

# Self-funding social care:

Experiences of navigating the system in Rutland

**March 2025**



**Summary report of findings**

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## Introduction

The Care Act 2014 requires local authorities to offer their residents free needs assessments when requested to do so, to determine what care and support might be required with their activities of daily living such as washing, dressing, taking medications etc. Such help is known as 'social care'. There is also a duty to provide free assessments of the needs of unpaid carers. Further to this, local authorities have a duty to provide accessible information, advice and guidance about the types of support and care available and where and how to access these within their area.<sup>1</sup>

Where the need for social care is identified, a free financial assessment must also be offered to residents. Since the financial year 2010–2011, people with assets above £23,250 (in some cases including their own home) must fully fund their own social care, with no upper limit on the amount they might have to eventually pay. People with assets of between £14,250 and £23,250 must contribute towards their social care costs according to a sliding scale<sup>2</sup>.

People who have to pay for their own social care are known as 'self-funders'. Healthwatch Rutland was commissioned by Rutland County Council (RCC) in October 2024 to engage with people in the county to find out about their experiences of the information, advice and guidance that is available to self-funders and what they need to help make the best decisions. This report is a summary of detailed results provided to the commissioners of the work.

## Aims and Objectives

The aim of this project was to provide insight into what people need to help them make confident decisions and to identify what works well and where there are gaps in the provision of information and guidance.

With the following objectives:

- Researching the experiences and needs of self-funders who have sought information, advice and guidance about social care and support within the last 2 years.
- Understanding the wider factors that influence the care and support decisions that people make.
- Identifying the key information, advice and guidance that self-funders need to help make the right decisions and what sources they prefer to use.
- Making recommendations for improving the information, advice and guidance offered by Rutland County Council.

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<sup>1</sup> Department of Health and Social Security (2016) *Care Act Fact Sheets* Accessed 27/2/2025 at: <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>

<sup>2</sup> House of Commons Library (2021) *Adult Social Care: Means-test parameters since 1997* Accessed 28/2/2025 at: <https://commonslibrary.parliament.uk/research-briefings/cbp-8005/>

## Method

A mixed approach was taken, using online and hard copy surveys and qualitative feedback, gathered through survey free text comments, interviews and focus groups, to provide rich detail of people's needs and experiences.

## Summary

A total of 129 people participated in the project comprising 86 through semi-structured focus groups, 12 individual interviews and 31 fully completed survey responses. Of those 129 people, 65% (84) were women, 32% (41) were men and 3% declined to say.

The project explored the experiences of self-funders navigating the social care system in Rutland. Some participants in the project have found their journey to be easy and have been happy with the outcomes. However, many individuals and their families funding their own care feel isolated in the process, lacking clear guidance on available services, financial planning, and decision-making. In order to make good decisions about getting the right care in the right place at the right time, the system expects them to independently source reliable information, understand complex financial policies, make objective care decisions and manage ongoing care arrangements, often without prior experience or support.

People put off planning and paying for social care and their first experiences of navigating the system works can be in a crisis situation. For people with little prior knowledge of the financial considerations, the cost is perceived to be high and there is resistance to buying in to it. In addition, with rising costs in the social care market in recent years, savings can be eroded very quickly. Consequently, self-funders are anxious about what will happen as funds become depleted and when deteriorating health means more care is needed.

## Key Recommendations

1. **Increase public awareness** – Launch a targeted campaign to inform residents about social care options and financial responsibilities.
2. **Improve access to information** – Review Rutland County Council's (RCC) information resources to ensure clarity, consistency, and availability in multiple formats by:
  - a) Providing a streamlined information hub which collects all information and guidance together. This could mean the development of an existing platform with links out to other platforms (as subsidiaries or 'spokes').
  - b) Creating a checklist for self-funders that charts the journey of making decisions about social care and the options.

- c) Making the online version of the LLR Adult Care and Support Services Directory properly searchable and clearly distinguish the differences between narrative guidance and provider advertisements.
- d) Ensuring that all information and guidance is available in all media – online, print and in-person.
- 3. **Establish a care navigation role** – Provide a dedicated point of contact (professional or trained volunteer) to support self-funders through their care journey.
- 4. **Enhance financial guidance** – Improve transparency, information and help with planning. around: funding thresholds, care costs, Continuing Health Care awards; and funds depletion.
- 5. **Review how much information and support is available for Rutland residents trying to arrange care elsewhere** – provide a generic checklist of information and support that people should seek out in other areas.

