

International examples of measures to support unpaid carers during the COVID-19 pandemic

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Corrections and comments are welcome at info@ltccovid.org. This document was last updated on 20 May 2020 and may be subject to revision.

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Key points:

- Voluntary sector provides tangible support
- Several countries have developed guidance documents to support family carers
- Lack of recognition that unpaid carers need to get goods for people with care needs
- Existing financial support mechanisms in some countries continue, only one country so far has increased support for family carers during the COVID-19 pandemic
- Emergency support structures in case the family carer becomes unable to provide care have been addressed in some countries
- Technological interventions, such as helplines and online carer groups but also the provision of tele-health have been newly established and/or expanded.

1. Introduction

This document provides examples of policy and practice measures that have been adopted internationally to support unpaid carers in caring for a person with long-term care needs during the COVID-19 pandemic. The information has been gathered, mostly, from the country reports on the COVID-19 long-term care situation published in the LTCcovid.org website.

This is a “live” document that will be updated regularly and expanded as more information becomes available. Comments, updates, suggestions and additional information are very welcome, please email k.h.lorenz@lse.ac.uk.

While this first version simply aims to list the measures described in the current country reports, future versions will also seek to cover early evidence (as and when it becomes available) of the success and impact of those measures in supporting unpaid carers.

2. Background

Across countries, many family members and friends take on the responsibility to support a person with care needs. In Germany, there are an estimated 4.7 million¹, in England there are around 5.4 million² and in the United States there are more than 41 million unpaid carers³, to give just few examples. Already before the COVID-19 pandemic these family carers have carried large responsibility and received limited support. It is estimated that unpaid carers save the care system in England around £132 billion⁴ and in the United States about \$470 billion⁵.

¹ http://www.gbe-bund.de/gbe10/abrechnung.prc_abr_test_logon?p_uid=gast&p_aid=0&p_knoten=FID&p_sprache=D&p_suchstrin g=21301

² <https://www.england.nhs.uk/commissioning/comm-carers/carer-facts/>

³ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁴ <https://www.nice.org.uk/news/article/unpaid-carers-need-more-support-to-cope-with-financial-and-emotional-stress>

⁵ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

Around the world, the costs of care are disproportionately carried by women and people with low socio-economic status.

In some countries, family carers can access in-kind and/or financial support, such as carer allowance or respite care. People with care needs can also get support interventions, such as paid domiciliary carers, respite care or day care interventions, that may also benefit the unpaid carer by giving them a break from their care responsibilities. Government support for people with care needs and for their family carers is usually needs tested and often means tested.

The COVID-19 pandemic has led to many community services, such as day care centres, closing. This means that the care responsibility for people with long-term care needs, across countries, has been handed to family carers.

Carers UK have conducted an online survey among 5,000 current and former family carers during the COVID-19 pandemic. The results among family carers in the United Kingdom show that a large proportion (70%) are providing more care because of the pandemic. Around a third report that their care responsibility has increased due to closure of community services. Almost 40 per cent express concern around their financial situation and over half of survey respondents agreed that they 'feel overwhelmed and [...] worried that [they're] [...] going to burnout in the coming weeks.'⁶

The increased responsibility among unpaid carers, who are often frail themselves and in need of support, has also been reported in Germany. Particularly older spouse carers, who usually can get some support from other family members now find themselves mostly on their own as their family members are not allowed to visit. Some families in receipt of domiciliary care are concerned about the risk of the care worker or home health aide carrying the virus and have cancelled these services.⁷ Similarly, families relying on migrant workers may find themselves without their usual support if the carer is unable to travel.⁸ In Italy it has even been reported that family carers had difficulties purchasing food and medication for the people they support.⁹

Across countries, politicians have recognised the importance of family carers to sustain the support for people with care need. For example, the English Action Plan reads '*we [...] recognise the crucial role unpaid carers play, especially during this difficult period. They make an invaluable difference to the lives of the people they support and are an integral part of our health and social care system.*'¹¹

⁶https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

⁷<https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁸https://ltccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-6-May-2020.pdf

