



Living with dementia in Rutland

March 2023





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List of Acronyms

CT scan	Computerised Tomography scan
GP	General Practitioner
HWLL	Healthwatch Leicester and Healthwatch Leicestershire
HWR	Healthwatch Rutland
LLR	Leicester, Leicestershire and Rutland
MRI scan	Magnetic Resonance Imaging scan
POA	Power of Attorney
RIS	Rutland Information Service
TASL	Thames Ambulance Service Ltd

Summary

In January 2023 Rutland had achieved a 48% dementia diagnosis rate; with the English average of 61.8% and the ambition for all England to achieve 66.7%¹

Recognising these deficits in the Rutland diagnosis rate for dementia, Healthwatch Rutland (HWR) joined with Healthwatch Leicester and Healthwatch Leicestershire (HWLL) in a research project to help inform the developing Joint LLR Dementia Strategy by hearing about and representing the experiences of care and gaps in services for those living with dementia.

This Rutland-specific report details the responses from people in Rutland to the joint HWLL and HWR project with the aim of informing the provision of Rutland Place and Neighbourhood dementia care and support services and the Proactive Care pilot which is intended to provide holistic, wrap-around care for people living with dementia in the county.

Statistically, there will be many more people in the future living with dementia in Rutland, with similar care and support needs that are described here. All partners, including health and care commissioners and providers, the voluntary sector and Rutland residents, should be prepared to tackle this challenge.

Throughout the report, we talk about people who have a dementia diagnosis, or have dementia-associated problems but have not yet received a diagnosis, as ‘people (person) with dementia’ and people who are looking after them in an unpaid capacity as ‘carers’. The feedback shows that people who have a confirmed diagnosis or have registered carer status find barriers to accessing services. But those without a formal diagnosis or registered carer status may face even greater challenges as support is not always available to them. Some issues, previously highlighted², such as transport problems and difficulties in accessing care or information, remain unresolved.

¹ See Former prime minister, David Cameron’s 2015’ ‘challenge’ at <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020#fnref:23>

² See for example: Healthwatch Rutland (2021) report *Rutland People Tell us what they need and want from place-based care*



Key findings

- Delays in seeking a diagnosis can be attributed to: people not knowing the early signs of dementia; uncertainty about when the natural forgetfulness of old age ends and dementia begins; not knowing where to get help; stigma and/or fear of a dementia diagnosis; misdiagnosis and flaws in cognition tests.
- Diagnostic pathways have long delays following COVID-19 restrictions and appear to differ for individuals for no obvious reason. Before, during and after the diagnosis there is a need for information but this is not always given.
- The ongoing healthcare needs of dementia patients are not always met in primary care, hospitals and community care (including care homes) and fears were expressed for those who have no one to advocate for them.
- Rutland unpaid carers are filling multiple roles and are multi-tasking in order to maintain the safety and well-being of people with dementia in the domestic environment. They feel they are less well supported than their Leicester and Leicestershire counterparts.
- Barriers for carers in accessing support include: digital exclusion; lack of transport; people living with dementia unwilling to leave home; inability to attend support groups because there is no one to sit with the person with dementia; unaffordability and lack of availability of services; lack of knowledge about what is available; falling outside of the system whilst awaiting diagnosis; and lack of public awareness of dementia.
- Carers talked about having support withdrawn when the people they care for are admitted to care homes. They can experience feelings of guilt that they could not continue to care themselves and worries about the standards of care.
- There were few comments from people with dementia which raises the question of whether they are being given sufficient opportunities (or want) to express their needs and opinions.

Recommendations

- Raise public awareness of dementia in Rutland about the symptoms, how to engage with services for diagnosis and how to support family members and unpaid carers.
- Standardise dementia diagnostic pathways and make them locally accessible in a timely manner and accompanied by information about dementia before, during and after the diagnosis.

<https://www.healthwatchrutland.co.uk/sites/healthwatchrutland.co.uk/files/What%20Matters%20To%20You%20Final.pdf>



- Provide up-to-date digital and hard copy information about dementia care and support services in Rutland for all those living with dementia.
- Reinstate the Memory Clinic in Rutland.
- Attention should be given to identifying and diagnosing people in Rutland with young onset dementia and meeting the support needs of all age groups.
- More research is needed to understand whether people with dementia are being provided with sufficient means to express their voices and have their own self-identified needs met.
- Improve the ongoing physical healthcare needs of patients with dementia in primary care, secondary care and in the community. A dementia care co-ordinator/advocate, perhaps part of the proposed Proactive Care pilot, could be appointed to oversee and drive forward all aspects of care and support to ensure the delivery of seamless, holistic care.
- Improve the availability of group support by making sessions affordable and sensitive to rural transport difficulties for both carers and people with dementia. Such arrangements need to take account of difficulties in attending carer-only support groups when the person with dementia cannot be left unattended.
- People who are digitally excluded from accessing online support should be offered help and training, if they wish, to improve their skills. Service providers must take steps to identify and cater for those who cannot or do not wish to use technology.
- Social service providers and associated agencies should consider wider family members who might be in need of support even if they are not formally recognised as the main carer.
- Continue to offer support to carers after a patient has been admitted to a care home.

Response from Commissioners

On behalf of Rutland County Council, I would like to thank Healthwatch Rutland for this report. The feedback and recommendations will be integrated into our LLR Dementia Joint Strategy and Rutland's delivery plan, aiming to further improve Dementia Services and address any gaps you have highlighted in your feedback.

Dementia has always been a priority for us at Rutland County Council, so it is heartening to know you value the Admiral Nurse service and Age UK, working together, to provide an excellent service for people living with Dementia and their carers. Most importantly I would like to thank those who have engaged in this report, your voice is important in helping us deliver Dementia services for Rutland.

Kim Sorsky, Director of Adult Services and Health, Rutland County Council



On behalf of Leicester, Leicestershire and Rutland Integrated Care Board (LLR ICB), I would like to thank Healthwatch Rutland for carrying out this much-needed engagement exercise with members of our Dementia community.

The Recommendations in the report will inform our LLR Joint Dementia Strategy Refresh, which encapsulates the ICB's Dementia programme priorities for the future. We will continue to support an LLR system-based approach in addressing the health needs of people with Dementia and their carers. We look forward to collaborating with system partners to help improve placed-based Dementia support services. Finally, I would like to thank everyone working in LLR who contributes to improving the quality of lives of those with Dementia, especially those who share their experiences to help transform our NHS and wider community services.

