



# Taking a break

Hearing from unpaid carers in Northumberland:  
the challenges of taking breaks

## Summary

We asked carers about their experiences of taking breaks from their caring role and what had worked well and not so well. We also wanted to find out what would help them take more breaks and what the impact would be if they were able to take more breaks.

We heard that many carers had not taken breaks, particularly longer ones, in the past 12 months. Those who had taken breaks largely relied on family or friends to provide alternative care for their loved ones. Most who did not take breaks had either not tried to access a break or said their loved one did not like others caring for them. However, many carers also said they were unaware of the options available to them in getting help to take breaks from their caring role.

Some carers had no options to take breaks if they had no family support or alternative options for their loved ones being cared for by someone else and many felt guilt, stress or worry in taking breaks and leaving their loved ones. However, carers told us that taking more breaks would positively impact their mental health and wellbeing and we heard a strong message around the impact of caring on mental health.

Fewer numbers of carers had used formal respite services but those that had told us of difficulties in accessing suitable care due to costs, inability to pre-book or services being unable to meet their loved ones needs.

## Key findings

- A third of carers were unable to regularly enjoy activities for themselves such as socialising or hobbies
- 45% of carers responding had not taken a short break from caring in the past 12 months
- 76% of carers responding had not taken a longer break from caring in the past 12 months
- 70% of carers relied on family or friends to enable them to take longer breaks and 53% for shorter breaks
- Of those who had not taken breaks in the past 12 months 33% stated they were unaware of the options available to them to take a break from their caring role
- 64% of carers responding would like more opportunities to take a break from their caring role
- Those struggling the most to take longer breaks were arguably those in the greatest need; carers who provide care for over 81 hours each week

## Recommendations

- Work with the local carers forum and Carers Partnership Board to identify the wide range of respite options available to carers
- Ensure information about respite and how carers can access breaks from caring is readily available on Northumberland County Council website and as hard copies. This should be available to both people who fund their own care and those in receipt of care via Northumberland County Council Adult Social Care.
- Ensure transparency on costs of 'respite' services and promote, where possible, low cost and free services
- Carers assessments: Prioritise the importance of taking breaks during carers assessments and with those being cared for. Where possible, conduct carers assessments separately for those that they are providing care for to allow more open and honest discussion
- Use existing good practice resources to help support carers to take breaks: [Carers Trust Time Away From Caring: Good Practice in Carer Breaks](#)

## Background

Each year we run an Annual Survey to find out people's experiences of health and social care and ask what the public think we should focus on as work priorities in the following year. Respondents to our Annual Survey 2025 asked us to focus on adult social care as one of our work priorities. In our care home forums, we heard concerns raised from carers and those who supported them around 'respite care', particularly an inability to book advance respite care. These concerns were amplified by a Carers Northumberland report which resulted from a survey of carers showing barriers in the process.

The term 'respite care' refers to services that carers may use to enable them to take a break from caring whilst those they care for are looked after by other people. This could be for a short period like a few hours or a longer period, for example, to allow the carer to take a planned holiday. Respite care could take place in the person's home, in a day care facility, or in a residential care home. Many carers may think of more formal care services when using the term 'respite'.

As many carers may not have experience of this type of respite care, we wanted more generally to ask carers about experiences of 'taking a break' from their caring role. We wanted to understand what was working well and not so well in taking both shorter and longer breaks and the impact on carers.

Thank you to everyone who shared views and experiences with us and helped to promote our request for feedback. Thank you to Carers Northumberland for helping us to engage with carers and co-produce the survey.

This report is an overview of the findings and draws out key themes based on the issues raised by carers.

## Who we heard from

167 people responded to our taking a break survey. Whilst not all survey respondents gave demographic information of those that did the following can be highlighted.

Most carers responding were between 65–79 years of age (39%) or 50–64 years of age (35%).

72% of carers responding were female.

60% of carers responding had their own health conditions or disabilities, most notably high blood pressure, physical/mobility impairment and mental health.

Responses were received from across the county with most being from North Northumberland (29%).

Whilst we heard largely from carers of adults, we also heard from a small number of parent carers (of children with additional needs). We understand that routes to seeking formal respite may be different for each, however, the general themes that we heard around experiences of taking breaks were universal.

