

Dementia Carers Survey Patient and Public Report February 2026



Introduction

The NHS Lincolnshire ICB sought feedback to find out what's working well and what could be improved for people living with dementia and their carers in Lincolnshire.

This survey asked about peoples experience with dementia care in Lincolnshire – from diagnosis and support to prevention, community resources, and overall wellbeing. The feedback received will help us improve services and support for people living with dementia and their carers.

The results of the survey will be shared with the NHS Lincolnshire Integrated Care Board and the Lincolnshire system partners.

The survey was available to complete between **22 December – 9 February** and received **136 responses**.

Feedback received has been analysed across all population groups and equality categories and where there are differences these have been highlighted within the report.

136
responses to the
survey

Promotion of engagement

The survey was available in different formats on request as well as being available on the NHS Lincolnshire ICB and other partner websites. The NHS Lincolnshire ICB engagement Team produces a fortnightly bulletin which is distributed to a variety of community and voluntary groups, Patient Participation Groups, support groups, stakeholders and people who have subscribed via the NHS Lincolnshire ICB website.

The survey was regularly promoted through various channels including:

- Featured in **3** fortnightly NHS Lincolnshire ICB engagement bulletins and **2** Primary care bulletins.
- **4 posts** on the Nextdoor online forum - the total reach of the NHS Lincolnshire ICB Nextdoor account is 110,269 members spanning across **471 'neighbourhoods'** enabling us to reach a variety of communities, villages and towns across Lincolnshire.
- Providers' member databases and staff networks.



Social media and website activity

NHS Lincolnshire ICB Communications team's used Facebook to push traffic towards the survey on the website. The team posted:

7 Facebook posts, reaching 10,052 people and generating 201 engagements

169 people visited the webpage - [Dementia Carer and lived experiences survey - Lincolnshire ICB](#)

They also draft posts in the system Hootsuite to enable providers to duplicate and share across their channels and tagged in providers to some of the posts which were shared across provider organisations.

Promotion of engagement

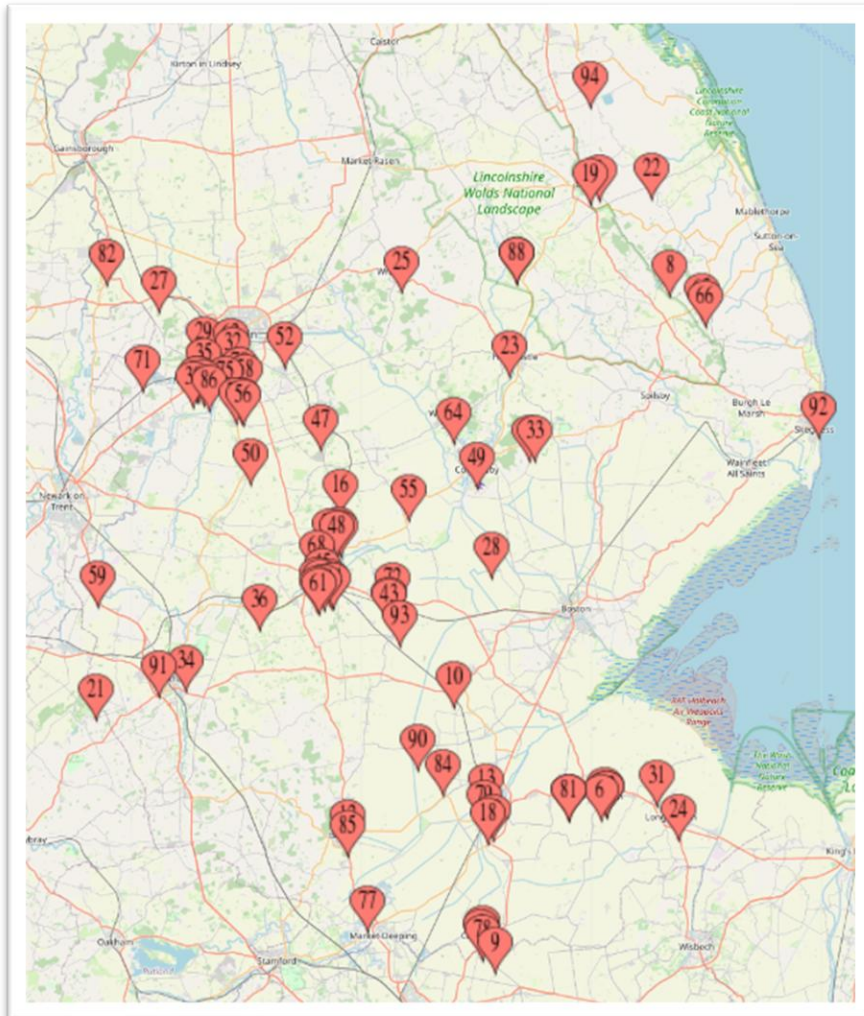
The below groups receive the distribution via NHS comms cascade or the ICB engagement bulletin (11,000 contacts):