⁹<https://www.ndr.de/nachrichten/schleswig-holstein/coronavirus/Pflege-zu-Hause-in-Corona-Zeiten-sehr-belastend,pflegendeangehoerige102.html>

¹⁰<https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID19-situation-in-Italy-30-April-2020.pdf>

¹¹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/ovid-19-adult-social-care-action-plan.pdf

Yet, constructive policies that support family carers financially or that offer emergency support structures, should the family care become unable to care, are largely lacking. It appears that in most countries innovative support structures responding to the COVID-19 situation are frequently developed by the voluntary sector. Examples are virtual carer groups, support calls or guidance documents. However, these services are likely to be only available in small local areas and it is unclear how they will be sustained given the financial implications of the pandemic.¹² This is likely to be particularly problematic in low- and middle-income countries.¹³

3. Demands

Some of the country reports (Brazil¹⁴, England¹⁵, United States¹⁶) covered in this document included demands to support family carers from interest groups and academics. Here we present them together:

- *Clearer guidance*
Family carers need to be able to easily access relevant and clearly communicated information.
- *Prioritise testing*
Family carers are worried that they may bring COVID-19 to the person they support, especially if they live away from the person they care for and may not be able to stay home or stop working.
- *Help with contingency planning for emergency situations*
Many family carers are worried about what would happen to the person they support if they become unable to provide care. The COVID-19 pandemic has meant that some supportive services, such as day or respite care, had to be cancelled. Sometimes domiciliary carers are no longer able to provide their support. Family carers need information and support to identify available alternative care arrangements, how they can prepare for this situation and how they can communicate the needs and preferences of the person they care for.
- *Access to PPE for family carers*
Many family carers provide personal care and may support more than one person with care needs. They are worried about exposing the person(s) they care for to COVID-19 should they themselves become infected. Family carers should be prioritised in access to PPE if sufficient supply for the health and long-term care workforce is available.
- *Increase of financial support*
Even before the COVID-19 pandemic many family carers have felt the economic consequences of not being able to work due to their care responsibility. For some carers

¹² <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

¹³ <https://ltccovid.org/2020/04/10/supporting-people-living-with-dementia-and-their-carers-in-low-and-middle-income-countries-during-covid-19/>

¹⁴ <https://ltccovid.org/wp-content/uploads/2020/05/COVID-19-Long-term-care-situation-in-Brazil-6-May-2020.pdf>

¹⁵ https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

¹⁶ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

the COVID-19 pandemic has meant that they had to give up working to avoid exposing the person with care needs to the risk of a COVID-19 infection, or because the usual care support enabling to maintain their job is no longer available. Households may have reduced income because the main earner has a reduced income or lost their job due to the economic consequences of the pandemic. Family carers are providing vital support for people with care needs and deserve appropriate financial recognition.

- *Recognition of the main family carer on medical notes of the person with care needs*
Family carers often provide an important constant in the life of a person with care needs. If main family carers would be recognised in medical notes, they could be an important source of information for the health and long-term care workforce. It would also empower family carers to support the person with care needs or to speak on their behalf if they themselves should not be able to (e.g. carers may be able to communicate the preferences of people with care needs such as on food, music, etc but also around end-of-life support), which could improve their quality of life.
- *Increased funding for remote support interventions*
The distancing measures implemented around the world have meant that family carers, many of whom already experience social isolation due to their care responsibility, had to stop attending carer groups and other interventions that support their well-being. Some organisations have moved their services online. Increased funding could support family carers during the pandemic and in the long-run to be less socially isolated, to participate in meaningful and effective activities and to improve their well-being.

4. Types of measures

It is important to note that in this document we bring together evidence of guidance from different countries. We are aware that they may not necessarily have been implemented yet (fully). We will update this document as evidence emerges.

4.1. Guidance and resources for unpaid carers

In most countries, governments and advocacy organisations have put together guidance and resource documents. These documents usually capture information on hygiene measures to prevent a COVID-19 infection, advice on how to respond if the person receiving and/or providing develops COVID-19 related symptoms but also on how unpaid carers may be able to support the specific needs of the person they care for, such as addressing anxiety caused by the disruption of their normal routine or how to address loss and grief. Some resource documents offer suggestions for meaningful activities with the person with care needs and approaches to reduce the impact of social isolation.