## Caring responsibilities

**Further graphs and charts can be found at Appendix A**

- Most carers responding (58%) were providing unpaid care for over 81 hours each week
- 83% live with those that they provide care to
- 57% of carers responding had been providing care for more than five years with over a third of those providing care for more than 10 years
- Most carers responding were caring for someone with multiple health conditions, most notably physical disabilities, long-term physical health conditions, dementia and mental health.
- Most carers responding were providing multiple care tasks, most notably household help, medical support and emotional support

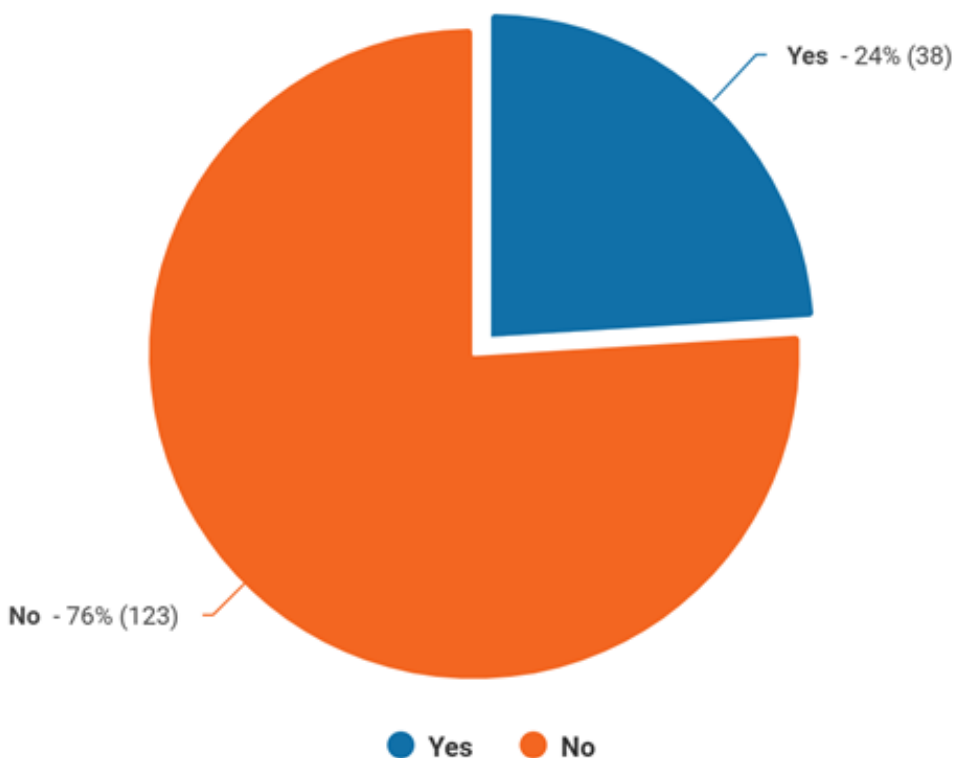
## Taking a break from caring

Whilst half of carers responding were able to go out at least once a week to enjoy activities for themselves such as sports, leisure, socialising or hobbies, 33% stated that they were unable to do so.

Most carers responding had taken a short break in the past 12 months (a few hours to a day), however, this was not a significant majority with 45% of carers (74 respondents) stating they had not taken any short breaks.

Taking longer breaks presented more of a challenge for carers responding with 76% of carers stating they had not taken a longer break (over two consecutive days or more) in the last 12 months. Those with the greatest caring responsibilities i.e. caring for more than 81 hours each week were least likely to have taken a longer break proportionately (85%).

**In the past 12 months have you taken any longer breaks from your caring role?  
For example, over two consecutive days plus, for example, to book a planned holiday.**



Some key themes arose throughout the feedback we received from carers, as detailed below.

## Carers mental health and wellbeing

The responsibility of caring for someone and associated impacts on a carers mental health and wellbeing presented the largest overriding theme.

For many carers the worry or guilt experienced when they did take a break meant that they were less likely to take breaks.

*"Taking a break just means having to push the responsibility on another member of the family and that makes me feel guilty. The person I care for also make me feel guilty for taking breaks."*

The guilt centred around either leaving their loved one, particularly if those they cared for did not like others caring for them, or 'putting responsibility on other people' to provide care.

Carers also expressed worry around the risk of leaving those they cared for unattended (for short breaks), worrying about how the person would cope without them being there or with others who might not be capable of meeting their needs.

