

# Improving carer breaks for unpaid carers in North Lanarkshire:

A report on findings from a consultation by North Lanarkshire Carers Together on behalf of Health and Social Care North Lanarkshire 2023



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# Introduction

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*It's really important for me as a carer to have access to time out for health and wellbeing. You need an outlet from having to navigate the systems...the present approach is completely random and completely uncertain... - unpaid carer.*

North Lanarkshire Carers Together (NLCT) was commissioned to carry out a consultation into carer breaks on behalf of Health and Social Care North Lanarkshire (H&SC NL). This topic was high on the agenda for H&SC NL, but a carer's story brought to the attention of the department proved a catalyst for progressing this work.

The carer's experience was of attempting to access respite care for her husband ahead of taking a holiday, a break from her caring role. However, the process became difficult and arduous with poor outcomes both for the carer and for the person being cared for. Being denied the ability to book respite more than two weeks in advance, the carer had to resort to calling around 12 care homes (with the help of a social worker) desperately trying to access a respite place in their own locality and then in wider North Lanarkshire to no avail.

The eventual outcome was that the person being cared for could only access a respite place in a care home outside of North Lanarkshire which was inadequate for their care needs. The stress involved in both arranging the respite and related to the lack of required standard of care, hugely impacted the point of taking a break in the first place as well negatively impacting on the person being cared for in the aftermath of respite.

This example led to H&SC NL commissioning a wide-ranging consultation to assess carers' experiences of accessing breaks in North Lanarkshire. This is with a view to making improvements in the overall carer breaks systems across our localities.

As part of this consultation, 59 carers responded to an online survey, 110 carers on average responded to 4 key questions posed on carer breaks at the NLCT Annual General Meeting on 5th June 2023 and 8 carers in total responded via our Carer Forum focus groups.

The findings of this consultation present a landscape in which carers are in great need of breaks, yet report too many barriers in the way of them being able to access them. These barriers span lack of knowledge and information to practical elements such as lack of replacement care and the work involved in taking a break in the first place.

NLCT has made recommendations and considerations that we hope will be taken into account on behalf of the carers we consulted with for this report. A key recommendation is that carers are involved in every future step of the work in North Lanarkshire to improve the carer breaks systems.

Thank you to every carer who took the time to respond to our survey, attend our AGM and take part in our focus groups. At NLCT we continue to fulfil our 'We asked, You said, We did' promise, and will report back to carers on the outcomes of this consultation report.

# Executive Summary

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## Findings show the need for breaks across North Lanarkshire's unpaid carer community:

- 70% of respondents care for 55+ hours per week
- 44% of respondents are working carers in paid employment alongside their caring role
- 54% of respondents have never had a break from their caring role

## Carers' responses showed key barriers to accessing breaks including:

- Work, admin and planning were shown to be off-putting
- Carers did not know where to go to find information on taking a break
- Many found the idea of a break too overwhelming on top of existing caring responsibilities
- Over a quarter stated that there is no replacement care available and the same number reported that they wouldn't want to leave the person they care for behind to be able to take a break
- Some carers said they had looked into breaks but could not find anything to suit their needs

## Respite; an appetite for continuation of this service. Our survey return showed that:

- 23% of carers still want to be able to access traditional respite services
- Our AGM consultation returned a much higher number of 86% of people surveyed in favour of continuation of respite services in North Lanarkshire (demographics around the disparity in these findings are discussed below)

## Anticipatory care:

- 55% of carers reported via our survey that they do not have good anticipatory care/ emergency planning in place

## Recommendations and considerations:

- Our key recommendation is that this consultation and report marks the beginning of a process to improve the carer breaks systems across North Lanarkshire. We recommend that a working group comprising carers along with health and social care teams is set up to carry the work forward
- We have also outlined key considerations to be taken into account as improving carer breaks is progressed including improving flexibility around what constitutes a break from caring and allowing carers to set the agenda on what works best for them so that breaks are truly meaningful

# The importance of carer breaks

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The Social Care Institute for Excellence (SCIE) defines a carer breaks as:



*...something that carers want to use for themselves. It should be planned, meaningful and positive. The arrangements need to work for both the carer and the person they care for in order to be beneficial and improve carer wellbeing.*

At present carer breaks in North Lanarkshire, and indeed UK wide, may be understood quite narrowly as traditional respite, or taking a 'short break' or holiday. However, work by the SCIE and other organisations including Carers Trust in their recent report 'Time away from caring: good practice in carer breaks',<sup>1</sup> shows that carer breaks must be more wide ranging than 'traditional' offerings. Carers, as part of this consultation crucially told us that carer breaks need to offer a wider range of styles and opportunities for time out of caring roles.

A key element of carer breaks should be 'choice', whereby the carer themselves defines what kind of break will work for them and when that will work for them and the person or people they care for.

## Fundamental to wellbeing

Breaks for carers are fundamental to carer wellbeing and overall health. Most paid employees are protected by labour laws in the UK that ensure they are given adequate breaks from work. In 2023 unpaid carers still have no legal right to a break. That is despite in North Lanarkshire, as shown in our results below, most carers who responded to our survey are caring for 55+ hours per week.

