

Lincolnshire Joint Strategy for Dementia 2010-2014 Refresh

Consultation Questionnaire

The aim of this questionnaire is to help improve the experience of people living with dementia in Lincolnshire.

It may be completed by anyone who has experience of or an interest in dementia. You may be living with dementia yourself, or living with dementia by caring for a loved one. You might be a professional in the field of health or social care, or working for a care provider or the voluntary sector. You may simply have an interest in promoting better dementia services in the county.

The first section asks questions about the impact of the [current Dementia strategy](#), and your views about priorities for the future.

The sections after that ask questions about your own experiences, using the **Dementia Journey** below as a guide. This deepens our understanding of what is working and helps identify priorities for improvement.

There are opportunities throughout for you to give your ideas.

We recognise that this is a personal and sensitive subject, and ask you to respond in a way that is right for you. We would like to thank you in advance for your time and help.

The Dementia Journey¹



¹ The Dementia Journey is designed by Dementia Partnerships UK

A refreshed strategy for Lincolnshire

Q1. How aware are you of the current [Joint Lincolnshire Dementia Strategy](#)?

| | Yes/ No/ Don't Know |
|----------------------|------------------------|
| I am not aware of it | |
| I am aware of it | |
| Has it worked? | |

Q.2 Do you think attitudes and awareness towards people living with dementia have changed in the last three years, since the launch of the [National Dementia Strategy](#) and Lincolnshire's Joint Dementia Strategy?

| Thinking about... | Yes/ No / Don't Know |
|-------------------------------------------|-------------------------|
| Healthcare professionals (e.g. GP, nurse) | |
| Social workers | |
| Care providers | |
| Voluntary organisations | |
| Shops, banks, supermarkets | |
| Employers | |
| Friends | |
| General public | |
| Any other comment – please explain | |

Q3. What is most important to help improve attitudes and awareness towards people living with dementia (up to five priorities)?

Q4. Are you aware of some of the following national initiatives in Lincolnshire from the [Prime Ministers Challenge?](#)

| Tick all that apply | Yes/ No | Involved | Would like to know more or be involved |
|-----------------------------------------------|---------|----------|----------------------------------------|
| Dementia Action Alliance | | | |
| Dementia Friendly Communities | | | |
| Dementia Friends | | | |
| Dementia Champions | | | |

Q5. Thinking about the impact of the Joint Dementia Strategy over the last three years, has the experience of people living with dementia in Lincolnshire improved?

| What people said was important in 2010 | Rate 1- 5 where 5 is most improved; 1 is least improved and 0 is 'Don't know' |
|------------------------------------------------------------------|-------------------------------------------------------------------------------|
| People with dementia and carers being at the heart of everything | |
| Easy access to accurate and up to date information | |
| Early diagnosis and swift follow up | |
| Easy to access medication and monitoring | |
| Identifying carers and support for carers | |
| Easy to access short breaks and respite | |
| Supportive, enjoyable social and community services | |
| Flexible, reliable and responsive care at home | |
| Stimulating and caring residential care | |
| Active respectful care in hospital and for end of life | |

Q.6 Thinking about what needs to be achieved in the next three years, how important do you think are the following?

| Thinking about... | Rate how important this is on a scale of 1-5 where 5 is most important and 1 is least |
|------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Joined up care and support from health, social care and the voluntary sector | |
| Earlier diagnosis, increased levels of diagnosis | |
| More support after diagnosis for people and carers living with dementia | |

| | |
|-------------------------------------------------------------------------------------------|--|
| Dementia friendly communities | |
| Improving skills of families to understand and manage living with dementia | |
| Reliable, personalised support for people to live well at home | |
| Knowledgeable, skilful staff working in all sectors | |
| Reduced use of anti-psychotic medication (e.g. medication to manage behaviour) | |
| All service providers signed up to deliver the outcomes of the National Dementia Strategy | |
| Preventing unnecessary hospital admissions and delayed discharge | |
| Effective support for families when things get difficult | |
| Ensuring the most effective use of current spending on dementia | |
| The best possible care at the end of life for the person and carer | |
| Other priorities or comments (please specify) | |

The next sections ask about your experience of getting help and support, and help us understand what is working well at present, and what requires improvement.