Dr Wafaa Nawaz, All Age Mental Health & Learning Disabilities Transformation Lead, LLR ICB

Background

Healthwatch Leicester and Healthwatch Leicestershire (HWLL) and Healthwatch Rutland (HWR) undertook engagement to understand the experiences of people in Leicester, Leicestershire and Rutland (LLR) who are living with dementia and their families and carers. The results are contained in an LLR-wide report to commissioners and providers to inform the development of the refreshed Joint Dementia Strategy in 2023. Locally, the Rutland Proactive Care pilot is now being developed with the aim of delivering more holistic and wrap-around care for people living with dementia. It is hoped that this Rutland-specific report can also help to inform both the pilot and ongoing services for people living with dementia.

Dementia is defined by the NHS as ‘*Not only about memory loss. It can also affect the way you speak, think feel and behave.... [It is] a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning*’³. There are several causes of dementia including: Alzheimer’s disease, vascular dementia and dementia with Lewy bodies. Frontotemporal dementia is often a cause of ‘young onset’ dementia in people under the age of 65⁴.

Table 1 sets out population estimates in the 65+ and 85+ age groups for 2021 and 2040 and the risks of developing dementia in older age groups:

³ <https://www.nhs.uk/conditions/dementia/causes/>

⁴ <https://www.nhs.uk/conditions/dementia/causes/>



Age	2023 estimated Rutland population ⁵	2040 estimated Rutland population ⁴	A person's risk of developing dementia (2014) ⁶
65+	11,102	14,882	1 in 14 people
80+	3,312	5,073	1 in 6 people

Table 1 Rutland population estimates (2018)⁴ and national expected dementia prevalence⁵

Rutland health and social care providers and support services will therefore be challenged by an increasing aged population and dementia prevalence.

Memory Clinics assess, diagnose and suggest treatment options for patients with memory problems referred by their GP. The Memory Clinic Service at the Rutland Memorial Hospital has been suspended since the COVID-19 pandemic.

Table 2, below, shows the number of people in England and Rutland diagnosed with dementia, the estimated prevalence of cases and the estimate current diagnostic rate. The national ambition is to achieve a 67.7% diagnostic rate:

	England	England diagnostic rate	Rutland	Rutland diagnostic rate
Diagnosed dementia cases (aged 65+ years)	417,797	61.8%	345	48%
Diagnosed dementia cases (0-64 years)	14,048	N/A	N/A	N/A
Estimated prevalence of dementia (65+ years)	675,542	N/A	708	N/A

Table 2. Prevalence of dementia in England and Rutland (January 2023)⁷.

The Rutland estimated diagnosis rate of 48% falls well below the England ambition of 66.7% and the LLR diagnosis rate of 60.7% (see footnote 7).

In January 2023 there were 14,048 people aged under 65 years with a recorded dementia diagnosis⁸. Dementia UK estimates that 7.5% of those estimated to have dementia experienced symptoms under the age of 65 years. Using this percentage suggests an estimated prevalence of young onset dementia in England of 50,666 with 53 cases in Rutland (7.5% of 708). We were anecdotally informed there were approximately 5 known Rutland cases.

The average time taken to diagnose young onset dementia is 4.4 years compared with 2.2 years for the 65+ age group⁸. Alternative diagnoses often initially given

⁵ <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/localauthoritiesinenglandz1>

⁶ <https://dementiastatistics.org/statistics/prevalence-by-age-in-the-uk/>

⁷ Source: Digital NHS UK <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/january-2023>

⁷ https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf

⁸ <https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures/>



include depression, anxiety, stress or the menopause. No Rutland respondents to this project had been diagnosed with, nor were caring for, people with young onset dementia.

Rutland County Council provides an online [information service](#) of local dementia support, social groups and organisations including:

- Rutland Adult Social Care Services - carry out support needs assessments
- Admiral Nurse Service - supports families, carers and patients throughout the dementia journey
- Rutland Reminders - a local volunteer group providing social activities for people with dementia
- Age UK - provides a Rutland Dementia Support Service and informs about and signposts people with dementia and carers to appropriate services. Age UK also hosts social support and activity groups

Purpose of this report

Further to the aims and objectives of the LLR Living with Dementia Report (*link will be added once document is published*) we felt that it would be useful to local commissioners and providers to draw together the Rutland responses to inform ongoing Rutland Place and Neighbourhood work and the Proactive Care pilot.

Method

The British Sociological Association (2017) Statement of Ethical Practice⁷ guidelines were followed to ensure participants' and researchers' well-being and research integrity.

We ran widely-advertised, digital and hard copy surveys for people with dementia and their carers through October and November 2022. The survey included free text responses. We also invited the public to take part in semi-structured interviews and focus groups. The questions and prompts for interviews and focus groups can be found in the appendix of the main Living with Dementia in Leicester, Leicestershire and Rutland report

Quotations from earlier HWR projects have been used occasionally in this report to emphasise or introduce a relevant point and are identified accordingly.

Data analysis

In the Joint Healthwatch Dementia Survey across LLR, 111 out of 127 responses indicated the place of residence. **With just 337 diagnosed dementia cases in**



