

# Understanding carers' need for breaks to develop innovative solutions through co-production



An Accelerating Reform Fund co-produced project by Bristol City Council, Bristol Black Carers, Carers Support Bristol and South Gloucestershire, Chinese Community Wellbeing Society, and Rethink Mental Illness. The report was written by Dr Susy Giullari, policy engagement lead at Carers Support Bristol in November 2024. Special thanks are given to the seventy carers that contributed their lived experience to this project.

**Bristol Black Carers** has been supporting and empowering carers across the whole of Bristol for over 25 years by providing services which include their cultural background. We provide person-centred and holistic care, recognising and acknowledging that people from the Caribbean, Africa and Asia have vast social and cultural similarities and differences. For more information about Bristol Black Carers, please visit their website.

**Carers Support** is an independent charity formed in 1997 which provides support, information, and advice to unpaid carers of any age living in the Bristol and South Gloucestershire areas. For more information about Carers Support, please visit their website.

**Chinese Community Wellbeing Society** exists to support the health and wellbeing of the Chinese speaking community in Bristol and across southwest England. To find out more about the Chinese Community Wellbeing Society, please visit their website.

Founded nearly 50 years ago by carers of people living with mental illness, **Rethink Mental Illness** has a proud history of meeting the needs of carers and fighting for their rights. We believe this work is important, as carers are often neglected, despite the crucial support they provide to individuals and the positive impact they have on society. To find out more about Rethink Mental Illness, visit their website.

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# Executive Summary

**Bristol City Council (BCC) received funding from central government as part of the Accelerating Reform Fund (ARF) and formed a stakeholder panel made up of carers with lived expertise, commissioners, and carer representatives from local carers' organisations to co-produced innovative projects.**

**This project focuses on 'ways to support unpaid carers to have breaks which are tailored to their needs.' Between July and September 2024, four carers' support organisations (Carers Support, Rethink Mental Illness, Chinese Community Wellbeing Society, and Bristol Black Carers) conducted focus groups with carers to understand their experiences of different types of breaks and how they want to access information about them. The groups engaged with seventy carers from a range of cultural backgrounds, ages, genders, and unique needs for the person they care for.**

The project's objectives were to develop innovative access to breaks and inform Bristol's All Age Carers Strategy (2025 to 2029).

Carers said the key barriers they face to taking breaks are:

- guilt at leaving the person they care for
- finding and planning breaks being too time intensive
- complex adult social care processes and delays in assessments or getting a carers' Direct Payment
- difficulty in finding good quality replacement care for the person that they care for
- a lack of family support

Participants experienced different types of breaks and highlighted their advantages and disadvantages and concluded that carers need a range of breaks. They also suggested new types of breaks that are not generally available to carers, such as short notice breaks, vouchers for gaming and music for young adult carers and flexible use of carers' Direct Payments to reciprocate any family support.

The 70 carers from diverse backgrounds that took part in this project recommend the development of innovative solutions to:

- 1.** Broaden the type of breaks accessible to carers. The breaks that carers need is a lot more diverse than most respite services and carers' Direct Payments offers, which tend to be central to adult social care commissioning and provisions. The need for different types of breaks changes over time, according to the intensity of caring, age and ethnicity.
- 2.** Ensure that carers can get breaks quickly and when first identified

3. Making information about all kinds of breaks locally available is crucial. An easy-to-navigate carers breaks website covering all types of breaks should be locally available. It will need a search function or flow chart to enable carers to find the break that is right for them, without having to read lots of information. It should be promoted on local radio, GP surgery and hospital screens, and through social media pop up ads and other inclusive printed information.
4. Carers' organisations should be supported to offer support to carers to help find breaks that suit their specific needs and circumstances. A website or a leaflet alone is not thought to be enough. They suggested volunteer-run carers information services about breaks. This could include a phone number or callback option on the carers' breaks website, run by carers' support organisations commissioned to answer the phone.

These innovative measures would go some way to enabling local authorities to meet their duties under the Care Act 2014 and prevent any further care breakdown.



# Introduction

Breaks are a key priority for carers. In 2022, the Carers Trust ran a survey on carers priorities and found that getting a break was their second highest priority <sup>1</sup>. Unfortunately, the need for carers to take breaks is rising but demand is not currently being met.

Even before the pandemic it was hard to get breaks, but now a break has become a luxury that is inaccessible to most exhausted carers. Carers UK's 'Carers Week 2021 Breaks or Breakdown' report <sup>2</sup> found that during the pandemic 72 per cent of carers had to go without a single break. In 2022, South Gloucestershire Council asked 230 unpaid carers about breaks and 77 per cent said they had not been able to access a break since the start of the pandemic. The Carers UK survey <sup>3</sup> is the largest annual carers survey in Europe, and in 2022 it found that only 11 per cent of carers said that they had access to appropriate support including respite and carer breaks. In 2023, almost half of carers said they needed more breaks.