The establishment of a National Care Service in Scotland aims to see a legal right to breaks for carers put in place. However, what will be defined as a break remains to be seen, and is a long way off being narrowed down and ratified in law.

In the meantime, too many carers across North Lanarkshire are shown in our research not to have been able to access breaks from their caring roles. We must view this with urgency.

Unpaid carers are the largest workforce in North Lanarkshire with an estimated 50-60,000 living across our localities. They are the backbone of our social care system. We must ensure their health and wellbeing is prioritised and maintained so that people who wish to continue with their caring roles can do so.

<sup>1</sup> <https://carers.org/downloads/carers-trust-carer-breaks-hwa-report2.pdf>

## Supporting carers, supporting our health and social care structures

By assessing the current landscape around carer breaks for carers in North Lanarkshire we can see there is much work to do to make breaks more accessible, meaningful, and positive for carers. Investing now in redesigning, with a co-design approach, how carers access breaks, and what they can access as a break, will ensure we put carers and the people they care for at the heart of services with wider positive outcomes for our health and social care systems and communities.

Colin Smith, Manager, NLCT states:



*Providing care to someone can feel overwhelming, yet it's important to remember that taking breaks is vital to physical and emotional wellbeing.*

*What that time out means to each of us is as individual as we are, and that has come across loud and clear in this consultation with carers in North Lanarkshire.*

*Carers are the foundation of the entire social care system, they are providers of services, and until we see a break from their service as a statutory right, we have a moral duty to ensure small, regular, and more substantial breaks are provided in a person-centred manner.*

*While there are good practice examples locally and nationally, we see from this research that much has still to be done; and we look forward to planning a refreshed carer break landscape alongside carers in the immediate future.*

## A note on anticipatory care and emergency planning

Anticipatory care and emergency planning for carers and the people they care for is high on the agenda for Health and Social Care North Lanarkshire. As such it was requested that we take the opportunity of this carer breaks consultation to ask about this topic in addition to its main focus.

It must be noted that neither H&SC NL nor North Lanarkshire Carers Together views emergency planning or anticipatory care as being part of a 'breaks from caring' agenda. These are distinct elements that will be treated as such when findings are considered by H&SC NL.

We at NLCT subscribe to the view reflected by the UK wide 'Carers' breaks reference group' in 2019 that:



*A break is not about carers having time off to manage essentials such as attending their own health care appointments. GP appointments are a fundamental right - not a break.<sup>2</sup>*

Anticipatory care, forward planning to allow carers to access healthcare, and any emergency-imposed time out of a caring role is not the same as a break from caring. This distinction will be reinforced at relevant points in this report.



<sup>2</sup> <https://www.scie.org.uk/carers/breaks/adults/introduction>

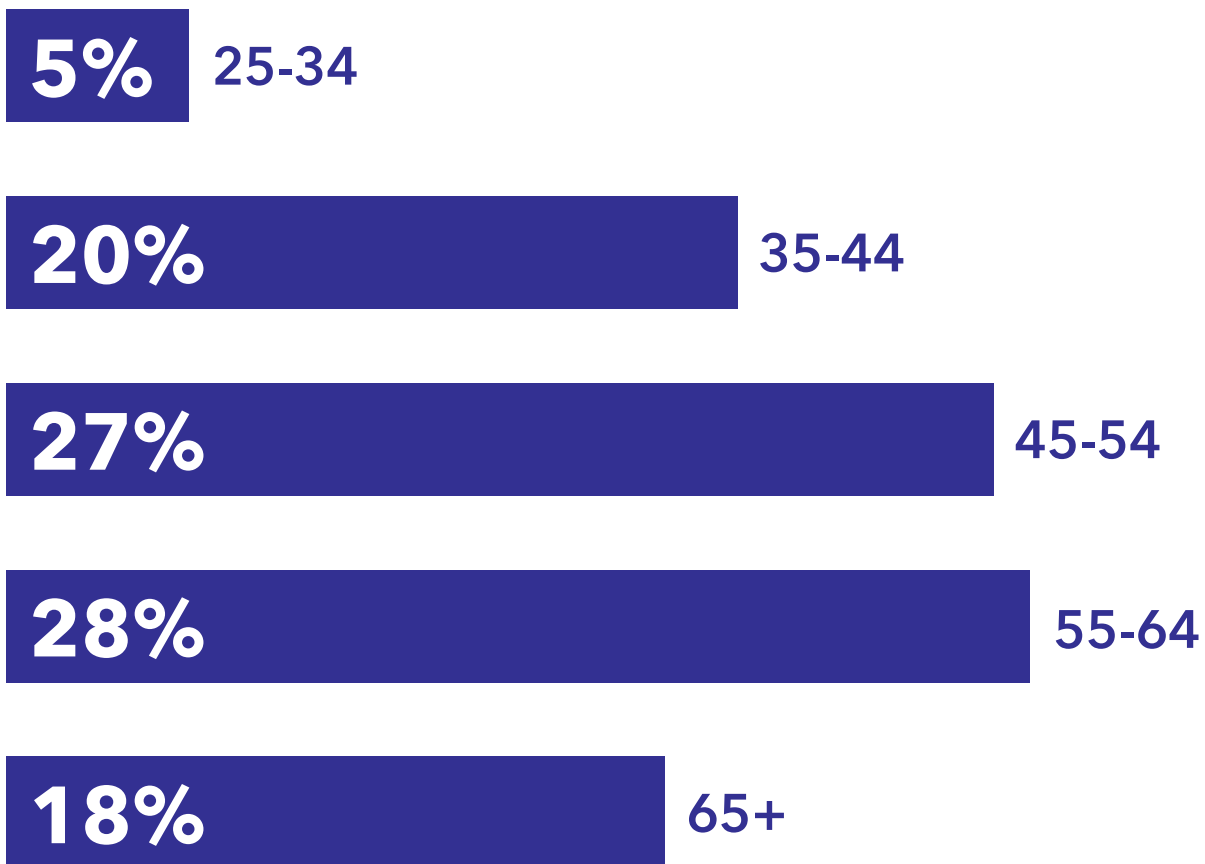
# Demographic findings – who we heard from