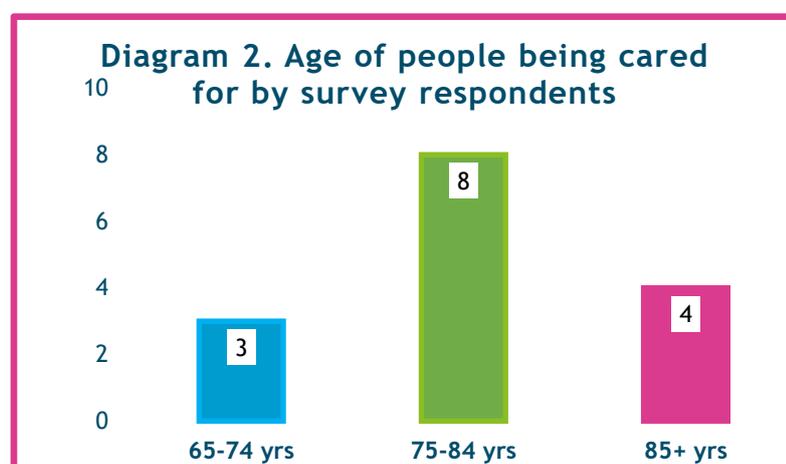
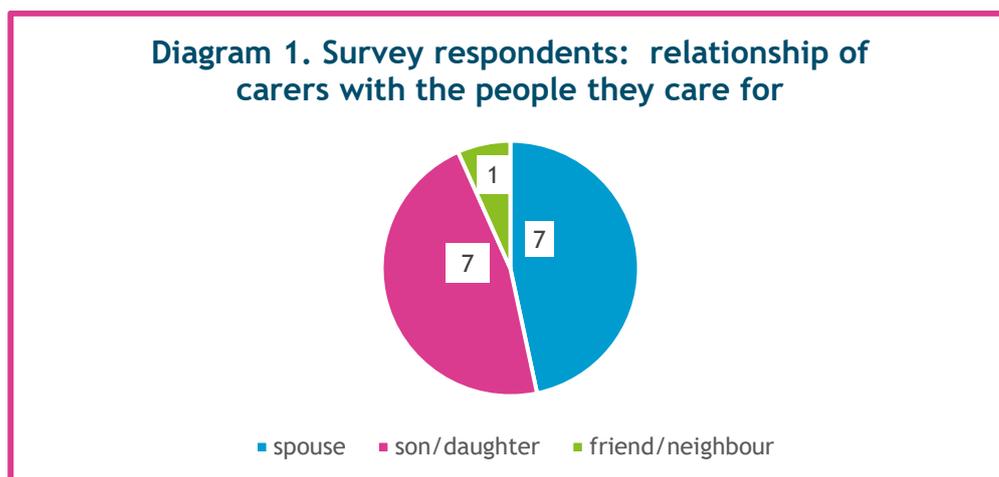
Rutland the response rate, as expected, was low and the percentages in all the tables presented lack statistical significance but do provide indications of people’s experiences:

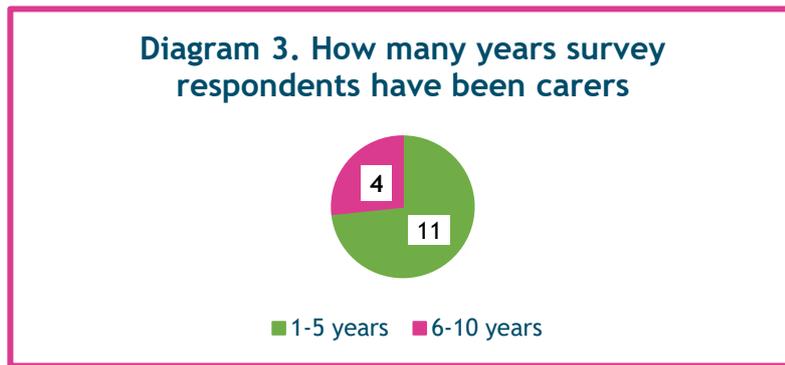
	Leicester	Leicestershire	Rutland	Total
People with dementia	7	1	2	10
Carers	40	56	15	111

Table 3 LLR survey respondents

Survey respondents	Age group of survey respondents			Not stated
	45-64	65-74	75-84	
Carers	5	5	4	1
People living with dementia		1	1	

Table 4 Rutland survey respondents’ age groups





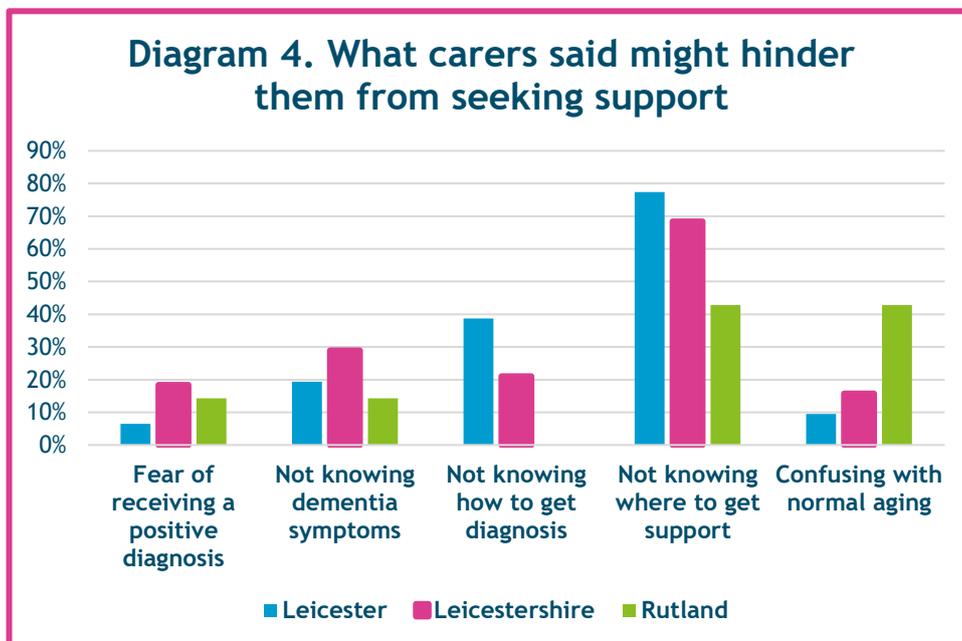
In addition to the survey respondents, a focus group of twelve people, consisting of people with dementia and their carers and a further four individual carers spoke about their experiences in one-to-one interviews.

All spoken and free text comments were thematically analysed with emerging themes being double checked by a second person to eliminate bias and omissions.

What people told us

1. Late diagnosis

The survey looked for possible reasons for delaying getting a diagnosis by asking the question: **What might hinder you from seeking help or support? (please tick all that apply)**



No Rutland respondent said they did not know how to get a diagnosis.

We combined the survey figures with free text data and focus group and interview comments in order to further understand reasons for delayed diagnoses in Rutland.

Not knowing where to get support - 3 out of 7 Rutland carers (43%) said in response to the survey that ‘not knowing where to get support’ might be a barrier



for contacting services to get a diagnosis. This compares with 24 of 31 responses (77%) for Leicester; 26 of 38 responses (68%) for Leicestershire; and 53 out of 76 responses for LLR (70%)

A comment from a Rutland resident explained further:

'We need to aim to inform those entering the dementia care phase what support is available.'

Thinking that memory problems are a normal part of ageing - In the survey, 3 out of 7 Rutland carers (43%) said that 'thinking that memory problems were a normal part of ageing' was a barrier to getting support. This compares with: 3 out of 31 responses (10%) for Leicester; 7 out of 38 responses (18%) for Leicestershire; and 13 out of 76 (17%) across LLR

The focus group report states:

Participants described a 'grey area' or a continuum along which it is hard to define the difference between the natural ageing process and dementia.