*"I still worry as he doesn't eat or drink much when I'm not there as he says he's not hungry, though he eats a lot when encouraged to do so. When I know he's home alone, I always worry!"*

Many carers found the process of taking breaks 'stressful' either in trying to organise someone else to care for them -

*"When I have took a break in the past, the amount of pre-preparation that's involved has nearly put me off going"*

- or because it was not really a 'break' as they were worrying or 'on call' on the phone whilst being away

*"My loved one when needing help will ring me first so I have my phone with me 24/7 even if I'm taking time away. Additionally, I am the nominated contact for their caring, medical, financial needs so all calls come through to me."*

Others mentioned that the person they care for resents them taking time away or there is more work to do on return from a break making the process more stressful.

Many carers mentioned that knowing their loved one was receptive to alternative care or getting suitable care with trusted and reliable carers would help them take more breaks as it would ease their worry and guilt.

*"If my wife was completely safe, happy and well-cared for in my absence then I would perhaps consider a short break."*

For several carers who did manage to take short breaks these did not necessarily allow significant time to relax and recharge.

Some mentioned that they are only able to get very limited short breaks from caring –

*“The only breaks I have are short walks with a friend – up to an hour. They come to see me once a fortnight then sometimes we have a chat and cup of tea, if there is time.”*

– whilst others used the time to do essential household tasks like shopping or cleaning and in one case to access mental health support –

*“Get two hours every Tuesday and Friday morning. Usually spend this time doing household shopping.”*

64% of carers said they would like the opportunity to take more breaks. Many carers mentioned that taking more breaks would have a positive impact on them and several carers said having regular breaks would also make them a better carer –

*“I think I would be a better carer as I’d have time to rest and recover.”*

Having better physical and mental health featured in many comments with carers saying that taking more breaks would improve their health, particularly mental health. Carers used words like stressed, depressed, anxious, tired, overwhelmed, exhausted, irritable, robotic and burnt-out and that taking more breaks could provide some relief from these negative emotions.

*“It would give me a chance to rest and recuperate and recharge my batteries after more than three years continuous care. It would boost my wellbeing and mental health.”*

*“I’d be a lot more patient. I find I’m very nattery as I’m not getting the rest I need, especially as I have health issues myself, and then I feel like I’m not providing adequate care, and then I beat myself up for being selfish, and end up feeling bad.”*

*“I might not have a breakdown, my relationship might survive, my other child might have a break too.” (parent carer)*

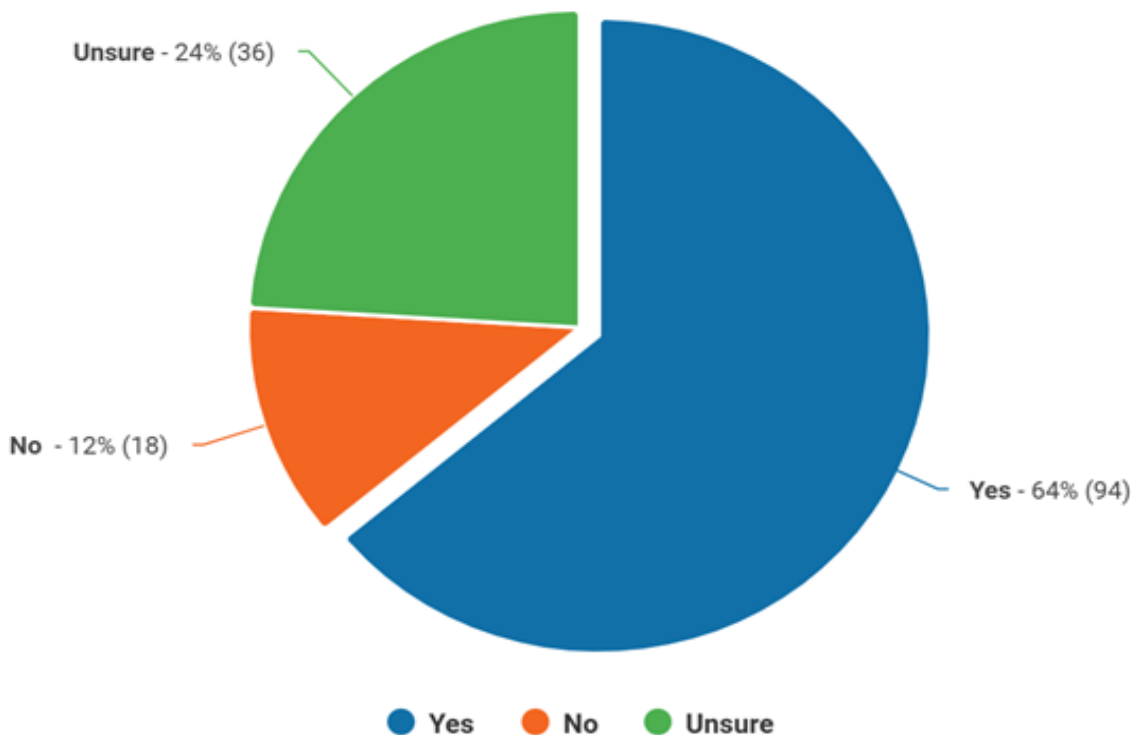
Others mentioned that taking a break would allow them to do more activities that interested them such as hobbies or socialising, leading to increased wellbeing -

