissioning Board
- University Hospitals of Leicester NHS Trust
- Leicestershire Partnership NHS Trust
- Leicester, Leicestershire and Rutland Dementia Friendly Community
- Age UK Leicester Shire and Rutland
- Alzheimer's Society
- Healthwatch
- National Institution of Health Care Research
- Local Universities
- Admiral nurses
- Dementia UK

## **Section 8: What people have told us**

Healthwatch Leicester, Leicestershire and Rutland spoke to a range of people through focus groups, 1 to 1 interview and a large-scale survey to learn about the views of people living with dementia and their carers. This focused on people's experiences regarding the support that they have been in receipt of and their overall dementia journey from pre diagnosis. Overall, approximately 350 people were engaged with through 36 focus groups, 34 through semi structured interviews and 126 through survey responses, these counts include people with dementia, carers and professionals. Some useful feedback was given for example, inconsistencies around access to support and information as well as waiting times. Some suggestions for how support could be improved were made. This research is of great value to us and have informed our priorities for this strategy.

People with younger onset dementia are often underrepresented and can have varying priorities to those 65 years old and over. DPB members arranged an event in November 2022 which focused specifically on the support for people with younger onset dementia and encouraged befriending and advice sharing between them and their carers. During the event three focus groups were held in which people with younger onset dementia and their carers were encouraged to share their experiences and advise on what support could be offered to improve their dementia journeys. This information is also of great value to the Dementia Programme Board and has been used to inform our priorities.

Both of these engagement exercises are reflected in Section 9 of this strategy.

## **Section 9: What we are planning to do 2024-2028**

We aim to provide and develop specific activity using the well pathway to meet our overall approach. Some areas will continue to be part of our usual day to day business and some we will aim to refocus and refresh and so have higher priority. This strategy identifies the high-level actions which will be specifically addressed by each organisation's delivery plan. The organisational plans can also focus on place and neighbourhood to ensure specific support is provided where needed. Each organisation is responsible for drafting, following, and maintaining their delivery plan and reporting annually on its progress to the Dementia Programme Board. The expectation is that the delivery plans will be SMART (specific, measurable, achievable, relevant, time bound) and organisations are accountable to the DPB governance to ensure high-level actions are being met.

This strategy does not have specific financial investment allocated in order to deliver the high-level priorities cross organisationally. Each organisation is responsible for ensuring that the activity and objectives are met using existing resources through allocated budgets by each organisation. For example, the Dementia Support Service is commissioned by Leicester City Council and Leicestershire County Council, these organisations had allocated a budget for the service, this ensures our 'Living Well' objective is met. Members of the Dementia Programme Board will continue to explore opportunities for funding through potential government allocated grants, however the priorities outlined are aimed to be achieved irrespective of extra funding being allocated.

## **Leading, Integrating, Commissioning Training, and Monitoring Well**

The overarching themes in the Well Pathway are important to address in this strategy and relate to how we work as a health and social care system with our key partners.

The Dementia Programme Board (DPB) will continue to take responsibility for the following activities:

### **Leading, Integrating and Commissioning Well**

- Promote practice that develops a strength-based approach to supporting families living with dementia.
- Support and respond to the development of neighbourhood or place-based plans and other interdependent projects that impact on this strategy.
- Respond and adapt the strategic action plan as required to address any local or national policy change that impacts on people living with dementia.
- Refresh the health and social care pathway for people living with dementia from diagnosis to end of life to ensure they are effective and efficient. We will aim to prioritise diagnosis and hospital discharge pathway.
- Use Public Health led Joint Strategic Needs Assessments to support the commissioning of dementia friendly services for people with dementia. We will consider opportunities for joint commissioning and continue to jointly commission the Dementia Support Service.

### **Training Well – Quality Improvements and Workforce Competency**

- Ensure the quality aspects of personal care for people living with dementia are monitored within NHS and adult social care contracts and work with providers to address any gaps.
- Promote and support access to good quality dementia training.

### **Monitoring Well**

- Report progress of the strategy to the Mental Health Collaborative Board at least annually.
- Review the systems in place to implement, monitor and report on the strategy adapting as required at least annually.
- Support local and organisational focused delivery plans, within which system-wide actions will be agreed and implemented. System-wide means across health, social care and housing responsibilities.