## Findings

### 1. Awareness and knowledge at the start of the care journey

Most participants began their social care journey with limited or no knowledge. Although 70% of survey respondents had sought information, only a few felt confident in their knowledge. Sources of information included media, friends or prior professional experience. A recurring theme was, "I don't know what I don't know," indicating disempowerment and lack of preparedness.

#### Key challenges:

- Lack of general public awareness about social care before it is needed.  
'The issue is that no-one thinks about social care and help before it happens.'
- Limited awareness and understanding of services such as Continuing Health Care (CHC), JOY platform, and the RISE team.  
'Although the RISE team were brilliant, I'm not sure who came out to me and I don't really know what they do... No, I've never heard of that (JOY platform).'
- Confusion and misinformation about financial thresholds and assessments.  
'I was told you are assessed as a married couple.'

### 2. Accessing information, advice and guidance

While many sought guidance from a variety of sources, national charities were consistently seen as the most helpful (e.g. Age UK, Alzheimer's Society, Carers UK etc). In contrast, local resources like the Rutland Information System were underutilised and rated poorly. The RCC website was described as hard to navigate.

## Which of the sources of information was the most useful?

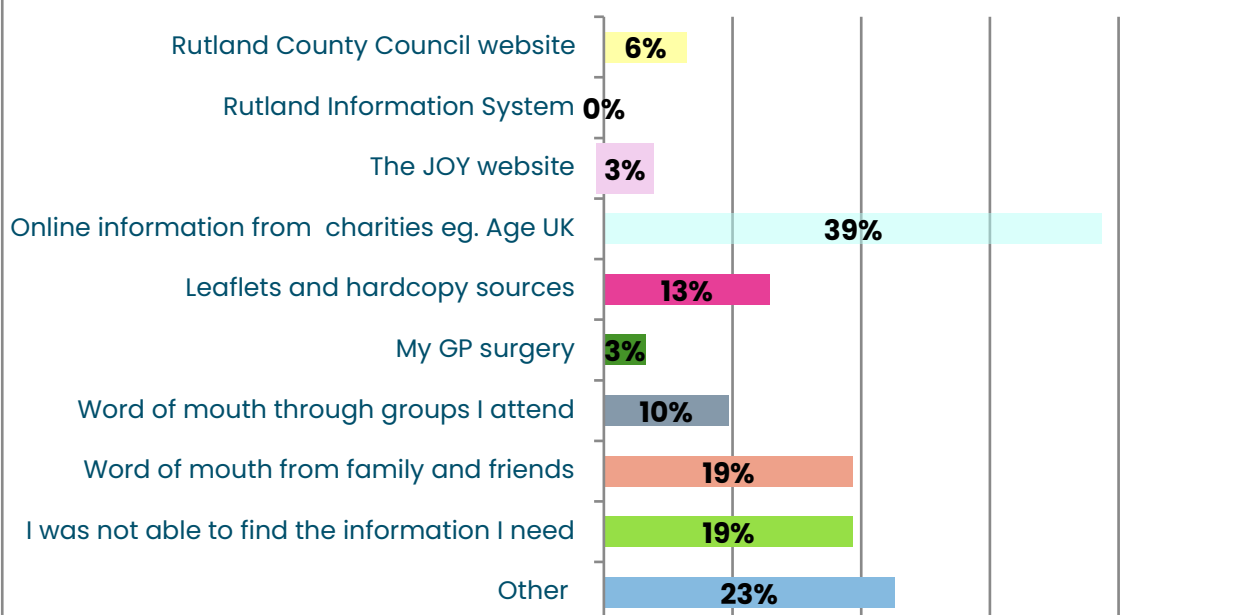


Fig. 1 Which sources of information from a previously selected list were the most useful? 'Other' included Google searches, email/hardcopy guide

### Qualitative insights:

- Information was often difficult to find, understand, or apply:  
 'The whole process of finding information and working out what to do was bewildering...'
- Online resources were helpful for some, while others preferred face-to-face or printed formats.
- Friends, community groups, and health professionals were key sources of help:  
 'I got help about caring and social care from Age UK and from talking to people at Voluntary Action Rutland.'

