End-of-life support for people in care homes in the context of COVID-19: international report

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Corrections and comments are welcome at info@ltccovid.org. This document was last updated on 1 May 2020 and may be subject to revision.

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Please note that this is report will be updated on a regular basis. It is written based on the information we were able to identify on this topic. We invite comments on this report including where information are not accurate or dated. In addition, we are inviting people with an interest in this area to become involved as co-authors in future updates of the report (contact Annette Bauer, a.bauer@lse.ac.uk).

1. Key points

- Up to half of COVID-19 deaths occur in care homes; all people dying of COVID-19 should have access to palliative care.
- Palliative care has an important role to play in the response to COVID-19, in order to ensure that people dying as a result of COVID-19 – including care home residents - do so with dignity, with emotional support available and free of pain.
- Countries have primarily focused measures in care homes on the prevention or control of the infection rather than on palliative care. Most care homes are unprepared for the pandemic and not all are well-positioned to provide palliative care to their residents in this context.
- Whilst most countries have developed national or local guidance for health and social care staff on palliative care, in many countries this is not setting-specific or is contradictory and inconsistent; lack of personal protective equipment for staff and/or visitors and palliative care medication have been major barriers to ensuring a good quality of death for care home residents; financial measures to support palliative care providers have also varied between countries (leaving some providers potentially unable to support care homes in a timely way).
- The COVID-19 crisis has exposed the weaknesses of many health and social care systems, including the under-staffing and under-funding of care homes and palliative care.
- We have not found data publicly available for any of the COVID-19 outbreak countries on how many people received adequate palliative care at end of life. This kind of information will be essential in order to understand the performance of health and social care systems in terms of whether equitable care was provided for those reaching the end of life during the COVID-19 pandemic.

2. Palliative care needs in care homes

2.1. COVID-19 care home mortality

Data from Europe and Canada suggest that care home residents have so far accounted for about half of the deaths related to COVID-19[1]. In the UK, around 410,000 older people currently live in what are altogether about 11,300 care homes[2]. On 14th April, between half and two-thirds of these long-term care facilities reported that they have residents who are infected[3]. It has been estimated that at least a quarter of those in care homes, in which there is an outbreak, will die because of the virus[4]. There is uncertainty about the number of deaths linked to COVID-19 in care homes in the UK, the latest estimates from official sources suggest

[1] https://ltccovid.org/wp-content/uploads/2020/04/Mortality-associated-with-COVID-26-April-1.pdf
[2] https://www.gov.uk/government/publications/care-homes-market-study-summary-of-final-report/care-homes-market-study-summary-of-final-report
[3] https://www.ft.com/content/574ca84a-e735-4e42-8faf-62c641953efc
[4] https://www.ft.com/content/574ca84a-e735-4e42-8faf-62c641953efc

that since the beginning of the year to the 17th April there had been 3,096 deaths in care homes linked to COVID-19[5] and that between the 10th and 24th of April 4,343 deaths[6] had been reported to the Care Quality Commission. Data from other countries in Europe and from Canada suggest similar trends. In contrast, COVID-19 case numbers and death rates have been low so far in Australia and in Hong Kong, where there have been no infections reported in care homes thus far[7]

In pandemics, the resources of health and social care systems are steered towards preventing new infections, and providing treatment and care for those infected and thus towards saving lives.[8] Less focus is on how to ensure that those dying receive the palliative care they need. Deaths in a pandemic occur rapidly and systems are challenged to provide best care, including palliative care. Without access to palliative care people are less likely to die with dignity, pain free, and with necessary emotional and spiritual support. Some countries have made it clear that all dying COVID-19 patients should have access to palliative care including care home residents.[9]

2.2. Number of people receiving palliative care in care homes

The World Health Organisation defines palliative care as, *'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'* [10] Palliative care is sometimes also called supportive care and is part of end of life care. Palliative care is aimed at improving quality rather than quantity of life (although it can be provided alongside disease-modifying treatments). It includes pain and symptom control, hands-on nursing care or personal care, practical and emotional support as well as advance care planning[11].