This is not surprising because since Covid-19 we have seen caregiving needs intensify. According to the latest census, there are 34,000 carers living in Bristol. Of these, 13,000 provide over 35 hours of care a week, with the majority (9,318) providing over 50 hours of care a week. The Association of Directors of Adult Social Services (ADASS) 2023 Spring survey <sup>4</sup> showed a national increase in referrals to adult social services due to carer breakdown - one of the main drivers being carer burnout. Despite this, NHS national data shows that since 2015, funding for breaks and respite has declined by a staggering 37 per cent. <sup>5</sup>

The Social Care Institute for Excellence (SCIE) conducted a literature review of evidence <sup>6</sup> on carers breaks up to 2019 and found that diversity is key to understanding and responding to carers' needs for breaks. They found that uptake of respite for carers of people with dementia is low and breaks for carers of people of mental health needs are often not considered properly. Carers from racially minoritised communities are less likely to access carers services due to language and cultural appropriateness barriers. Young carers also need opportunities to take different forms of breaks.

Clearly understanding carers' diverse needs for breaks and how to meet those needs is important not just to carers, but also to local authorities, which under the Care Act 2014, must promote carer wellbeing and prevent their needs from getting worse.

## Methodology

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Bristol City Council (BCC) was successful in a bid for the Accelerating Reform Fund (ARF), where the aim is to address barriers to adopting innovative practices and build capacity and capability in adult social care. Bristol City Council adult social care ran stakeholder meetings with carers' support organisations in Bristol, carer experts by experience and carers' representatives to co-design the ARF projects. It was decided to do a project on carers breaks which is Accelerating Reform Fund priority four, "ways to support unpaid carers to have breaks which are tailored to their needs." Carers and organisations that support carers in Bristol explained that carers need more support to get breaks, and to know where to get the right information, advice, and support to get a break.

Between July and September 2024, four Bristol carers' organisations conducted focus groups with carers. These organisations were Carers Support, Rethink Mental Illness, Bristol Black Carers, and the Chinese Community Wellbeing Society. To ensure the findings were reliable, Carers Support with its research capacity, led the co-design of the questions with all the facilitators and commissioners, analysed all the data collected and authored this report.

## Aims and objectives

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To understand:

- 1.** Carers' experiences of different types of breaks
  - 1.2.** The breaks that different carers need
  - 1.3.** What provision works well and what is missing?
  - 1.4.** The barriers they encounter and what would help to overcome them
- 2.** How carers want to access information about breaks

To

- 2.1** Inform Bristol City Council 'All Age Carers Strategy 2025 to 2029'
- 2.2.** Develop an effective and easy to use directory of local breaks

## Sample diversity

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There were eleven focus groups and seventy participants in total. To engage an ethnically diverse sample, two groups were led by Bristol Black Carers and four were with Chinese speaking carers. The same questions were asked to all participants.

The Chinese Community Wellbeing Society engaged with 20 Chinese speaking carers and ran four groups. Four facilitators led the discussion groups in Chinese and translated it later to English. This culturally appropriate practice ensured engagement and accuracy of data. Data from the two discussion groups led by Bristol Black Carers were also collected as written notes. The other focus groups were recorded and later transcribed. Carers Support then analysed all the data using thematic analysis to identify and present themes within the responses.

Young adult carers' experiences of caring and need for support are vastly different from those of adults yet there is no targeted provision for this group. Carers Support ran a focus group for young adult carers only. Five young adult carers aged between 18 and 26 (two men and three women), took part in this focus group; all had been carers for most of the lives.

Gender shapes experiences of caring and the need for support and although most participants were women, twelve men (17 per cent) also took part.

Diversity of experience also changes according to the needs of those cared for. We engaged carers with experience of caring for people with different impairments. These included physical impairment or limited mobility, mental ill health, learning disability and/or autism, long term illness, dementia, and sight or hearing loss.

As the findings show, these choices of method have resulted in rich data and innovative solutions to address the diverse need and want for carer breaks.

## Findings

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### 1. Carers' experiences of accessing and taking breaks: a difficult and complex process

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In line with the literature, the findings show that breaks are of huge importance to carers. Most of the participants had experienced taking breaks, some more than others. The process of getting a break is often complex and difficult for carers, who encounter many barriers. It is crucial that commissioners, practitioners, and providers understand how difficult this process can be.

#### 1.1. Guilt and exhaustion

Many participants felt guilty for leaving the person they care for, some of whom do not want to be cared for by anyone else.

**“My husband does not want someone else to care for him, and so I do it because I do not want to make him miserable. I did take a long break by asking someone else to step in, but the person I care for was not happy at all.”**

Many carers are exhausted and finding out about and planning a break takes far too much time and energy. **“Breaks fall through the cracks because there is too much to do in my life, and getting a break takes so much coordination, and you think is this worth doing? So, you just carry on and hope for the best.”**

#### 1.2. Getting a break: complex processes and delays

Participants recounted that when they managed to get over the guilt and exhaustion, they had to deal with a complex process and delays to get a carers' Direct Payment, and great difficulties in finding good quality replacement care.