An interview participant said:

'I didn't tell the doctor because I don't think I'm there yet. If my body is not doing any good, my body is ageing, so is my mind ageing, too? My mind is not as sharp as it was.'

Lack of knowledge about dementia symptoms - Two survey respondents referred in the free text to the lack of knowledge and information among the general public about the symptoms of dementia:

'No advice and information have been given except for what I found out myself.'

'There are huge delays in patients being seen. The primary care side needs sharpening up. They need to take more of a primary role in this. I was told that a psychiatrist leads at the memory clinic. Shouldn't this be a neurologist? People that meet my friend in the street don't always know she is ill. I have another neighbour that understands her illness and I can talk to them and they understand.'

Stigma and fear. One person with dementia, referring to how cancer was viewed in her childhood, told the focus group, *'Dementia is the new cancer'* and a carer stated that receiving a diagnosis of dementia is *'frightening, disempowering and carries a stigma.'*

Misdiagnosis. One carer in the focus group said their partner had been referred to a specialist due to mobility and incontinence problems. Recognising cognitive problems, the specialist also ordered a CT brain scan. Vascular dementia was diagnosed as the cause.

A few participants in the focus group suggested that deafness can be misinterpreted as dementia when seemingly confused or inappropriate replies are given or there is an almost complete lack of response to a conversation.

'He's quiet, I go with him. He can't hear so I go with him because he will say 'yes' to everything and anything because he can't hear. There's



no point him coming in here [to join the interview] because he wouldn't hear.'

Perceived flaws in cognitive testing. Concerns have previously been expressed in past HWR projects⁹ that tests do not detect a cognitive decline in previously high-performing people although close friends and family had noted problems:

'The Doctor did a series of tests - the clock test where he had to draw a clock with a certain time and others. You thought it was simple, though, didn't you?' (carer, speaking to partner who had held a high-level managerial job) (link)

'I've been referred three times for memory issues and the same tests used each time. So I remembered the answers... [they] should improve and vary the memory clinic tests so that you don't learn the answers' (link).

Reluctance of carers. Relatives and friends, noticing memory problems in advance of the patient acknowledging them, might be reluctant to approach the issue:

'I knew her memory was failing for 2 years; she was a nightmare for losing things. She didn't say anything but after two years she acknowledged it for herself and went to the GP'.

2. Getting the diagnosis

2.1 Variable pathways and delays

Carer number	How many months did you wait to get a diagnosis?	Were you happy with this length of time taken to get a diagnosis?	Did you receive any information before diagnosis?	After diagnosis did anyone sit down with you and explain what might happen?
1	<3	Yes	Yes	Don't know
2	<3	Yes	Don't know	No
3	3-6	Don't know	No	Don't know
4	3-6	Yes	Yes	Yes
5	3-6	Yes	Yes	Yes
6	3-6	Don't know	No	No
7	6-9	Don't know	No	No
8	6-9	No	No	Yes
9	6-9	Yes	Yes	No
10	9-12	No	No	No
11	9-12	No	No	Yes
12	>12	No	Yes	No
13	>12	No	Yes	Yes
14	>12	No	No	Yes
15	>12	No	No	No

Table 5 responses from Rutland residents to survey questions about the diagnostic pathway

Table 5 demonstrates variability, and, perhaps, inequity, in experiences and a correlation between being satisfied and having a shorter wait for diagnosis. We then compared the LLR carers' responses to the question:

⁹ What would you do? Healthwatch Rutland Engagement Report: The NHS Long Term Plan



Were you happy with this length of time taken to get a diagnosis?'

	LLR	Leicester	Leicestershire	Rutland
Yes	45% (49)	47% (18)	47% (26)	33% (5)
No	44% (48)	40% (15)	47% (26)	47% (7)
Don't know	10% (11)	13% (5)	5% (3)	20% (3)

Table 6 Carers' satisfaction with the length of time to achieve a diagnosis

In percentage terms, Table 6 indicates a lower satisfaction rate in Rutland than the LLR average and lower than Leicester and Leicestershire individually.

Two Rutland participants described their different experiences of the diagnostic pathways:

'[My friend] went to the GP and was referred to the Memory Clinic in Leicester. It took 8 months to get the appointment... [My friend] wasn't talked to by the GP during that waiting time, or by any other professional. At the Memory Clinic, [my friend] was seen by a triage nurse and it took about 1.5 hours. I mentioned the need for a brain scan but was told that they didn't need one. [The nurse] said that [the clinicians] think it's Alzheimer's....and that they would talk to the team and there would be another appointment. This was cancelled because they didn't have scan results. It was annoying as I had prompted about the need for a scan. They couldn't give any treatment without the scan. My friend went private for an MRI. This gave more information than the CT scan and they said it was Vascular Dementia.'

'The Admiral nurse signposted us to the Age UK Dementia services and facilitated a referral to the Memory Clinic for a formal diagnosis. Still waiting for that, as advised it could be a six-months, or longer, wait.'

The survey responses indicate further variability in the diagnostic pathway across the whole of LLR, with different professionals making the diagnosis:

	LLR	Leicester	Leicestershire	Rutland
Specialist doctor/nurse	31% (32)	21% (8)	42% (21)	20% (3)
Memory Service	53% (55)	61% (23)	46%(23)	60% (9)
GP	6% (6)	8% (1)	2% (1)	13% (2)
Don't know, other, none	10% (10)	11% (5)	10% (5)	6% (1)

Table 7 Survey carers' responses: who gave the diagnosis

A similar percentage of people from Leicester and Rutland received their diagnosis from a specialist doctor or nurse (below the LLR average) and from the Memory Service (higher than the LLR average). However, a higher percentage of Leicestershire respondents received their diagnosis from a specialist (above the LLR



average) and a lower percentage received their diagnosis from the Memory Service (below the LLR average).

2.2 Information

The survey asked carers if they were given information prior to and after being given a dementia diagnosis. We compared the Rutland results with LLR as shown in the following two tables:

Did you receive any information before diagnosis?

	LLR	Leicester	Leicestershire	Rutland
Yes	23% (25)	21% (8)	20% (11)	40% (6)
No	69% (75)	71% (27)	71% (40)	53% (8)
Don't know	8% (8%)	8% (3)	9% (5)	7% (1)

Table 8 Survey carers' responses: indicating how many received information before diagnosis

Across LLR 69% of respondents said they had received no information before diagnosis. Rutland responses indicate that the availability of information before diagnosis is better than in Leicester and Leicestershire.