At the moment, there are no reliable data available for any country on how many people receive adequate palliative care before death, but it is generally thought to be less than those who need it (although defining need is challenging)[12]. Figures can also refer to formal or

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5 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending17april2020

6 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/numberofdeathsincarehomesnotifiedtothecarequalitycommissionengland

7 https://ltccovid.org/wp-content/uploads/2020/04/Hong-Kong-COVID-19-Long-term-Care-situation-27-April-2020-1.pd

8 https://www.jpsmjournal.com/article/S0885-3924(09)01143-9/fulltext

9 https://smw.ch/article/doi/smw.2020.20233

10 https://www.who.int/cancer/palliative/definition/en/

11 https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/

12 https://uk.reuters.com/article/us-health-palliative-nursing-homes/nursing-home-residents-eligible-for-palliative-care-often-dont-get-it-idUKKBN1DL28S

specialist palliative care provision, whereas many care home workers will provide some form of care that is palliative in nature as part of regular practice. Nonetheless, even under normal conditions and in well resourced systems, not everyone who needs palliative care, receives it. In the UK, which is ranked highest in the world in quality of death due its advanced hospice network and statutory involvement in end of life care[13], it has been estimated that about half of those who need palliative care, receive specialist palliative care, while another 25% are estimated to receive palliative care from generalist providers such as general practitioners and care home staff[14]. In the US, about 60% of hospitals offer specialist palliative care but provision in care homes is much lower.[15] In Canada, a nationally representative study found that only about 3% of care home residents had a record of receiving palliative care – and that people with dementia were less likely to receive palliative care compared to people dying of cancer[16]. In Australia, a study found that only around 4% of care home residents receive specialist palliative care.[17] In Europe, it is estimated that in some countries including France, Sweden and Switzerland the majority of care home residents receive palliative care at end of life, whilst rates are 20% or lower in Iceland, Austria and Spain and less than 5% in many Eastern European countries.[18]

There is a concern that in the context of a pandemic, palliative care provision may be even less adequate. Evidence from past experiences of pandemics[19] [20] and anecdotal evidence from this pandemic suggest that many people are dying without having their palliative care needs fully met. In an open letter to the Secretary of Health and Social Care, Alzheimer's UK and other organisations reported: *"We're seeing people [in care homes] being abandoned to the worst that coronavirus can do. (…) they are told they cannot go to hospital, routinely asked to sign Do Not Resuscitate Orders, and cut off from their families when they need them most."* [21]

3. Role of care homes in providing palliative care

Although originating with the hospice movement,[22] palliative care has traditionally come to be seen as the responsibility of health care systems, commonly with a focus on hospitals. However, this is changing in many countries as the number of people dying in the community (in care homes and at home) increases. In addition to achieving a better quality of death,

[13] https://eiuperspectives.economist.com/healthcare/2015-quality-death-index
[14] https://www.pssru.ac.uk/pub/4962.pdf
[15] https://uk.reuters.com/article/us-health-palliative-nursing-homes/nursing-home-residents-eligible-for-palliative-care-often-dont-get-it-idUKKBN1DL28S
[16] https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0480-z
[17] https://onlinelibrary.wiley.com/doi/epdf/10.1111/ajag.12480
[18] https://www.eapcnet.eu/Portals/0/adam/Content/xwkGGSw2ykCLpHNMPZRxkA/Text/WP1_EAPC%20report%20Feb_25_2016.pdf
[19] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30822-9/fulltext
[20] https://www.jpsmjournal.com/article/S0885-3924(09)00950-6/fulltext
[21] https://www.alzheimers.org.uk/news/2020-04-14/our-letter-secretary-state-health-and-social-care
[22] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282179/

palliative care provided in care homes has been linked to potential reductions in unplanned and emergency hospital admissions, and overall cost savings[23].

Care homes are defined as long-term care facilities that serve older populations who need access to personal care and other therapeutic and support services, and includes facilities that provide 24-hours nursing care. In many high resource settings, care homes are already a common place of death (e.g. in England about a fifth and in Australia about a third die in care homes)[24] [25], and this is expected to become even more so the case as people continue to live longer with many requiring 24-hours support, often in the context of dementia. In the U.S, it is estimated that by 2030 more than three million people will reside in care homes and that 40% of all deaths will occur in care homes.[26] In many countries the provision of palliative care in care homes has received increasing attention over the past ten years or so.[27] [28]

The following measures to improve palliative care provision in care homes have been called for by researchers, practitioners and national associations in most countries, whilst in some countries, states or regions some of these measures have been already introduced.