## Carers' Direct Payments

Most carers need a break so one of the most common outcomes of a carers assessment is a carers' Direct Payment which the carer can use to pay for breaks of their choice. Participants had mixed experiences. On the one hand they welcomed the break and their ability to choose. One carer said, **"I used mine for massages, which was really relaxing. One year I used my carer's (Direct) Payment to buy a push bike because cycling released me from some of the stresses."**

But participants also said, **"It is just a big faff, so people do not do it. When you spend 24/7 caring you think, 'stuff the paperwork'."**

**"Imagine if you said to someone I am going away for the weekend, but I need to fill in a big form first."**

The process is further exacerbated by lengthy delays in carers' Direct Payments and assessments. Carers told us:

**"Mine fell through the cracks. I had to call and chase it."**

**"It did not used to be like this, but it has slowed down so much. Sometimes you need a break quickly."**

**"I mean I found out it might take over six months to get a social worker assessment and at that point I put my hands in the air and thought I can't be dealing with that right now."**

**"What stops me getting a break is I have been waiting for about one and a half years for a carer's assessment from Bristol City Council and that is how we access a carers' Direct Payment. It is not that I have been forgotten, I am on the list, I was calling weekly at one point."**

What is more, other participants felt that just being given money was not enough. **"I just lie in bed thinking I should be doing something because I am not going to get this chance again, but I do not have the energy to plan or think about what to do."**

**"The money is good but there needs to be some encouragement and help finding a break because caring is exhausting, and it isolates you."**

### **1.3. Getting a break: unavailable, low quality, and expensive replacement care**

To get a break most participants had to find replacement care. This is not easy, one carer said, **"It is almost like we need to put a system in place before you can even think about having a break - some sort of deputy."**

**"Finding someone else to look after the person - that is tough."**

Respite is important for carers. Participants who care for their adult children with learning disabilities and complex health needs received regular respite. One parent carer of an adult son with learning disabilities and complex health needs said, **"My adult son requires a lot of care as he has complex health needs and severe learning disabilities and so we get one night respite a week and 12 weekends a year."**

Others experienced the Shared Lives respite model and found it worked well. A parent carer of an adult son with a learning disability and complex health needs said, **“I care for my son, so it has to work for him too. The way I see it is I have a break when he is having a break. If he has a weekend away respite where he can do something he wants to do, like Shared Lives, it builds up over time.”**

However, most participants were not keen on respite. Some do not want to put their loved ones in a home. Others tried it and found it too unsettling for the person they care for, making their caring much harder when they returned. A carer of her mum with dementia said, **“It would make her very unsettled and make my job harder when I return.”**

Unfortunately, many experienced low-quality respite care in care homes. A carer of a husband with dementia said, **“There are some good care homes, there are some average care homes, and there are substandard care homes. I would not put my husband in a care home for respite.”**

A carer of a wife with dementia commented, **“Years ago, I had a respite. I researched the homes and found one that ticked all the boxes. When I came back, I had one look at her, and she looked 10 years older. I thought, “what have I done?” They had not looked after her. She was incontinent, I gave them the pads and instructions and she was not wearing any pads, she was not clean. It took me three years to put her in a care home again.”**

Finally, respite is not always available. A carer said, **“There is no respite for people with early-onset dementia, they are too young to go into a home, so what chance of a break is there for their carers or their children?”**

Respite can enable carers to go away on holiday or for a weekend break - something that many of the participants wish for but find difficult to achieve. One participant said, **“I have never been able to book one. Every time I tried, there is no availability when I can get respite or someone to give me a break.”**

Some carers get breaks via Direct Payments, and these can be very welcome, but the process is even more complicated. A parent carer of their adult son with learning disabilities and complex health needs said, **“What we have had more recently once or twice over the last couple of years is a night away, me and my wife, when carers stay over and look after my adult son.”**

Others commented:

**“The process is very complex; you need to employ them.”**

**“With Direct Payments the problem is finding someone that fits, that has the right skills. Personal Assistants tend to choose those with less needs.”**

Some carers get a break by having care workers come into the home, known as home care. Self-funders found it too expensive, one saying, **“I get Carer’s Allowance, but with the cost of the bills and increase rents, that is going on to that now, not on me as it is supposed to be.”**

Others find home care far too short and of low quality and therefore not worth having. They said:

**“I have been let down so many times. I have had to go in and check.”**

**“What is the point of having someone for 15 minutes? They stayed for 15 minutes, they were not allowed to give medication, and much of that time was spent asking me questions.”**

**“They must record what they have done so the 15 minutes is spent doing that!”**

**“We had someone coming in to help but it was always someone different. That does not work.”**

Some participants got regular short breaks using a sitting service from the voluntary sector. In contrast to home care, they trusted these services because the person they care for is matched with the volunteer and continuity is guaranteed, **“That works better because there is continuity, not a different carer all the time.”** But the big problem with sitting services is that the volunteers cannot do personal care. If the cared for person requires personal care, then the carer needs to stay nearby or even in the house.

