



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 17 June 2020 and may be subject to revision.

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Key points:

- The responsibility of many unpaid carers has increased during the COVID-19 as their usual support networks (e.g. day care, respite care, home care, other unpaid carers) are no longer available or can only provide support at reduced capacity
- Voluntary sector is providing tangible support across countries
- Most countries report virtual support interventions for unpaid carers
- Many countries provide unpaid carers with guidance and resource documents
- Existing financial support mechanisms continue in a number of countries, but there is limited evidence of new or additional financial support measures being put in place to support unpaid carers during the COVID-19 pandemic
- Lack of recognition that unpaid carers need to get goods for people with care needs and support with navigating other restrictions to be able to provide care
- There is limited recognition that unpaid carers need support with contingency planning
- There is limited recognition that unpaid carers need access to testing and PPE

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](https://lccovid.org) as well as from a ‘rapid’ review of evidence.

This is a “live” document that is 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.

This version aims to list the measures described in the current country reports and starts to cover early evidence (as and when it becomes available) of the success and impact of those measures in supporting unpaid carers. This will be explored further in future iterations.

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

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_suchstring=21301

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.

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

In some countries, family carers can access in-kind and/or financial support, such as carer allowances 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 even more care responsibility for people with long-term care needs, across countries, has been handed to family carers. An online survey of 5,000 current and former family carers in the United Kingdom conducted during the COVID-19 pandemic by Carers UK found that there has been an overall increase in the time spent caring. The results 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. Similar issues have been identified in Australia. A report highlighted that mutual support structures, such as grandparents providing childcare, adult children taking their parents to appointments if they are unable to do so themselves or neighbourly check-ins, have all been affected.⁷

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.^{8,9} Similarly, families relying on migrant workers may find themselves without their usual support if the carer is

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

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

⁷ <https://nationalseniors.com.au/uploads/NSA-ResearchReport-Whocares.pdf>

⁸ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁹ https://ltccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-6-May-2020.pdf

unable to travel.¹⁰ In Italy it has even been reported that family carers had difficulties purchasing food and medication for the people they support.¹¹

Across countries, politicians have recognised the importance of family carers to sustain the support for people with care needs. For example, the English COVID-19 Adult Social Care 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.'*¹²

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.¹³ This is likely to be particularly problematic in low- and middle-income countries.¹⁴

3. Demands

In some of the country reports (Brazil¹⁵, England¹⁶, Germany¹⁷, India¹⁸, Indonesia¹⁹, Jamaica²⁰, Malta²¹, Mexico²², the Netherlands²³, South Korea²⁴, the United States²⁵) covered in this document, a number of demands to support family carers have been formulated. Here I present them together:

¹⁰ <https://www.ndr.de/nachrichten/schleswig-holstein/coronavirus/Pflege-zu-Hause-in-Corona-Zeiten-sehr-belastend,pflegendeangehoerige102.html>

¹¹ <https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID19-situation-in-Italy-30-April-2020.pdf>

¹² https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

¹³ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

¹⁴ <https://ltccovid.org/2020/04/10/supporting-people-living-with-dementia-and-their-carers-in-low-and-middle-income-countries-during-covid-19/>

¹⁵ <https://ltccovid.org/wp-content/uploads/2020/05/COVID-19-Long-term-care-situation-in-Brazil-6-May-2020.pdf>

¹⁶ https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

¹⁷ https://ltccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-6-May-2020.pdf

¹⁸ <https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID-situation-in-India-30th-May.pdf>

¹⁹ <https://ltccovid.org/wp-content/uploads/2020/06/The-COVID-19-Long-Term-Care-situation-in-Indonesia-30-May-1.pdf>

²⁰ <https://ltccovid.org/wp-content/uploads/2020/05/The-COVID-19-Long-Term-Care-situation-in-Jamaica-25-May-2020-1.pdf>

²¹ <https://ltccovid.org/wp-content/uploads/2020/06/LTC-covid-situation-in-Malta-6-June-2020.pdf>