Audience	Distribution
Community stakeholders including volunteer groups, support groups etc. via the engagement bulletin	LPFT involvement database— 430 (service uses, carers, staff, voluntary sector reps & public supporters) Cancer groups Community, voluntary and support groups BAME communities LGBT Communities Carers Older people groups Young people groups Eastern European communities Disability groups (mental and physical)

Audience	Distribution
Health and Care Partners	NHS Providers Lincolnshire Resilience Forum Community Connectors Neighbourhood leads Carers Service
District Councils inc. elected members and staff	City of Lincoln Council Boston Borough Council East Lindsey Council West Lindsey Council North Kesteven Council South Kesteven Council South Holland Council
Local Employers	University of Lincoln
Public sector providers	Lincolnshire Police and Crime Commissioners Lincolnshire Fire and Rescue

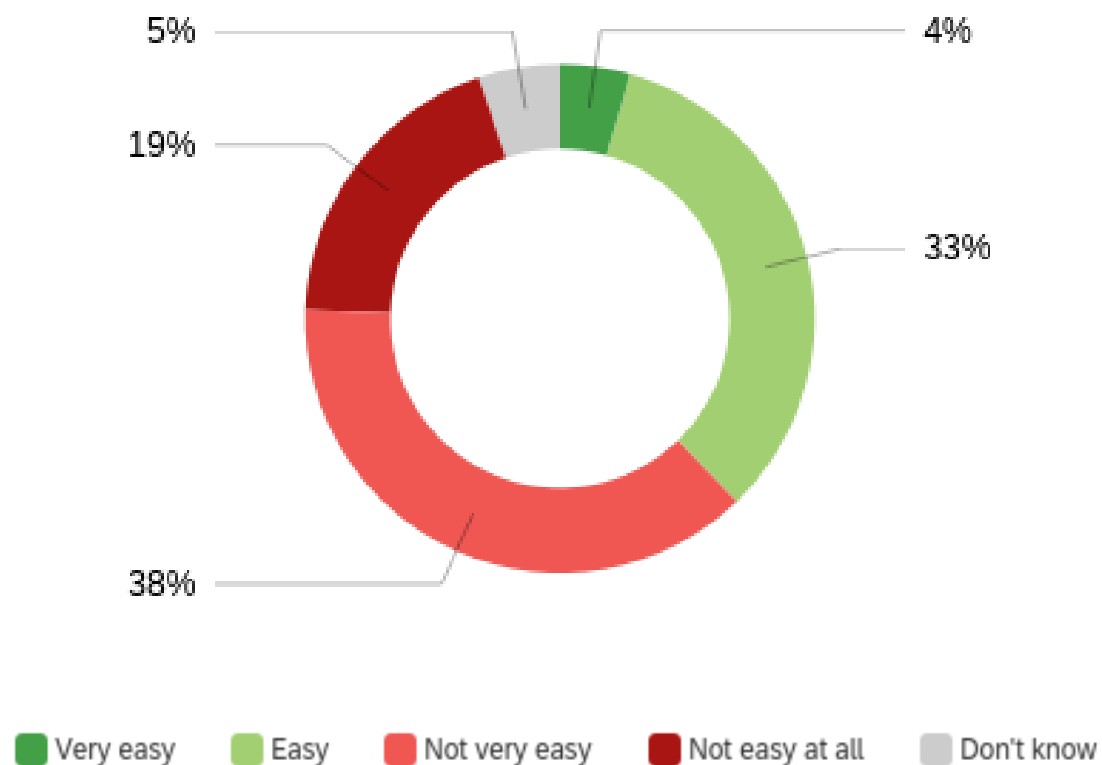
About the respondent

91% (123) of survey responses were completed by a carer/family member or friend of someone living with dementia. **5% (7)** by a person living with dementia and **1% (2)** people are awaiting a diagnosis and **3% (4)** were unknown.