The COVID-19 pandemic showed us that digital technology can be useful in enabling carers to have a break. Some participants who care for semi-autonomous people used tech aids:

**“I have a camera; I watch my mum, and I can keep an eye on the carers too.”**

**“I use Alexa, and I drop into it, and I speak to my husband if he does not have his phone on.”**

**“The falls button when we had that was useful because we could go out for longer.”**

**“Tags work for people that wander off and get lost.”**

For less autonomous people technology can be unhelpful or dangerous:

**“I have a camera to watch my mum but that is not really a break because I have to keep watching the camera.”**

**“My mum kept pressing the pendant like a toy and ringing the police or the ambulance.”**

**“My father has a pendant, but he never uses it. The number of times I found him on the floor, and he did not use it.”**

Participants concluded that technology can be useful in certain circumstances, but it cannot substitute the need for human care. One said, **“Technology cannot substitute for actual care. I worry when people think we can send them home to a virtual ward, but hospital wards only work because there are nurses on the ward. It is the human relationship that is key to all of this.”**

## **2. Diversity and the need for a directory of breaks**

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Participant experiences show that carers want and need diverse types of breaks. We explored this a bit deeper and found that the types of breaks that carers want and need can vary with age, ethnicity, and the stage and intensity of caring.

### **2.1. Age**

Young adult carer participants want and need quite different breaks from older carers, partly because of their youth, but mostly because of their vastly different experience of being a carer. These young adult carers had always been carers and being there for their parents has always been part of their lives. They take breaks that enable them to

socialise with other young people whilst not leaving the person they care for, such as gaming and listening to music. One said, **“It is normal for me not to be able to leave the house so (with) gaming I can socialise with my friends and care for my mum at the same time.”**

**“Six weeks of school holidays has been hell for me as I don’t get a break, so gaming when I can helps me to escape the real world.”**

**“Listening to music with one AirPods in I am still around to help. I can still have a conversation, but I can get away from it all in my head. Just listening to music helps immensely.”**

Young adult carers wanted somewhere to meet other young adult carers on a regular basis to socialise, chat, and have fun. They said:

**“I do not want to go away with older people. I want to do things that people of my age do which I have never been able to do. It’s hard to connect to my friends because of what I am going through.”**

**“Like, why don’t we do more of this type of thing? It has been really nice (to be honest). Not necessarily to talk about breaks but to sit here and chat.”**

**“You know I would never take any notice of the materials on your website, but I would come to this, here, every time.”**

But they do not want to commit to something that requires planning. Like other young people they want to be able to organise their social life at the last minute through social media. They also need this immediacy because they are not prepared to leave the parents they care for unless they are well enough to be left on their own. One said,

**“If I know there is something on tonight and if I can make it, I’ll go. But it is not a big deal if I cannot make it.”**

## **2.2. Ethnicity and extended families**

Extended families were discussed more in the Chinese and in the Black carers focus groups. In the other focus groups, carers did not mention families or friends unless prompted, and did not see them as a source of replacement care. For example, one carer said, **“It’s important that one should never do away with voluntary giving, but it is really limited, and we need to fall back on a decent professional service provided by the local authority or the local NHS.”**

In contrast, when asked about barriers to take a break, Black and Chinese carers identified a lack of family support as a primary barrier:

- No family member or anyone else to take over.  
(Carers from a Bristol Black Carers group)
- Family members who cannot support in emergencies.  
(Carers from a Bristol Black Carers group)
- No one is willing to give their time to relieve the main carer.  
(Carers from a Bristol Black Carers group)
- This carer’s daughters used to help, but then one moved to a different city, the other to a different country. This left her with no one to help care for her husband, she has not been able to take a break to go back to her home country for many years  
(Carer from a Chinese Community Wellbeing Society group)

One carer said, “In certain cultures, being able to pay a friend or family, someone who knows the person well and can take care of them for example, being able to give them something for it. ‘Thank you here is a bunch of flowers,’ so you don’t feel like you are taking advantage of people.”

### **2.3. Stage and intensity of caring**

Participants were keen to stress that choices of different breaks were key as their need and capacity to take breaks vary according to the intensity and stage of their caring journey:

**“It depends on what is going on. Sometimes I could do with a week, other times for one hour. You need variation.”**

**“Dementia changes depending on the stage of it, at the beginning you might be able to go out together and do activities, like a memory cafe. But when the need for care intensifies the carer might want a break on their own doing whatever they want to do, go for a walk, read a book whatever.”**

**“Sometimes you cannot leave people. It would be very difficult to find someone for a crisis, people would not do it or are not capable of doing it.”**

**“When there has been an intense crisis situation, say you spent the last three months, twenty-four seven looking after someone who is not sleeping, breaking everything up, and then when they are finally taken into hospital or wherever, that is when you need two to three days to go away and just look after yourself. Because everyone is looking after them and no-one is looking after you!”**

### **2.4. What is missing? Improving availability of breaks for carers: carers’ suggestions**

Carers said there was a need for regular short breaks as, **“Short, regular, and often is easier to manage.”**