²² <https://ltccovid.org/wp-content/uploads/2020/06/LTC-Covid-19-situation-in-Mexico-8-June.pdf>

²³ <https://ltccovid.org/wp-content/uploads/2020/05/COVID19-Long-Term-Care-situation-in-the-Netherlands-25-May-2020-1.pdf>

²⁴ <https://ltccovid.org/wp-content/uploads/2020/05/The-Long-Term-Care-COVID19-situation-in-South-Korea-7-May-2020.pdf>

²⁵ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

- *Identification of unpaid carers*
 In many countries unpaid carers are not recognised for the care and support they provide. In order for support to become accessible the role of unpaid caregivers must be destigmatised so that carers can be identified.
- *Training and capacity building*
 Unpaid carers should be provided with information and training opportunities to enhance their ability to provide good quality care and to look after their own well-being.
- *Information and data on unpaid carers*
 There is an absence of information/data on the situation of unpaid carers as well as on the situation of people receiving care by family members. The lack of information is of particular concern for people providing and receiving unpaid care in crowded environments, such as in illegal settlements, favelas etc.
- *Clearer guidance*
 Family carers need to be able to 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 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, support more than one person with care needs and 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.
- *Access to services*
 As unpaid carers carry responsibility for the wellbeing of many people with care needs, it is important that unpaid caregivers can continue to access healthcare services throughout crisis situations, such as the COVID-19 pandemic, to support them in their ability to continue to provide care. It is also important that carers can access shops other services and that services providers recognise that unpaid carers sometimes need flexibility in how they access services.
- *Development and expansion of support structures for unpaid carers*
 In some countries no formal LTC systems have so far been established. As these systems develop, support structures for unpaid carers should be integrated into the network of services emerging. In existing systems, support structures for unpaid carers should be expanded so that all unpaid carers can access relevant services.

- *Provision and expansion 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. The COVID-19 pandemic has meant for some carers that they had to give up working to not risk 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. Household 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 and protection.
- *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 and robust evaluations could support family carers not just during the pandemic, but also in the long run to be less socially isolated, to participate in meaningful and effective activities and to improve their well-being. Funding should also be used to expand carers' access to telephone and internet connections.
- *Perspective of a COVID-19 'exit strategy' for unpaid carers*
While other people are starting to emerge stepwise from lockdown, people providing and receiving care find it difficult to continue to shelter at home and are looking for guidance on how to safely reconnect with their social contacts.

A report by National Seniors Australia compares the role of unpaid carers in the COVID-19 pandemic in their report to that of the 'rural fire service in national fire protection' but point out that carers do not receive the same level of acknowledgement or funding (including funded support structures and information). The report, based on findings from a survey among carers demands improvements in practical assistance including respite care options, in 'social, emotional, and psychological support' for people receiving and providing care, in financial assistance and subsidies for services, in transparency regarding carer assessments and in the training requirements for the long-term care workforce. ²⁶ (page 39)

²⁶ <https://nationalseniors.com.au/uploads/NSA-ResearchReport-Whocares.pdf>

4. Types of measures

It is important to note that this document brings together evidence of guidance and interventions from different countries. We are aware that they may not necessarily have been implemented yet (fully) or that the information on services available to family carers may not cover all support services available across the countries. This includes that some of the measures we have listed here may also be available in countries where we did not highlight this information as it may not have been picked in the country reports on which this report is based. We will update this document as more evidence emerges.

In the table below you can find an overview of the type of measures available to support family carers in the different countries. Many countries (n=12 out of 19 countries) have put in place services to provide family carers with information around COVID-19. In most countries the use of virtual support interventions has been reported (n=16). When developing this overview, the importance of virtual support to facilitate social contact, to offer structured interventions, such as psychological support, physical exercises or virtual training became apparent.