Guidance and resources for unpaid carers

Austria: various guidance and resource documents have been published.

Brazil: Disease specific associations, such as The Brazilian Society of Geriatrics and Gerontology and the Brazilian Alzheimer Association, have provided technical and educational guidance. The National

Institute for Health Care Research developed a guidance booklet on how unpaid carers can protect themselves and the person they support and how to control the spread of respiratory viruses.

England: The government issued guidance for unpaid carers and for unpaid carers of people with learning disabilities and autistic adults. Guidance offers advice if the person they care for or the unpaid carer themselves develop symptoms of COVID-19.

Ireland:

- The Dementia Services Information and Development Centre, Ireland's national centre for excellence in dementia, has responded to the crisis by developing a collection of resources to support family carers and mitigate the impact of social isolation on people with dementia. A selection of meaningful activities for people with dementia, families and carers has been compiled into a booklet by an occupational therapist attached to a Memory Technology Resource Room (MTRR).
- The Alzheimer Society of Ireland provides ongoing and up-to-date information and support for carers of people with dementia during the pandemic. So too does the Dementia Services Information and Development Centre (DSIDC), which provides resources aimed at addressing social isolation among carers of people with dementia during the pandemic
- The ASI provides tip sheets to help support people with dementia and their families during COVID-19 and lists supports available from organisations in Ireland during COVID-19.⁶⁷

The Netherlands: The government recently issued guidelines for informal carers. These guidelines include advice on hygiene standards and guidelines on how a caregiver should act if their care-recipient develops symptoms of COVID-19

United States: To help provide reassurance and support to your patients and their families, the CDC has guidance for those living with serious illness, and their caregivers.

4.2. Virtual support and interventions

Some countries report virtual interventions to enhance people's ability to maintain social contacts. The government of Australia, for instance, invested \$10m into the Community Visitors Scheme. Particularly voluntary support organisations appear to have taken the lead to providing their usual in-person interventions online. In Austria and Ireland, training for unpaid carers has been moved online. Examples from Austria, Hong Kong, Ireland and the United States show organisations facilitating games and carer support groups online. There are also examples of countries where carers can access dedicated psychological support virtually or per telephone. In addition, a number of countries have set up or expanded telephone helplines for unpaid carers.

Virtual support to facilitate social contact

Australia: \$10M has been allocated to the Community Visitors Scheme (CVS), focusing on telephone and virtual friendships to older socially isolated people

United States: At a community-level or an individual health system level, there are also many small scale caregiver support programs are trying to help caregivers of institutionalized loved ones connect with their family members through video calls such as FaceTime.

Germany (Bavaria): A telephone support service (Silvernet) has been set up for lonely and isolated people.

Virtual interventions

Austria: self-help through online support networks,

Hong Kong: Some NGOs such as Hong Kong YWCA Elderly Service are using videos to guide sensory stimulating activities at home for maintaining cognitive function and boost moral for older people and their carers at home. Activities include games that target visual, olfactory, tactile, auditory and taste stimulation. Other NGOs such as Christian Family Service Centre have introduced an online 'daily anti-epidemic exercise' for older people and family members during the period of home isolation.

Ireland: Care Alliance Ireland have set up an online Family Carer Support Group through the Facebook platform in a closed private group format. This initiative is facilitated by a number of health and social care professionals with social work and counselling qualifications, as well as by volunteer current and past carers sharing their experience

United States: At a community-level or an individual health system level, there are also many small scale caregiver support programs that are adapting during the pandemic, moving services to virtual support calls, reaching out to caregivers, It is unclear how these voluntary and community-programs are faring during the pandemic since they are often not implemented on a large scale.

Psychological support

Austria: The national Chamber of Commerce has set up a telephone line that family carers can call for psychological support.

China: Psychological support services for older people requiring care and their family carers were strengthened, with prompt assessment and intervention

Brazil: The Ministry of Health and PAHO published videos to support people's mental health during the pandemic

Ireland: For example, the government's mental health and well-being initiative launched on 11 April to support the diverse mental health needs of all people during COVID-19 may be especially relevant and timely for family during the pandemic

Virtual training

Austria: The Austrian Red Cross offers an online course for unpaid carers

Ireland: Its online family carer training is still running.