Phase 1
Seeking help

Q.7 When you or someone you know began to shows signs of changing behaviour or memory problems, where did you go for information or help? Please tick all that apply.

| Source of help | Yes/ No | Rate helpfulness on a scale of 1-5 where 5 is most helpful and 1 is least |
|--------------------------------|----------------|----------------------------------------------------------------------------------|
| Family | | |
| GP | | |
| Nurse | | |
| Pharmacist | | |
| Voluntary organisation (name): | | |
| Employer | | |
| Friend | | |
| Internet Website (name) | | |
| Other – please explain | | |

Q.8 What other support would have helped ? Please list up to five priorities.

Phase 2
Learning that the condition is Dementia

Q.9 Have you or a loved one been given a diagnosis of dementia?

| | | |
|-----|----|----------|
| Yes | No | Not sure |
| | | |

Q.10 If yes, were you given information to help manage the present and plan for the future? Please tick all that apply.

| Thinking about... | Yes/ No | Rate helpfulness on a scale of 1-5 where 5 is most helpful |
|-------------------------------------------------------------------------------------------------------------------------------|---------|------------------------------------------------------------|
| Understanding dementia and how it might affect you; learning to manage its symptoms | | |
| Appointments just for you as the carer | | |
| Available treatment options | | |
| Information about local help available | | |
| National helplines and support | | |
| Access to help for family carers | | |
| Access to counselling | | |
| Support groups | | |
| Lincolnshire's online information and advice service www.mychoicemycare.org.uk | | |
| Please tell us about your experience | | |

Q.11 What would have helped most after a diagnosis? Please tell us your priorities (up to five).

Phase 3
Learning more and planning for the future

Q.12 Have you had an assessment of your needs and a care plan? If so, were any of the following agencies involved? Tick all that apply.

| Agency | Yes/ No | Rate helpfulness on a scale of 1-5 where 5 is most helpful |
|------------------------------------------------|----------------|-------------------------------------------------------------------|
| GP | | |
| Lincolnshire Foundation Partnership Trust | | |
| Psychologist | | |
| Occupational Therapist (OT) | | |
| Neurology | | |
| Old age physician | | |
| Lincolnshire County Council Adult Services | | |
| Carers Team | | |
| Voluntary organisation | | |
| Were your needs as a carer taken into account? | | |

Q.13 What support have you and your family been offered to live with dementia? Tick all that apply.

| Thinking about... | Yes/ No | Rate helpfulness on a scale of 1-5 where 5 is most helpful |
|-------------------------------------------------------------------------|----------------|-------------------------------------------------------------------|
| Understanding more about dementia, its impact and managing its symptoms | | |
| Ongoing health appointments and support | | |
| A carer's assessment and carers emergency plan | | |
| Access to counselling | | |
| Dementia Awareness or Carers Education courses for families | | |
| Help for the patient to manage memory loss | | |
| Information about support groups | | |
| Social care assessment | | |
| Help with early onset dementia (under 65) | | |
| Help if you have a learning disability and dementia | | |
| Planning care for the future | | |
| What to do in a crisis | | |

| | | |
|---------------------------------------------------------------------|--|--|
| Information about managing money, lasting power of attorney & wills | | |
| Adapting the home to make it more dementia friendly | | |
| Housing options for the future | | |
| No information and help | | |
| Other (please specify) | | |

Q.14 What are your top five priorities to help families learn more about managing living with dementia and to plan for the future?

Phase 4
Living well with Dementia

Q.15 Thinking about living day to day with dementia, what helps you and your family to live as well as possible with the condition? Tick all that apply

| Thinking about... | Yes/ No/ Don't Know | Rate helpfulness on a scale of 1-5 where 5 is most helpful |
|-------------------------------------------------------------------------------------|---------------------|------------------------------------------------------------|
| Easy to contact knowledgeable help and support | | |
| Equipment, telecare and telehealth | | |
| Local support group | | |
| Supportive and enjoyable social and community activities | | |
| Day service | | |
| More personalised day time support (please specify) | | |
| Help to maintain paid employment | | |
| Accessible transport | | |
| Support of family & friends | | |
| Activities and support appropriate for someone with early onset dementia (under 65) | | |
| Help if you have a learning disability and dementia | | |
| Personal budget, direct payments or personal assistant | | |
| Accessible short breaks and respite for carers | | |
| Help with housework, shopping or other tasks | | |
| Home care or other paid support in the home | | |
| Other (please specify) | | |