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It is important to understand who completed our survey. As well as providing essential information, we can better understand the scope of the caring roles the people carry out. Every single carer needs and deserves to access a break. However, understanding how acute this need may be allows us to assess carers' needs with more context.

59 carers from across North Lanarkshire filled out our online survey.

**Carers from ages 25 to 65 plus responded. The majority were over 35 years of age:**



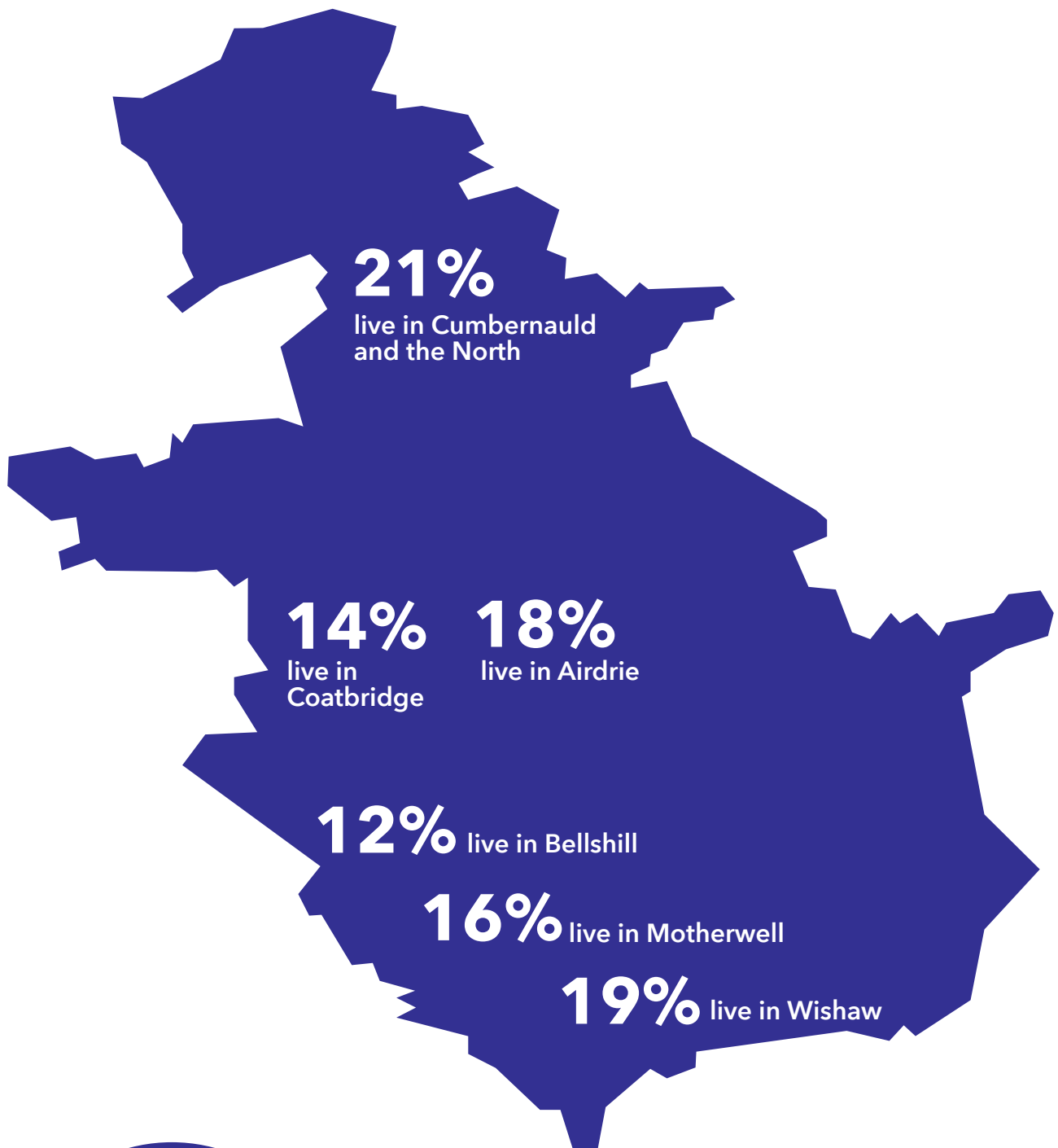
In terms of gender, 76% of respondents were female, 34% male which closely reflects the Scottish Government's census return from 2021-2022 that reported 73% of carers were female.<sup>3</sup>

97% of respondents reported their ethnic group as 'white Scottish' with the remainder being from mixed or multiple ethnic groups and white European.