## **The Well Pathway**

### **Preventing Well**

There is increasing awareness of the role of prevention in addressing dementia, particularly vascular dementia. Locally there are still gaps in understanding the connection between healthy living and dementia and opportunities with the public and patients to raise awareness. People have told us that there seems to be a grey area between a natural forgetfulness of ageing and the recognition of the onset of dementia and younger people



have told us that dementia is also confused with depression. We have raised awareness of the risks of dementia through activity during Dementia Action Week such as through local publications, and a BBC Radio Leicester feature. Furthermore, Dementia Friendly Community Networks encourage dementia friendly work cross organisationally. Health promotion activity was reduced during the Covid pandemic due to the need to use available resources for public health infection control measures.

We will continue to

- Screen for risk factors for dementia within Primary Care Health Checks and raise awareness of the risk factors for dementia.
- Raise awareness of dementia and its symptoms.

We will aim to

- Promote dementia prevention methods such as lifestyle behaviour changes.
- Promote the Global Council on Brain Health's message: 'What is good for the heart is good for the brain', meaning a healthy diet, exercise and lifestyle are good for both body and brain.
- Encourage people to get involved in research and promote the advantage of early diagnosis.

### **Diagnosing Well**

Research suggests that timely diagnosis of dementia is important to enable the start of appropriate treatment and support. From recent engagement from Healthwatch, people indicated they waited on average 1-2 years before seeking help, some as long as five years. We also know that people from South Asian communities are underrepresented in the figures we hold about diagnosis.

Government aspirations are that there is 6-week average wait between referral from GP to initial assessment and starting treatment. There is also a national target of 67% people with dementia having a diagnosis. Memory Assessment and Diagnosis services were severely disrupted during the Covid pandemic both locally and nationally and referrals from GPs also declined. Locally, we were doing well before the pandemic and had reached the diagnosis targets across areas with Leicester reaching 85%. Unfortunately, the impact of the pandemic lead to these falling by 13% across all areas. Annual NHS dementia care plans are also lower than the expected national average.

Local NHS diagnosis rates are recorded by clinical commissioning group areas and are:

- West Leicestershire 57.9%
- Leicester City 72.5%
- East Leicestershire and Rutland 56.5%

The percentages represent the proportion of people living with dementia that have a formal diagnosis as of January 2023.

We will continue to

- Use pharmaceutical treatments and a range of treatment options that have proven benefits to people with dementia.

We will aim to

- Reduce diagnosis wait times.
- Refine the dementia assessment pathway to ensure that people are diagnosed in a timely manner.
- Improve patient access to the pre and post diagnosis dementia support service.
- Improve the diagnosis experience for people from underrepresented communities.
- Explore culturally appropriate dementia diagnosis tools.

### **Supporting Well**

National and local guidance reinforces the importance of having person-centred support in place for individuals living with dementia and their carers. This is the ethos and working practice in this area and we continue to promote, influence and commission support aimed at both health and social care as well as within the voluntary sector. We aim to ensure this support is of good quality and meets the needs of individuals accessing these services. People have told us there are some barriers experienced by people accessing support.

We know that dementia is a progressive condition so people are likely to have increasing health and social care needs over time and most people will need personal care support in the later stages of dementia. They may also have other health conditions or frailty associated with old age. There are national criteria and assessment processes in place for adult social care and continuing health care so some people will be required to self-fund their care.

The Covid pandemic had a substantial effect on families living with dementia, visiting care settings was restricted, people with dementia were particularly vulnerable to infection and informal carers, where possible, were providing an increased level of care and support. People living with dementia were also affected by changes in routines and increased isolation. Priority actions remain in place to discharge people safely from hospital as soon as they are medically fit for discharge and the stresses on informal carers and professional organisations who are providing care remain. Not all people with dementia have complex needs but where this is the case there are additional challenges to meeting their care, particularly where there are changes in behaviours that challenge the person and those caring for them.

We will continue to

- Improve the hospital experience for people with dementia.
- Apply the Leicester, Leicestershire and Rutland Carer Strategy actions to support people with dementia and their carers.
- Raise awareness of support available for people with dementia and their carers.

We will aim to

- Review how we can avoid unnecessary hospital and care home admissions.
- Review hospital discharge pathways and post discharge support that assist people returning home or into their residential care home.
- Support, review and manage pathways for people who have complex needs including where there are behaviours that challenge.
- Promote the development of 'dementia friendly' accommodation including in the community and residential care sectors.
- Review pathways and person-centered support for seldom heard groups such as younger onset dementia, diverse ethnicities, people with a learning disability, prison populations, rural and farming communities and armed forces.
- Promote and develop good risk reduction methods that keep people safe and promote independence.

