

Leicester, Leicestershire & Rutland's Living Well with Dementia Strategy 2019-2022

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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 the Leicester, Leicestershire and Rutland ambition to support people to live well with dementia. It reflects the national strategic direction outlined in the Prime Minister's Challenge on Dementia which details ambitious reforms to be achieved by 2020. The strategy is informed by what people have told us about their experiences either as a person living with dementia or as a carer and is written for those people; specifically, those with memory concerns, those with a dementia diagnosis, their families and carers and the organisations supporting them

Leicester, Leicestershire and Rutland's Living Well with Dementia Strategy 2019-2022 has been developed in partnership between local health, social care and voluntary sector organisations.

An important focus of our strategy is to move towards delivery of 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 transforming 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 also aim to improve access to diagnosis and support services for all patients and service users, especially those from Black, Asian, minority ethnic and hard to reach groups who currently do not access services.

We want the well-being and quality of life for every person with dementia to be uppermost in the minds of our health and social care professionals.

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 behaviours 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 over the age of 65. Early onset dementia refers to younger people with dementia whose symptoms commence before the age of 65. Younger people with dementia often face different issues to those experienced by older people.

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

Section 3: Vision, guiding principles and aim

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 guiding principles:

- Preventing Well

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

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 compassionate care and support not only prior to diagnosis but post-diagnosis and through to end of life.

Section 4: National Context and background

There are a number of national drivers that shape and influence the way the UK should tackle dementia as a condition.

Key legislation:

- [Care Act 2014](#)
- [Equality Act 2010](#)

Context:

In February 2015, the Department of Health published the Prime Minister's Challenge on Dementia 2020, which 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, were to improve health and care, promote awareness and understanding and research.

Other documents that give context to dementia care are:

- Living Well with Dementia 2009
- Dementia 2015
- NHS & Adult Social Care Outcomes Frameworks
- Fix Dementia Care 2016

Section 5: The National Picture

There are currently 850,000 people living with dementia in the United Kingdom. 42,325 of these have early onset dementia. The number of people with dementia is forecast to increase to 1,142,677 by 2025 – an increase of 40%.

In the United Kingdom 61% of people with dementia are female and 39% are male. There are a higher proportion of women with dementia as women tend to live longer, however, this does reverse when considering the data for people with early-onset dementia.

It is estimated that there are 11,392 people from black and minority ethnic (BME) communities who have dementia in the United Kingdom. 6.1% of all those are early onset, compared with only 2.2% for the United Kingdom population as a whole reflecting younger age profile of BME communities.

1 in every 14 of the population of the United Kingdom over the age of 65 has dementia. Of those people that die over the age of 65, 1 in 3 has a dementia. Dementia now accounts for 11.6% of all recorded deaths in the United Kingdom.

It is estimated that 1 in 3 people in the United Kingdom will care for someone with dementia in their lifetime.

Section 6: Local context and background

Better Care Together (BCT) is the programme of work that plans to transform the health and social care system. The Sustainability and Transformation Partnership (STP) in Leicester, Leicestershire and Rutland is derived from this programme and is developing proposals across a variety of health and social care areas, to enable us to plan and be responsive to the needs of the whole population. The dementia workstream has established a programme board with membership across partnership organisations and links to the wider STP programme.

Membership of the Dementia Programme Board is made up of representatives from the following organisations:

- Leicester City Clinical Commissioning Group
- West Leicestershire Clinical Commissioning Group
- East Leicestershire and Rutland Clinical Commissioning Group
- Leicester City Council
- Leicestershire County Council
- Rutland County Council
- Healthwatch
- Leicestershire Partnership Trust
- University Hospitals of Leicester
- The Alzheimer's Society
- Age UK Leicestershire & Rutland
- Leicestershire Police
- De Montfort University

The Dementia Programme Board has written this strategy and high-level delivery plan. The multi-agency partnership works to ensure that interdependencies are identified including but not limited to:

- Home First
- Urgent and emergency care
- Integrated locality teams
- Resilient primary care
- Planned care
- Mental health
- Prevention
- Medicines management
- Learning disabilities
- End of life
- Continuing health care and personal budgets

The key local policy documents that influence the delivery of the strategy are:

- Leicestershire County Council’s Strategic Plan - Working together for the benefit of everyone 2018 – 2022
- Leicester City Council – Adult Social Care: Strategic Commissioning Strategy 2015-2019
- Rutland County Council – The Future of Adult Social Care in Rutland 2015 – 2020
- Clinical Commissioning Group Operational Plans 2018 – 2019
- University Hospitals of Leicester NHS Trust - Dementia Strategy 2016 2019

Section 7: Local Picture

There are currently 13,372 people living with dementia across Leicester, Leicestershire and Rutland. This number is set to increase to 16,969 by 2025. 269 of these people have early onset dementia. Across LLR 60% of people with dementia are female and 40% are male. This reflects the national trend. 1 in every 14 of the population of Leicester, Leicestershire and Rutland over 65 years has dementia which is again reflective of the national trend.