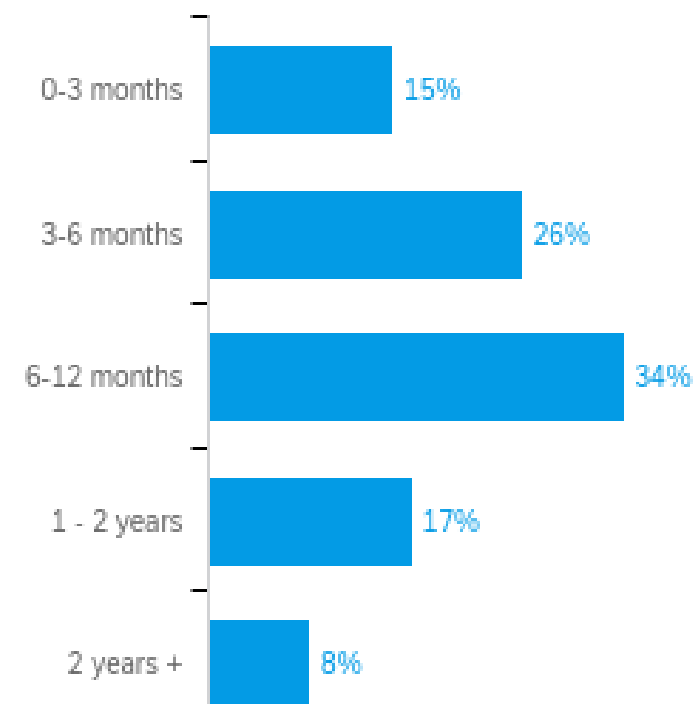
District	%	Count
North Kesteven	41%	56
East Lindsey	17%	25
South Holland	17%	24
South Kesteven	13%	14
Lincoln City	8%	9
West Lindsey	4%	5
Boston Borough	1%	2
<i>Unknown</i>	0%	1
Total		136

Just **37% (51)** of respondents found it **very easy/easy** to get a diagnosis, whereas **57% didn't find it easy/easy at all** and **5% were unsure**.



(Base N = 133 response count)

How long did it take for you to get your diagnosis?



Just over **one third (34%, 45)** of respondent's waited **6-12 months** to get their diagnosis, **8% waited 2 years or more**.

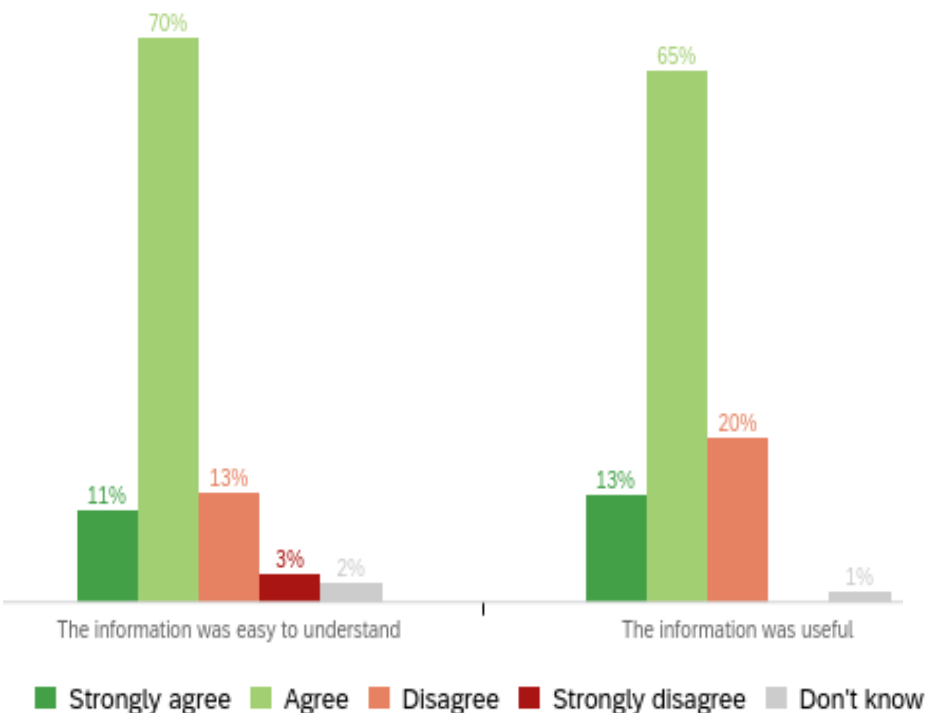
(Base N = 132 response count)

67% (89) of respondents **did** receive information on their diagnosis, 26% **didn't** and 7% we're **unsure**