While many family carers are likely to benefit from these measures, some shortfalls have been identified. Reports from Kenya and Finland pointed towards the shortfalls of relying on virtual support. Family carers may not necessarily have access to an internet connection or do not have the relevant technical knowledge to operate the technological devices. With lockdown measures in place it is difficult for family carers to access support that shows them how to use the relevant technologies. Furthermore, the report from Finland added that some carers do not like virtual support groups as they cannot tell who might be listening to the conversation. This may be especially the cases if people share sensitive information and do not want the family member of other carers to listen to their experience or worries.^{27,28} Finally, the report from the United States highlights that it is quite likely that only a small proportion of family carers benefits from virtual support programmes as many are unlikely to access the often small-scale programmes.²⁹

Several countries also provide financial support structures (n=8) and some have recognised the importance of emergency support structures (n=3) as well as support for unpaid carers in navigating restrictions (n=3). Others have given healthcare providers responsibility to support people receiving and providing unpaid care (n=2) and have given unpaid carers access to testing and PPE (n=2).

²⁷ <https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Long-Term-Care-in-Kenya-30-May.pdf>

²⁸ https://ltccovid.org/wp-content/uploads/2020/06/ltccovid-country-reports_Finland_120620.pdf

²⁹ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

Table: Overview of types of measures to support family carers in 19 countries

	Australia	Austria	Brazil	China	England	Finland	Germany	Hong Kong	India	Indonesia	Ireland	Jamaica	Kenya	Malaysia	Malta	The Netherlands	Slovenia	Spain	The United States	Σ
Guidance and resources	X	X	X		X	X			X	X	X		X			X		X	X	12
Virtual support and interventions	X	X	X	X	X	X	X	X	X		X	X	X	X	X			X	X	16
Emergency support structures				X	X						X									3
Financial support					X		X			X	X		X				X	X	X	8
Healthcare providers responsibility																X			X	2
Support with navigating restrictions					X				X			X								3
COVID-19 testing (and PPE)					X											X (PPE)				2

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

Australia: The My Aged Care Information website and phone service that also provides information for family carers received \$12.3m extra funding.³⁰

Austria: various guidance and resource documents have been published.³¹

Brazil: NGOs, 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. In addition, the Ministry of Women, Family and Human Rights provide a dedicated website with information around COVID-19 for people with rate conditions and disabilities and their family carers.³²

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-19.³³³⁴

Finland: Carers Finland and member associations provide information around COVID-19 for family carers.³⁵

India: The National Institute for Empowerment of Persons with Intellectual Disabilities provides information for people with disabilities and their families around COVID-19. NGOs working to support people with dementia have provided guidelines for family carers. The Nightingales Medical Trust further has produced the DemKonnnect app to provide family carers with expert advice during the COVID-19 pandemic.³⁶

³⁰ <https://ltccovid.org/wp-content/uploads/2020/04/Australia-LTC-COVID19-situation-24-April-2020.pdf>

³¹ <https://ltccovid.org/wp-content/uploads/2020/06/The-COVID-19-Long-Term-Care-situation-in-Austria-15-May-1.pdf>

³² <https://ltccovid.org/wp-content/uploads/2020/05/COVID-19-Long-term-care-situation-in-Brazil-6-May-2020.pdf>

³³ <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>

³⁴ <https://www.gov.uk/government/publications/covid-19-providing-unpaid-care-to-adults-with-learning-disabilities-and-autistic-adults>

³⁵ https://ltccovid.org/wp-content/uploads/2020/06/ltccovid-country-reports_Finland_120620.pdf

³⁶ <https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID-situation-in-India-30th-May.pdf>

Indonesia: all televised official press conferences are now supported by Indonesian sign language interpreters to make the information more accessible for people, including for family carers.³⁷

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-19.³⁸

Kenya: Family carers have been provided with telephone numbers to contact in case the person they care for develops COVID-19 symptoms.³⁹

The Netherlands: The government recently issued guidelines for informal carers. These guidelines include advice on hygiene standards and guidelines on how a care-giver should act if their care-recipient develops symptoms of COVID-19.⁴⁰

