

# **Policy and practice briefing: Improving carers' access to food and carer ID**

## **Introduction:**

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This briefing is designed to provide additional insight into carers struggling to access food. It contains:

- Additional analysis from *Caring Behind Closed Doors*, April 2020
- Examples of what organisations have been doing locally to support carers
- Recommendations for action – currently and for the future.

Since the start of the coronavirus outbreak, accessing food has been a major issue for many carers. For some, easing of lockdown carries additional worries and concerns. Continued support from volunteers, neighbours, local authorities, supermarkets and local convenience stores will continue to be important for many carers.

If, in the future, there are local outbreaks and local lockdowns or a second wave, it is important that we learn from our experiences and make life better for carers going forward.

This briefing is based on the findings from our survey, *Caring Behind Closed Doors* looking at carers' experiences of coronavirus<sup>1</sup>. Specifically, it is drawn from analysis of the 18% of respondents to this survey who reported that they were having significant problems accessing food.

The purpose of the briefing is to set out what evidence there is about carers who have been struggling to access food, what Carers UK has been advocating to the Government and to supermarkets on this issue and what we would like to see happen going forward.

The briefing also looks at best practice at a local level in supporting carers. Throughout, the briefing will be supplemented by what carers have shared with us through our advice line, online forum, social media channels and other communications.

Carers UK carried out an online survey from the 3<sup>rd</sup> April to the 14<sup>th</sup> April. A total of 5,047 carers and former carers responded to the survey. This included 4,830 current carers and 217 former carers. Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

## **Summary of findings – who have been struggling to access most? What is their profile?**

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<sup>1</sup> Carers UK "*Caring behind closed doors: Forgotten families in the Coronavirus Outbreak*" April 2020, based on findings from Carers UK "*Carers experiences during the coronavirus outbreak*" An online survey open between the 03/04/20 and 12/04/2020

Specific analysis of carers struggling to access food revealed the following:

- That these carers were likely to be time poor with 75% caring for 50 hours or more per week.
- That 54% of these carers were worried about their financial situation.
- That these carers have been impacted by loss of support services with 43% having increased the amount of care provided as a result of local services reducing or closing.
- That some of these carers cannot go to the supermarket due to their caring responsibilities or the needs of the person/people they care for.
- That for carers who cannot go to the supermarket, accessing an online delivery slot has been a major challenge.
- That 71% of these carers felt overwhelmed and were worried about burnout in the coming weeks.
- That just 24% of these carers felt able to manage their own health and wellbeing
- That these carers are isolated with 68% feeling they had no support network.

## About carers who are struggling to access food:

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### Amount of care provided

Carers who were struggling to access food were more likely to have been caring for a significant period of time. **43% had been caring for over 15 years and a further 20% had been caring for 10-14 years.** This compares to 36% and 17% of all carers that filled in the survey. We know from other research, that the longer someone cares, the more likely that they are to be in poverty<sup>2</sup>.

**These carers are also likely to be providing a significant amount of care a week with 57% caring for 90 hours or more and 75% caring for over 50 hours a week.**

For many, this is a significant increase in the amount of care they are providing, previously just 57% were caring for over 50 hours a week.

The amount of care these carers have to provide may mean they are most reliant on online delivery services. Worryingly, through our online forum, advice line and social media platform we have consistently found that many carers are having significant challenges with online food shopping.

*“Our last delivery was before the lockdown. Absolutely unable to get one now. I could go shopping, but then run the risk of bringing Covid home. That would be the end of both of us.”*

*“All we ask is to have a delivery slot to get food for those we look after but it’s a constant nightmare finding one.”*

Carers that were struggling to access food were more likely to have seen an impact of local services reducing or closing. **43% had increased the amount of care provided as a result of the local services reducing or closing** this compared to 35% of all carers who responded to the survey.

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<sup>2</sup> Carers UK “Caring for Your Future” November 2018

The increase in care is having a significant impact on these carers with them experiencing disruption to normal routines, new practical difficulties in day to day life and losing access to breaks which can be essential to health and wellbeing.