What information would have been helpful for those who didn't receive any

Clear information about the diagnosis and progression	Respondents frequently expressed a need for clearer, more transparent information about the dementia diagnosis itself, including what the diagnosis meant, the specific type of dementia, and the difference between symptoms, side effects, and normal progression. Many felt confused by vague language or inconsistent terminology, and some reported not receiving any formal written explanation at all, leaving them uncertain and unsupported at a critical moment
Practical "what to do next" guidance	Many respondents felt lost after the diagnosis and wanted clear, actionable next steps. They highlighted the need for direction on navigating referrals, managing symptoms at home, understanding when and how to seek further help, and dealing with practical challenges. Simple guidance such as step-by-step plans or signposting to immediate actions would have made their experience more manageable.
Information on support services	A strong theme was the desire for better information about available support services, including local help, emotional and financial support, carer groups, and crisis contacts. Respondents wanted a straightforward guide or resource pack outlining where to find help, who to contact, and what support they were entitled to, as many felt they had been left to identify services on their own.
Carer focused information	Carers expressed a need for tailored information to help them support their loved one and cope themselves. They wanted guidance on how to help practically, how to explain the diagnosis to family members (including children), and how to manage the emotional strain of caring. Respondents also mentioned wanting tools and resources that would help them understand the condition and navigate their new responsibilities.
Emotional and psychological support	Underlying many responses was a need for emotional support to help people cope with the shock, sadness, and uncertainty that often accompany a dementia diagnosis. Respondents wanted guidance on how to manage their feelings, access to counselling or grief support, and reassurance that their experiences and emotions were valid and understood

Of the 89 respondents who **did** receive information, 81% **agreed** it was **easy to understand** and 78% **agreed** that it was **useful**.



(Base N = 89 response count)

What could have improved respondents experience of receiving their diagnosis

(The below themes are presented in order of most mentioned. Themes at the top have been mentioned the most and those at the end, the least)

Theme	Suggestions and feedback
Timely, efficient, and well coordinated diagnostic pathway	<ul style="list-style-type: none"> • Respondents repeatedly highlighted delays as one of the most distressing parts of the diagnostic journey. Long waits for referrals, assessments, scans, and follow-up appointments left many feeling anxious, unsupported, and forced to chase progress themselves. Several described lost or unprocessed referrals, unclear timelines, and services that did not communicate with each other, creating confusion and unnecessary stress. • A smoother and better coordinated pathway across GP practices, memory services, mental health teams, neurology, and social care would have improved their experience.
Clear, compassionate, and consistent communication	<ul style="list-style-type: none"> • Many respondents described communication around the diagnosis as rushed, impersonal, or insensitive. Some felt the diagnosis was delivered abruptly, not directed to the patient, or provided without explanation, empathy, or space to ask questions. Others noted a lack of clear information about expected waiting times or next steps. • Respondents wanted honest, patient-centred conversations that acknowledged the emotional impact of the diagnosis, ensured understanding and ideally in person rather than via letter or remote consultation.
Better information and guidance about the condition and what to expect	<ul style="list-style-type: none"> • A large number of respondents felt they lacked clear, practical information about the condition, how the diagnosis had been reached, what would happen next, and how symptoms might progress. Many said written materials were overwhelming, too general, or insufficient, leaving them to search for information themselves. • Others wanted guidance on navigating support options, including financial help, local services, and wider care pathways. Clearer explanations, tailored information, and accessible guidance would have made the process far less confusing and more empowering.
Regular support and follow-up after diagnosis	<ul style="list-style-type: none"> • One of the strongest concerns was the absence of support after receiving the diagnosis. Many described being told the news and then having no further contact for months or years, with no opportunities to ask follow-up questions or seek advice as symptoms changed. This left families feeling abandoned and unsure where to turn. • Respondents emphasised that regular check-ins, scheduled follow-up appointments, and a clearer sense of ongoing support would have provided reassurance and helped them navigate the challenges that followed.
Earlier recognition and diagnosis	<ul style="list-style-type: none"> • Some respondents believed their concerns were not taken seriously early enough, leading to delays in diagnosis and missed opportunities for treatment, support, or future planning. • They felt that earlier recognition by professionals—particularly GPs—could have significantly improved outcomes and reduced distress. Earlier assessment and intervention would have allowed families to access necessary help sooner and prepare more effectively for the changes ahead.