### Key challenges:

- Digital exclusion and distrust of online information.
- Lack of a single, reliable, comprehensive source.
- Inconsistent, confusing, or outdated guidance from online sources.

### 3. Financial Information and Support

There is widespread confusion and concern around paying for care among self-funders. Some expressed feelings of inequality in support compared to those who qualify for state-funded care. Participants noted the financial threshold had not kept pace with inflation.

#### Core issues:

- Complex financial considerations that people find 'difficult to get to grips with':  
*'Very complex, eg top-ups, third party payments and deferred payments plus continuing healthcare, short term reablement, using home to pay care fees.'*
- Misinformation or conflicting advice, particularly around what services are chargeable:  
*'I was told different things by different people about the payments. Direct payments can be complicated as well – a nightmare.'*
- Affordability barriers led some to reduce or delay care:  
*'They put up their costs for nursing care and it was too expensive for us...'*

#### Key challenges:

- Lack of clear financial planning tools and upfront cost transparency.
- Emotional and practical strain around affordability.
- Carers uncertain about their financial responsibilities.

### 4. Preferences and accessibility of information

Respondents had diverse preferences in how they wanted to access information, advice and guidance – face-to-face, hardcopy brochures, or online. Whilst digital sources are good for some, many felt frustrated with the technology and lack of empathetic, human interaction.

#### Summary of preferences:

- Some preferred printed materials and clear written guides:  
*'I'm much happier reading information – you have something you can refer back to.'*
- Others were comfortable online but needed more intuitive, filterable formats.  
*'The booklet is online, which is what I used, but it's a document not like a searchable website that you can look for specific things. If you were on a mobile it would be impossible.'*
- A desire for trusted, human guidance (like a "navigator" or "social care doula") was clear:

'It depends on the problem or issue – sometimes you want to get some guidance face-to-face from someone who gives empathy'

### Key challenges:

- Online only formats exclude people with low digital literacy or poor access.
- Improvements to online content are needed; online brochures were difficult to search and not user-friendly.
- Trust issues with unverified online content – how to interpret trustworthy guidance versus advertising.

## 5. Choices and decision-making

Some people felt confident in making decisions based on advice and support from the local authority:

'[the lady] at the Council advised me that with Power of Attorney, I could choose sheltered living or I wouldn't have known that.'

Others' ability to make informed choices was hindered by slow local authority assessments, lack of available options (e.g. nursing beds in the county), and urgency caused by deteriorating health or sudden transitions.

Less than a third of survey respondents approached RCC for information or support, and less than a quarter had approached RCC for a care and support assessment. When asked the reason for this, the most common response was 'I did not know that the council could help':