*“Round the clock care required due to self harm risk. Nobody able to visit so I can have a break. Daughter follows me round needing to constantly be close to me. Have had to get meds prescribed from CAMHS to help her sleep so I can rest a bit. Totally exhausted.”*

*“Where school and respite would help me out, I am now doing it all alone. We are not classed as a priority so won't get access to delivery slots or click and collect for food shopping yet I can't take all three kids out with me”.*

### **Finances**

The majority of carers (54%) who are having significant difficulties in accessing food are worried about their financial situation. Among all carers who completed this survey, this figure was significantly lower. **Worryingly, 85% of carers who are struggling to access food are also reporting having to spend more on it.**

19% of respondents within this cohort are also having significant problems accessing medicine and 47% are having significant problems accessing cleaning and hygiene products. A worry considering the importance of good hygiene in preventing the spread of coronavirus.

Carers in this cohort are having to spend their savings on basic necessities.

*“Spending more, overdrawn all the time”*

*“My emergency savings have been used up to support my family”*

*“As an unpaid carer, I rely solely on my savings to support myself and to make purchases for my mum if she can't afford them”*

### **Access to supermarkets**

A common issue raised across our platforms is carers not being able to go to supermarkets. This can be because the person they care for cannot be left alone or cannot accompany the carer to the supermarket but it can also be due to time constraints of the carer. Many carers are also worried about the risk of bringing back coronavirus infection to the vulnerable person they care for.

*“My kids don't understand social distances and I am scared to take them to the supermarket, can't get a delivery slot whatsoever with any supermarkets and I can't keep relying on my mother in law*

*“I cannot go to my local supermarket to do a shop as I am a full time carer for my dad and he cannot be left alone. I have to ask other people to get me essentials like milk and bread. It is worrying”*

For those who can go to the supermarket, some find that their lack of official identification makes the experience stressful or embarrassing and at times, this has prevented them from accessing priority shopping hours for vulnerable people.

*"I am a full time carer to my two Disabled adult Daughters and I am having issues with shopping...queuing for different shops is difficult due to their disabilities*

*"Am I eligible for some sort of card ? Normally they would shop with carers but as this is not possible, I need to find a solution without the current embarrassment of explaining my situation"*

We have also found that there is a significant proportion of carers who simply do not know where to turn to get advice and help accessing food.

*"No support. I am unsure what is available if anything."*

*"We are struggling without food. No help. Plenty of signposting but no actual help"*

### **Emotional impact**

**Carers having significant problems accessing food were more likely to be worried about burning out.** 71% of respondents either agreed or strongly agreed that "I feel overwhelmed and I am worried about burning out in the coming weeks" compared to 51% of all respondents in the survey.

**Of the carers struggling to access food, only 24% felt able to look after their own health and wellbeing.** 56% of carers felt unable to do so. This is particularly striking when compared to the figures from the wider survey in which 44% of carers felt they could manage their own health and wellbeing and 33% felt they could not.

**These carers were also more likely to be isolated.** 68% disagreed or strongly disagreed that they had a network of people around them to support them compared to 42% of all carers. This may suggest that a contributory factor to carers struggling to access food is the lack of a support network around them.

**Carers in this cohort often feel abandoned and feel unable to access help.**  
*"life is overwhelming"*

*"I wish I had the sort of support network which was a constant factor, but I haven't. I have to be at deaths door or incapacitated and even then no one offers to help, I have to ask and I get the strong impression that they feel I'm putting on them."*

## **Other evidence from the Universities of Birmingham and Sheffield – Sustainable Care – use of foodbanks and hunger**

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Working in partnership with Carers UK, new research from the Universities of Birmingham and Sheffield as part of Sustainable Care found that carers were twice as likely to be using food banks as non-carers<sup>3</sup> up until April when the survey was conducted.

The research found that 106,000 unpaid carers, looking after someone outside of their household, had used a foodbank during the pandemic. Nearly double that number,

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<sup>3</sup> Bennett M, Zhang Y and Yeandle S, Caring and COVID-19 – hunger and mental wellbeing, Care Matters Series 2020/01, June 2020, published by Circle, University of Sheffield.