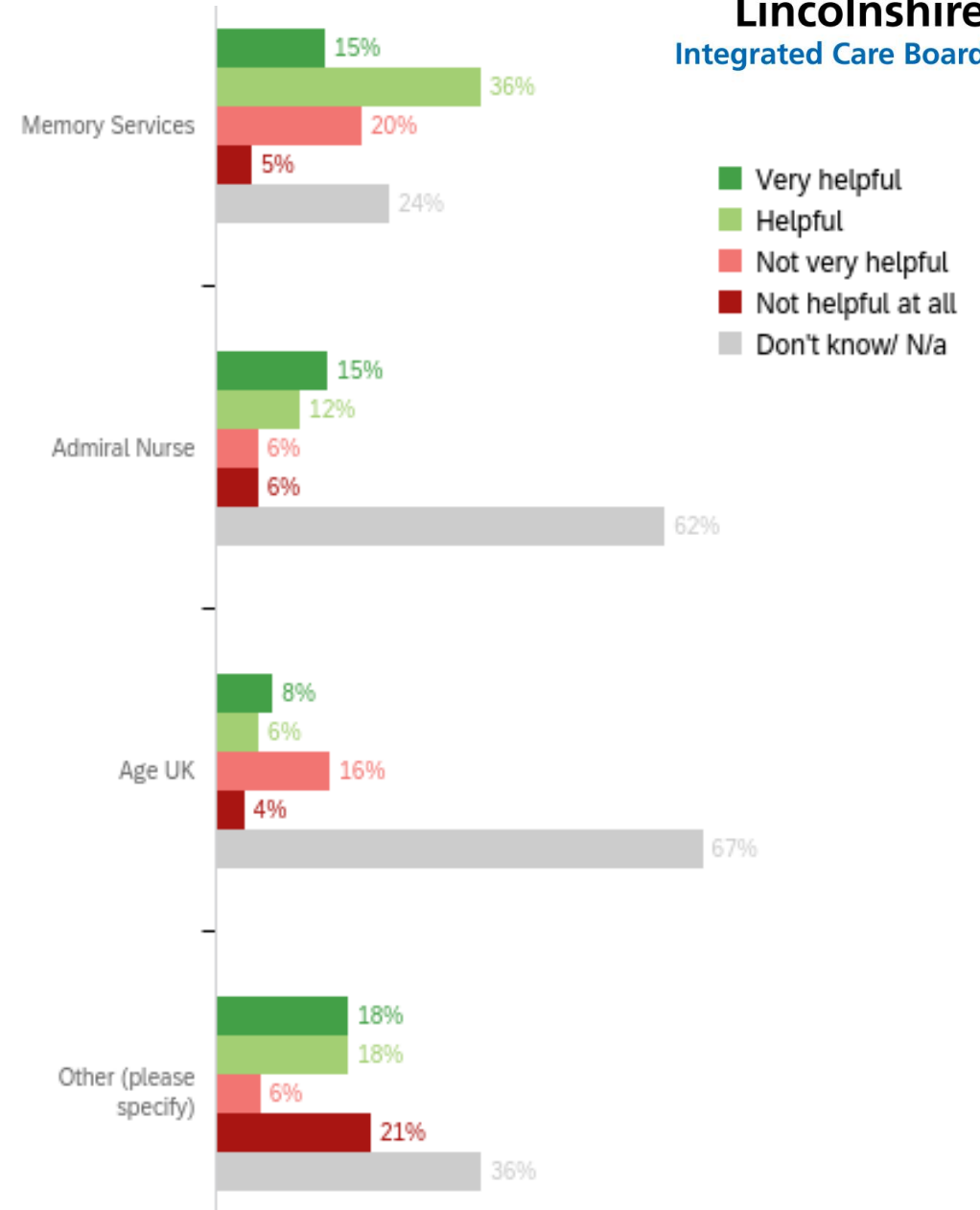
Support after a diagnosis

Just **under half** (48%, 64) of respondents received professional support after receiving a diagnosis. 44% (58) **didn't** and 8% **don't know**.

The graph to the right details how helpful respondents found they professional support they received.

What support would have made the biggest difference?

Ongoing contact	Regular check-ins, home visits, and predictable support would have stopped them feeling abandoned and helped them manage changes early.
Single point of contact (SPOC)	People wanted one named person who could answer questions, guide them through services, and coordinate support. A SPOC would have reduced confusion, prevented families from having to “fight” the system, and offered reassurance during crises
Practical information	What support exists, how to access it, financial entitlements, what to expect as dementia progresses - Most felt left to “figure it out themselves” or overwhelmed with leaflets
More in person support	People strongly preferred face-to-face rather than telephone-only or digital contact, especially older carers who struggled with online systems. In-person support felt more personal, clearer, and easier to navigate.
Access to groups, day centres and respite	Support groups for carers, social groups for patients, day care services, and affordable respite breaks were repeatedly requested. These gave families relief, connection, and practical help but were often unavailable or unknown.