For those that care for someone intensely, ‘regular’ meant a couple of hours a day, or at least two to three times a week. For others, it is a couple of hours a week, or a monthly evening out or day trip would be enough. In terms of activities, many participants were keen on wellbeing activities and socialising. For example:

- **“I like the idea of a massage once a month.”**
- **“I would like a regular swim or a walk once a week.”**
- **“Go out for an evening meal to feel a bit normal.”**
- **“A local informal group in a cafe to chat and learn from each other.”**
- **“It is quite isolating being a carer and I would not have anyone to go away with for a weekend on my own. For me, an organised pamper day for a group of carers, to chat to people who understand, or a carers’ night out. People I can have fun with, not a support group talking about carers’ problems.”**
- **Many agreed with a participant’s suggestion that “a voucher scheme for wellbeing breaks for carers would be great.”**

- Others suggested a carer's ID card or a carer's passport <sup>7</sup> to gain access to free or heavily discounted evenings out at the cinema, the theatre, museums, cafes, or restaurants. A young adult carer suggested, **"a card that offers free spaces for carers in their own right. Now in lots of places you get a free place if you are with a disabled person you care for but not for you on your own."**
- Young adult carers wanted vouchers for gaming and/or listening to music.

Participants stressed the need for short notice breaks, one said, **"now what I need is a break that I can book at short notice, for example, I have an appointment at 2pm tomorrow, can someone come and look after my wife? I had to go to the hospital the other week and I had to take my wife with me which was not easy."**

- **"The council could put together a list of people that could provide a break at short notice, and it should be affordable or free. This list should specify the level of competence of the carer."**

Others just wanted the chance to sleep once a week, **"my wife used to wake me up five to six times in the night and so when you say what break do I want I say time to sleep to recover."**

**"In Australia, they offer a night sleep a week as a break; a carer comes in."**

To summarise this section, carers' needs for breaks are a lot more diverse than the main respite and carers' Direct Payments offers, which tend to be central to adult social care commissioning and provisions. Participants highlighted crucial types of breaks that are missing and suggested ways to make them available. To meet the diversity of carers' needs for breaks, flexibility and a choice of breaks was considered most important. As was accessible, free, or affordable, reliable, skilled replacement care.

Carers breaks provision should not boil down to a payment. A carers' Direct Payment is not enough to encourage exhausted carers to take the breaks they so desperately need, **"the money is good but there needs to be some encouragement because caring is exhausting, and it isolates you."**

Instead of investing in cutting assessment and Direct Payment waiting times, resources should be targeted to creating early and fast information about breaks when carers are identified:

**"Professionals should tell carers they can be entitled to support to get a break! That is the first thing you need to hear; not have you ever had an assessment...what does that mean?"**

**"Have you had an assessment yet? I didn't like that. It really scared me. If they said come and see if we can help you get a break, I would have been there like a shot."**

**"When (identified as a carer), things should kick in straight away for the carer, including breaks."**

**"Unfortunately, it is often at crisis point or where we just cannot take a break because we need to care and that is when we are told you need a break! We need to know before!"**

Finally, as one participant argued, **"carers should have an actual right to a break."**



### 3. Finding out about breaks and having a council carers' breaks website

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During the focus groups, participants shared information on breaks as most of them had not heard about one type of break or another. All stressed that one of the key barriers to getting a break is finding out about them and having to navigate far too much information.

**“When my partner was diagnosed, we were given reams of stuff, and I put it in the bin. It is too much. Someone said you can look at our website and all I wanted was someone to tell me what there was.”**

They suggested:

- **“A council carers' break website that had information about all kinds of breaks available locally.”**
- **“You can click on it and find out how get a break, you can tell other carers about it.”**

#### 3.1. What should a carers' breaks website look like?

Participants said that to work for carers such website needs to be:

- **Easy to navigate** with a search facility that allows carers to **“search by type of break so a regular short break, holiday, a day off, a weekend off, a chance to sleep or a break at short notice.”**
- **Visually easy:**
  - **“A flow chart that you can click on each bit.”**
  - **“Maybe in the home page it could ask what kind of carer you are, if you live with them, if they could be left on their own or not, and how much care they need.”**
- **Inclusive**
  - Easy to read and simple language.
  - Audio and video content, **“with a YouTube clip of a carer saying how important the break has been as some of us need convincing!”**
  - In different languages. **“Chinese speaking participants stressed language barriers as most of them could not navigate information about support for carers because they do not read English.”**

#### 3.2. How do carers find out about the carers' breaks website?

Participants were concerned for carers who are not used to going on websites and agreed that inclusive printed information to direct people to the website is still important. They also identified the key sites where printed information should be made available:

- **“GPs should give out a leaflet about the breaks website.”**
- **“But also, leaflets should be available in pharmacies because not everyone goes to the GP often.”**
- **“When people apply for an emergency card.”**
- Leaflets should be made available in **“libraries, community centres, churches, mosques. Give them to carers to pass them on to other carers.”**

- **“They should be in Easy Read, braille and in different languages.”**

The carers’ breaks website should be promoted using:

- local radio
- GP surgeries and hospital screens
- a young adult carer also suggested, **“social media pop up ads that say something like, ‘do you look after someone? This is the best way to get a break if you are a carer.’ ”**

### **3.3. The role of local carers’ organisations**

Many participants found out about breaks through local organisations supporting carers and argued that carers are more likely to take a break if the encouragement or the actual break service is from a trusted service. Some participants said:

**“My GP referred me to the Alzheimer’s society support group and that is how I got my assessment and carers’ (Direct) Payment.”**

**“We just found out about the hotel break from Rethink (Mental Illness), but this is part of the issue knowing what is out there, whether it is working or not.”**

**“In my GP, they have a monthly carers surgery and that is where I met someone from Carers Support who told me about breaks.”**

This was crucial for Chinese speaking carers, who want culturally appropriate breaks, **“through the Chinese Community Wellbeing Society (CCWS) we can get accurate information with correct translation, sometimes the translation from other services is wrong.”**

They also suggested that carers’ organisations could have the following roles:

- **“Carers Support, the Dementia Wellbeing Service, Rethink Mental Illness, Chinese Community Wellbeing Society, Bristol Black Carers, and Age UK websites directly linked to the council carers’ breaks website.”**
- Play a key role in encouraging and supporting carers to find and take appropriate breaks, because a website or a leaflet is not enough:
  - **“If we see that there is no access to a human being, are we going to bother, I wonder?”**
  - **“Yes, we go to the phone first, not to a website.”**
  - **“On the breaks website, there could be a call back option or a phone number.”**
  - **“Someone that can facilitate it for you, find the right break for you.”**
  - **“Could we not get a bunch of volunteers that could man a carers’ breaks phoneline? I would do that a couple of hours a week. I am sure there are other carers that would do that especially if they could do it from their own homes, trained up a little bit, to help callers to make the right choice of break and how.”**

- Provide breaks directly <sup>8</sup> like the Chinese Community Wellbeing Society sitting service,  
**“It gives me some time to deal with my own business. It is the only service I can use, as it is in Chinese and culturally appropriate. I get some money from the council to pay for the sitting service.”**
- Translate information about culturally appropriate breaks.

## Conclusion and recommendations

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Participant accounts of how they managed or failed to get a break reveal a difficult and complex process. Most deal with feelings of guilt and exhaustion, but once they manage to get over those feelings, they encounter a complex process to access Direct Payments for breaks or find suitable and good quality replacement care.

- It is crucial that commissioners, practitioners, and providers understand how difficult this process can be.
- Carers' needs for breaks are a lot more diverse than the current respite and carers' Direct Payments offers, which are often central to adult social care commissioning and provisions.
- Participants highlighted crucial types of breaks that are missing and suggested ways to make them available.
- The need for diverse types of breaks changes over time and according to the intensity of caring.
- Meeting the diversity of carers' needs for breaks with flexibility and choice of breaks was most important. As was accessible, free, or affordable, reliable, skilled replacement care.

Participants experienced several types of breaks and highlighted their advantages and disadvantages and concluded that carers need a range of breaks. **Respite** is important for carers. However, most participants were not keen on respite, either because their loved one did not want to go into a home, or because they had already experienced low-quality residential care. Additionally, respite is not always suitable or available, for example, there is no provision for people with early-onset dementia.

Many participants highlighted the need for a range of **short regular breaks** - from a couple of hours twice a week for those who cared intensively, to a monthly evening out or day trip for others. Home care is a way of getting this type of break, but it is too expensive, and when it is free, it is too short to enable a carer to get a break. Sitting services provide continuity but do not allow those who provide personal care to take a proper break. Technology is another way to support carers to get regular short breaks, but only when the person cared for has an element of independence. Otherwise, it proves dangerous and certainly no substitute for the human relationship.

Carers suggested a **voucher scheme for wellbeing breaks and carer's passports** to gain access to free or discounted day trips or evenings out at the cinema, theatre, museums, cafes, and restaurants. **Short notice breaks** are missing and crucial to so many carers, to allow them to take care of their own health and attend GP or hospital appointments.

Like adult carers, young adult carers want informal carers groups, but these need to be with peers and without the need for commitment. Unlike adults, they would like vouchers to spend on gaming and listening to music, as this helps them to socialise with others, whilst being around the person they care for.

Unlike White English carers, Black and Chinese speaking carers see family as a primary source of their breaks. **They want flexibility in the use of carers' Direct Payments**, to be able to reciprocate the support from family and friends with gifts, and to not feel like they are taking advantage.