229,000, had gone hungry during lockdown. You can read the research here:  
[www.carersuk.org/news-and-campaigns/press-releases/unpaid-carers-twice-as-likely-to-have-used-a-food-bank-during-pandemic](http://www.carersuk.org/news-and-campaigns/press-releases/unpaid-carers-twice-as-likely-to-have-used-a-food-bank-during-pandemic)

## **What has Carers UK done, what have we been advocating to Government and to food retailers?**

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Carers UK has taken the experience of carers, trying to use this to improve the situation for carers:

- Raising carers' issues quickly with a range of Government Departments to try to tackle this situation.
- Working with Government to encourage action on identifying carers. The COVID-19 Adult Social Care Plan recommended that local areas develop identification letters if they did not already have a scheme in place. We set more out below about how local areas have already responded.
- Our colleagues in Carers Northern Ireland have worked with their Government and Health and Care Trusts have issued Carers ID cards to all known carers on their lists. This was launched in Carers Week 2020.<sup>4</sup>
- Promoted sources of help e.g. NHS Responders. The range of people that could be helped by NHS Responders was broadened to include carers thanks to work by NHS England.
- Joined other organisations to work with DEFRA on their support for disabled and older people and carers. DEFRA have responded positively and we are now on a regular working group feeding in carers' views about:
  - How supermarkets might best support carers – eg. including carers in the limited number of priority slots for home delivery and making other areas more accessible.
  - Looking at access to food for those who are:
    - on low incomes for whom this is financially challenging
    - unable to access food through other means e.g. online but otherwise would not normally have problems accessing food
  - Data management and those who within the shielded category or vulnerable to not being able to access food
  - Definitions that include carers and young carers
- We have been working with a group of charities such as Age UK, Alzheimer's Society, Parkinson's UK, MS Society and National Autistic Society who are trying to make this better. We have contributed to guidance for supermarkets and local convenience stores from charities on how to support disabled people and carers.
- We continually look at practice that supports carers.
- We are continuing to advocate for carers and people who are shielding as shielding ends that support must continue.

## **General principles locally for delivery of good practice to support carers:**

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<sup>4</sup> Announcement here: <https://www.carersuk.org/northernireland/news-ni/new-id-card-for-carers-launched>



Ensuring good continued support for carers and their families who are vulnerable continues to be a priority. These mechanisms also need to be in place should there be local outbreaks and lockdowns or a second wave.

**Principles:**

Having clear communication mechanisms and data sharing between different organisations of those most in need.

Good promotion of volunteer schemes e.g. NHS Responders – that clearly includes the definition of carers, so that carers know they can and continue to refer either themselves or on behalf of the person they care for. Carers UK received a number of queries from carers who were not sure they could use the service. Clear communication from NHS Responders to carers about what those volunteers do i.e. leave shopping at the door rather than carry it over the threshold if carers are worried about risk of infection. The reference to carers is here:

<https://volunteering.royalvoluntaryservice.org.uk/nhs-volunteer-responders-portal/isolating>

Good joint communication and understanding about carers needing support within food programmes. All local authorities should join the Supermarket Referral Scheme to ensure they are able to refer carers and people who are vulnerable for priority delivery slots.

Good joint working between GP practices (high referral rates to NHS responders), Link Workers, local voluntary organisations and local authorities, including data sharing, but only with necessary information being transferred.

Recognition that around one third of people will start caring at any given time throughout the year, and this should not be any different during this time. Core messages about getting help with food need to continue as long as those who are shielding or vulnerable measures remain in place.

After the first rush of help from families and neighbours to help carers and people needing care by families, is this support still being sustained? Some families are reporting sustained additional help and their lives have improved, others are reporting that some informal help has tailed off. It is important to keep checking in with carers as situations change and some may need new support.

