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

Overview

The key aim of the local Dementia Programme Board is to support people affected by dementia to live well in Leicester, Leicestershire and Rutland.

The board has drafted a new strategy showing the actions we intend to take. It reflects the national strategic direction and is informed by what people have told us about their experiences either as a person living with dementia or as a carer.

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 before diagnosis but after diagnosis and through to end of life.

We also aim to improve access to diagnosis and support services for patients and service users from Black, Asian, minority ethnic and hard to reach groups.

Why we are consulting

We would like to know your views on the actions listed in the strategy.

The strategy is for everyone affected by dementia – people with a diagnosis of dementia, their families and carers, and people and organisations who work to support them.

When the consultation closes in June the Dementia Programme Board will update the strategy taking into account views that have been expressed. Each board member will support the strategy by developing their own action plan, based around their offer for people affected by dementia and their carers.
Introduction

Dementia describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. Alzheimer’s disease and vascular dementia are the most common types.

In the UK

- Around 850,000 people are living with dementia. This is forecast to increase by 40% by 2025.
- Significant numbers of people have dementia but are not diagnosed.
- Dementia now accounts for 11.6% of all deaths.
- 1 in every 14 of the population over 65 years has dementia.
- 1 in 3 people will care for someone with dementia in their lifetime.

In Leicester, Leicestershire and Rutland

Approx 7% of people over 65 are living with dementia.

- Leicestershire: 9642
- Leicester: 3026
- Rutland: 704

About us

The Dementia Programme Board is made up of representatives from:

- Age UK Leicestershire & Rutland
- The Alzheimer’s Society
- De Montfort University
- East Leicestershire and Rutland CCG
- West Leicestershire CCG
- Healthwatch
- Leicester City Council
- Leicester City CCG
- Leicestershire County Council
- Leicestershire Partnership Trust
- Leicestershire Police
- Rutland County Council
- University Hospitals of Leicester
Our strategy

We achieved many successes under our previous strategy, which focused on collaboration with partners and joint commissioning of services. This new strategy is more focused on people and patients.

Aims of the strategy

- To minimise the impact of dementia whilst transforming care and support, not only for the person with dementia but also for carers.
- To move towards personalised and integrated care.
- To put the individual and their carer at the centre of service planning and design
- To improve access to diagnosis and support services for patients and service users from Black, Asian, minority and hard to reach groups.

The next few pages ask for your views on our proposed actions. These are arranged under five guiding principles:

- Preventing well
- Diagnosing well
- Supporting well
- Living well
- Dying well

Preventing well - your views

We plan to:

- help GP practices to be more aware of and give support to people with dementia by using a standard professional guide
- promote health checks in primary care
- increase involvement of Public Health in the board’s work.

1 Do you think these actions will raise awareness of risk factors associated with developing dementia?

Please select only one item

☐ Yes  ☐ No  ☐ Don't know
2 If no, please give reasons why:

3 Is there anything else we could do to raise awareness of risk factors associated with developing dementia?

Diagnosing well - your views

We plan to:

- promote information on what people should do if they are worried about their memory or have a diagnosis of dementia
- speed up process of diagnosis
- review memory assessment and referral processes
- introduce diagnosis toolkit to care homes
- promote post diagnostic information and support for people who have a diagnosis of dementia.
4 Do you think these actions will ensure that people receive a timely diagnosis?

*Please select only one item*

- Yes
- No
- Don't know

5 If no, please give reasons why:

6 Is there anything else we could do to diagnose dementia well?
7 Is there anything else we could do to improve diagnosis and raise dementia awareness amongst Black, Asian, minority ethnic and hard to reach groups?

Supporting well - your views

We plan to:

- monitor the dementia support services we buy to ensure they provide high quality support, provide equal access for all and give good value
- raise awareness of dementia with housing providers
- develop high levels of expertise among staff delivering personal care
- improve the experience of inpatient care and the hospital discharge process by ensuring staff involved are dementia aware.

8 Do you think these actions will give people with dementia (and their carers) access to safe, high quality health and social care?

Please select only one item

☐ Yes  ☐ No  ☐ Don't know
Living well - your views

We plan to:

- make sure we talk with people with dementia and their carers to make our services relevant to their needs
- support the Dementia Action Alliance to develop more dementia friendly communities
- review the dementia information available to ensure it covers a range of topics including accommodation options
- promote dementia support services
- agree a common set of care and support standards across Leicester, Leicestershire and Rutland
- support work to improve residential services for people with complex dementia
- develop training and support for care homes and other providers to manage crises.
11 Do you think these actions will enable people living with dementia to live well and safely within their communities?

*Please select only one item*

- Yes
- No
- Don't know

12 If no, please give reasons why:

13 Is there anything else we could do to support people with dementia to live well?

Dying well - your views

We plan to:

- strengthen links with other working groups (such as palliative care teams), particularly around care for people with dementia who are approaching the end of their lives.
14 Do you think this action will ensure people with dementia can die with dignity in the place of their choosing?