Spain: Town halls (e.g. Madrid, Gandía) offer booklets and guidelines for family carers. NGOs (e.g. Fundación Matía⁴¹, Plena Inclusión, Federación de Mujeres Rurales) also provide information and infographics for family carers. In addition, online advice, leaflet and guidance for family carers of people with dementia has been developed by institutions (e.g. the Spanish Neurology Society, the Hospital Universitario Central de Asturias), some municipalities and NGOs (e.g. The Fundación Matía).⁴²

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.⁴³

Help Age International: Information on how family carers can protect themselves and the person they support. Information on how to support a person with care needs if they develop symptoms of COVID-19. Information on how to support the well-being of the person with care needs. Specific advice for family carers of people living with dementia. Suggestions for family carers on how to maintain their own well-being.⁴⁴

³⁷ <https://ltccovid.org/2020/03/25/report-from-indonesia-improved-access-to-covid-19-information-required-for-people-living-with-a-disability/>

³⁸ <https://ltccovid.org/wp-content/uploads/2020/05/Ireland-COVID-LTC-report-updated-13-May-2020.pdf>

³⁹ <https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Long-Term-Care-in-Kenya-30-May.pdf>

⁴⁰ <https://ltccovid.org/wp-content/uploads/2020/05/COVID19-Long-Term-Care-situation-in-the-Netherlands-25-May-2020-1.pdf>

⁴¹ <https://www.matiafundazioa.eus/es/documentacion-covid-19>

⁴² <https://ltccovid.org/wp-content/uploads/2020/05/LTCcovid-Spain-country-report-28-May-1.pdf>

⁴³ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁴⁴ <https://www.helpage.org/what-we-do/covid19-guidance-and-advice-for-carers-of-older-people-at-home/>

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 moving their usual in-person interventions online. In Austria and Ireland, training for unpaid carers has been moved online. Examples from Austria, Hong Kong, Ireland, United States show examples 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 and interventions

Australia: \$10M has been allocated to the Community Visitors Scheme (CVS), focusing on telephone and virtual friendships to older socially isolated people⁴⁵

Austria: The national Chamber of Commerce has set up a telephone line that family carers can call for psychological support. There are also self-help through online support networks and the Austrian Red Cross offers an online course for unpaid carers. In addition, the government has increased the capacity of telephone hotlines to support family carers and to point people to relevant services.⁴⁶

Brazil: Some NGOs have initiated psychosocial activities that can also support family carers (e.g. the Brigades (Brincada de Apoio and Brincada da Educação), the Age Knitting (Tecer Idades). Furthermore, a mental health campaign (through online videos) to support people during the COVID-19 has been issued by The Ministry of Health, in collaboration with PAHO. This may also benefit family carers. There is also support for people with specific needs. For example, some NGOs (e.g. the Alzheimer's Association) have established helplines for family carers (of people living with dementia).⁴⁷

China: Psychological support services for older people requiring care and their family carers were strengthened, with prompt assessment and intervention. Interdisciplinary teams including mental health professionals support people with suspected and confirmed COVID-19 as well as those who recovered and their families in the province of Hubei and other areas that were heavily affected by COVID-19.⁴⁸

England: The government provided additional funding to the Carer UK helpline offering information and advice for unpaid carers.⁴⁹

⁴⁵ <https://ltccovid.org/wp-content/uploads/2020/04/Australia-LTC-COVID19-situation-24-April-2020.pdf>

⁴⁶ <https://ltccovid.org/wp-content/uploads/2020/06/The-COVID-19-Long-Term-Care-situation-in-Austria-15-May-1.pdf>

⁴⁷ <https://ltccovid.org/wp-content/uploads/2020/05/COVID-19-Long-term-care-situation-in-Brazil-6-May-2020.pdf>

⁴⁸ <https://ltccovid.org/wp-content/uploads/2020/04/Report-from-Mainland-China-18-April-final.pdf>

⁴⁹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

Finland: Carers Finland have provided telephone support for family carers during the COVID-19 pandemic. They also offered virtual peer or individual support. However, some, especially older carers, were unable to access these services due to a lack of technical equipment or internet access.⁵⁰