Helplines

Austria: The government increased the capacity of telephone hotlines to support family carers and to point people to relevant services.

England: The government provided additional funding to the Carer UK helpline offering information and advice for unpaid carers.

Germany: In Bavaria unpaid carers are referred to the 110 offices for unpaid carers that have been in place for 20 years. Neutral Advice is available via telephone and email free of charge and during extended hours. There is also a helpline for carers experiencing violence or conflict.

. The Senate of Berlin has provided a list of sources of support and advice for family carers.

Ireland: Alzheimer Society of Ireland is continuing to support people with dementia and their families through its National Helpline. Dementia Advisers are available to work with and provide information to people with dementia and their family carers. The ASI has introduced a new service through its National Helpline offering people with dementia or family carers a 1:1 telephone or video conference call with a Dementia Nurse or a Dementia Adviser.

4.3. Emergency support structures in case the unpaid carer can no longer provide care

In England and Ireland carers are encouraged to develop an emergency plan with information on the specific needs and preferences of the person they support. In China, people without available unpaid carers either receive home-based care or temporary residential care.

Emergency support structures

China: Older people who live alone, with intensive care needs, or whose family carer is in quarantine or is a healthcare worker were provided with a service such as home-based or temporary residential care

England: Unpaid carers are encouraged to develop an emergency plan together with the person they care for.

Ireland: Family Carers Ireland have produced information and advice for carers across their platforms including how to prepare an emergency care plan should family carers be unable to continue to care during the crisis.

4.4. Financial support

Unpaid carers, as outlined above, incur a number of costs. Some countries have put measures in place that provide some financial support for unpaid carers. In England and Ireland, for example, carers may be able to access carer allowance following an assessment. In both countries eligible carers continue to receive this financial support. While access to carer allowance and similar benefits is tied to employment restrictions, eligible working carers in both countries can receive Pandemic Unemployment Payment (Ireland) or to be furloughed (England). In addition, employees with care responsibilities are entitled for the furlough scheme to respond to care needs, which enables them to maintain 80% of their income.

Similarly, in Germany a number of financial support strategies are available for unpaid carers. For example, employees can take leave to ensure or organise replacement care in emergency situations. Carers are also allowed to reduce their working hours due to care responsibilities and can access an interest-free loan to support their living cost while they are on a reduced income. These regulations remain in place.

People with care needs in Germany can receive funding to reimburse the support of recognised neighbourhood support. In some federal states the requirements to enter the scheme have been relaxed during the COVID-19 pandemic. Furthermore, in the Federal State of Brandenburg people can receive financial support for telephone support, which may also support their unpaid carers.

In addition, the federal government implemented a law to respond to the COVID-19 pandemic, which recognises that family carers require extra support by extending the length of support of some of the existing measures.

In Slovenia pensioners with a low income can apply for a one-off solidarity payment. This may also support unpaid carers.

Financial support

England: Unpaid carers can be furloughed by their employers, which enables them to maintain 80% of their income. Some carers may also be eligible for carer allowance or other care related benefits¹⁷.

Germany: On 14 May the federal government agreed the second law for the protection of the population during an epidemic situation of national significance (*zweites Gesetz zum Schutz der Bevölkerung bei einer epidemischen Lage von nationaler Tragweite*). This law includes additional provisions for unpaid carers

- Under normal circumstance family members can receive up to 10 days financial support to compensate for a loss of income if a sudden care need emerges within the family and the person needs to organise care in the community (If the carer does not continue to receive their pay during their care leave, they can apply for care support through long-term care insurance. This amounts to 90 per cent of the lost income (after tax)). The new law will apply until 30 September 2020 and will provide family carers with care support money (*Pflegeunterstützungsgeld*) for up to 20 days in situations where a gap in the community care their relative normally receives occurs.
- The right to stay away from work due to an acute care situation within the own family will also be extended from 10 to 20 days until 30 September 2020. Additional measures to make the caregiver leave act (*Pflegezeitgesetz*) the family care leave act (*Familienpflegezeitgesetz*) more flexible to respond to the pandemic are being undertaken.¹⁸

In addition, existing measures are available to support unpaid carers.

