



Experiences of living with dementia: Informing the System Strategy and local services

Background

Dementia diagnosis rates

	Rutland	England
Diagnosed dementia cases Jan 2023	345	417,797
Diagnostic rate (England ambition 66.7%)	48%	61.8%

Rutland's ageing population

	2023	Forecast 2040	Risk of dementia (NHS <i>About dementia</i> guide)
Over 65 yrs	11,102	14,882	1 in 14
Over 80 years	3,125	5073	1 in 6



Who took part?

- **Survey:**
 - 2 people with dementia (Leicester 7, Leicestershire 1)
 - 15 carers (Leicester 40, Leicestershire 56)
- **Focus groups:** (Rutland) 12 carers and people with dementia
- **Individual interviews** (Rutland):
 - 4 carers
 - Nobody with young-onset dementia

Carers survey: differences across LLR

	Rutland	Leicester	County
Happy with time taken to get diagnosis	33%	47%	47%
Received information before diagnosis	40%	21%	20%
Received explanation about what next	40%	14%	43%
Carers having some or all support needed	60%	89%	70%
Carers not getting support, not knowing where to get it, not offered it	40%	10%	30%
Use and value of Admiral Nurses	50%	11%	22%
Never used carers group	55%	34%	35%
Carers not knowing about advice/info services	25%	14%	13%
Carers not knowing about Admiral Nurses	0	66%	33%

Experiences of getting diagnosed: Rutland

Time taken to get diagnosis

<3mths	3-6mths	6-9mths	9-12mths	> 12 mths
2	4	3	2	4

Who gave the diagnosis

Specialist doctor	Memory Service	GP
3	9	2

Were you satisfied with the process?

Yes	No	Don't know
5	7	3



Possible reasons for low rates of diagnosis?

- Uncertainty about when decline associated with older age ends and dementia begins
- Fear and stigma – ‘*dementia is the new cancer*’
- Lack of knowledge about dementia symptoms
- Misdiagnosis eg depression, menopause, deafness, urological problems
- Perception of flaws in the cognitive testing
- Reluctance of friends and family
- Closure of memory clinic due to COVID might have influenced?



What Rutland Carers Said

- - Feeling overwhelmed - multi-tasking, unrelenting

- - Physical illness care for people with dementia needs improving

- - Biggest barrier to accessing services is lack of knowledge about what is available

- - Other barriers:

- Affordability of groups

- Transport

- Digital exclusion

- Can't leave person with dementia (or they won't leave home)

- Public lack of knowledge/understanding about dementia

- ***'Finding information on-line locally is not easy and Rutland County Council's website is not that user-friendly.'***



Recommendations



- Better information – a hub?
- Pathway consistency
- Raise public awareness/understanding
- Reinstate memory clinic in Rutland
- Improve care for physical illnesses of people with dementia
- Increase availability of, and transport to, support groups & activities
- Ensure all who want them have face to face appointments
- Offer help with digital access for those that want it
- Continuing support for carer after person with dementia is admitted to care home

6 Finally...

- Just 11 people with dementia responded to the LLR survey (2 from Rutland). In focus groups, often the carer or family member did the talking. How can people with dementia be given a voice of their own?

Stop writing me off. I want and need a proactive health service that provides me with the skills, understanding and support to achieve a good quality of life at whatever stage I am at. A dementia diagnosis should not be met by a 'sit in that armchair and die' prescription

(HWR What Matters To You Report 2021)