Germany: A telephone support service (Silvernet) has been set up for lonely and isolated people in Bavaria. In addition, unpaid carers in Bavaria are being 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 experience violence or conflict. The Senate of Berlin has provided a list of sources of support and advice for family carers.⁵¹

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 the Christian Family Service Centre, have introduced an online 'daily anti-epidemic exercise' for older people and family members during the period of home isolation.⁵²

India: The Ministry of Health and Family Welfare provides online medication and yoga videos and offers advice for people on how to support their own mental health as well as that of people they support. The Ministry of Health and Family Welfare also operates a psychosocial behavioural helpline. Furthermore, some states (e.g. Telangana) provide free helplines for older people and people with disabilities during the lockdown period. In addition, some NGOs (e.g. Alzheimer's Related Disorder's Society of India (ARDSI), Nightingales Medical Trust (NMT), Silver Inning's) that usually operate day care centres are reaching out family carers via social media platforms and offer virtual/telephone counselling as well as virtual carer support groups.⁵³

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. Furthermore, 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. Online family carer training continues to run. The Alzheimer Society of Ireland is also 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.⁵⁴

Jamaica: NGOs (e.g. Caribbean Community of Retired Persons) and academic groups (e.g. Mona Ageing and Wellness Centre and the STRiDE project (Strengthening Responses to Dementia in

⁵⁰ https://ltccovid.org/wp-content/uploads/2020/06/ltccovid-country-reports_Finland_120620.pdf

⁵¹ https://ltccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-26-May-2020.pdf

⁵² <https://ltccovid.org/wp-content/uploads/2020/04/Hong-Kong-COVID-19-Long-term-Care-situation-27-April-2020-1.pdf>

⁵³ <https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID-situation-in-India-30th-May.pdf>

⁵⁴ <https://ltccovid.org/wp-content/uploads/2020/05/Ireland-COVID-LTC-report-updated-13-May-2020.pdf>

Developing Countries) provide family carers of people with dementia with education as well as telephone or video consultation.⁵⁵

Kenya: In Kenya some NGOs have moved to virtual peer support. However, poor connectivity in some areas, costs of purchasing internet bundles and online fatigue pose challenges to efforts to support family carers.⁵⁶

Malaysia: Day care centre staff continues to be able to provide virtual support to the people they support through video calls as well as share activities and exercise videos. This may allow family carers some breaks from their care responsibility or enable the care dyad to engage together in meaningful activities.⁵⁷

Malta: Restrictions on usual service provision led the Dementia Intervention Team to maintain contact with family carers through telephone calls.⁵⁸

Spain: The Andalusian cooperative Macrosad provide family carers with psychological telephone support. In addition, many NGOs (e.g. Alzheimer Associations) offer support for family carers through telephone and videoconferencing.⁵⁹

United States: At a community-level or on individual health system level, there are also many small-scale caregiver support programs are trying to help caregivers of people living in residential care settings to connect with their family members through video calls such as FaceTime. Other interventions, such as virtual support calls, to support unpaid carers have also been put in place. It is unclear how these voluntary and community-programs are faring during the pandemic since they are often not implemented on a large scale.⁶⁰

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.⁶¹

⁵⁵ <https://ltccovid.org/wp-content/uploads/2020/05/The-COVID-19-Long-Term-Care-situation-in-Jamaica-25-May-2020-1.pdf>

⁵⁶ <https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Long-Term-Care-in-Kenya-30-May.pdf>

⁵⁷ <https://ltccovid.org/wp-content/uploads/2020/05/Malaysia-LTC-COVID-situation-report-30-May.pdf>

⁵⁸ <https://ltccovid.org/wp-content/uploads/2020/06/LTC-covid-situation-in-Malta-6-June-2020.pdf>

⁵⁹ <https://ltccovid.org/wp-content/uploads/2020/05/LTCCovid-Spain-country-report-28-May-1.pdf>

⁶⁰ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁶¹ <https://ltccovid.org/wp-content/uploads/2020/04/Report-from-Mainland-China-18-April-final.pdf>

England: Unpaid carers are encouraged to develop an emergency plan together with the person they care for.⁶²

Ireland: Family Carers Ireland have produced information and advice for carers across their platforms including how to prepare an emergency care plan, as a contingency, should family carers be unable to continue to care during the crisis.⁶³

Help Age International: Information on how to prepare for situations if the family carer becomes unable to provide care and support.⁶⁴

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. 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.