<sup>3</sup> <https://www.gov.scot/publications/carers-census-scotland-2021-22/pages/information-on-carers/>



There was a relatively even spread of respondents across North Lanarkshire localities:



It is important to note that 44% of those who responded are working carers, holding down jobs as well as carrying out caring roles.

This becomes more important in the context of the number of caring hours people reported carrying out, with 70% across all respondents caring for 55+ hours per week.

**7%**

of carers cared for less than 20 hours per week

**7%**

cared for 20-34 hours per week

**8%**

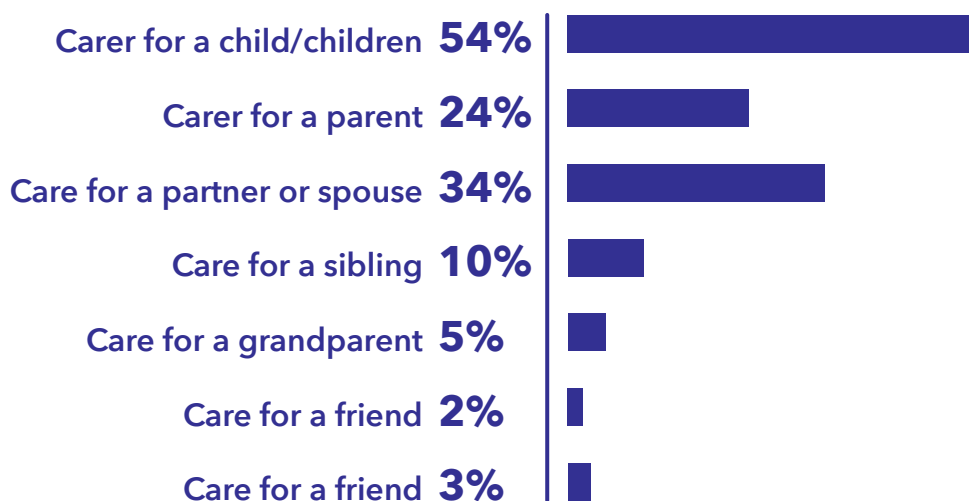
35-44 hours per week

**70%**

cared for 55+ hours per week

This is a significant finding. That most carers care for 55+ hours per week reflects the scale of caring roles being carried out across our North Lanarkshire localities. The majority of carers are therefore classed as caring 'full-time'.

In terms of whom unpaid carers are caring for, responses to our survey are as follows. Note that multiple answers can apply where a person has more than one caring role:



Note that caring for a child as reported here encompasses caring for an adult child as well as a young child across all long-term conditions, disabilities and additional support needs.

# Findings on accessing carer breaks, barriers and carers' preferences

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**54%**

**of carers have never accessed a break**

## Accessing breaks

The picture across quantitative findings on carer breaks is mixed, and often spread relatively evenly across positive experiences, and experiences that evidence barriers and lack of access to breaks.

Whilst the positive survey returns are encouraging, the focus of this consultation is on making improvements for carers and we must acknowledge that too many carers are not getting what they need from North Lanarkshire-wide existing systems.

Regarding accessing carer breaks, of any description, 46% of carers responding to the survey had accessed a break, with 54% never having accessed a break.

This is a significant finding. That over half of carers responding to the survey have never accessed a break, points to issues in our systems and wider elements that are preventing carers from taking time out of their caring role. To understand these issues, we asked specific questions to ascertain what barriers might be in place.

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## Knowledge barriers

To understand why carers may not be able to access breaks, we asked about the impact of the work, admin and effort around breaks. 49% said this had put them off even trying to access a break. This is an important finding as it identifies a particular barrier that is in the way of carers taking time out.

In addition to the barrier of work being involved in arranging breaks, 59% of carers responded that they do not even know how to access a break, likely a contributing factor to the previous statistic.

**49%**

**of carers said planning, admin and work put them off**

**59%**

**of carers said they do not know how to access a break**

In further findings, carers told us:

**“ I am too tired to begin the process [of arranging a short break]**

**“ I haven't applied for a break, but from conversations with carers it seems to be hard work to apply for and get a short break.**

**“ It would be nice if the breaks were made more open to people instead of carers asking for help. I feel like when your mental health isn't good, we seem to be forgotten about and while still trying to care for loved ones.**

If carers simply do not know where to begin, even searching for initial information creates a task. This is in the context of most carers already being fully occupied with their caring roles. We must recognise the significance of this barrier.