It is estimated that there are 105,000 carers across Leicester, Leicestershire and Rutland. For further information relating to carers, please see the Leicester, Leicestershire and Rutland’s Joint Carers Carers Strategy 2018-2021 ‘Recognising, Valuing and Supporting Carers in Leicester, Leicestershire and Rutland’.

The dementia diagnosis indicator compares the number of people thought to have dementia with the number of people diagnosed with dementia. The target set by NHS England is for at least two thirds of people with dementia to be diagnosed (67%). The national prevalence of dementia is 1.3% of the entire UK population equating to approximately 850,000 individuals.

Local NHS Diagnosis Rates are recorded by clinical commissioning group area and are:

- West Leicestershire 73%
- Leicester City 87%
- East Leicestershire and Rutland 67%

The percentages represent the proportion of people living with dementia that have a formal diagnosis as of November 2018.

Further information relating to the dementia population of the three areas, can be seen in the table below:

Leicestershire	9,642 individuals are thought to be living with dementia 9,458 of these are 65 years or over The total population of people aged 65 years or over is 139,400 which equates to 6.78% of this cohort of the population living with dementia
Leicester	3,026 individuals are thought to be living with dementia 2,951 of these are 65 years or over The total population of people aged 65 years or over is 41,700 which equates to 7.07% of this cohort of the population living with dementia
Rutland	704 individuals are thought to be living with dementia 694 of these are 65 years or over The total population of people aged 65 years or over is 9,500 which equates to 7.3% of this cohort of the population living with dementia

What people affected by dementia told us during the development of the Strategy

- “My husband needs to go somewhere to help him feel like a man again” – carer of person with dementia
- “I was very depressed after diagnosis. I felt suicidal.” – person living with dementia
- “My GP couldn’t find anywhere to accept the referral for my husband when seeking a diagnosis because he was too young” – carer of younger person with dementia
- “Once you have a diagnosis of dementia, you are written off as far as any other problem is concerned” – person living with dementia
- “All agencies need some understanding of dementia” – person living with dementia
- “We need somewhere for people to go and sit down and get proper advice” – person living with dementia

Section 8: How dementia support currently looks across Leicester, Leicestershire and Rutland

Support for people living with dementia across Leicester, Leicestershire and Rutland is provided by:

- General medical practice
- Memory clinics
- Community dementia support services such as those provided by Admiral Nurses, the Alzheimer’s Society and Age UK, including support for carers
- Social care services including care management and assistive technology services
- Advocacy services and deprivation of liberty safeguards services
- Extra care, residential and nursing homes
- Members of Dementia Action Alliances working towards creating more dementia friendly communities
- Advice and information services, including welfare benefits

Section 9: Achievements of the previous Leicester, Leicestershire and Rutland Strategy 2011 -2014

There have been many achievements under the previous local dementia strategy and these are considered below.

GP’s have been supported to understand and promote key preventative messages as well as developing health checks and a dementia friendly GP toolkit.

Engagement with people living with dementia and their carers has been undertaken across the area to understand their experiences of the health and social care system to inform future work.

All Clinical Commissioning group areas are meeting the 67% national target in relation to diagnosis rates and appropriate referrals are being made to memory assessment clinics, underpinned by a shared care agreement.

The memory pathway is well embedded across the area with good connections from primary care, memory clinics, post diagnostic support services, social care.

A new community and hospital-based Dementia Support Service has been commissioned across Leicester and Leicestershire, with a single point of access for people with dementia, carers and professionals.

Rutland commissioned a dementia support service who worked with local partners to support people with dementia and their carers.

Contract monitoring was undertaken by all commissioners and aimed to ensure that people with dementia were cared for and supported well.

Carers are supported through specific services, including advice, information, training and respite.

Voluntary and community sector organisations offer training programmes for people with dementia and carers. NHS and social care organisations offer staff training programmes.

Advocacy services and deprivation of liberty safeguards services are in place to give people with dementia a voice.

Assistive technology solutions are widely offered to people living with dementia and carers.

Strong links have been made with the local Dementia Action Alliance social movement to recruit dementia friends and work towards creating more dementia friendly communities.

A variety of social opportunities such as activity groups, memory cafes, befriending are available to support people and carers to live well with dementia.