*Please select only one item*

- [ ] Yes
- [ ] No
- [ ] Don't know

15 If no, please give reasons why:

16 Is there anything else we could do to ensure people living with dementia can die with dignity?

Additional information

If you choose to give us your email address in question 19, it will be kept in accordance with terms of the Data Protection Act and will only be used to contact you about dementia services. Your details will not be passed on to any other individual, organisation or group. Leicester City Council is the data controller for the purposes of the Data Protection Act.
17 Are you commenting on the dementia strategy in...? (tick all that apply)  
(Required)

*Please select all that apply*

- [ ] Leicester city  
- [ ] Blaby  
- [ ] Charnwood  
- [ ] Harborough  
- [ ] Hinckley and Bosworth  
- [ ] Melton  
- [ ] North West Leicestershire  
- [ ] Oadby and Wigston  
- [ ] Rutland

18 Tell us about yourself (please tick all that apply)  
(Required)

*Please select all that apply*

- [ ] I have a diagnosis of dementia  
- [ ] I am a family member / carer of a person with dementia  
- [ ] I am an interested member of the public  
- [ ] I work for a council  
- [ ] I work for a dementia service provider  
- [ ] I am a representative of a voluntary sector organisation or charity  
- [ ] I work as a GP / pharmacist or other healthcare professional  
- [ ] I am a stakeholder (like an elected member, representative of statutory body)  
- [ ] Other (please specify)
If you would like to be involved in future work to develop plans and improve services, please provide your email address:

Email

What is your postcode? (home or work as appropriate)

Please note: we collect postcode data to gain a better understanding of which parts of the city / county respond to our consultations. We cannot identify individual properties or addresses from this information.

Equality monitoring

The information you provide in this final section of the questionnaire will be kept in accordance with terms of the Data Protection Act and will only be used for the purpose of monitoring. Your details will not be passed on to any other individual, organisation or group. Leicester City Council is the data controller for the information on this form for the purposes of the Data Protection Act.
21 Ethnic background:

*Please select only one item*

- Asian or Asian British: Bangladeshi
- Asian or Asian British: Indian
- Asian or Asian British: Pakistani
- Asian or Asian British: Any other Asian background
- Black or Black British: African
- Black or Black British: Caribbean
- Black or Black British: Somali
- Black or Black British: Any other Black background
- Chinese
- Chinese: Any other Chinese background
- Dual/Multiple Heritage: White & Asian
- Dual/Multiple Heritage: White & Black African
- Dual/Multiple Heritage: White & Black Caribbean
- Dual/Multiple Heritage: Any other heritage background
- White: European
- White: Irish
- White: Any other White background
- Other ethnic group: Gypsy/Romany/Irish Traveller
- Other ethnic group: Any other ethnic group
- Prefer not to say

If you said your ethnic group was one of the 'Other' categories, please tell us what this is:


22 Age:

*Please select only one item*

- under 18
- 18 - 25
- 26 - 35
- 36 - 45
- 46 - 55
- 56 - 65
- 66+
- Prefer not to say
23 Disability

The Equality Act 2010 defines a person as disabled if they have a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day-to-day activities and has lasted or is likely to last for at least 12 months. People with HIV, cancer, multiple sclerosis (MS) and severe disfigurement are also covered by the Equality Act.

Do you consider yourself to be a disabled person?

*Please select only one item*

- [ ] Yes
- [ ] No
- [ ] Prefer not to say

If you have answered YES to the previous above, please state the type of impairment that applies to you. People may experience more than one type of impairment, in which case you may need to tick more than one box. If none of the categories apply, please tick ‘Other’ and state the type of impairment.

*Please select all that apply*

- [ ] A long standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
- [ ] A mental health difficulty, such as depression, schizophrenia or anxiety disorder
- [ ] A physical impairment or mobility issues, such as difficulty using your arms or using a wheelchair or crutches
- [ ] A social / communication impairment such as a speech and language impairment or Asperger’s syndrome / other autistic spectrum disorder
- [ ] A specific learning difficulty or disability such as Down’s syndrome, dyslexia, dyspraxia or AD(H)D
- [ ] Blind or have a visual impairment uncorrected by glasses
- [ ] Deaf or have a hearing impairment
- [ ] An impairment, health condition or learning difference that is not listed above (specify if you wish)
- [ ] Prefer not to say
24 How would you define your religion or belief?

*Please select only one item*

- [ ] Atheist
- [ ] Bahai
- [ ] Buddhist
- [ ] Christian
- [ ] Hindu
- [ ] Jain
- [ ] Jewish
- [ ] Muslim
- [ ] Sikh
- [ ] No religion
- [ ] Prefer not to say
- [ ] Any other religion or belief (please specify)

25 Sexual orientation. Do you consider yourself to be ...

*Please select only one item*

- [ ] Bisexual
- [ ] Gay / lesbian
- [ ] Heterosexual / straight
- [ ] Prefer not to say
- [ ] Other (please specify)

26 What is your gender identity?

*Please select only one item*

- [ ] Male
- [ ] Female
- [ ] Other (e.g. pangender, non-binary etc)
- [ ] Prefer not to say

If Other, please specify

Is your gender identity the same as the gender you were assigned at birth?

*Please select only one item*

- [ ] Yes
- [ ] No

Please return completed questionnaires to:

RTUK-BGBB-URGB
NC consultation
Bosworth House
1F West Wing
Leicester City Council
Leicester
LE1 6TH