In addition, people with care needs are entitled 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. In addition, in the Federal State of Brandenburg people can receive financial for telephone support, which also may support their unpaid carers

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 benefits⁶⁵.

⁶² <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>

⁶³ <https://ltccovid.org/wp-content/uploads/2020/05/Ireland-COVID-LTC-report-updated-13-May-2020.pdf>

⁶⁴ <https://www.helpage.org/what-we-do/covid19-guidance-and-advice-for-carers-of-older-people-at-home/>

⁶⁵ <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/benefits-for-carers/>

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.⁶⁶

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

- 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.⁶⁷

Indonesia: A change in the age eligibility (from 60 to 70 years) for the Family Hope Program in December 2019 has meant that an estimated 518,000 householders with older people have lost access to the support scheme, according to the think tank Perkumpulan Prakarsa. Some social assistance programmes (e.g. food assistance, subsidized contribution to the National Health Insurance, free or subsidised electricity bills) have been put in place during the COVID-19 pandemic that may also support family carers. The Ministry of Social Affairs will also pay IDR 15 million for each heir of people who died of COVID-19 to provide social assistance. In addition, the Ministry of Social Affairs aims to increase the number of beneficiaries of social security programmes for older people from 9.2 million to 10 million to as a response to the COVID-19 pandemic.⁶⁸

⁶⁶ <https://www.bundesgesundheitsministerium.de/covid-19-bevoelkerungsschutz-2.html>

⁶⁷ https://itccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-26-May-2020.pdf

⁶⁸ <https://itccovid.org/wp-content/uploads/2020/06/The-COVID-19-Long-Term-Care-situation-in-Indonesia-30-May-1.pdf>

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.⁶⁹

Kenya: The Ministry of Labour and Social Protection offers an Older Persons Cash Transfer for one person aged 60 and older per household. By 2019 833,129 households have received Cash Transfer support. During the COVID-19 pandemic that amount received was increased by 12 billion Kenya shillings to enable the most vulnerable people to afford food.⁷⁰

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.⁷¹

Spain: Family carers can access cash allowances through the *Prestación Económica para Cuidados en Entorno Familiar (PCEF)*. Since 18 March 2020 care workers who also carry family care responsibility are entitled to request an adjustment or reduction of their work (including a proportional adjustment of their income) to be able to respond to changing needs in their role as family carers. People who qualify as financially vulnerable and family carers can apply to plan MECUIDA which provides the opportunity for a mortgage debt moratorium.⁷²

United States: In some states, family carers can be paid through self-directed Medicaid funds. Some states have additional financial support programmes for carers (e.g. Hawaii) or offer tax credits. In addition, Veterans Affairs is supporting military personnel through caregiver stipends and direct support (for more than 40,000 family carers over the past 10 years).⁷³

4.5. Healthcare providers given responsibilities to support unpaid carers

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

⁶⁹ <https://ltccovid.org/wp-content/uploads/2020/05/Ireland-COVID-LTC-report-updated-13-May-2020.pdf>

⁷⁰ <https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Long-Term-Care-in-Kenya-30-May.pdf>

⁷¹ <https://ltccovid.org/wp-content/uploads/2020/04/COVID19-and-Long-Term-Care-in-Slovenia-impact-measures-and-lessons-learnt-21-April-2020.pdf>

⁷² <https://ltccovid.org/wp-content/uploads/2020/05/LTCCovid-Spain-country-report-28-May-1.pdf>

⁷³ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

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.⁷⁴

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. Recording the main family carer may enable important communication around preferences of the person with care needs and end of life wishes.⁷⁵

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 on 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.⁷⁶