35% (46) of respondents found their local community supportive of people living with dementia, whereas **63% (70)** found it not supportive. **45%** of respondents have attended local community groups, cafes or dementia-friendly activities (*full list in appendix 1*)

Most frequently mentioned helpful resources

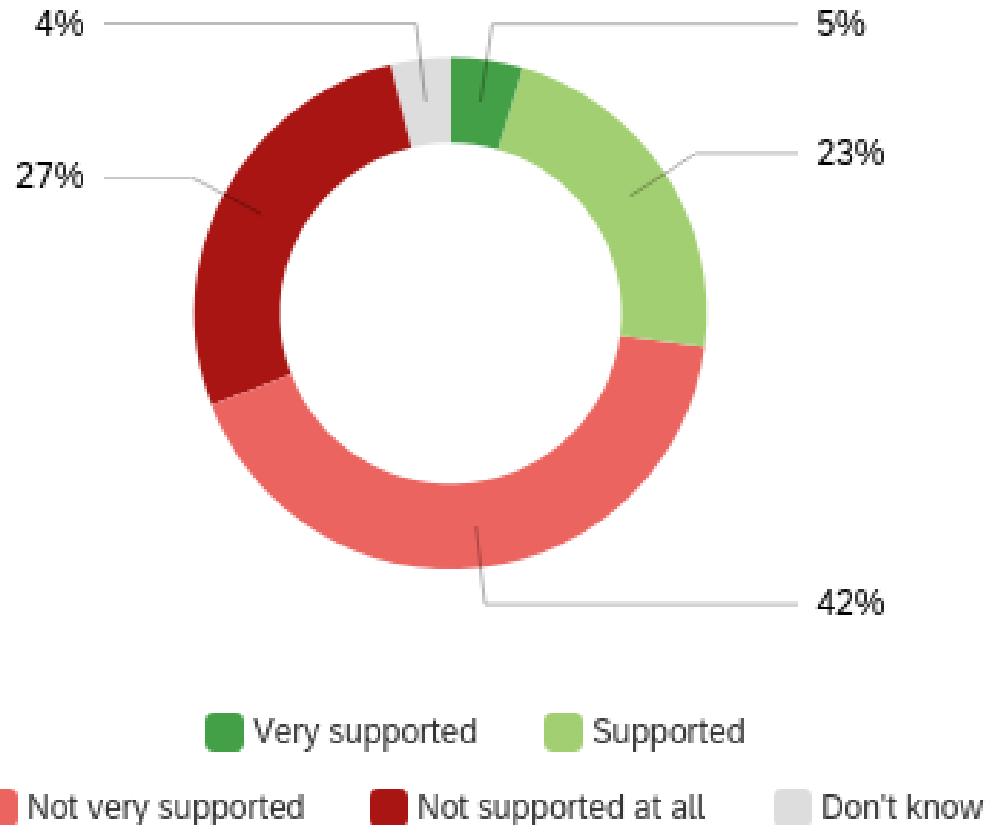
- **Carer related support** – e.g. Carers First, support groups, emotional support and peer groups
- **Dementia cafes** – respondents say they are friendly, helpful, social and one of the few accessible ongoing resources
- **Support groups** – examples include local dementia groups, carer's groups, Tonic Health and church groups
- **Admiral nurses** – highlighted as supportive and effective
- **Respite services** – where available, respite is valued

What respondents say is missing

- **Ongoing follow-up and consistent contact** – respondents told us they often receive a diagnosis and then there is no follow up, sometimes for years.
- **Respite care and breaks for carers** – a major gap, respondents describe exhaustion, burnout and no access to breaks, especially for complex needs
- **Carer specific support** – e.g. clearer guidance, 1-to-1 check in for those stuck at home and emotional support.
- **Professional support vs volunteers** – people feel that volunteers are providing more support from formal services. They also highlighted the lack of professional intervention e.g. district nurses or specialist dementia support
- **Activities and stimulation for people with dementia** – people want more than just coffee mornings e.g. therapy, skill building activities, cognitive stimulation therapy etc.

Overall, most respondents (**69%, 92**) said that they **do not** feel supported in Lincolnshire. **28%** said that they **do** feel supported and **4%** don't know.

How supported do you feel as a carer/person living with dementia in Lincolnshire?