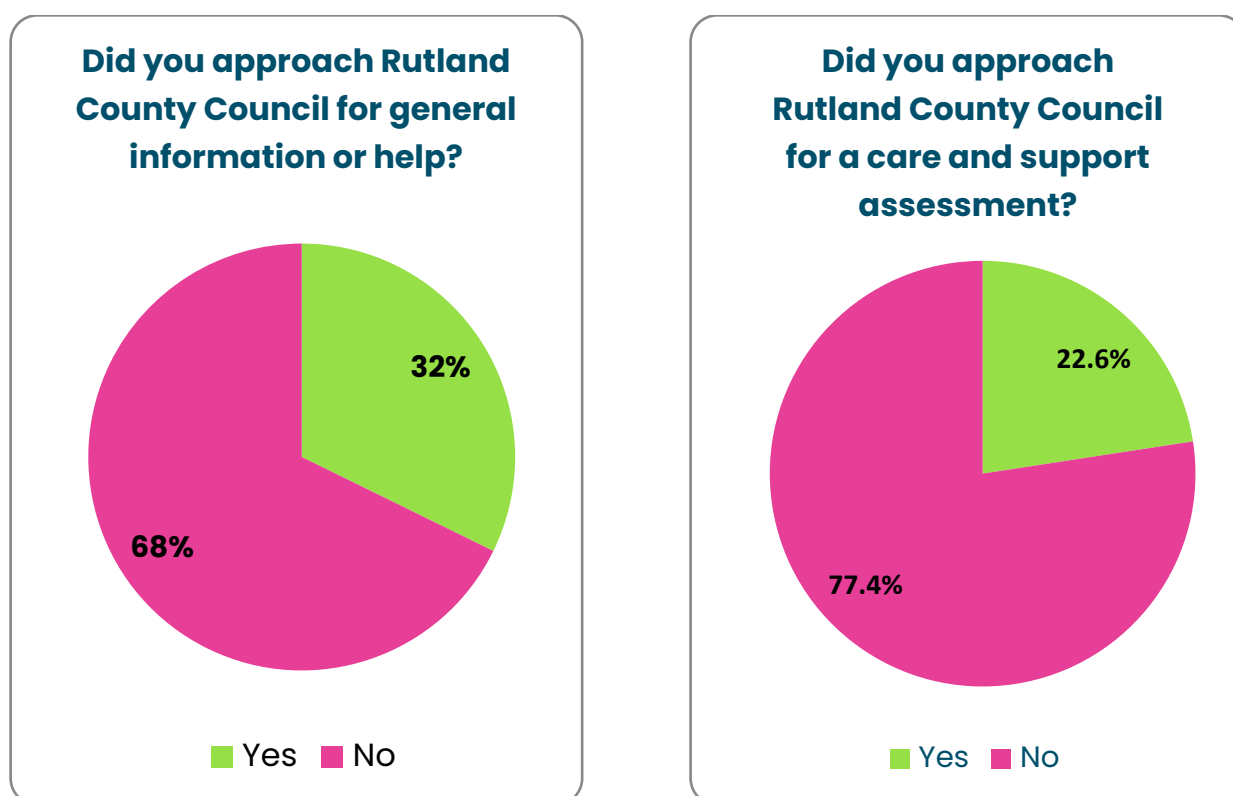


Fig 2 The extent to which survey respondents approached RCC for information and assessment.



### **Influences on decisions:**

- Family proximity, cost, and quality were major factors.
- CQC ratings were widely used.
- Some relied on previous experience or internet reviews.
- Others struggled without help.

### **Key challenges:**

- Wait times for RCC assessments:  
*'I needed an assessment from the Council but they had too much of a waiting list. I couldn't get it in time.'*
- Gaps in support during transitional periods (moving between care homes, end of life).
- Limited availability of suitable nursing care options in Rutland:  
*'I didn't have any choice but to move here... We needed a nursing home, not a care home. We chose this [home] due to locality. My son thought there was no other nursing homes in Oakham. The next closest one would be near Stamford and I wanted to be where I know. It all happened very quickly. I would have liked to have more choice.'*

## **6. Organizing and managing care**

After decisions were made, organising care presented new challenges. Participants described the difficulties of coordinating care to fit specific personal needs (such as time preferences) or finding replacement carers.

### **Key challenges:**

- Difficulty sourcing tailored or flexible care arrangements:  
*'It's really difficult to organise things as you need them based on the person. Some people don't want to get up at 7am and go to bed at 7pm...'*
- Heavy reliance on unpaid carers, leading to burnout and need for respite:  
*'He can't be left alone. It's very tough, I don't get time for myself so it's been difficult.'*

## **7. Geography and cross-boundary care**

Residents involved in arranging care for relatives outside Rutland or vice versa talked about complications navigating different councils' policies and accessing services at a distance.

**Key Challenge:** No local resources for those arranging care outside the county:

‘Less than 12 months ago I suddenly had to find care for a great aunt in Hampshire which was a complete nightmare. It was really difficult because of course I live miles away.’

## 8. Transitions and bureaucracy

Participants found it challenging to navigate the system during times of transition – such as moving into care homes, managing options as funds deplete, or deterioration in health.

### Barriers:

- Lack of understanding of options as funds deplete:

‘Transition is going to be a worry, when the money runs out – I’m not sure what will happen then?’

- Complexities of Continuing Health Care funding and limited availability of information:

‘[He is] in a Rutland care home, self-funded, paying £1600 per week and very poorly, getting towards the end of his life, but we can’t find out anything about Continuing Health Care without being referred. There is just no information out there about it and we can’t get the care home to do anything about it.’

## 9. Emotional impact

For some, the emotional burden of self-funding care was huge, especially for family carers. Many described feelings of guilt, confusion, and emotional exhaustion. In contrast, some care recipients reported improved wellbeing and a sense of safety in being well looked after (a feeling shared by family members).

