

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



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.

*list of reference websites provided at the end

2. What is dementia?

'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.'

Prime Minister's Challenge on Dementia 2020

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.

Links to further information about the different types of dementia are provided at the end.

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:



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.

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

Prime Minister's Challenge on Dementia 2020

In February 2015, the Department of Health published a document detailing why dementia remains a priority and outlined the challenges the UK continues to face in relation to dementia.

The priorities identified within this are:

- 1) To improve health and care
- 2) To promote awareness and understanding
- 3) Research

Legislation

Care Act 2014

Equality Act 2010



Context

Living Well with Dementia
2009

Dementia 2015

NHS & Adult Social Care
Outcomes Frameworks

Fix Dementia Care 2016

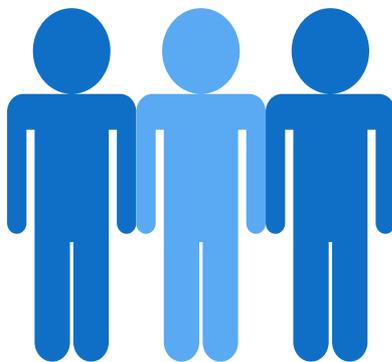
National picture

There are currently 850,000 people living with dementia in the UK. 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%.

1 in every 14 of the population over 65 years has dementia

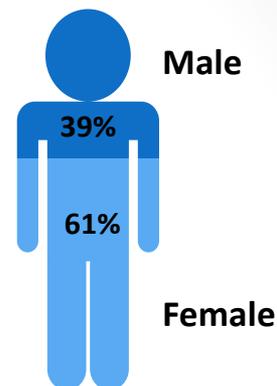
It is estimated that 1 in 3 people in the UK will care for someone with dementia in their lifetime



1 in 3 people who die over the age of 65 years have dementia. Dementia now accounts for 11.6% of all recorded deaths in the UK.

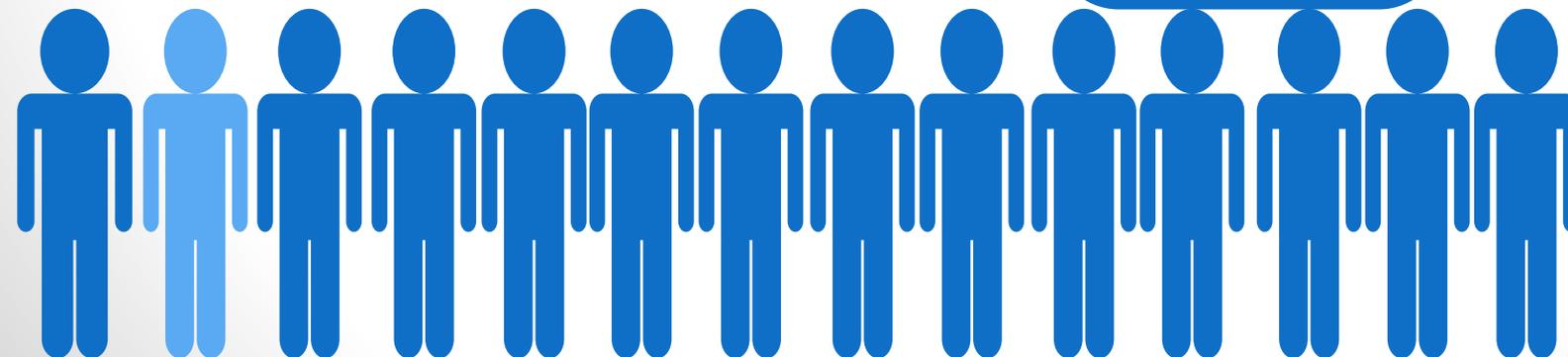
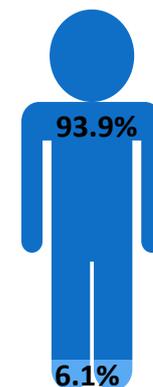
In the UK 61% of people with dementia are female and 39% are male. There are a higher proportion of women with dementia as women tend to live longer, however, this does reverse when considering the data for people with early-onset dementia.