Q.16 How well do you feel you are managing day to day, living with dementia? Tick all that apply.

| Thinking about... | Yes/ No |
|------------------------------------------------------------|---------|
| We are managing day to day for now | |
| We are managing day to day but would like more help | |
| Some days are very difficult but I have support | |
| Some days are very difficult and I would like more support | |
| We feel well supported | |
| We feel isolated | |
| We are struggling to cope right now | |
| We know how to find out about getting more help | |
| Other (please specify) | |

Q.17 How aware are you of what telecare can do to help people with dementia?

| | Yes/No |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
| I am aware of how telecare can help people with dementia | |
| I know how to find about telecare | |
| I don't know how it can help people with dementia | |
| For more information see www.lincstelecare.co.uk or call the Lincolnshire County Council Customer Service Centre 01522 782155 | |

Q.18 What improvements would most help you and your family to live with dementia as well as possible in your part of Lincolnshire? Please list up to five.

Q.19 What improvements would you most like to see to help meet **your** needs as a family carer, to help you manage caring for someone with dementia? Please list up to five.

Q.20 If a break from caring or household tasks is helpful to you, what sort of break do you most value? Please tick all that apply.

| What sort of break is most helpful to you? | Do you receive this now? Yes/ No | Can you get this in your area? Yes/ No | Rate helpfulness on a scale of 1-5 where 5 is most helpful |
|----------------------------------------------------------------------------------------------------------------------|---------------------------------------------|---------------------------------------------------|-------------------------------------------------------------------|
| A sitting service for a few hours at home in the day or evening | | | |
| Care in your home | | | |
| Planned respite in a care home so you can go on holiday | | | |
| Help with household tasks/ garden that helps take the pressure off and allows time to make memories with a loved one | | | |
| Flexible, personalised & consistent support to suit the needs of your family | | | |
| Regular breaks that let you plan and maintain activities & friendships | | | |
| Support for your loved one out and about doing things that they enjoy | | | |
| Doing enjoyable things together | | | |
| Other (please specify) | | | |

Phase 5
Managing at more difficult times

Q.21 When things get harder, do you know where to go for information, advice, guidance or support? Tick all that apply.

| | Yes/ No | Rank in order of helpfulness 1-5 where 5 is most helpful |
|--------------------------------------------|---------|----------------------------------------------------------|
| No | | |
| Family | | |
| GP | | |
| Community Nurse | | |
| Carers Team or Carers Support | | |
| Support group (name) | | |
| Lincolnshire Partnership Foundation Trust | | |
| Voluntary organisation (name) | | |
| Friend | | |
| Lincolnshire County Council Adult Services | | |
| Website (name) | | |
| Pharmacist | | |
| Palliative Care | | |
| Other – please explain | | |

Q.22 What would help you most to manage difficult times at home? Please tick all that apply.

| Thinking about... | Yes/ No | Rank in order of helpfulness 1-5 where 5 is most helpful |
|-------------------------------------------------------------|---------|----------------------------------------------------------|
| Community Nurse or GP | | |
| Advice and information about managing challenging behaviour | | |
| A single point of contact I know and trust | | |
| Lincolnshire Partnership Foundation Trust | | |
| Support for you as a carer (please specify) | | |
| Support group (name) | | |
| Regular breaks for you as a carer | | |
| Adult Social Care assessment and support | | |
| Telecare and equipment | | |
| Home care support | | |
| Day centre or other support in the community | | |

| | | |
|------------------------------------------------------------------------------|--|--|
| What to do in a crisis | | |
| Advice and information about housing options and residential or nursing care | | |
| Other – please explain | | |

Q23. If you or a loved one with dementia has had experience of going to hospital, what help - prior to admission, or on discharge - do you consider might have helped prevent or reduce the length of stay in hospital?

| | Tick any that apply | Helped/ Would help/ Didn't help | Not aware of this |
|-----------------------------------------------------------------------------------|---------------------|---------------------------------|-------------------|
| This Is Me scheme | | | |
| Message in a bottle scheme | | | |
| Carers emergency response service | | | |
| More intensive home care | | | |
| Telecare & equipment | | | |
| Falls clinic advice | | | |
| Respite care/ break for carer | | | |
| Reablement | | | |
| Staff skilled in dementia nursing | | | |
| Family liaison in hospital | | | |
| Help and support when you come home from hospital | | | |
| Discharge planning with carer as equal partner and carer needs taken into account | | | |
| Other (please specify) | | | |

Q.24 What is most important to you about care in hospital for a patient with dementia? Please list up to five things.