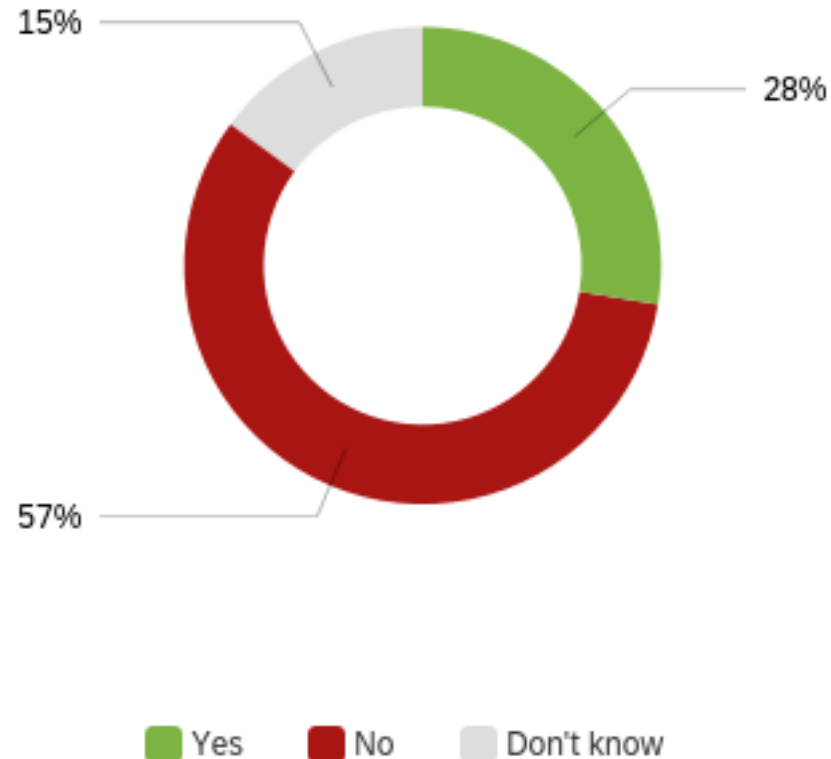


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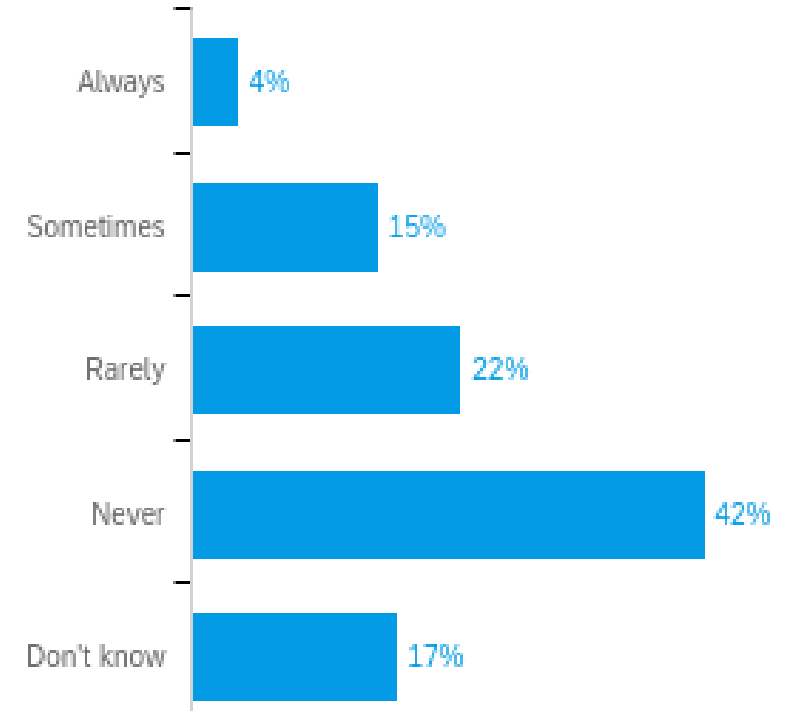
Theme	What people want:
Proactive, regular follow-up and contact	<ul style="list-style-type: none"> Scheduled calls/visits, routine reviews, and not being “crossed off” without notice. <ul style="list-style-type: none"> ➤ “Regular follow-ups, I feel that I have been left to sort everything”
Better information & signposting (especially at diagnosis)	<ul style="list-style-type: none"> A simple, comprehensive “what’s available and how to get it” pack/hub at diagnosis and as needs change.
A single point of contact / navigator	<ul style="list-style-type: none"> A named person or “one-stop shop” who explains support, helps access it, and is there when things change.
Respite & day-centre options for carer	<ul style="list-style-type: none"> Reliable, local day centres or sitting services so carers can rest, work, or run errands. <ul style="list-style-type: none"> ➤ “An hour off caring now and again”
Care-home / self-funding guidance	<ul style="list-style-type: none"> Clear advice on care-home options, fees, and entitlements—without having to “google everything separately.”
Face-to-face support / home visits (less digital self-service)	<ul style="list-style-type: none"> In-person help and home visits; less reliance on websites and tech. <ul style="list-style-type: none"> ➤ “More person-person support, physical help, less being told to investigate websites”

Over one half (57%, 77) of respondents said they **weren't** offered information about reducing dementia risks. Similarly, when asked if they had enough opportunities to take part in activities to reduce dementia, **42%** of respondents said they **never did**, **22%** **rarely did**, and only **4%** said they **always did**.