Gender



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

Dementia and Ethnicity

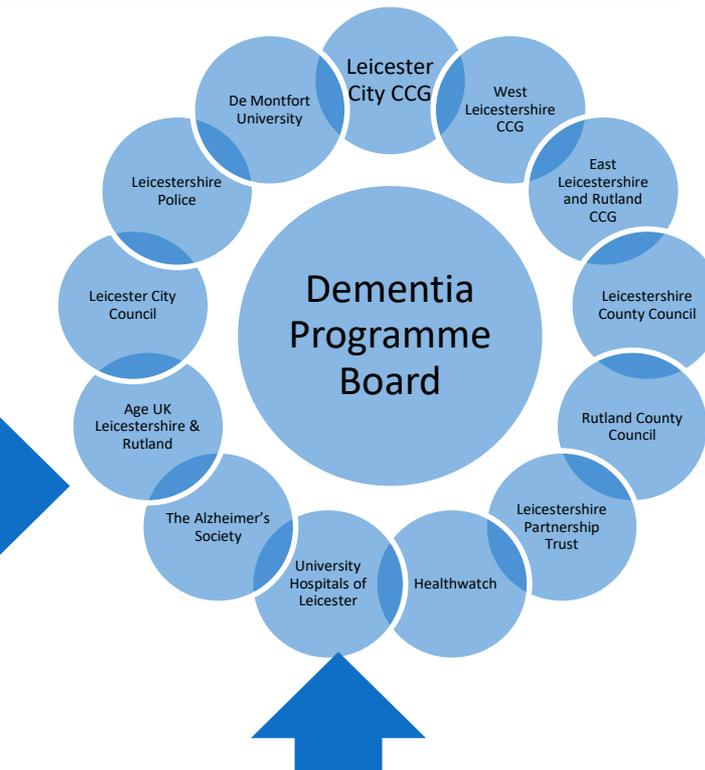


5. Local context and background

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 LLR 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 work stream has established a programme board with membership across partnership organisations and linked to the wider STP programme.

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



Funding in relation to dementia is not directly addressed within this strategy. However the financial position cannot be ignored therefore the available resources for each organisation will be reflected in individual organisational plans that will be developed by partners setting out their role in the delivery of the strategy.

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

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

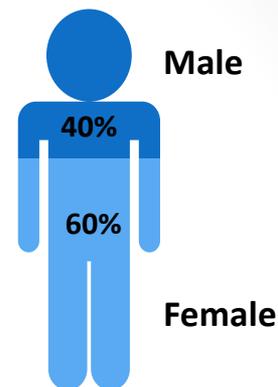
University Hospitals of Leicester NHS Trust Dementia Strategy 2016-2019

Local picture

There are currently 13,372 people living with dementia across Leicester, Leicestershire & Rutland. This number is set to increase to 16,969 by 2025. 269 of these people have early onset dementia.

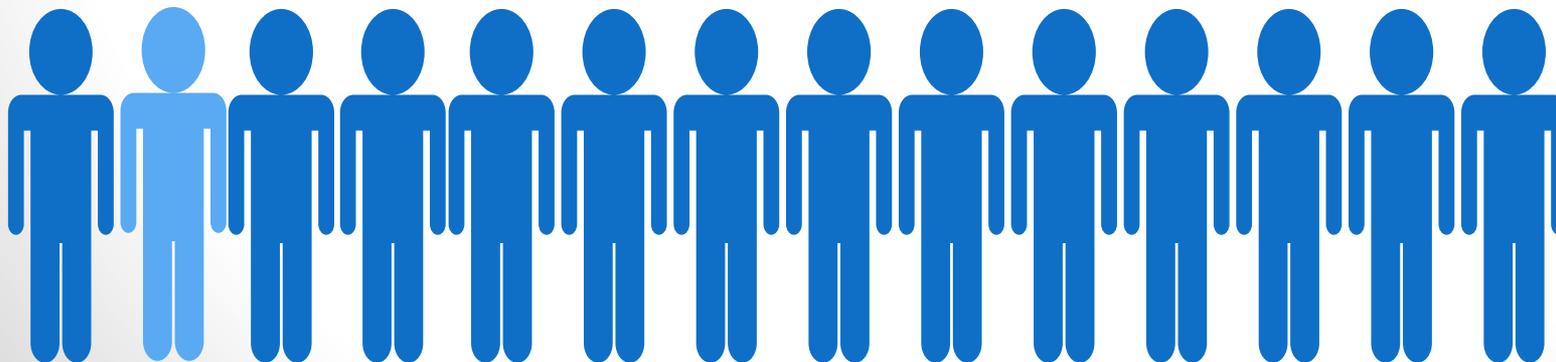
Across LLR 60% of people with dementia are female and 40% are male. This reflects the national trend.

Gender



It is estimated that there are 105,000 carers across LLR. For further information relating to carers, see the draft LLR Carers Strategy.