Phase 6
At the end of life

These are delicate questions, and if you are affected by them, there are helplines that are available at the end of this questionnaire.

Q.25 What is most important to you about making decisions around end of life care? Please identify up to five aspects.

(for example [advance care planning](#), or being surrounded by loved ones)

Are you aware of ['The Patient's Journey' – an End of Life Care Pathway?](#)
Yes/ No

Q.26 What is important to you as the carer of a loved one at the end of their life, to help you manage? Please identify up to five points.

Q.27 If there are any further comments you wish to make, please do so here:

Thank you very much for taking the time to complete this questionnaire. Your contribution will help improve support for people living with dementia.

Please fill in the below to help us understand the feedback we receive. Personal contact details are optional.

Please indicate which stage you, or the person you care for, feel you are at in the Dementia Journey (or which stage you provide care at). **Please tick below:**

| | |
|------------------------------------------------------|--|
| Phase 1 Seeking help | |
| Phase 2 Learning that the condition is Dementia | |
| Phase 3 Learning more and planning for the future | |
| Phase 4 Living well with Dementia | |
| Phase 5 Managing at more difficult times | |
| Phase 6 At the end of life | |

| About me (please tick all that apply): | |
|----------------------------------------------------------|--|
| I have dementia | |
| I care for a loved one with dementia | |
| I am a health professional. Please state which sector... | |
| I am a social work/ social care professional | |
| I am a care provider | |
| I work for, or support a voluntary organisation | |
| I am none of the above, but I am a Lincolnshire resident | |
| Other (please state) | |

Monitoring information

| | |
|-------------------------------------------|--|
| Where in Lincolnshire do you live? | |
| Postcode (first part only) | |

Gender

Male Female

Are you married or in a civil partnership Yes No

Age 16-24 25-29 30-34 35-39 40-44 45-49 50-54 55-59 60-64
65+ Prefer not to say

How would you describe your national identity?

English Welsh Scottish Northern Irish

British Other Prefer not to say

What is your ethnicity?

Ethnic origin categories are not about nationality, place of birth or citizenship. They are about the group to which you as an individual perceive you belong. Please indicate your ethnic origin by ticking the appropriate box

White English Welsh Scottish Northern Irish

Irish Gypsy or Irish Traveller Other White background

Mixed/multiple ethnic groups

White and Black Caribbean White and Black African

White and Asian Any other mixed background

Asian/Asian British

Indian Pakistani

Bangladeshi Chinese

Any other Asian background

Black/ African/ Caribbean/ Black British

African Caribbean

Any other Black/African/Caribbean background

Other ethnic group

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Arab Any other ethnic group

Prefer not to say

Do you consider yourself to be disabled? Yes No Prefer not to say

What is your sexual orientation?

Heterosexual/straight Gay woman/lesbian

Gay man Bisexual Other Prefer not to say

What is your religion or belief?

No religion Buddhist Christian

Hindu Jewish Muslim

Sikh Any other religion Prefer not to say

Do you have caring responsibilities? If yes please tick all that apply

None

Primary carer of a child/children (under 18) Primary carer of disabled child/children

Primary carer of disabled adult (18 and over) Primary carer of older person (65+)

Secondary carer Prefer not to say

Helplines

If you are affected by any of the issues raised in this questionnaire and would like to talk to someone who can help:

Alzheimers Society Lincolnshire 01522 692681 (Mon-Fri 10-4)

Alzheimers Society UK Helpline 0300 2221122 (Mon-Fri 9-5; Weekend 10-4)

Admiral Nursing Direct UK 0845 2579406 (Tues & Thurs 11-8.45 and Sat 10-1)

Lincolnshire Carers Team 01522 782224 (Mon-Fri 8-6)

Alternative Formats

The information contained in this document can also be provided in other languages as well as other formats including large print, please request on the number below.

Further information about this consultation

If you have any further questions or would like to talk to someone about this consultation please contact Paul.Herniman@lincolnshire.gov.uk on 01522 554219.