## **Examples of practice at a local level**

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Locally, many local carers organisations, local authorities and health partners have worked quickly to ensure that there was a mechanism for carers to identify themselves. The need for this was twofold:

- To help with shopping and identification for those unable to wait in queues, etc. and to access any priority slots
- To help identify carers if they were stopped for any reason or queried why they were going out so much (necessary 'medical' care which includes providing care for someone who cannot manage without your support has always been allowed).

The following are examples of what different organisations have done:

- **Action for Carers Surrey** quickly developed a letter in conjunction with **Surrey County Council**, and have a very comprehensive section on their website about local shopping arrangements: [www.actionforcarers.org.uk/coronavirus-advice-for-carers/important-information/shopping-information/](http://www.actionforcarers.org.uk/coronavirus-advice-for-carers/important-information/shopping-information/)
- **Care for the Carers, East Sussex** developed a similar letter quickly for carers on how to get support and they also have their [Carers Card](#) scheme which doubles up as an emergency card and discount scheme for carers.
- Carers Passport schemes, like the longstanding scheme with [Carers in Herts](#), have been used to identify carers locally.
- **Telford and Wrekin Council** developed a [Carers Priority Card](#) to make sure that carers were able to identified and provide that they were providing essential visits if stopped by the police. This has been a key concern from carers across the UK.
- **Birmingham City Council** worked with their local carers' hub over identification and with the local supermarkets to try to get their carer identification recognised. Their new Carer ID and discounts cards have seen a real spike. Since March Birmingham Carers Hub has processed **697** cards from their online application form and received **1029** visitors to the Carer Discount Card and benefit online portal.

*"I would just like to say a big Thank You to carers hub for introducing the carers card. It has been so helpful I don't need to queue in Asda I have a young son, nonverbal with Autism who is with me all the time so I leave in car with sibling or dad run in Asda grab few things and back home. Otherwise it would mean me waiting in a queue for an hour and my son having a complete meltdown. Once again thank you we appreciate you in these difficult times. Caring is hard at the best of times but now in these uncertainties life gets more difficult."*

- **West Yorkshire and Harrogate Partnership** developed a template letter for the Integrated Care System that could be tailored locally. It carried the NHS logo.
- **Brighton and Hove Council** issued their Carers Cards to local carers as soon as possible to provide identification.
- **Durham County Carers Support** have operated a Carers discount card on behalf of Durham County Council for 8 years. We also distribute a Carers Emergency Card for Carers to access support in an emergency. Durham County Carers Support worked with **Durham Council** with both organisations working together to contact local supermarkets who nearly all now accept either of these cards to identify carers and let them access priority shopping hours.

The Association of Convenience Stores (ACS) have published guidance for their members on supporting unpaid carers. Often carers find local convenience stores helpful as they build up a relationship with staff, are very local and easier to get to. Many local stores adapted quickly to make things easier for families – with online

deliveries and remote payment methods. Carers UK working with the ACS welcomed their quick response and guidance. You can find their guidance here:

[www.acs.org.uk/news/acs-launches-new-guidance-support-unpaid-carers-local-shops](http://www.acs.org.uk/news/acs-launches-new-guidance-support-unpaid-carers-local-shops)

The challenges that have faced different organisations trying to embed and implement these have been:

- Raising awareness of new letters or measures created with carers
- Getting the Carers Card/Carers Passport/Letter to carers. Some Carer Passport schemes relied on plastic cards being printed, this was not always been possible.
- Individual local supermarkets not understanding about unpaid carers

Some areas have had very positive results with no carers reporting any issues. Other areas are finding contact with local supermarkets variable and it is also time consuming to contact them.

### **Working with supermarkets to make carers aware of support:**

Action for Carers Surrey developed a poster which signposts carers to support. They have contacted supermarkets locally who have agreed to display them.



### **What could be kept and built on going forward? Could a Carers Passport in your local area help carers in the future?**

Our feedback from carers is that identification matter to many. Proof of identity as a carer has become even more important during COVID-19. The letter/card/identification remains one of the most important questions that Carers UK receives through its helpline and we are signposting to local organisations, some of whom have their own local systems in place.