Were you offered information about reducing dementia risks (e.g. being active, eating well, learning, staying connected)?



Have you had enough opportunities to take part in activities that help reduce dementia risk in your community?



The below comments and suggestions are displayed in order of mention. Those at the top were mentioned the most and those at the end, the least.

Top messages and activities people want promoted

Stay socially connected (groups, cafés, singing, coffee mornings).	People repeatedly ask for more social opportunities and for help getting to them—choirs/music, group meet-ups, coffee mornings, and “keeping connected” are seen as valuable for mind and mood.
Additional carer support	Respondents want activities that welcome carers and families and messaging that recognises how social contact helps both the person and the care
Move more (exercise, dancing, walking)	Calls for group exercise, dance, walking, and even specific asks for exercise classes to be promoted more widely
Know the signs and act early (checks and advice)	Requests for early diagnosis messaging, how to seek help when symptoms appear, and even an annual “MOT” style check to discuss memory and cognition.
Make activities reachable (transport, buddy/escort schemes).	Many can’t attend because of transport, confidence, or needing a buddy/escort to get out; they want this barrier acknowledged—and addressed—in promotions
Keep the brain active (cognitive stimulation).	Requests to promote brain games, word games, Scrabble and other “keep your brain active” message

The below comments and suggestions are displayed in order of mention. Those at the top were mentioned the most and those at the end, the least.

Theme	Comments and suggestions
Access & coordination of care	People describe fragmented pathways: difficulty getting through by phone, calls not returned, uncertainty about who to contact, infrequent reviews, and variable experiences with the Memory Clinic. A named/dedicated contact is a common ask
Information, diagnosis & planning	Strong demand for clear, practical guidance on disease progression, life expectancy, and “what happens next,” alongside concerns about how diagnoses are delivered (including by phone) and the need for regular reviews to understand changes.
Carer impact & support needs	Carers report relentless emotional/physical load, isolation, and being overwhelmed—especially without family support or respite. Some note the knock-on impact on children and wider family
Care delivery experiences (hospital/A&E and equipment/OT delays)	Mixed experiences in acute care: reports of unnecessary trips to A&E and wards not being dementia-aware; separately, long waits for OT assessment causing delays in receiving equipment and adding to the stress at home.
Positive experiences	Responsive GP/older persons’ nurses, proactive care coordinators, and strong local groups/charities that check in and are easy to reach.
Palliative & end-of-life / diagnostic pathway	Calls for clearer palliative pathways and anticipatory planning; concerns about slow or insensitive diagnostic processes (e.g., diagnosis over the phone) and misdiagnosis.

Survey respondent demographics

Age	%	Count
Under 16	0%	0
16-20	0%	0
21-29	0%	0
30-39	2%	2
40-49	4%	5
50-59	15%	31
60-69	25%	31
70-79	25%	31
80-89	22%	27
90+	3%	4
Prefer not to say	0%	4
Answered		122

Ethnicity	Responses	
Bangladeshi	0%	0
Indian	1%	1
Pakistani	1%	1
Any Other Asian Background	0%	0
African	0%	0
Caribbean	0%	0
Any Other Black Background	0%	0
White and Asian	0%	0
White and Black African	1%	1
White and Black Caribbean	0%	1
Any Other Mixed Background	1%	0
White British	88%	106
White Irish	0%	0
Any Other White Background	2%	2
Chinese	1%	1
Gypsies/Travelers/Roma	0%	0
Any Other Ethnic Group	6%	7
Answered		120

Gender	%	Count
Male	22%	34
Female	75%	84
Intersex	0%	0
Non-binary	0%	0
Prefer not to say/ don't know	2%	4
Answered		122

Physical disability or mental illness expected to last more than 12 months	%	Count
Yes	59%	41
No	40%	29
Prefer not to say	1%	1
Answered		71

Survey respondent demographics

Health inequality information	%	Count
Have served in the UK's regular or reserved armed force	47%	9
Currently working in the Farming/ agricultural industry	11%	2
Have worked in the Farming/ agricultural industry	26%	5
Currently homeless	0%	0
Have experience of being homeless	11%	2
Currently serving in UK's armed forces	5%	1
Refugee, immigrant or asylum seeker	0%	0
Previous experience of being a refugee, immigrant or asylum seeker	0%	0
<i>Answered</i>		19

Employment status	%	Count
Employed full time	17%	15
Employed part time	14%	12
Homemaker	3%	3
Not employed and looking for work	0%	0
Not employed and not looking for work	18%	16
Retired	24%	21
Self employed	6%	5
Student	5%	4
Prefer not to say	6%	5
Other	7%	6
<i>Answered</i>		119