Even if carers are simply *perceiving* that short breaks are difficult to access via conversations with other carers, this perception matters and will inform carers' willingness to explore breaks for themselves.

Backing up these findings, 45% of carers also said that they don't know where to go, who to ask or how to start the process.

**45%**  
**of carers don't know where to go, who to ask or how to start the process of accessing a break**

It is clear from these findings that our wider systems in North Lanarkshire can be improved in terms of carers accessing basic information on breaks. Carers would benefit from an approach to breaks that prioritises providing essential material on breaks as standard at the earliest opportunity of carers engaging with any service across statutory, third sector and the independent sector. This includes NHS services as well as Health and Social Care services.

Where there are touch points with carers, even whereby a service is being provided to a person or people being cared for, conversations on carers' rights overall and carer breaks should be a standard practice for all professionals where a carer is present.

**“ Conversations on carers' rights overall and carer breaks should be a standard practice for all professionals where a carer is present.**

A simple piece of literature in the form of a flyer with essential contacts on carer breaks could be the difference between a carer accessing time out of their caring role or continuing without a break with potential negative health and wellbeing consequences.

Lack of knowledge on how to access breaks or where to even access initial information is not the only barrier. Carers also face practical barriers to taking breaks.

## Practical barriers to carers accessing breaks

Key to improving how carer breaks work for carers across North Lanarkshire is understanding the practical barriers that prevent carers from seeking out or taking breaks. Carers reported further reasons beyond lack of knowledge that are preventing them from accessing breaks.

Responses from our survey reflected that:

**30%**

found the idea of taking a break too overwhelming on top of caring responsibilities

**27%**

of carers do not want to leave the person cared for behind

**27%**

stated that there is no replacement care available

**14%**

looked into taking a break, but could not see anything to meet their needs

That 30% did not take a break because it is perceived as overwhelming is a valid concern for carers and should raise questions around what kind of breaks work for carers. An individual approach to breaks must be taken. A holiday is not necessarily the kind of break that works for all carers. One carer told us that a holiday does not help them take a 'break':



*Going away means a lot of organising and then sorting it all again when you come home. Coming home and sorting everything can take days and be so exhausting it defeats the point of the break.*

That 27% of carers do not want to leave the person they care for behind points to carers either being unaware that they may be able to access additional funded support to go on a family holiday with a support worker, or that they have perhaps tried to access this to no avail. One carer explained that they would like to access this kind of break:



*I enjoyed and benefited from the short break I had on my own, but we have a holiday home that we could use on a regular basis with no need for packing etc if we could access carer support and equipment while there.*

The lack of access to replacement care for the person or people being cared for is a significant barrier to carers taking breaks. Many people being cared for have high care needs and, equally, many may not wish to access respite accommodation while their carer takes a break. Many carers cited a preference for the person they care for to have replacement care provided in their own home so that they could take a break.



*If my mother could be cared for in her own home to allow me to get a break. Her wish was to never go into a home, which I want to uphold, but it is exhausting.*

Overall, the practical barriers to taking breaks should be addressed via creating a menu of options of the types of breaks available to carers. Carers told us some of what might work for them.

## **What kind of breaks carers said would work for them**

There were four leading findings on the kind of carer breaks carers were most interested in. These scored relatively evenly as first choices on a scale of options and include in order of preference:

- Mini breaks, like a night away now and again, or access to a spa day or activity for time out from the caring role
- The person being cared for receiving support in their own home while the carer can go away for a holiday or break
- A family/couples/joint holiday with the person/people being cared for, with financial support for an additional paid carer to support with the caring role so we can all have time out and relax
- The person I care for going to a 'respite' service in a care home to give me a break

It is clear that one size does not fit all and throughout the survey, as identified above, there is appetite for more flexibility around what is viewed as a break.

However, what these findings also show is that we must go above and beyond providing straight forward breaks where a carer leaves the person or people they care for in a respite service while they take a break. The appetite for more bespoke solutions is clear. That people wish for the person to be cared for in their own home, and also are showing appetite for family breaks with additional support provided shows there are solutions to breaks that we are not currently providing.

## More on breaks carers would like to access

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We asked carers to elaborate on what kind of breaks would work for them. This gave people an opportunity to share exactly what they would like to be able to access that would keep them well in their caring roles. The responses were vast in range and reflect that one size, or one type of break offering does not fit all and reiterates the idea of having a menu of options available.

Carers expressed appetite for the following types of breaks:

### Time to engage with hobbies and social life



*Having some time to myself, being able to take some time out to do things I like and improve my social life.*



*I am a photographer as a hobby. I love to get around Scotland taking photos of our scenery, and I find that is perfect for me...it is 'good for the soul'.*



*Gym, massage, spa facilities I can use in my own time to allow some downtime but not have to worry about care for my children.*



*Being able to get time on my own, maybe to be creative.*

Importantly, carers here have identified that they would like to use their own time for a break in a way that suits them and allows them to engage in hobbies or time out of their choice. This should be a key consideration in redesigning carer break services in North Lanarkshire in terms of offering flexibility around breaks, how these are funded and taking a willing and creative approach. In practice this means allowing the carer to set the agenda for their own break. We need to move beyond prescribed ideas of what carer breaks are and put carers in the driving seat in terms of choice and control to ensure meaningful time out of caring roles is achieved.