If local areas have not established a Carer Passport scheme (they are called different things in different areas e.g. Carers Discount Card in Durham), this would have added benefits to those already identified going forward. Carers in Herts scheme is one of the most well developed and established. Because the application involves a short interview, it means that they quickly get a picture of the carers' situation and can then develop the appropriate level of support. Find out more here: [www.carerpassport.uk/](http://www.carerpassport.uk/)

**Tell us what you are doing to help unpaid carers on these topics:**

[policy@carersuk.org](mailto:policy@carersuk.org)

## **Recommendations and next steps**

From the evidence presented Carers UK has been recommending the following:



**Carers identification to enable unpaid carers to access local supermarkets and local convenience stores:** Carers Northern Ireland worked with their Department for Communities on a Carers ID card which is now being delivered by Health and Care Trusts across Northern Ireland<sup>5</sup>.

**A commitment from supermarkets and other food shops to implement the following:**

- Recognition of unpaid carers within current policies and action by supermarkets and other food shops to give priority access
- Understanding of disability and the challenges people face in shopping and specific measures to counter this.
- Prioritising online delivery for those most in need including parents of children with highly specific eating as a consequence of disability – where they eat a very narrow range of specific foods.

**Stronger messages about carers and disabled people's needs throughout supermarket chains into local stores to help embed local practice.** This would help local implementation. Local carers' organisations are trying to work with local supermarkets are having very variable and patchy take-up. There are some very positive experiences, but not the universal coverage they need to see. Stronger messages throughout supermarkets would help support this community effort.

**Volunteering schemes, both NHS Responders and locally arranged schemes responding to carers who are unable to shop themselves will continue to be important going forward.** Ensuring that carers can be referred by local organisations or directly themselves has been important for the NHS Responders.

**Positive and sustained promotion locally of sources of help with clarity about local systems** – it is clear that carers have been confused about where to turn and systems are not wholly clear to the organisations who are part of them. Some carers are clearly overwhelmed, getting little support, in poor mental health and don't know where to turn. As around one third of carers start caring every year, some will be new to needing this help as their situation changes.

**Food poverty amongst carers is an issue with increasing costs.** Some carers are among a vulnerable population who are financially poor, often have health issues and are also time poor. Carers and the people they care for need to continue to be considered a priority.

**Local authority Emergency Assistance Grant for Food and Essential Supplies.** Carers who have seen increased costs and struggling to access and afford food should be a priority group for local authorities when distributing the local authority Emergency Assistance Grant for Food and Essential Supplies.

**Young carers and young adults are also a key group.** Identification as outlined above will help young people under 18 shopping on behalf of a family member. With different local ID schemes in England, again, it will be important to ensure that young carers are able to shop for their families.

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<sup>5</sup> <https://www.health-ni.gov.uk/sites/default/files/publications/health/advice-for-carers-during%20-vovid19.pdf>

**The issue of income and those in receipt of carers' and disability benefits which have not risen during COVID-19 continues to be an issue.** Carers UK welcomed the Government's swift action to increase Universal Credit to help deal with additional costs during the crisis. However, legacy benefits, such as Carer's Allowance and disability benefits, have not increased. These additional costs outlined above are extremely worrying and are placing additional challenges on carers. We are calling for a short-term increase to match the Universal Credit rises and a longer term increase in Carer's Allowance.

## About Carers UK

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Across the UK there are 6.5 million carers, but could be as many as 8.8 million. We are run by carers, for carers. We have a membership of over 30,000 members, an Affiliate network of 300 mostly local organisations, run an employer-led Forum, Employers for Carers, with over 150 employers in membership. As well as a robust research and engagement programme with carers to highlight their experiences such as the State of Caring series, we look at the best practice to support carers. With our nation colleagues in Carers Wales, Carers Scotland and Carers Northern Ireland we constantly innovate to find new solutions to supporting carers, such as developing one of the first apps to help carers to organise care, Jointly. We share good practice where we find it.

## Contact us

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