India: Guidelines recommended that family carers should be issued with travel passes during the lockdown so that they can commute to the person they support.⁷⁷

Jamaica: Following lobbying from the Caribbean Community of Retired Persons family carers were permitted to travel during the curfew if they can produce the relevant paperwork.⁷⁸

⁷⁴ <https://ltccovid.org/wp-content/uploads/2020/05/COVID19-Long-Term-Care-situation-in-the-Netherlands-25-May-2020-1.pdf>

⁷⁵ <https://ltccovid.org/wp-content/uploads/2020/04/USA-LTC-COVID-situation-report-24-April-2020.pdf>

⁷⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf

⁷⁷ <https://ltccovid.org/wp-content/uploads/2020/05/LTC-COVID-situation-in-India-30th-May.pdf>

⁷⁸ <https://ltccovid.org/wp-content/uploads/2020/05/The-COVID-19-Long-Term-Care-situation-in-Jamaica-25-May-2020-1.pdf>

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 & access to protective equipment

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 symptoms⁷⁹

The Netherlands: All family care caregivers that experience symptoms of COVID-19 can get tested (since 18 May). In addition, family carers can access free PPE from 19 May if they support vulnerable people (70 years and older, with chronic conditions) who experience symptoms of COVID-19 and where personal care (with less than 1.5 metres distance) is required.⁸⁰

5. Discussion

The COVID-19 pandemic has highlighted the importance of unpaid carers. Even before the COVID-19 pandemic the support structures available for unpaid carers have been patchy, but since the onset of the COVID-19 pandemic many carers have been providing care non-stop without their usual support structures. The survey conducted by Carers UK showed that over half of carers interviewed felt overwhelmed and worried about burning out over the next few weeks. Unpaid carers in the survey also voiced financial concerns⁸¹.

The voluntary sector has been found to have responded quickly to the distancing requirements introduced across countries by providing people receiving and providing care with information and by moving support services where possible online or to provide them over the phone. Some governments have also set up and expanded telephone and virtual support structures and developed guidance and information material. As discussed above, access to telephone and internet connections as well as the costs involved can post a barrier to access for unpaid carers.

In several countries financial support mechanisms were available for unpaid carers before the COVID-19 pandemic. These services continue to be in place throughout the COVID-19 pandemic and some countries (Germany and Spain) have also extended existing financial support structures recognising the additional responsibility and pressure unpaid carers experience during this time.

⁷⁹ [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)/)

⁸⁰ <https://itccovid.org/wp-content/uploads/2020/05/COVID19-Long-Term-Care-situation-in-the-Netherlands-25-May-2020-1.pdf>

⁸¹

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

England and Ireland have recognised that in a situation where the usual support networks may not be available for people providing and receiving unpaid care, it would be useful to develop contingency planning in case the main unpaid carer should become unable to continue their care responsibility. However, the planning remains the unpaid carers responsibility and it is unclear whether there is any practical support available. Only in China we have found evidence of a system where home-based care or temporary residential care was reported to replace unpaid care if the family carer was unable to care. Similarly, two countries (the Netherlands and the United States) have enabled healthcare to provide telecare visit or have given GPs responsibility to monitor the health of people providing and receiving care.

Infection prevention has been another aspect where unpaid carers received limited support. Even though it has been recognised that unpaid carers may themselves be and/or care for people who may be particularly vulnerable to a COVID-19 infection there has been limited practical support in enabling unpaid carers to access PPE or testing. Only in two countries carers specifically were specifically given access to testing (England and the Netherlands) and only in the Netherlands are carers able to access PPE free of charge, however, only if they provide personal care to a person displaying symptoms.

Finally, restrictions put in place around traveling, access to shops or quantity of items that can be purchased can pose challenges for unpaid carers who may not be able to leave the person they support, who have to purchase goods for more than one household or who need purchase a greater quantity of specific products to support the specific needs of the person they care for. Some countries (India & Jamaica) have given unpaid carers travel permits to enable them to travel to the person they support during lockdown, while others (England) have lobbied retailers to provide unpaid carers with extra support.