## Breaks from caring related tasks around the home

Some carers reported that the type of break that would work for them would be one that allowed them to take a break from the essential caring related tasks they routinely carry out.

Carers said:



Would be good if I can get someone to do the washing and ironing.



Some help in my own home.



...financial assistance with daily house work, washings etc.

This type of break may seem 'untraditional' in terms of how Health and Social Care structures nationally and UK wide view breaks for carers. However, carers are telling us that breaks can be entirely different to how policy and decision makers may view them. Having routine chores taken care of to free up time from what is, essentially, extra tasks on top of the basics of a caring role can provide a meaningful break that keeps carers well.

It is key to note that household chores for unpaid carers are much more intense than in non-unpaid caring households. For example, many carers have much more laundry and cleaning due to incontinence, many have much more intense cleaning requirements than other households and many are managing increased tasks around medical care that require increased levels of cleaning and maintenance.

Such breaks that would support with household chores, and funding of these, should be considered as part of a flexible menu of options for carers.

## Further feedback

Further qualitative feedback from carers on breaks centred on the types of breaks that may already be available, but difficult to access. These include access to respite, providing replacement care in the home environment and taking a family holiday with additional funded support provided, as described above.



# Carers' feelings around carer breaks

Carers were surveyed on their feelings around the topic of carer breaks, based on the knowledge they currently have. Understanding carers' feelings can point us to further context around why carers may be reticent to even explore breaks, or why they do not or cannot access them. Responses returned the following:

**19%**

of carers said breaks do meet their needs

**10%**

of carers said breaks do not meet their needs

The remainder of carers did not outright answer this question as they were either unsure as to what was available in terms of breaks, simply found accessing breaks too much work or selected 'other' with some of the following responses provided:

“

Not getting funding.

“

I feel guilty asking for help.

“

Fear of being judged for asking for a short break.

“

Feel there are others in greater need.

“

North Lanarkshire Council were not helpful. Could only arrange respite 2 weeks in advance.

Some positive feelings were also reflected by carers:

“

Process was seamless, and I was supported throughout.

“

Everyone deserves a break now and again.

“

A carers break is good if there is a suitable service for the person you are caring for while you are on the break.

It is clear there are a wide variety of feelings around accessing breaks from whether what is available appears to work for carers, to specific feelings around guilt, others being more deserving as well as problems accessing breaks via statutory services.

A key element that policy and decision makers should be cognisant of is the guilt experienced by carers. Every carer deserves a break, and we must understand that guilt itself can be a barrier to carers seeking out a break from their caring role.



## Being denied breaks – a further barrier

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A crucial question asked to ascertain if there were further barriers to carers accessing breaks was around being denied a break having applied for one. 19% of the carers who responded to our survey stated that they had previously tried to apply for a break but had been denied it, a high proportion. 68% however stated this has not occurred and 13% were unsure.

It is encouraging to see that the majority of carers had not experienced applying for a break and denied it, however the 19% that did have the experience may be discouraged from applying for a break in future and this must be taken into account as a barrier to applying for future breaks. In the instances of this relating to qualifying criteria, a menu of options would go some way to alleviating this barrier.

## Respite services – do carers still want to access these?

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23% of carers reported that they do still wish to access traditional respite services. This is a significant number, almost a quarter of survey respondents.

**23%**

**of carers do want to access traditional respite services**

**77%**

**of carers do not wish to access traditional respite services**

That this number of carers wishes to access respite points to an appetite for a service that should not be removed in North Lanarkshire at present. However, we know from carer experience that respite services, as they exist, are not necessarily working well for the carer or person they care for.

As noted in the introduction of this report, the catalyst for this consultation on carer breaks was one carer's experience of attempting to access respite care in North Lanarkshire. The stressors of this experience including having to call around 12 care homes at the last minute, then having to go out of area to an inadequate service does not properly support the carer to have a break or the person being cared for to access the correct level of care for them. Across North Lanarkshire the system of respite care must be reviewed with the ability to book in advance set as one priority so that carers can arrange their holidays, rather than only being able to book 2 weeks ahead of taking a break. Further recommendations and considerations on respite are included at the end of this report.

# Anticipatory care – what do carers have in place?

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Health and Social Care North Lanarkshire were keen that we understand, as part of this consultation, what carers have in place in terms of anticipatory care/emergency planning in the event of not being able to carry out their caring role.

It must be pointed out that any forms of emergency care provided for a person being cared for should not be seen as a carer break. These are two distinct elements of time away from a caring role under very different circumstances.

The survey returned the following results:

**55%**

**of carers said they do not have good emergency planning in place**

**45%**

**of carers said they have good emergency planning in place**

The qualitative findings around anticipatory and emergency care not only show the level of replacement care that would be required for a person being cared for, but also evidence the intensity of some caring roles.