After diagnosis did anyone sit down with you and explain what might happen?

	LLR	Leicester	Leicestershire	Rutland
Yes	33% (34)	14% (5)	43% (23)	40% (6)
No	61% (63)	78% (28)	53% (28)	47% (7)
Don't know	7% (7)	8% (3)	4% (2)	13% (2)

Table 9 Survey: carers responses, indicating whether they were informed after diagnosis

Leicester residents received the least explanation about what to expect after diagnosis but across LLR more people (61%) said they had not received such information whereas only 33% did. The lack of information was also mentioned in the survey free text comments:

'Fuller information about how it [dementia] may affect my mother and how I and my father can support her on a day-to-day basis is needed. Finding information on-line locally is not easy and Rutland County Council's website is not that user-friendly.'

Focus group and interview comments included:

'There was no information on what to expect next, but I already knew about the Age UK support.'

'I picked up some leaflets when I went to the Memory Clinic appointment with my friend so I found contacts for Age UK and the Admiral Nurse.'



Although all 15 carers who responded to the survey said they felt confident in accessing information and support on-line, one interview participant spoke of their own difficulties:

'I have a computer now but, with the changes they put on each time, it's leaving me behind and I can't catch up. I can use the telephone and talk to anyone. Everybody should have a landline - but not a mobile. [My daughter] helps me. If I want to know anything about doctoring, she looks it up.'

3. Living with dementia - patients

3.1 The voices of people with dementia

We received one free-text survey comment from a person with dementia:

'[I need to know] how to get respite care as [my] carer needs a break.'

A focus group participant stated:

'I was diagnosed a year ago. I look in the mirror and can't see that I look any different from this time last year when I was diagnosed. I have clear memories of taking 6 old pennies to the sweet shop when I was a child.' (Focus group)

To gain further insight into the experience of living with a dementia diagnosis we looked through previous HWR reports. In response to the question asking a person living with dementia in 2019¹⁰, 'If one more thing would help you manage and choose how the NHS supports you, what would it be?' The reply was:

'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.'

This gives some insight into the experience of having a dementia diagnosis - especially in the earlier stages. There is acknowledgement of the diagnosis and also a recognition that things are going to get worse and increasing help and support will be required. People diagnosed with dementia want to be seen as an individual.

As the poem in Appendix 1 demonstrates, people with dementia have difficulty in finding the right words and following a conversation or may speak inappropriately¹¹. Having reflected on why few people with dementia responded to this project, we question whether they are being given, or want, an appropriate platform for their voices across the health and care system.

3.2 Ongoing healthcare for people with dementia

There were reports of dissatisfaction with ongoing healthcare in primary care, community care, hospital care and care homes during the focus group and interviews, and one comment expressing satisfaction with a care home:

¹⁰ HWR (2019) *What matters to you? Engagement report: The NHS Long Term Plan*

¹¹ <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/dementia-and-language>



Primary care:

'One carer needed to get medical attention for their spouse. They rang their GP practice in October and were told that no new appointments would be released until 2pm on 1st November. They rang on 1st November and they were given an appointment for a triage on 25th November. They do not know if or when, they would be seen and by whom.' (Focus Group report)

'[We need] periodic face to face consultation with the same GP from the practice so they can assess the progress of the dementia and when necessary amend and adjust their [medication].'

Hospital appointments:

'[She] needs wheelchair-based transport. TASL [providers of non-emergency patient transport] take the booking, so you assume you have the transport booked. But you can get a phone call on the day to say it's not happening even though you have been told to be ready 2 hours beforehand, which is really difficult with a person with dementia. It happened to [us] so she missed her audiology appointment.'

Hospital inpatient care:

'[She] also spent 3 weeks in City Hospital, again with no visits allowed. Whilst there she was really distressed and too confused and scared to stand and couldn't hear - they never checked her ears. My biggest concern is how people with dementia are treated and considered - no family was allowed to help her even though she is diagnosed.'

'Seriously? You don't want to hear about it [hospital inpatient care]. Shockingly poor - really shocking! Worse than third world countries.'

Care in the community:

'The nurse used to ring once a month. I couldn't get through to the nurse that he's an individual. I can't get through to her that he's different in the morning. Now I have another one who hasn't rang for a while.'

Care homes

'My wife is happy and secure in a care home as I couldn't cope any longer. The cost is nearly £6000 per month, which we can afford for the time being.'

'We also had no input into the care plan at [the care home] after she arrived in the September. [She] never left the room and she was not encouraged to use the lounge. There were no activities and no co-ordinator, just the occasional carer to read a magazine or paint her nails.'

'Mum didn't like the food so didn't eat well. She is vegetarian and [the care home] food is very meat based or processed vegetarian - not the nuts and cheese she likes. [She] also didn't want male carers and wasn't supposed to have them but we discovered a man and woman had



washed and changed her. The team leader said it wouldn't happen again, but it did. They just didn't respect people enough.'

'I really think there needs to be more prevention help in care homes to keep people well - there's no personalisation or treating people as individuals. I think she would have had a better life in prison and would have been more looked after.'

'There were lots of agency staff at [the care home] who didn't know what they were doing. Obviously, that makes it stressful for the carers themselves. We felt like it wasn't safe - she wasn't eating as the food was awful...But they did give Fortisips at mealtimes if she wasn't eating. The thing is she gets delirium/hallucinations if over tired or needs to eat and drink...She was also put on antibiotics often for urinary tract infections. Overall I think it was easier to just keep her in her room.'

Patient advocacy

'What about people with dementia who have no one - who is there for them? They need to know they can get help and be advocated for.'