1 in every 14 of the population of LLR over 65 years has dementia, reflective of the national trend



Local picture

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

West Leicestershire

71%

Leicester City

86%

East Leicestershire & Rutland

67%

(Percentages represent the proportion of people living with dementia that have a formal diagnosis as of August 2018)

Leicestershire

- 9,642 individuals 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 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 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

Local picture - What people told us

“We need somewhere for people to go and sit down and get proper advice”
(person living with dementia)

“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)

“All agencies need some understanding of dementia”
(person living 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)

6. How dementia support currently looks across LLR

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

7. Achievements of the previous LLR Strategy 2011 – 2014

GPs 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 CCG 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

7. Achievements of the previous LLR Strategy 2011 – 2014

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 is available to support people and carers to live well with dementia

Advice and information is available throughout the memory pathway

8. LLR 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 LLR Dementia Programme Board will reflect these delivery actions in their own organisational plans and the needs of under-represented groups will be considered in all of the actions listed below.

Action	Responsible	Guiding Principle	Actioned By
Pilot the Dementia Friendly general practice template and consider how to rollout more widely	CCGs	Preventing Well	2019/2020
Promote the inclusion of dementia risk reduction messages within health checks across primary care	CCGs	Preventing Well	2019/2020
Increase Public Health involvement in the work of the Dementia Programme Board	LLR Dementia Programme Board	Preventing Well	2019
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
Review memory assessment pathway and referral processes	CCGs and LPT	Diagnosing Well	2019/20
Promote memory pathway	LLR Dementia Programme Board	Diagnosing Well	2019/20
To develop a process to increase the number of people receiving a dementia diagnosis within 6 weeks of a GP referral	CCGs	Diagnosing Well	2020/21

8. LLR Dementia Strategy Delivery Plan



8. LLR Dementia Strategy Delivery Plan

Action	Responsible	Guiding Principle	Actioned By
Support the Dementia Action Alliance to develop more dementia friendly communities	LLR Dementia Programme Board	Living Well	2019/2020
Develop routine engagement processes with people living with dementia and carers to inform our work	LLR Dementia Programme Board	Living Well	2019/2020
Review the dementia information offer to ensure it covers a range of topics, including accommodation options	LLR Dementia Programme Board	Living Well	2020/2021
Review the current care and support standards used across LLR and agree a common set	Health and Social Care professionals and providers	Living Well	2020/2021
Work with care homes and other providers to develop training and support to manage crises and work with reablement principles	Health and Social Care professionals and providers	Living Well	2020/2021
Make stronger links with STP End of Life work-stream	LLR Dementia Programme Board	Dying Well	2019/2021
Ensure that people living with dementia and their carers are aware of Advanced Care Planning	LLR Dementia Programme Board	Dying Well	2020/2021

9. Useful websites

Context

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

Further information about the different types of dementia: nhs.uk/conditions/dementia-guide/Pages/dementia-choices.aspx and alzheimers.org.uk/info/20007/types_of_dementia

Prime Ministers Challenge on Dementia: gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

Living Well with Dementia: gov.uk/government/uploads/system/uploads/attachment_data/file/168221/dh_094052.pdf

Dementia 2015 – Aiming Higher to Transform Lives (report by the Alzheimer’s Society): alzheimers.org.uk/info/20093/reports/253/dementia_2015

NHS Outcomes Framework & Adult Social Care Outcomes Framework 2016-17:

gov.uk/government/uploads/system/uploads/attachment_data/file/513157/NHSOF_at_a_glance.pdf

gov.uk/government/uploads/system/uploads/attachment_data/file/629812/ASCOF_handbook_definitions.pdf

Fix Dementia Care 2016: alzheimers.org.uk/info/20175/fix_dementia_care

Legislation

Care Act 2014: legislation.gov.uk/ukpga/2014/23/contents/enacted

Equality Act 2010: gov.uk/guidance/equality-act-2010-guidance

Local Policy

Leicestershire County Council Adult Social Care Strategy 2016 – 2020:

leicestershire.gov.uk/sites/default/files/field/pdf/2016/3/23/ASC_Strategy_2016_2020_0.pdf

Leicester City Council – Adult Social Care: Strategic Commissioning Strategy 2015-2019:

leicester.gov.uk/media/179825/strategic-commissioning-strategy-2015-2019.pdf

Draft Leicester, Leicestershire and Rutland Carers Strategy: leicestershire.gov.uk/carers-strategy.

Rutland County Council – The Future of Adult Social Care in Rutland:

rutland.gov.uk/my-services/health-and-family/adult-social-care/adult-social-care-strategy/

East Leicestershire and Rutland Operational Plan 2016-2017

West Leicestershire Operational Plan 2016-2017

Leicester City Operational Plan 2016-2017

University Hospitals of Leicester NHS Trust Dementia Strategy – April 2016 – March 2019:

leicestershospitals.nhs.uk/EasysiteWeb/getresource.axd?AssetID=41809&type=full&servicetype=Attachment