Carers caring for people with acute and complex needs told us what they need for successful emergency care:

**“** *There needs to be somewhere for my child to go. At the moment, there's absolutely nothing.*

**“** *To ensure someone can keep track of them [the person being cared for] and be careful they do not asperate.*

**“** *I would need someone to take care of my child as if they were looking after a baby of about 12 months. The person would need to do everything for them and provide 24-hour care if they weren't at school, wash, dress them, provide personal care, cook, cut up food.*

**“ Care over a 24-hour period, including help to wash and dress, breakfast, lunch and dinner provided and someone to stay overnight for a 95-year-old who can [only] be left for short times on their own. For the other cared for person, I would require someone to cook meals and support with washing and dressing.**

**“ Someone with experience of Acquired Brain Injury, seizure activity, absence episodes, behavioural issues, mood swings, peg feeding, asthma, COPD, angina, double incontinence, manual handling, poor balance, skin issues, pressure point sores, able to give prescribed medications including dangerous classed drugs.**

**“ My husband is immobile from the neck down. He needs constant 24-hour care. He needs someone with him at all times.**

These examples from carers evidence the high level of support and care not only that they are providing day-to-day, but that would be required from emergency care provision. To prevent people who are cared for being admitted to hospital unnecessarily due to a carer having to take time out of their caring role, it is important for H&SC NL to assess how high-level replacement care can be provided, in partnership with the NHS.

Current anticipatory care tends to take the form of filling out an emergency plan in document format. However, if our health and social care structures do not have capacity to provide services during emergency situations in practice, and provide high quality replacement care, the onus will always fall on carers to either continue caring in impossible circumstances, or to give up their caring role meaning the wider system is impacted as well as, and most importantly, the carer and the person being cared for.

Less acute replacement care needs as reported by carers took the form of short visits to the home of the person being cared for to prepare meals and carry out support with personal care, befriending and companionship, and transport provision to enable people to continue to access support services in the absence of the unpaid carer.

# North Lanarkshire Carers Together AGM carer breaks consultation

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At the North Lanarkshire Carers Together Annual General Meeting on 5th June 2023 we surveyed an average of 110 carers across four key questions on carer breaks. The findings are as follows:

**Q1: Do you think the current system around carer breaks is working for unpaid carers in North Lanarkshire?**



That 55% of carers did not think the current system is working encapsulates much of the above findings around knowledge barriers, practical barriers, and a lack of options available to carers. The overall findings should be taken into account when reflecting on this AGM finding.

**Q2: Do you think traditional respite should remain an option for unpaid carers and the people they care for in North Lanarkshire?**



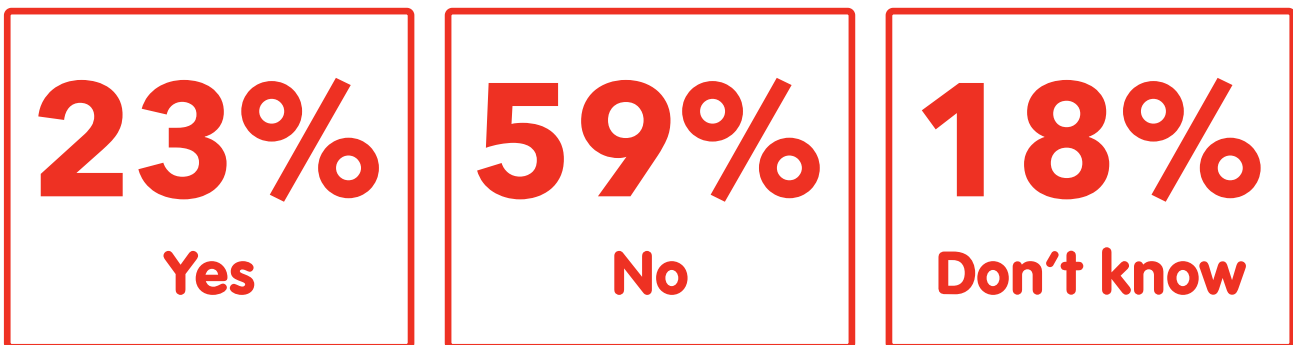
There is a large disparity between survey findings (23% did want respite to be an option) and AGM consultation findings. This may be explained by those carers attending our AGM as being our most engaged carers often with the most intense caring roles, a greater proportion of older carers and parent carers of children with acute additional support needs. These groups may be more likely to feel that respite is an essential option to them in terms of being able to take a carer break.

**Q3: Do you think we need to expand what we make available as a 'carer break' in North Lanarkshire?**



This finding supplements results on the wide array of carer breaks indicated as preferences by carers from accessing respite, to being able to arrange care for the person being cared for in their own home, taking a family holiday with additional support funded and provided, accessing hobbies and time out of the carer's choice and getting a break from domestic chores. That carers have identified such a wide range of options must be listened to and considered when redesigning our carer breaks system in North Lanarkshire so that many more carers will feel there are options available for breaks that work for them.