*"Would be easier to arrange appointments and not have to cancel them. I could see family and friends. Could attend support groups and resume hobbies".*

Or more generally that it would give them a positive sense of independence and identity not just as a carer -

*"It would give me the chance to feel I still have a life of my own and give me things to look forward to".*

### Would you like more opportunities to take a break from your caring role?



## Reliance on family and friends

Most carers relied on family and friends to enable them to take both shorter and longer breaks rather than seeking formal respite care. The reasons for this were not explored during the survey. Reliance on family or friends was particularly evident in those who had taken breaks with 70% of carers choosing this as an option for longer breaks and 53% for shorter breaks.

Some mentioned reliance on family or friends as something that had helped, however, this usually came with caveats that it was 'putting responsibility' onto someone else, led to feelings of guilt and worry or that they would still need to be 'on call' by telephone if they did take a break.

*"The best thing is if one of my siblings rents a holiday let nearby for the time when we are away, but that is a lot to ask."*

Some carers mentioned that there were no options available to take breaks as they had no family support. Others said that family or friends were unable or unwilling to care for their loved one's complex needs.

*"Family can no longer cope with looking after my husband overnight so short breaks at no longer an option."*

For parent carers often any breaks were when their partner would provide care, however, this did not allow them important time as a couple or allow other children in their household a break.

## Access to suitable respite services and support

Most of what we heard were experiences, more generally, about being a carer, whether carers responding had taken breaks from their caring role and any barriers in doing so.

When asked the reasons they had not taken breaks in the last 12 months most carers responding said that they had not tried to access breaks and that the person cared for would not want others caring for them. This was particularly pronounced with longer breaks where 59 respondents had not tried to access longer breaks and 48 respondents said the person they cared for would not want others caring for them.

However, a third of carers who had not taken breaks said they were unaware of the options available to them to take breaks indicating that clear information about how to enable breaks and/or access formal respite services would be useful to carers. Over a third of carers who had not taken short breaks also worried about costs of accessing respite services.

Much fewer numbers of carers responding stated they had accessed, or tried to access, formal respite services in the past 12 months. Again, the reasons for this were not explored during the survey.

25 respondents said they had used formal respite services, either self-funded (10), through children's social care (1) or through Adult Social Care (14) for short breaks. Only seven respondents had used formal respite services for longer breaks, two of these accessing help through Adult Social Care. Eight respondents said they had tried, and been unable, to access formal respite for short breaks (five through Adult Social Care). Ten respondents said they had tried, and been unable, to access formal respite for longer breaks (seven through Adult Social Care).

For those that had used formal respite several people mentioned that self-funding short or longer periods of respite had been successful, however, for most of these the expense of doing so was prohibitive -

*"I pay for a lovely day service for him to attend three times per week but at £100 a day it's hard to maintain."*

One person had a positive experience of self-funding longer respite care to enable pre-planned holidays -

*"We have worked with a care home locally who will reserve accommodation places several months in advance. The arrangement is not cast in iron - but so far both parties have been able to honour the planned for arrangements".*

However, another carer who had previous positive experiences of getting self-funded pre-planned respite in a care home had subsequent difficulties after offers of care were rescinded due to a lack of space.