### Key Insight:

- Carers often felt unsupported and emotionally overwhelmed:

‘It’s really confusing all the different information from different people, no-one says the same thing. I don’t have the energy for it all, it tires me out thinking about it.’

- The system’s complexity exacerbated emotional strain:

‘It was a terrible time emotionally and such big decisions to take I felt very ... unsupported and ill-informed generally. I didn’t even know who could help or how.’

- Obtaining the right care at the right time improves wellbeing:

‘Coming here helped me grieve, there’s lots of people to talk to and they are nice and like me and, if I’d been at home, I would have been a worry.’

## 10. Feedback from professionals

Care providers and support professionals shared the views of Rutland residents feeling that the most useful sources of information and guidance for the public

include word of mouth, care-specific websites and online search engines. Several professionals had not heard of the JOY platform.

**Key opportunity:** When asked for suggestions on improvements, professionals talked about a desire for better collaboration and communication between health, care, and voluntary sectors to improve public experience of making decisions and choosing social care.

## 11. Suggestions from participants

Participants made numerous practical suggestions, including:

- A step-by-step checklist or flowchart.
- Multi-format information (face-to-face, online, print).
- Online searchable directory of services.
- Readily available cost of care and service breakdowns.
- Improved practical guidance on platforms like JOY rather than just a list of services.
- Centralised “navigator” or “one-stop shop” for help.

## The journey of a self-funder: Jane’s Story

Jane’s Story offers a deeply personal narrative of her self-funding journey, highlighting times of excellent support while also identifying areas where improvements are needed. It underscores the value of good support at the right time and the importance of consistent, personalised support which recognises the emotional impact on carers.

### Jane’s Story (2020–2024)

**So far so good...** The Council system was brilliant when we first needed to find care. The Admiral nurse unlocked everything. She put me in touch with Council social care who sent me a list of Personal Assistants (PAs). I was amazed by the work that had gone in around that list – there were about 50 people on it. But there was no other information about the PAs – how was I meant to choose?

One of the Admiral Nurses put me in touch with a PA who gave us a good 12 month’s support, working 7am to 6pm, Monday to Friday. We agreed our own price. It wasn’t cheap but it was reliable and consistent. Unfortunately, as my husband became worse, the relationship got worse. More care was needed so the PA got a couple of other people involved to help out.

Via the Admiral Nurse, it was Age UK that prompted me to get Attendance Allowance. They filled in the form – it’s very long and difficult – so that was really useful and I got the allowance within a couple of weeks and it was backdated.

The Admiral Nurse also prompted Longhurst to come out to us. [They] provided banister rails, key safe and assistive technology like a light to show when he got out of bed at night. We also got a fire check.

The support and information up to this had been great and the signposting from the Admiral Nurse for us as self-funders was so good.

**Struggles with bureaucracy...** We got to a point where I was not able to sleep and needed help. The Admiral Nurse suggested I get some respite care. At this point the information and support from the Council was useless. He ended up going to [a Rutland care home] for respite and it was horrible. After that I asked for a carer's assessment which was carried out, but I never saw a copy and no agreed actions were taken. I asked for a care needs assessment, which I got.

I had set up a separate bank account for my salary as I was still working. I knew that my income was treated as separate from his assets but not if it went into a joint account. No-one advised me of this – I knew it already and I wonder if other people understand this. Does anyone tell married self-funders this? How do they find out?

I started to think about live-in care. I knew about it because I'd had previous experience with a parent and I knew about ELDER. We ended up with a couple of live-in carers. As [my husband] was getting more behaviourally difficult, I started to worry about the carers themselves. By now we were moving towards [my husband] being a partial self-funder and I started to look at direct payments.

**Continuing Health Care...** I then had to access out-of-hours healthcare through NHS 111. My husband attacked me while I was on the phone to them and they sent the police. The upshot was that he was referred into the Mental Health services. This led directly to the Continuing Health Care route. I received [only] the national guidance from the CHC team about the process before the referral to the assessors, but I was lucky, I have expert friends who helped. They advised me to keep a diary and photos as evidence, so that I could demonstrate the behaviour. When I had the assessment, there was an Admiral Nurse present and a social worker that had done the care needs assessment, no GP.