**Q4: Do you feel that as a carer you have adequate anticipatory or emergency planning in place in case you need to take enforced time out of your caring role?**



This finding is a relatively even reflection of the survey result which returned that 55% of carers did not feel they had adequate anticipatory/emergency planning in place. The finding from the AGM reiterates the above section on this area of need for carers across North Lanarkshire.

# Conclusion

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**It is key to base the conclusion to this consultation report on the evidence gathered. Carers have told us:**

- The current carer breaks system in North Lanarkshire is not working for them.
- 54% of carers responding to our survey have never taken a break.
- There are several barriers in place preventing carers from taking breaks including:
  - Lack of knowledge on how to access breaks and where to go for information
  - Perceived labour involved in accessing a break
  - Practicalities around taking breaks
  - Finding adequate replacement care
  - Finding a break format that works for individual carers and the people they care for
- There needs to be a wider menu of options provided to carers, and carers ultimately should have choice over how they take a break that will be meaningful to them.

**On anticipatory care and emergency planning we found that:**

- Over half of carers do not feel they have good emergency planning in place.
- Many carers evidenced that the person they care for has high levels of care needs that would require intensive 24-hour replacement care.

These findings come against the backdrop of the majority of carers who responded to our survey caring for 55+ hours per week, with 44% of respondents being working carers. The acute need for meaningful carer breaks that provide real rest for carers and a break from their caring role is clear.

At this point, ahead of the development of a National Care Service in Scotland and potential ratification in law of the right for carers to have a break, Health and Social Care North Lanarkshire has an opportunity to improve how carer breaks are provided and create a potential blueprint for other local authority areas.

A key element that must be incorporated into any redesign of carer breaks in North Lanarkshire is that this must be carried out with carers at the centre of the processes that will ultimately impact upon them. Co-design with carers should be embedded in every part of re-design going forward.

Health and Social Care North Lanarkshire now has a body of evidence upon which to make considerations, with carers, on next steps. We have produced key recommendations for next steps.



# Recommendations and considerations

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This consultation marks the beginning of what should be a collaborative, co-design process on improving carer breaks for carers, with carers in North Lanarkshire. For that reason, instead of making concrete recommendations, NLCT has laid out recommendations for next steps with a view to ensuring carers are at the heart of an ongoing process that will ultimately benefit them. Also detailed here are key considerations based on findings of this consultation.

## Recommendations for next steps

- 1** Form a carer break working group with meaningful carer representation, representation from North Lanarkshire's three commissioned carer organisations and H&SC NL carer leads to re-design carer breaks.
- 2** At key decision making points, take decisions public with wider carer engagement across North Lanarkshire's 6 localities, and 9 Community Boards, engaging carers in much the same way as the H&SC NL team that led on the Strategic Commissioning Plan for 2023 - 2026. This is to ensure key decisions are taken with carers at the heart of processes that will impact them.
- 3** A priority given to understanding how carers can best access initial information about breaks. This poses the question of whether there needs to be a central point of contact for all types of carer breaks accessed across the statutory and third sectors within H&SC NL or a commissioned service. A central point of contact for all types of breaks may reduce time consuming searching on the part of carers.
- 4** Priority must also be given to how H&SC NL will overcome the practical barriers affecting carers' ability to access breaks across its existing service provision in relation particularly to high level replacement care either in a home setting or care home setting.

## Considerations

**1** There remains significant need for traditional respite as part of a wider range of breaks. By removing respite as an option, many carers may be prevented from taking any form of break at all.

**2** Decision makers must be more flexible when it comes to defining what a 'break' is for a carer. While a range of options of choice is a good starting point (detailed below), a break should be defined by the carer for the carer. Flexibility should be applied when considering funding so that carers can access what works for them.

**3** Some carers have told us that having the option to take a break from household chores represents a break from caring. This option could be adopted as standard as an offering on a menu of options for carer breaks.

**4** A menu of options for carers to choose from is a good starting point. It should however not be the only source of options available (see point 2, above). The menu of options could include:

- a. Traditional respite so that the carer can take a break of their own choice.
- b. Replacement care provided for the person being cared for in their own home so the carer can take a break of their choice.
- c. Family breaks and holidays whereby the person or people being cared for can attend with family with funded additional support provided in the form of a support worker or personal assistant to ensure carers can take time out from caring whilst on the break.
- d. An offer of services or funding to pay for services to provide support with cleaning, laundry and other household tasks to give carers a break from this work and take time out from intensive elements of their caring roles.
- e. A bespoke offer whereby the carer can design their own break based on their needs, timings, regularity, flexibility and activities.

**5** There should be flexibility on timelines for durations of breaks for carers, i.e., carers should be able to choose between overnight breaks to breaks of several days or a week or more depending on what suits them. Prescribed timings present barriers for carers for whom specific timelines do not work.

**6** Where traditional respite services are continued to be offered, the system must work better for carers to avoid stress in arranging a break. The system must support continuity of care with the same teams supporting carers and the people they care for over months and years. This will ensure carers and the people they care for can access respite within North Lanarkshire in a way that works for them.



**“ Working for you ”**