*"Trying to get planned respite care is hard work and I am finding it increasingly impossible. In truth it does not exist for carers like me... I feel I have hit a brick wall. The care homes do not seem capable of planning ahead and appear to work on a day-to-day basis which is useless for people like me and my needs."*

Some carers mentioned a lack of options for suitable formal respite care or the inability to access it. Reasons given were varied and included the expense of respite, an inability for respite to be booked in advance or not being eligible as self-funders -

*"Adult Social Care just asked me how much we had in the bank - was told I was over the threshold and given a list of care homes. Do not know how to start. No help to do this".*

Some said their needs were not thought to be high enough or more usually that needs were too complex and could not be adequately met -

*"I don't have any family support or disposable income so tried asking social worker to try and get help they said they don't think our needs as a family are high enough for respite, I personally feel it's more to do with a lack of funding". (parent carer)*

*"Several homes that have been suggested by adult social services have not been able to meet my husband's complex needs."*

A few carers mentioned that previous negative experiences of accessing unsuitable respite services or support through Adult Social Care had resulted in barriers to, or concerns around, accessing it in future.

*"Experience of previous care homes for respite care has not been a happy experience - most are suitable for dementia patients but not others. Facilities and services here been disappointing and not tolerable. In-house funded respite care is not available."*

*"I go away for two weeks each summer. I contact Onecall and arrange extra carer visits for the time I'm away. This never works smoothly..... Now I worry whilst I'm away and can't relax, not knowing whether they're being cared for in my absence."*

Carers mentioned that having more available support and/or respite and more appropriate or suitable respite services available would help them to take more breaks -

*"Dad having activities to go to like a day centre with transport supplied".*

*"There being more home care services that will help care for young disabled adults rather than older people. Or more young adult respite care homes that you don't have to jump through hoops to access via social services."*

Some mentioned the barriers of cost in accessing formal respite services and that having more money available or having lower cost services would help them take breaks. Others mentioned being unaware of what services were available.

*"Knowing what is available would help in making a decision on taking a break from caring."*

Several people mentioned that being able to get help with befriending for their loved one would help. Similarly, others mentioned help with practical tasks for their loved one such as housework, cooking, cleaning, laundry, transport to appointments or school (for parent carers) and help arranging appointments would be useful to lighten their load as carers.

*"More domestic help. Cleaning, cooking etc. Also more help with financial admin. I just don't have the time to search for websites or continually ring places to try to find help. Admin to do with caring takes hours out of the day that I just don't have."*

## Conclusion

This report focuses on the experiences of carers in 'taking a break' from their caring role. The recommendations have resulted from what we heard, and we would again like to thank everyone who generously gave their time to feedback and promote the survey. We would also like to thank Adult Social Care Services for taking the time to listen and respond to what we heard.

There is a strong message from carers in the county responding that their needs are not being met in relation to taking breaks. Examples of the impacts of caring on mental health are a compelling concern, and feedback highlights the unrelenting nature of their caring responsibilities, often impacting those who are caring the most or caring for those with the most complex needs. Fragmented support or an inability to access appropriate respite services present barriers to taking breaks for some carers and many carers either do not ask for help or are unaware of what help is available.

## Response from Northumberland County Council Adult Social Care Services

Council officers have read the Healthwatch Northumberland report on taking a break and thank those people that have participated in the survey. The council has a responsibility to meet needs for eligible service users and their carers and typically has arranged for carers to take a break through traditional services including home care, day centres/activities, enabling, and home care services and overnight stays in accommodation such as care homes. The council also delivers a respite service for adults with a learning disability which provides a break for service users and their carers.