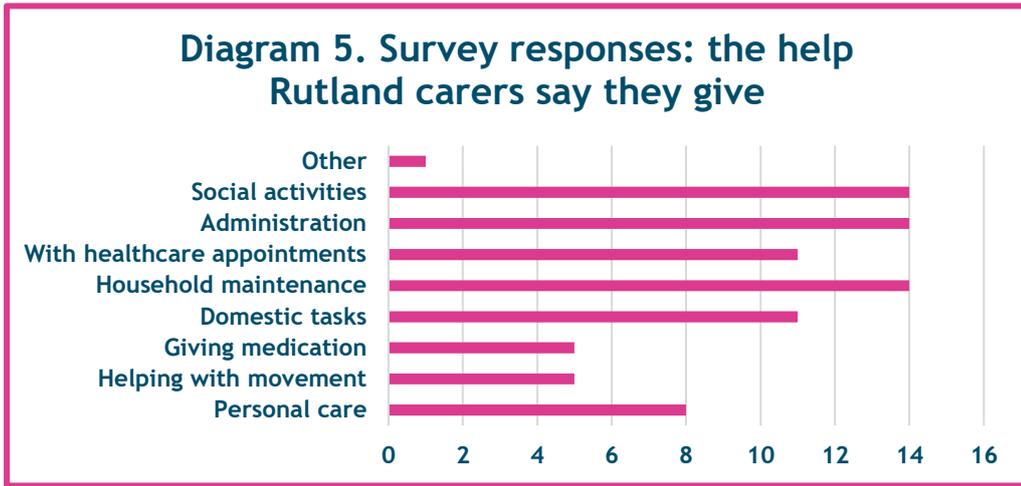
'I have to try and persuade the GPs and their receptionists to discuss my mum with me every time I call. I have a POA [Power of Attorney] in place for my father-in-law but continue to not be informed. It is very frustrating on top of the stress of caring for elderly relatives. I would like the medical professionals to listen to me and let me know when my mum or father-in-law have appointments etc. They both forget everything that they are told and asked, so I have no clue what has been discussed.'

These comments show carers' concerns that personalised, co-ordinated and holistic care is not being adequately provided in the health and care sector for the people with dementia they are caring for. There are particular worries about the quality of care. Carers see themselves as co-ordinators of care and are concerned for those with dementia who have no one to oversee their care.

4. Living with dementia - carers

4.1 Carers' tasks

The survey elicited responses about the practical help provided by Rutland carers of people with dementia or those awaiting diagnosis:



One interview participant, caring for a friend who lives alone, describes their role:

‘The problem we have is that a lot of help is in Oakham and as we are in a more rural location, transport is limited. A friend takes [them] to the Gym and I take them shopping. [They] also have a gardener and a cleaner. I also have Power of Attorney to help with their affairs with the input of a solicitor and accountant. The problem is [they] live alone.... I am worried about them taking medication. I got a pill box but I don’t know whether they are taking [the medications] correctly.’

Rutland carers are giving a lot of domestic help in terms of managing finances, household chores and maintenance. They are also concentrating on the social wellbeing of the person they care for. There is slightly less involvement with assisting with healthcare appointments and physical care.

4.2 Carers’ support and potential barriers to accessing it

Existing support

How well do you feel you are supported in your caring role?

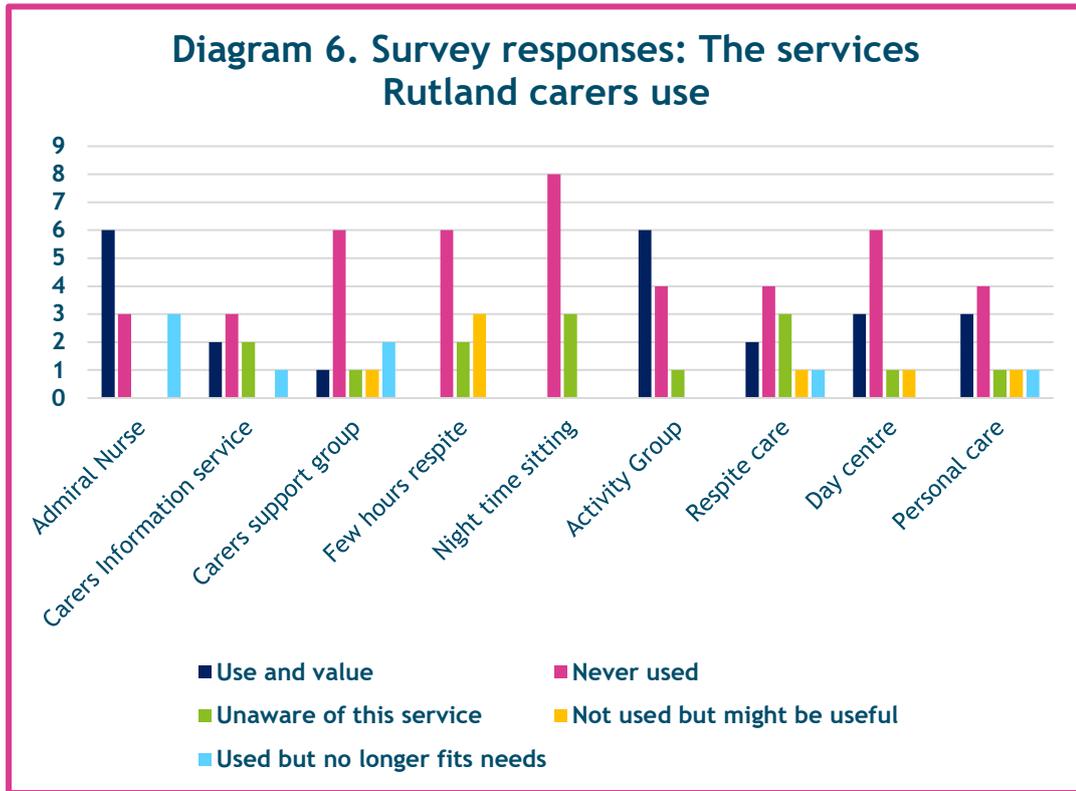
	Leicester	Leicestershire	Rutland
I feel I have all the support I need at this time	16 (43%)	14 (24%)	2 (13%)
I feel that I have some support but not enough	17 (46%)	27 (46%)	7 (47%)
I feel I have no support despite seeking help	2 (5%)	6 (10%)	2 (13%)
I have never been offered any support	2 (5%)	9 (15%)	4 (27%)
I wouldn’t know where to go to get help	0	3 (5%)	0
Total	37	59	15

Table 10 Survey responses: satisfaction with level of support received



Although a small number, Rutland carers feel less satisfied with the level of support than Leicester and Leicestershire counterparts.

Rutland responses to the survey question asking which support services they use:



The two services that Rutland carers use the most and find valuable are the Admiral Nurse Service and Group Activities for the person with dementia followed by Day Centre Care and Help with Personal Care for the person with dementia. The Rutland usage and value of these services was compared with Leicester and Leicestershire.