The social worker challenged whether he needed CHC on one of the domains which was very odd as she had no recent knowledge of him

He received the Continuing Health Care funding and so was no longer a self or partial funder. The personal health budget would have provided £3500 per week for care at home. I decided a large care package would be very difficult to commission and decided to look at care homes which in the event cost much less than managing him at home.

**Looking for a care home...** At this point there was no help finding a good home. He needed nursing care and of course there aren't many of those in Rutland – only 3 I think, and we knew one of them was no good from [our experiences of] the respite

stay. Nowhere else in Rutland would take him because of the behaviour. He went out-of-county to Lincolnshire.

**It feels like a divorce...** It's very different for a spouse than for children when [the parent] goes into a care home. It feels like divorce. Where a child might feel relieved that a parent is being looked after, I felt like I had got rid of him. The guilt was massive and I was lucky to have great support from his son, my stepson, and other people at this time

**Quality of care...** One day, when I went in, he was not hydrated and there were not enough staff, but no-one would listen. The Admiral Nurses said they could not support any more – we had been discharged when he went into the care home. I felt abandoned and very angry. Nobody would listen to the issues which had developed at the home when the initial manager had left. I ended up putting in a Safeguarding Concern as the care at the home was deteriorating and was affecting my husband and many of the other residents. The home pushed back once I did this and gave me notice, saying he had to leave.

**Totally alone...** I was alone with no-one to talk to and no support from anyone at all. The person who helped me through these decisions was a private therapist but of course most people don't have that. I think creating some kind of Doula-type model would be a huge help for people making decisions about care. We have to look to the voluntary sector because there is no money, so perhaps volunteer support workers trained by people like the Admiral Nurses. You are on your own. So, you need someone you can build trust in. You need a single trusted person – otherwise you talk to different people all the time & have to repeat over and over. It's exhausting and very emotional as you are right in the middle of it...

(Jane is a pseudonym to preserve anonymity)

## Conclusion

While some self-funders reported their journey as easy and are happy with the outcomes, the majority face significant challenges. Many have struggled to navigate the system, leading to frustration, anxiety, and feeling under confident in their decision-making. Addressing these concerns requires proactive measures from RCC, care providers and the voluntary sector, to ensure self-funders receive the guidance and support needed for informed, confident care choices.

Finally, Healthwatch Rutland is extremely grateful to everyone who participated in the project for giving their time to talk to us about some deeply personal experiences or to fill in a survey. We will use this evidence to inform service improvement plans and advocate for clear guidance and support that reflects the needs of people who pay for their own social care and the needs of their carers and families.

## Response from Rutland County Council

We would like to thank Healthwatch for their work on this project, to provide an independent view of the experience of adults who self-fund their care and support. Rutland Adult Social Care are committed to listening to the views of people within our community and recognise feedback as an opportunity to continue to learn and develop our services.

We acknowledge the recommendations outlined in this report and Jane's personal reflections of the journey of a self-funder. We will be taking the necessary actions to address them and several of the recommendations, including the development of our information, advice and guidance offer and overall accessibility of information, are already being addressed through our quality assurance activity. The learning from this report will help us to tailor the work further and provides us with valuable insights into different people's lived experience when making decisions about care and support.

We will create an action plan following this report which will hold us accountable and track our progression against the recommendations made.

Adult Social Care is focused on delivering high-quality care and support to all people in Rutland. We are committed to transparency, accountability, and continuous improvement. By following up on the actions specified in the report, we aim to further enhance our services and ensure the best possible outcomes for our community.

Finally, we would like to thank all of the people who gave their time to engage with the surveys, focus groups and interviews, as part of this project.

**Kim Sorsky**

**Director of Adults and Health  
Rutland County Council**

## About Healthwatch Rutland

Healthwatch Rutland is your health and social care champions. We make sure NHS leaders and Local Authority decision-makers hear your voice and use your feedback to improve care. We are part of a national network of 152 local Healthwatch in England. We have three main areas of work:

- Listening to people's experiences and seeking out feedback on health and social care services. We also spend time building relationships and attending meetings within the local health and care system so that the patient's voice can be heard in the right places, at the right time.
- We provide information, advice and guidance to help people to navigate health and care services.

Your experiences matter, we strive to be a strong voice for local people to help shape how services are planned, organised and delivered.

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