¹⁷ <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/benefits-for-carers/>

¹⁸ <https://www.bundesgesundheitsministerium.de/covid-19-bevoelkerungsschutz-2.html>

- People with care needs are entitled to financial support (€125 per month) to purchase services through recognised sources of support and neighbourly help (§ 45 b SGB XI). *North-Rhine Westphalia* has eased the requirements for reimbursable neighbourhood help. The person providing neighbourhood support does not need to provide a certificate until 30.9.2020. In *Saxony* people wishing to provide reimbursable neighbourhood support do not need to complete the usually required course (until 30 September 2020).
- The caregiver leave act also allows employed family carers to reduce their employment to 15 hours. Employees can maintain this arrangement for up to 24 months. In addition, they have access to an interest-free loan to cover their costs during this period.
- In *Brandenburg* people with care needs (until 31.05.2020) can receive financial support for services they receive over the phone. This may also benefit unpaid carers.

Ireland: Those family carers who qualify for the means tested Carers Allowance will continue to receive payment for care during the crisis – this payment is paid to people on low incomes looking after a person who needs support due to illness, disability or age. The allowance enables carers to engage in paid market work of up to 18.5 hours per week. The new Pandemic Unemployment Payment of €350 introduced by the government for all workers losing their job will be paid to those carers who may have lost their part-time job as a result of COVID-19, on top of the Carers Allowance

Slovenia: A one-off solidarity allowance has been announced, this will pay a one-off payment to 328,780 pensioners with low pensions, which will be paid in three different amounts (300 EUR, 230 EUR and 130 EUR), depending on the amount of their pension. The deadline for submitting applications for the recognition of rights under the Parental Protection and Family Benefits Act and for exercising rights from public funds is being extended. The validity of all entitlements from public funds (financial social assistance, care allowance, child benefit and others expiring on or after 31 March) is renewed monthly for one month.

4.5. Healthcare providers given responsibilities to support unpaid carers

Guidance from the Netherlands advises that general practitioners should take a monitoring role with their frail and homebound patients and become a case-manager if they develop COVID-19 related symptoms.

In the United States the Care Act means that unpaid carers should be recorded on each patient file. However, van Houtven, Boucher & Dawson (2020) explain that this may not universally be implemented.

Healthcare provider responsibilities

The Netherlands: Guidelines advise that general practitioners (GPs) play an important role in supporting unpaid carers. GPs should closely monitor those who are homebound and frail and should act like a case-manager when they develop COVID-19 symptoms.

United States: Expansion of home-based tele-health is being used by home health agencies. US states passed the CARE Act, model legislation requiring US hospitals and health systems to document a caregiver within everyone's health record.

4.6. Support with navigating restrictions

Many countries have imposed lockdowns and physical distancing measures. In several countries the number of people allowed to enter a shop or the hours in which people can go shopping have been restricted. In addition, several countries experienced problems with the supply of certain goods and had to restrict the quantity of specific items that could be purchased. This can be particularly problematic for unpaid carers who cannot necessarily leave the person they support own their own or who have to go shopping for more than one household.

In England this issue has been recognised. Unpaid carers are supposed to receive a letter that enables them to identify themselves and their needs to retailers.

Support for carers navigating restrictions

England: The Action Plan suggests that local commissioners will be asked to provide letters that allow unpaid carers 'to identify themselves and their needs' to retailers and other relevant service providers.

4.7. COVID-19 testing for unpaid carers

Access to testing varies considerably between countries. Especially in countries where testing is scarce many family carers would welcome having tests for COVID-19.

Testing of unpaid carers

England: On 7 May the government announced that unpaid carers would now be included in the group of people who could access testing if they present relevant symptoms¹⁹

¹⁹ [https://contact.org.uk/news-and-blogs/covid-19-testing-now-available-for-unpaid-carers-\(1\)/](https://contact.org.uk/news-and-blogs/covid-19-testing-now-available-for-unpaid-carers-(1)/)

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