	Percentage of responses from carers who use and value these services		
	Leicester	Leicestershire	Rutland
Admiral Nurses	11% (4 of 35 responses)	22% (10/46)	50% (6/12)
Group Activities	81% (30/37)	52% (25/48)	55% (6/11)
Day Care Centre	26% (9/35)	23% (11/47)	27% (3/11)
Help with personal care	14% (5/35)	26% (12/46)	30% (3/10)

Table 11 Survey responses: Comparing the 4 services most valued by Rutland carers with Leicester and Leicestershire responses

Table 11 indicates that:

- Rutland carers use and value the Admiral Nurse Service more than their Leicester and Leicestershire counterparts
- Leicester City carers value Group Activities for the Person with Dementia more than their Leicestershire and Rutland counterparts
- There is not much difference in value and use of Day Care Centres across LLR



- Leicester City carers use and value Personal Care for the person with dementia less than their Leicestershire and Rutland counterparts.

There are four Rutland services with the highest number of ‘never used’ responses: ‘Carer’s Support Group’; care in the home for a ‘Few Hours Respite’ for carers; a ‘Night-time Sitting service; and ‘Day Centre’ care. The responses for these were examined further:

	Percentage of responses from Rutland carers who say have never used these services		
	Leicester	Leicestershire	Rutland
Carers support group	34% (11/32)	35% (16/46)	55% (6/11)
Few hours of respite for carers	39% (13/33)	37% (18/49)	55% (6/11)
Night time sitting service	54% (20/37)	58% (26/45)	73% (8/11)
Day Centre Care	37% (13/35)	47% (22/47)	55% (6/11)

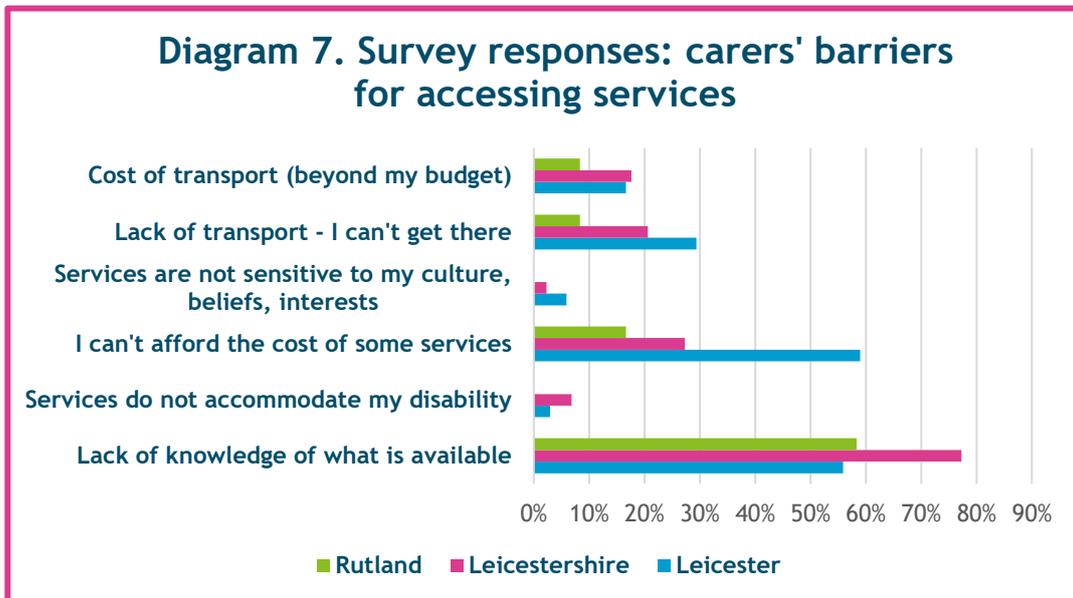
Table 12 Survey responses: Comparing the 4 services most Rutland carers say they have never used

The table above indicates that a higher percentage of carer respondents to the Rutland survey have never used all four of these services.

Barriers to accessing support

The survey asked:

‘If you don’t access any of the above services but would like to. What is it that prevents you from doing so?’



- No Rutland respondents said that lack of sensitivity to their culture, beliefs and interest and lack of accommodation of their disability, prevented them from accessing support services.
- A lower percentage of Rutland respondents said that transport costs, availability and affordability of services prevented them accessing support services
- The highest number of responses to this question was ‘lack of knowledge of what is available’.



- Although table 10 indicates that no Rutland carers said they would not know where to go for help, diagrams 6 and 7 show that there were named services that they did not know were available.

We combined the survey quantitative data and free text, focus group report and interview comments to provide a more in-depth analysis of the barriers carers encounter in accessing support services. The following themes emerged:

Lack of knowledge of what is available

As a major barrier to accessing services was highlighted in diagram 7 (above) we explored the survey data further to understand which services were not known about across LLR:

	LLR	Leicester	Leicestershire	Rutland
Carers advice/info service	13/88 responses 15%	5/35 (14%)	6/45 (13%)	2/8 (25%)
Admiral Nurses	38/93 (41%)	23/35 (66%)	15/46 (33%)	0/12
Carers support group	7/89 (7%)	2/32 (6%)	4/46 (9%)	1/11 (9%)
A sitter for a few hours respite	17/97 (7%)	5/37 (14%)	10/49 (20%)	2/11 (18%)
Night time sitter	20/93 (22%)	4/37 (14%)	13/45 (29%)	3/11 (27%)
Short break respite	15/94 (16%)	2/37 (5%)	10/46 (22%)	3/11 (27%)
Day centre	6/93 (7%)	1/35 (3%)	4/47 (9%)	1/11 (9%)
Help with personal care	3/91 (3%)	1/35 (3%)	1/46 (2%)	1/10 (10%)
Meals incl luncheon club	7/88 (8%)	0/34 (0)	5/43 (12%)	2/11 (18%)
Activity groups for person dementia	5/96 (5%)	1/37 (3%)	3/48 (6%)	1/11 (9%)

Table 13 Comparing across LLR for the numbers of survey respondents saying they were not aware of services named

Table 13 indicates all responses to the survey questions asking carers which services they had used and were aware of.

- All of the Rutland respondents were aware of the Admiral Nurse Service whereas 66% of Leicester residents and 33% of Leicestershire residents were not aware of it. This indicates further confirmation of the success of the Admiral Nurse Service in Rutland.
- Rutland people were less aware of all other services compared with the LLR average.
- This indicates a problem for Rutland people in receiving or accessing information about what services are available.