- National and regional policies, programmes and guidelines to support the provision of palliative care in care homes [29] [30]
- Harmonisation of payment and regulation standards to include palliative care[31]
- Contracts between care homes and hospice agencies or other external palliative care providers [32]
- Palliative care as part of the training curriculum for care home staff [33]
- Palliative care core competencies for care home staff [34]
- On-the-job training tools and educational and professional development [35]

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[23] https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/07/PCA019_Economic-Research-Sheet_4a_RACFs.pdf

[24] http://endoflifecareambitions.org.uk/wp-content/uploads/2017/08/Care-Homes-Survey-Report-August-2017.pdf

[25] https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/07/PCA019_Economic-Research-Sheet_4a_RACFs.pdf

[26] https://www.apcp.com.pt/uploads/guideall.pdf

[27] https://www.bgs.org.uk/blog/are-care-homes-the-hospices-of-the-future

[28] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/828120/Briefing_1_Care_home_provision_and_potential_end_of_life_care.pdf

[29] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/828134/Infographic_The_role_of_care_homes_in_EoLC.pdf

[30] https://palliativecare.org.au/palliative-care-in-aged-care

[31] http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf

[32] http://endoflifecareambitions.org.uk/wp-content/uploads/2017/08/Care-Homes-Survey-Report-August-2017.pdf

[33] https://palliativecare.org.au/palliative-care-in-aged-care

[34] https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2017/08/09/new-report-highlights-the-role-of-specialist-palliative-care-support-to-care-homes-in-delivering-high-quality-end-of-life-care

[35] http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf

- Introduction of palliative care standards into quality monitoring of care homes [36] [37]
- Palliative care data in care homes as part of national minimum data sets and reporting[38] [39]

However, whilst there are movements in the direction suggested by these measures, there have been also many barriers to progress. These include high staff turnover, recruitment challenges, lack of resources, and lack of legislation or regulation. [40]

4. Palliative care responses under COVID-19

4.1. United Kingdom

Supporting care home staff

Care home staff are likely to play a major role in providing end of life support in the context of the COVID-19 public health crisis. In addition to working with specialist palliative care teams (where those are available), it is recommended by the British Geriatrics Society (BGS) that they work with, and receive support, from community healthcare staff and community geriatricians.[41] This includes working together on reviewing advance care plans as a matter of urgency, and on meeting palliative care requirements. The BGS recommends the use of tools like RESTORE2 to identify deterioration, the National Early Warning Score (NEWS) to guide responses, and SBAR tool (situation, background, action, recommendation) to communicate concerns with external healthcare professionals.[42]

In addition to the many guidance documents and resources on palliative care in response to COVID-19 for all health and social care professionals published by the National Institute for Health and Care (NICE), Royal Colleges of General Practitioners and of Nursing, NHS England, Public Health England, Association for Palliative Medicine and third sector organisations such as Marie Curie[43], the BGS has developed specific guidance and recommendations for care home staff and healthcare staff working with care homes to support them through the pandemic.[44] The importance of close collaboration between General Practitioners (GPs) and care homes is emphasised in order to achieve continuity of care for those with end of life care needs.[45] Multi-professional support networks are also seen by the BGS to have an important role in supporting care home staff through the current crisis. The BGS guidance also refers to a national COVID-19 online care home community of practice, emerging as the initiative of a leading geriatrician and

[36] https://nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf
[37] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5754324/
[38] http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf
[39] https://palliativecare.org.au/palliative-care-in-aged-care
[40] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30822-9/fulltext
[41] Ibid
[42] Ibid
[43] https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/covid-19#covid-19
[44] https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes
[45] Ibid

organised via Whatsapp, which care home staff are encouraged to join.[46] It also refer to a Facebook page hosted by the Queens Nursing Institute specifically to support care home registered nurses.[47]

Access to personal protective equipment, testing and medication

However, care homes are reporting that they feel unsupported to deal with the crisis, in particular due to insufficient and delayed supply of personal protective equipment, testing toolkits and medication.[48] Access to specialist palliative care support might not always possible, and care home staff are advised to hold stock of medication that will be needed for managing pain and symptoms as people die[49]. However, this might not always be feasible due to a lack in stock and challenges in the supply chain. The government introduced a medicines reuse scheme on the 28th April, which applies only during the pandemic, and allows care homes to re-use medicines that are no longer needed by the person for whom they were originally prescribed.[50] However, this requires supervision from a registered healthcare professional, who needs to check the suitability for reuse. NICE advises that when prescribing and supplying anticipatory medicines to "take into account potential waste, medicines shortages and lack of administration equipment by prescribing smaller quantities or by prescribing a different medicine, formulation or route of administration when appropriate".[51] They also advise that in case of staff shortages, different medications might need to be prescribed that can be administered by carers or family members.[52]

The Health Secretary stated on 15th April that it is unacceptable for treatment-limiting advanced care plans, including 'do not attempt to resuscitate' orders, to be completed without a personalised process. A personalised process is also required with regard to communicating decisions taken by a doctor about appropriate end-of-life care treatment options, and discussing options for treatment with the person dying, or where capacity is lacking, their surrogate[53]. However, it is not clear how this can always be realised in situations where decisions have to be made quickly, or where certain treatment options are not available (either because of the COVID-19 specific circumstances, or for other reasons).