Advice and information is available throughout the memory pathway.

Section 10: Leicester, Leicestershire and Rutland Dementia Strategy Delivery Plan 2019 -2022

This delivery plan will be refreshed on an annual basis to ensure its relevance. Actions have been agreed as a result of engagement with stakeholders and feedback from public consultation. Each member of the Leicester, Leicestershire and Rutland Dementia Programme Board will reflect those delivery actions in their own organisational plans and the needs of under-represented groups will be considered in all of the actions listed in the table below.

Dementia Strategy Delivery Plan

Action	Responsible	Guiding Principle	Actioned by
1. Pilot the Dementia Friendly general practice template and consider how to rollout more widely	CCG's	Preventing Well	2019/2020
2. Promote the inclusion of dementia risk reduction	CCG's	Preventing Well	2019/2020

messages within health checks across primary care			
3. Increase Public Health involvement in the work of the Dementia Programme Board	LLR Dementia Programme Board	Preventing Well	2019
4. Promote opportunities to be involved in research to people affected by dementia and their carers throughout the memory pathway	LLR Dementia Programme Board	Preventing Well	2019/2020

Action	Responsible	Guiding Principle	Actioned by
5. Review memory assessment pathway and referral processes	CCG's & LPT	Diagnosing Well	2019/2020
6. Promote memory pathway	LLR Dementia Programme Board	Diagnosing Well	2019/2020
7. To develop a process to increase the number of people receiving a dementia diagnosis within 6 weeks of a GP referral	CCG's	Diagnosing Well	2020/2021
8. Work with care homes to pilot and roll out the dementia diagnosis toolkit	CCG and Local Authority Commissioners	Diagnosing Well	2020/2021

Action	Responsible	Guiding Principle	Actioned by
9. Monitor the Dementia Support Services contracts and take action as appropriate	Local Authority Commissioners	Supporting Well	Ongoing
10. Raise awareness of dementia with housing providers	LLR Dementia Programme Board	Supporting Well	2020/2021
11. Contribute to a review of the dementia training on offer with a focus on delivering personal care to	H&SC professionals, workforce development and	Supporting Well	2019/2020

ensure a high level of expertise	Programme Board		
12. Continue to focus on improving the in-patient experience and hospital discharge pathways	LLR Dementia Programme Board	Supporting Well	2019/2020

Action	Responsible	Guiding Principle	Actioned by
13. Promote Dementia Support Services across LLR	H&SC professionals and providers	Living Well	2019/2020
14. Support the work to improve residential provision for people with complex dementia	CCG and Local Authority Commissioners	Living Well	2019/2020
15. Support the Dementia Action Alliance to develop more dementia friendly communities	LLR Dementia Programme Board	Living Well	2019/2020
16. Develop routine engagement processes with people living with dementia and carers to inform our work	LLR Dementia Programme Board	Living Well	2019/2020
17. Review the dementia information offer to ensure it covers a range of topics, including accommodation options	LLR Dementia Programme Board	Living Well	2020/2021
18. Review the current care and support standards used across LLR and agree a common set	H&SC professionals and providers	Living Well	2020/2021
19. Work with care homes and other providers to develop training and support to manage crises and work with reablement principles	H&SC professionals and providers	Living Well	2020/2021

Action	Responsible	Guiding Principle	Actioned by
20. Make stronger links with STP End of Life work-stream	LLR Dementia Programme Board	Dying Well	2020/2021
21. Ensure that people living with dementia are aware of Advanced Care Planning	LLR Dementia Programme Board	Dying Well	2020/2021

Section 11: Useful links

Context

[NHS England Well Pathway for Dementia](#)

[Further information about the different types of dementia](#)

[Further information about types of dementia from The Alzheimer's Society](#)

[Living Well with Dementia](#)

[Dementia 2015 – Aiming Higher to Transform Lives \(report by the Alzheimer's Society\)](#)

[NHS Outcomes Framework 2016 – 2017](#)

[Adult Social Care Outcomes Framework 2016-17](#)

[Fix Dementia Care 2016](#)

Legislation

[Care Act 2014](#)

[Equality Act 2020](#)

Local Policy

[Leicestershire County Council Adult Social Care Strategy 2016 – 2020](#)

[Leicester City Council – Adult Social Care: Strategic Commissioning Strategy 2015-2019](#)

[Leicester, Leicestershire and Rutland Carers Strategy](#)

[Rutland County Council – The Future of Adult Social Care in Rutland](#)

[University Hospitals of Leicester NHS Trust Dementia Strategy – April 2016 – March 2019](#)