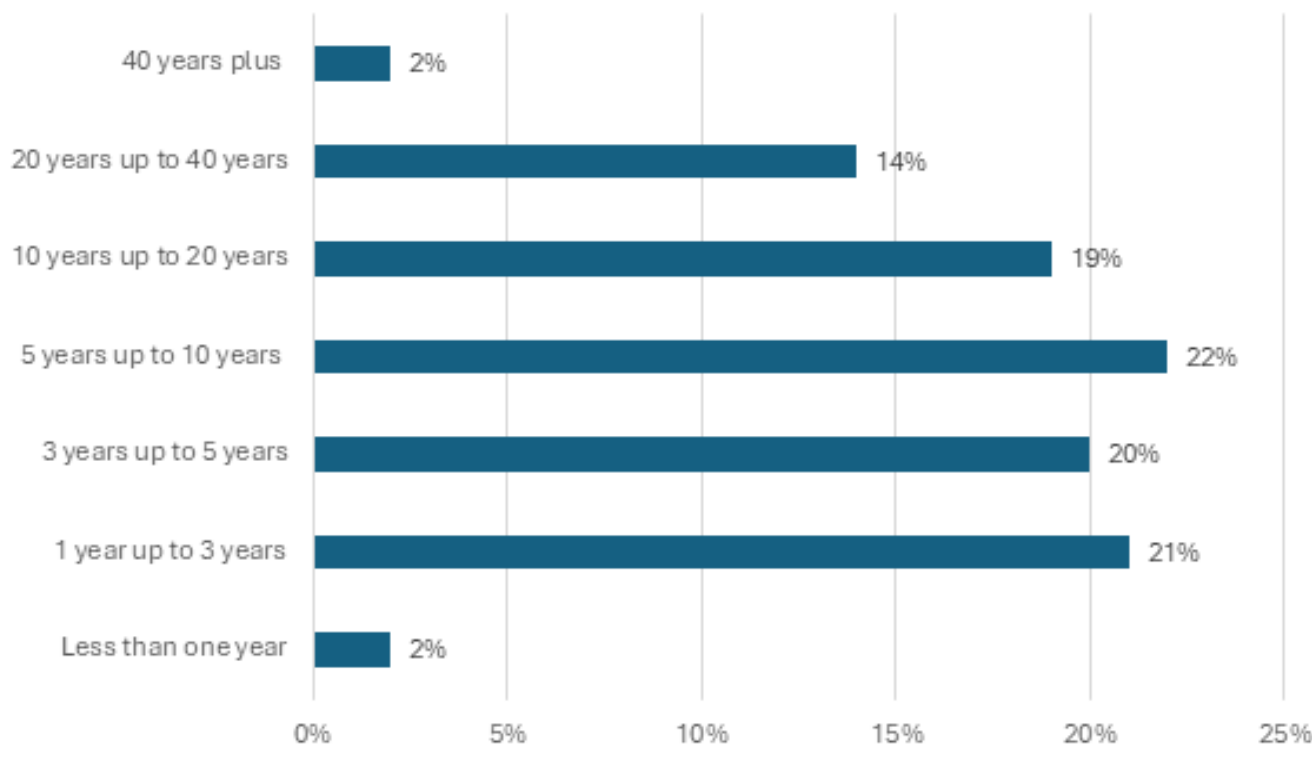
The council is keen to further explore the themes that the report identifies including the availability of services, information and promotion of these services, accessibility and the emotional impact of carers trusting services to replace their caring role when they take a break. In addition, there may be scope to increase the availability of services using a direct payment and this may be a route to overcoming some of the difficulties people describe in their questionnaire responses.

We look forward to working with Healthwatch Northumberland and other organisations in the future to improve our understanding of peoples' needs and aspirations and ensure carers have appropriate access to services to enable them to take a break from their caring role. Understanding the numbers of people who want to access services will be an important part of this work.

## Appendix A

Figures have been rounded up or down to nearest whole percentage.

### How long have you been an unpaid carer?



### What health conditions or disabilities does the person you care for have? Please tick all that apply

A physical disability	46%
A long-term physical health condition (e.g. diabetes, ME)	38%
Dementia	34%
Mental health condition	32%
Problems associated with ageing e.g. frailty	28%
Other (included range of conditions including but not limited to cancer, stroke, MS, autism spectrum disorders)	28%
A learning disability	18%
Sight, speech or hearing loss	18%

### What care or support do you provide to those you care for? Please tick all that apply

Household help e.g. shopping, cleaning, preparing food	93%
Medical support e.g. arranging medical appointments and transport to appointments, collecting prescriptions, giving or supervising medication	93%
Emotional support e.g. keeping them company, keeping in touch by phone or email	86%
Practical support e.g. help with paperwork, bills, finances, benefits	81%
Help with social and leisure activities e.g. arranging activities, socialising, transport to activities	77%
Personal care e.g. dressing, washing, continence care, help with eating and drinking	64%
Physical help e.g. with walking or moving around the home	46%
Other	14%

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