The Health Secretary also announced that no person should die in the pandemic without having had the chance to say their goodbyes to relatives. However, care home providers made it clear that without sufficient personal protective equipment, such promises made at the national

[46] Ibid
[47] Ibid
[48] https://www.ft.com/content/574ca84a-e735-4e42-8faf-62c641953efc
[49] https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes
[50] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881838/medicines-reuse-in-care-homes.pdf
[51] https://www.nice.org.uk/guidance/ng163/chapter/9-Prescribing-anticipatory-medicines-for-patients-with-COVID-19
[52] Ibid
[53] https://www.theguardian.com/world/2020/apr/15/families-to-be-allowed-to-say-goodbye-to-dying-relatives-in-care-homes

level could not be kept, in practice.[54] On 14th April it was reported that 7.8 million pieces of personal protective equipment had been delivered to over 26,000 care settings.[55] On 17th April, extra supplies were delivered to more than 1,000 care homes in Scotland.[56]

Hospice (funding)

At the same time, hospices, which are important providers of specialist palliative care, reported on 28th March that they faced substantial financial uncertainty as they were not able to secure their regular funding, which comes to a large extent from charity shops and fundraising events.[57] On 28th April the government responded to this, announcing an allocation of 25 million pounds to hospices to enable them to support an additional 200,000 people at the end of life.[58]

4.2. Australia

Supporting care home staff

Palliative Care Australia has formed the Australian COVID-19 Palliative Care Working Group (ACPCWG). A wide range of national associations are part of the group including the national Specialist Palliative Care and Advance Care Planning Advisory Service (known as Decision Assist) and the End of Life Direction for Aged Care (ELDAC).[59] [60] As part of the ACPCWG response to the COVID-19 pandemic, CareSearch, a palliative care knowledge exchange network, has created a resource hub for health and social care professionals as well as patients and carers.[61]

Some state governments (of regions most strongly affected by the virus) have published additional guidance. For example, the state of Victoria published their COVID-19 plan for the aged care sector. [62] The Victorian guidance states that palliative care physicians or other palliative care workers are allowed to visit care homes. A specific guidance document has also been developed by the State Government of Victoria for care home staff on how to recognise and respond to a person at the end of life in the context of COVID-19.[63] It states that advance care plans should be reviewed and that care should be focused on comfort, as transition to hospital and use of intensive care are unlikely to be appropriate. Specific guidance is also

[54] https://www.theguardian.com/world/2020/apr/15/families-to-be-allowed-to-say-goodbye-to-dying-relatives-in-care-homes
[55] https://www.ft.com/content/574ca84a-e735-4e42-8faf-62c641953efc
[56] https://www.bbc.co.uk/news/uk-scotland-52333608
[57] https://www.itv.com/news/2020-03-28/hospices-issue-dire-warning-of-closures-as-coronavirus-sparks-cutbacks-in-end-of-life-care/
[58] https://www.gov.uk/government/news/prime-minister-announces-25-million-cash-boost-for-hospices-to-secure-their-future
[59] https://www.health.qld.gov.au/__data/assets/pdf_file/0040/947965/2020-0317-Covid19-PCA-statement.pdf
[60] https://palliativecare.org.au/covid-19-updates
[61] https://www.caresearch.com.au/caresearch/tabid/5982/Default.aspx
[62] https://www.dhhs.vic.gov.au/aged-care-sector-coronavirus-disease-covid-19
[63] https://www.dhhs.vic.gov.au/recognising-and-responding-at-the-end-of-life-COVID-19

available on how to carry out advance care planning in care homes in the context of the COVID-19 public health crisis.[64]

Access to personal protective equipment, testing and medication

Since, in Australia, cases of Covid-19 infection are relatively few compared to other countries, it is not surprising that there is, as yet, no reporting of staff or equipment shortage.