When asked if they knew what help is available as the condition progresses, one interview participant said:

‘No. Another friend and I have decided to go and look around some care homes so that we are aware of what they are like... We haven’t talked about it with our friend with dementia yet. We are just gathering information.’



Other barriers included:

Digital exclusion means it is difficult to find out what support is available:

'They say we should go online to sort things out but 75% of over 75s don't go on line. They don't recognise that older people don't have the technology skills... I have a computer now but, with the changes they put on each time, it's leaving me behind and I can't catch up... Everybody should have a landline - but not a mobile. They fail to do anything about this ... not everybody has a mobile.'

Inability to leave the patient:

'Two carers said they would like to go to Carers events locally but to do this would involve trying to find someone to sit with their partners who have dementia. The suggestion was that perhaps carers events could be organised at the same time as an event for people with dementia.'
(Focus group report)

Transport problems:

'The problem we have is that a lot of help is in Oakham and we are in a more rural location, transport is limited.'

'I am not always free to provide transport and my friend can no longer drive.'

Person with dementia unwilling or unable to leave home:

'I tried to get mum to attend the Age UK support groups but mum was reluctant. And so we have just been left to it.'

'My mother wasn't keen on going out of the house and since Covid has been much worse. Now accessibility would be difficult as she can't self-transfer.'

Lack of affordability, availability and pressure on services:

'I use an excellent care company but it's too expensive so we only get 4 hours a week. Social services are a waste of space.'

'I attend some groups with dad and find these beneficial, sadly I would like to attend more sessions but these are every month. I feel these services would be used and accessed weekly if available for many families.'

'Social services are run off their feet and unless you are really desperate with no help you don't get support.'

'[They] attends Memory Club. Private and we pay. [There is] nothing Council-run locally.'

Time pressures as a barrier to seeking support:

'Getting through to a GP and arranging an appointment.'

'Having the time to arrange things. I work and find it impossible to get through on the phone, this adds stress levels.'



Lack of public knowledge of dementia and the need for friends' and neighbours' support:

'People that meet my friend in the street don't always know she is ill. I have another neighbour that understands her illness and I can talk to them and they understand.'

Falling outside of the 'system':

'I do all the health care and taking mum to all her appointments as well as managing finances. I have no power of attorney and, because I am not classed as the main carer, have had no offer of any carer assessment or support.'

'Is it appropriate that the services assume that someone who lives with a person with dementia is the main carer? It's not the case for us but I don't live in the same house. I feel left in the lurch as nothing has been offered to me.'

When the person with dementia enters a care home:

'My experience was during COVID my husband is now in a care home. My support from Admiral Nursing stopped on his admission to care.'

'There are still stresses and guilt when they are in care, particularly with staffing issues in care homes currently. It is a different stress, but not easy and the guilt is massive.'

Conclusion

In conclusion, the statistics show that Rutland is significantly under-performing in diagnosing dementia.

Despite county-wide promotion, including via care homes, Age UK, Admiral Nurses, social media etc, only 33 people told us about their experiences. However, these responses do give an indication of what people with dementia and their carers are experiencing. HWR therefore looks forward to working with the Dementia Programme Board in its development of the LLR Dementia Strategy and also with the Proactive Care pilot project in Rutland and hope that our findings will help to ensure that the needs of Rutland residents living with dementia will be met.

We were disappointed that we were not able to engage with more people with dementia or dementia-associated problems. This is a concern as the comments we have received indicate a wish to be recognised as individuals despite dementia problems and suggest more research with this group of people is needed. The low numbers also raise the question about how much people with dementia are facilitated or want to express their needs and preferences. This became even more salient when carers told us about the poor standards of ongoing healthcare they were encountering across our health and care system.



With Rutland being a statistical outlier in terms of diagnosing dementia we were particularly interested in delving into the data to identify potential explanations. With the Rutland Memory Clinic remaining closed since the COVID-19 pandemic and diagnosis backlogs, it is not surprising that we heard of delays in accessing diagnostic services. However, there appears to be an unexplained variability, or inequity, in both the times taken and the pathways followed to get a diagnosis.

Further, we were concerned to hear of the distress being experienced by people who are performing caring duties but are not recognised as the main carer for the people with dementia.

A recurrent theme throughout the project has been that of ‘not knowing’. This could be ‘not knowing’ about support services, ‘not knowing’ about dementia signs and symptoms or uncertainty about where a natural memory decline with old age ends and dementia begins. This lack of knowledge could be improved by accessible information. Yet, the participants told us that information is not easily available or not always readily offered to them. We leave the last words to a Rutland survey respondent:

‘The only comment I have is, that we need to aim to inform those entering the dementia care phase, what support is available. We need to ensure there is easily accessible information about dementia, how to get it diagnosed, what to do with patients who resist that diagnosis and what options are available for treatment, care and generally managing the patient before and after diagnosis’.

Acknowledgements

We are very grateful to everyone who advised and helped us to design the LLR Dementia project and introduced us to participants. We sincerely thank Rutland residents who shared their views and experiences with us.

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About Healthwatch Rutland

Healthwatch Rutland is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch Rutland and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at www.healthwatchrutland.co.uk





About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Rutland.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Connected Together
First for Community Engagement

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

Find out more at www.connectedtogether.co.uk





Appendix 1 A carer's poem

Finding the right words

I love the smell of new-mown linen,
And of hay that has dried on the line,
Of caring bathrooms and clean young women
And insects at breakfast with wine

I love the bleat of babes in the trees.
The wail of new-born steam train
The huff and hiss of a baby breeze,
The laughter of lambs in the rain.

I love the taste of cheese with honey
My breakfast egg on slippers,
The feel of fresh and pungent money,
And slipping my feet in the kippers.

I love the feathery touch of a tree
The feel of a branch on the birds
My senses, though intact, fly free,
So I can't always find the right words

By kind consent of Rita Duckham, a former Oakham resident and carer for her husband. John was a teacher, a keen Bridge player and a Rutland County Councillor. He passed away after a long struggle with dementia. This poem was awarded second prize in the Alzheimer's Society 2015 poetry competition.



Contact us

Address: Healthwatch Rutland
The King Centre
Main Road, Barleythorpe
Barleythorpe
Oakham
Rutland
LE15 7WD

Phone: 01573 720381

Email: info@healthwatchrutland.co.uk

Website: www.healthwatchrutland.co.uk

Facebook: [healthwatchrutland](https://www.facebook.com/healthwatchrutland)

Twitter: [@HWRutland](https://twitter.com/HWRutland)



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