### **Living Well**

Living well with dementia relates to staying active, healthy and connected to families and your community. It is also about a strengths-based approach (which focuses on strengths and not deficits, Social Care Institute for Excellence) to dementia both for individuals and communities. There is some research that both leisure activities and activities specifically for the brain can delay the progress of dementia. During the Covid pandemic, we saw a surge of community spirit and neighbourliness as well as people feeling more isolated and for some this seems to have hastened the progression of their dementia. We also note that using video calling became a regular feature of communications. Since the end of lockdown, we have seen a resurgence of social groups in local communities able to meet the needs of people with dementia, both within dementia only and generic leisure and social groups.

Through the Dementia Support Service in Leicester and Leicestershire provided by Age UK Leicester Shire and Rutland, people are supported to live well with dementia pre and post diagnosis. The service has a dedicated team of staff, volunteers and a co-production group including people affected by dementia, who have all contributed to shaping and developing its various elements. This includes specific post diagnosis information and advice sessions, 1-2-1 carer learning sessions and or group support. Many social groups developed have been launched with the view of offering a wide variety of activities to support people to live well with their dementia, including walking, music, gardening and woodwork groups as well as cognitive stimulation therapy. In Rutland the dementia support service is jointly provided by Admiral Nurses and a Dementia Support Worker providing a range of similar support as well as additional clinical support from the Admiral Nurses. There are also a range of other groups and activities run by a range of voluntary and public sector organisations aimed at supporting people with dementia, many can be found in the Dementia Friendly Guide. Furthermore, the LLR Living Well with Dementia Grant recently has helped local voluntary organisations to fund 29 community-based projects aimed to support people living with dementia and their carers. An event for people with Younger Onset Dementia was put

together by LLR commissioners in 2022 to offer people an opportunity to learn about support available to them and share their experiences.

People have told us that there is some variation in the availability and access to living well activities across Leicester, Leicestershire and Rutland. We know that people find it hard to access information about living well with dementia even though there are many good sources of information available. We also know that planning ahead can aid people to live well but also plan for potential changes in their abilities as their dementia progresses and manage crisis. Discussing “planning ahead” can be a difficult conversation and this is an area that needs more development.

We will continue to

- Provide information and advice about living well with dementia that is accurate, timely, accessible, and joined up across Leicester, Leicestershire and Rutland.
- Develop and promote dementia-friendly communities, dementia support services and other living well support.
- Use funding opportunities when they are available, to develop living well activities especially in areas that are less well-served.

We will aim to

- Engage with people living with dementia and their carers including people with lived experience, to be involved in strategy development and to inform our work.
- Support people with dementia to plan and live well by promoting crisis contingency planning, advanced care planning and the benefits of appointing lasting power of attorney.

### **Dying Well**

We know that having early conversations with those affected by dementia, about advanced decisions and care planning can help both the person, their family and care providers at end of life. There are good practise models that look at dying well and the guidelines about ReSPECT. According to the national census an estimated 65% of people with dementia die in care homes and 23% in hospital so these are the two care settings we aim to support good dying well practice in.

We will aim to

- Promote and develop good practice including strengthening the link with end-of-life pathways and the ReSPECT process (the ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices).

## Section 10: Useful links

NHS dementia guide <https://www.nhs.uk/conditions/dementia/>

Support with housing adaptations <https://lightbulbservice.org/>

Hospice care across LLR <https://loros.co.uk/>

NHS England Well Pathway for Dementia <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

LLR Carer Strategy <https://www.healthandcareleicestershire.co.uk/refreshed-joint-carers-strategy-highlights-commitment-to-supporting-carers/>

Dementia friendly design guidance <https://www.england.nhs.uk/publication/dementia-friendly-health-and-social-care-environments-hbn-08-02-2/>

NICE guidance for assesment, management and support for people living with dementia and their carers <https://www.nice.org.uk/guidance/ng97>

ReSPECT for patients and carers guidance <https://www.resus.org.uk/respect/respect-patients-and-carers>

Census 2021 <https://www.ons.gov.uk/peoplepopulationandcommunity/>