Participants argued that when making breaks accessible to carers, providing information about breaks is crucial but it needs to be manageable, easy to navigate, and in both digital form and in print. They suggested:

- **“A council carers’ break website that has information about all kinds of breaks available locally.”**
  - with a search function that **“searches by type of break, a regular short break, holiday, a day off, a weekend off, a chance to sleep at short notice.”**
  - A flow chart to direct you to the kind of break that you need. Perhaps organised according to whether you live with them or if they could be left on their own or not, and how much care they need.
  - Information from multimedia **“with a YouTube clip of a carer saying how important the break has been, as some of us need convincing!”**
  - Translated in different languages.
- **“Inclusive printed information to direct people to the carers’ breaks website.”**
- **“Promoted in local radios; GP and hospital screens and via random social media pop up ads.”**

They strongly argued for resources to be targeted to creating early and fast information about breaks when first identified as carers before carer’s assessments are completed. They saw local carers’ support organisations playing a key role here because they are trusted by carers.

Carers’ support organisations should be commissioned to:

- play a key role in encouraging and supporting carers to find and take appropriate breaks.
  - A suggestion was for carer volunteers to run breaks information services.
  - A phone number or call back option on the carers’ breaks website that could be answered by carers’ organisations commissioned to answer the phone.
- Provide breaks directly, like the Chinese Community Wellbeing Society’s sitting service that provides culturally appropriate services.

**To conclude**, the 70 carers from diverse backgrounds that took part in this project recommend the development of innovative solutions to:

- 1.** broaden the type of breaks accessible to carers
- 2.** develop and promote an easy to navigate carers' breaks website with updated information on locally available breaks
- 3.** ensure that carers can get breaks quickly and when first identified
- 4.** offer support to carers to identify breaks that suit their specific needs and circumstances

These measures would go some way towards enabling local authorities to meet their duties under the Care Act 2014 and prevent further care breakdowns. The King's Fund 2023 report on caring concluded that, **"to better support unpaid carers locally, commissioners and services need to develop and maintain a good understanding of their populations, build local support offers accordingly, and embed awareness of carers in strategic-level and commissioning decisions."**

Likewise, the Association of Directors of Adult Social Services' (ADASS) agenda includes **"working in partnership with local providers and community organisations. Commission support for carers including breaks, commission more flexible breaks for carers."**

Finally, as the Carers Trust <sup>ii</sup> highlighted, **"carer breaks have a potentially crucial role in helping local authorities meet their Care Act duties: Prevent, reduce, and delay."** This could be done through the Better Care Fund 2023 to 2025 which continues to suggest how the money can be used to support unpaid carers.

# Appendix 1

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## Focus Group on Carers Breaks

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### 10.30-10.35 ICEBREAKER

- Thank you for coming!
- Please say your name and share something unique about yourself. For example, I am Susy, and I was born in Italy next door to the Ferrari racetrack!

**10:35- 10.40 INTRODUCTION - Bristol City Council has been given funding from central government to support carers. The fund is called the Accelerating Reform Fund, and it aims to improve the quality and accessibility of services and provide more support for carers.**

**The aim of this focus group is to find out about**

- Your experiences of accessing breaks: what works and what is missing
- How to improve information about carers breaks

**The objectives are:**

- To create a Bristol City Council directory of carers' breaks.
- Inform the Bristol All Age Carers Strategy.

**Consent Form** Have you all sent in your consent form? IF NOT Go through it and get consent orally and ask to sign it.

**Ground rules:**

- You do not need to answer all the questions.
- The focus group will last until 12 pm.
- Please feel free to stop taking part at any time.
- Essentially this is a confidential, inclusive space where everyone should have a chance to speak and listen to others without being judged or treated disrespectfully.



## Key questions

### K1: 10.40 -10.55

**How and when would you like to take a break away from caring if you could?**

Prompts:

- How often? Regularly?
- For how long? Couple of hours; a w/end; a holiday
- When: during the day; evenings; overnight

### K2: 10.55 -11.10

**What stops you getting the breaks that you want and need?**

Prompts:

- Cost
- Information
- Quality of replacement care

### K3: 11:10 -11:30

**Are you aware of any support or services that can help you take the kind of breaks that you need and want?**

**What things do you like about this support or services?**

Prompt: getting a break via an assessment # services in the community

**How can this be improved? What is missing?**

### K4: 11:30 -11:50

**How did you find out about carer breaks? How can we make it easier for carers to find out about breaks?**

Prompts:

- Good assessments
- Digital
- Navigating information: key search words; checklists

### 11: 50 -12:00 END

**What 3 things are most important to enable you to access the breaks that you want and need?**

**VOUCHER FORMS**

**THANK YOU! NEXT STEPS-MORE PARTICIPANTS NEEDED**

## Appendix 2

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### Focus groups facilitators guidelines

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#### Recording and taking notes

As previously agreed, to inform the care directory and the all age carers strategy, we want to make the most of all the things that carers are telling us across all the focus groups.

To do so, susy (carers support centre) will pull all the information together, analyse it and write it up in a report.

Please record the information using a mobile phone app.

If you prefer to write notes, please take detailed notes, type them up and send them to Susy.

#### Some "probes" or follow-ups" designed to get more information on a given question:

- "Can you say more about that?"
- "Can you give an example?"
- "Jane says x. How about others of you. What do you think?"
- "How about you, joe. (Or, "you folks in the corner over there....") Do you have some thoughts on this?"
- "Does anyone else have some thoughts on that?"

#### Avoid using jargon and complex language

**E.L.M.O** stands for "enough, let's move on" and can be established as a meeting rule to cut unnecessary discussions. Once stated, anyone in the meeting can say "elmo!" At any time to indicate that it is time to move on to the next topic.

#### Dealing with someone that talks too much:

- Wait for a tiny pause, acknowledge them, and move the conversation to someone else
- Say you will let someone else that has not spoken go first
- Use reminder: tell people that if they are talking too much you will raise the "stop" paper/ card whatever

#### Engaging the quite ones

- Ask directly: do you want to share your experience about....What was it like for you....

#### Dealing with angry, emotional, negative experiences of adult social care

- Step 1: acknowledge the frustration
- Step 2: listen to it for a bit but do not allow it to go on too much
- Step 3: move it on by
- **validating** it by asking them to write it all down on a piece of paper you hand them so you can investigate it and get back to them; or signpost them to a service that can support them

## Appendix 3

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### Accelerating reform fund focus groups on carers' breaks

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**Thank you** for agreeing to participate in a focus group discussion on the **9 September 2024** organised by the Carers Support Centre at the Vassal Centre, Gill Avenue, Fishponds, Bristol BS16 2QQ.

**Participant information** Bristol City Council has been given funding from central government to support carers. The fund is called the Accelerating Reform Fund, and it aims to improve the quality and accessibility of services and provide more support for carers. Carer representatives and organizations that support carers in Bristol explained that carers need to know where to get the right information, advice, and support when accessing breaks from their caring role. 'Carers' breaks' are opportunities for carers to take a break from caring and do something for themselves. Breaks can range from an hour away from caring up to an extended break or a holiday.

**Focus group aim** is to understand the types of breaks you would like, find out about your experiences accessing breaks in Bristol, how we could make it easier for you to access breaks, and how you would like information to be given to you.

**Focus group objectives** Bristol City Council is working with organisations that support carers to create a 'Directory of Carers' Breaks.' This will have information about all the carers' breaks available locally, so that carers can have the right information and support they need to take a break. We want people with lived experience of caring to inform how we design this 'Directory of Carers' Breaks' to make sure that it meets their needs. This is called co-design. We will use this information to ensure that the Directory of Carers' Breaks is in the format carers want and is accessible and easy to use.

This focus group will last 1 hour 30 minutes, and we will be taking notes and audio recording the session. To acknowledge your contribution, you will be given a £30 voucher. All the information collected is confidential your feedback will be fully anonymised.

**Please fill in the consent form** overleaf that has further detail about how we will gather, store, and process the information you give us in the focus group. If you have further questions about the focus groups, then you can contact the Carers Support Centre.

## Informed consent form

Please tick all boxes

	Yes	No
I confirm that I have read and understood the participant information above for the project and have had the opportunity to ask questions.		
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.		
I agree to notes being taken/recording of the focus group about what I am saying as part of the project.		
I understand that all the information I provide will be treated in confidence and will be anonymised.		
I understand that the information I give will be stored electronically on a safe computer at the Carers Support Centre		
I understand that the information I provide will be anonymised and written up in a report for Bristol City Council to inform the development of a Bristol Carers' Breaks Directory.		
I understand that any personal information that can identify me, such as my name or where I live, will not be shared beyond the project team and in the report.		
I understand that I also have the right to change my mind about participating in the project for a short period after the project has concluded (within one week).		
I understand that I will be sent a copy of the report.		

Name of Participant (IN CAPITALS) .....

Signature of Participant: ..... Date .....

Email of Participant .....

Telephone number of Participant .....

Name of Project Officer (to be filled in by Project Officer)

.....  
I confirm that all the information relating to this research was provided prior to consent

Signature of Project Officer ..... Date .....

.....

## Endnotes

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1. Carers Trust [1016234\\_ct-report\\_i-feel-like-i-have-disappeared.pdf](#)
2. [carers-week-2021-research-report.pdf](#)
3. [State of Caring survey | Carers UK](#) The impact of caring on: health (November 2023)
4. [adass-time-to-act-april-2023.pdf](#)
5. [\(Adult Social Care Activity and Finance Report, England, 2022-23 - NHS England Digital\)](#)
6. [National evidence base for adult carers' breaks - SCIE](#)
7. Funded by the Council, [Carers in Hertfordshire](#) use a carer passport to encourage carers to come forward because it provides local discounts, as well as serving as unofficial identification. When the carer goes to sign up for the service, they are asked questions which serve as a triage point for the carer, including to help them identify their own needs. Introduction for adult carers' breaks | SCIE
8. Carers Trust Mid Yorkshire manage a service of short breaks, generally breaks are a few hours a week or a few hours every couple of weeks. This is within the overall framework of the contract. By giving the autonomy and freedom to Carers Trust Mid Yorkshire to discuss and respond to carers needs, this means the breaks are tailored to the needs of the carer. For example of good practice in carers breaks services see [Carers' breaks for adults: guidance for commissioners and providers - SCIE](#)