Telehealth

The Australian government has developed plans for specialist palliative care providers to provide fewer face-to-face direct consultations and to focus instead on supporting other generalist practitioners looking after patients with COVID-19 by providing advice and guidance[65]. Plans also exist to optimise the role of telehealth, including improved access to smart phones for community palliative care nurses. As of 13th March, new Medicare Benefits Schedule telehealth items have been introduced so that telehealth can be reimbursed. This support plans by the ACPCWG to increase the use telehealth free of charge to people with palliative care needs.[66]

4.3. United States (U.S.)

Supporting care home staff

In the U.S., a wide range of guidance documents and resources have been published by various professionals associations and networks for health and social care professionals to support them in providing palliative care to those dying during the crisis.[67] Guidance has also been produced by the Social Work Hospice and Palliative Care Network for social work professionals, some of which are providing palliative care to care homes.[68] The guidance suggests that visitors are still allowed to visit the care home in end of life situations but be limited to a specific room.[69] The guidance also states that hospice workers are allowed to enter facilities[70]. However, frontline social workers working in hospice and palliative care report that they are struggling to respond to frequently changing and inconsistent hospital visitation policies, and that they lack guidance on how to enter facilities without putting themselves or others at risk.[71] State-specific guidance, including from Missouri,[72] sets out that care homes should work with hospice agencies to ensure that residents' needs are met.

[64] https://www.dhhs.vic.gov.au/recognising-and-responding-at-the-end-of-life-COVID-19
[65] https://insightplus.mja.com.au/2020/11/integrating-palliative-care-into-covid-19-planning/
[66] https://www.health.qld.gov.au/__data/assets/pdf_file/0040/947965/2020-0317-Covid19-PCA-statement.pdf
[67] https://www.nationalcoalitionhpc.org/covid19/
[68] https://www.swhpn.org/covid-19
[69] https://www.nhpco.org/wp-content/uploads/Nursing_Home_Guidance_Hospice_Workers.pdf
[70] Ibid
[71] https://swhpn.memberclicks.net/assets/Allie%20Shukraft%20COVID19.mp4
[72] https://health.mo.gov/safety/homecare/pdf/guidance-hospice-care-ltc-facilities.pdf

Access to personal protective equipment, testing and medication

U.S. care homes widely report insufficient availability of personal protective equipment and medication to manage pain and symptoms (such as morphine). [73] Care homes are advised to initiate advance care planning discussions as early as possible. [74] Whilst many care home residents and/ or their carers may understand the risks and burdens of hospitalisation and the low chances of benefitting from intensive care, such discussions need to be carried out ideally before people become unwell[75]. Palliative care professionals have also discussed the introduction of guidelines that allow staff to potentially deviate from standard life-saving procedures and observance of the end of life care wishes of patients, where there presents a high risk of infection to nurses and doctors, in particular in cases of shortage of personal protective equipment.[76] Government guidance has also been developed to help health and social care practitioners without specialist palliative care knowledge to provide pain management medication, including a section on how to deal with medication shortages.[77] [78]

Hospice and telehealth

Hospice care providers (which, in the US, provide end of life care largely in peoples' own homes) are encouraged to use telehealth to make decisions about admissions, thus potentially freeing up capacity of staff and reducing the risk of Covid-19 infection. However, since hospices do not receive their normal rates for this service (because they do not provide the service as specified and telehealth cannot always be reimbursed) this puts them potentially at financial risk.[79] Many hospices are overburdened according to the National Hospice and Palliative Care Organization.[80]

4.4. Europe

Supporting care home staff

In many European countries, various guidelines have been produced to prepare and support frontline health and social care practitioners in providing basic palliative care. The European Association for Palliative Care provides an overview of various resources.[81] A range of toolkits have now been developed to help health and social care practitioners provide pain

[73] https://medicaring.org/2020/03/28/pragmatists-advice/
[74] Ibid
[75] https://medicaring.org/2020/03/28/pragmatists-advice/
[76] https://ltccovid.org/category/end-of-life-care/
[77] Ibid
[78] https://www.cms.gov/files/document/4220-covid-19-long-term-care-facility-guidance.pdf
[79] https://www.forbes.com/sites/nextavenue/2020/04/10/hospice-demanded-but-threatened-by-covid-19/#cf691e37e265
[80] https://www.forbes.com/sites/nextavenue/2020/04/10/hospice-demanded-but-threatened-by-covid-19/#cf691e37e265
[81] https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response

management medication, which include sections how to deal with medication shortages.[82] As is the case for the above countries, there is also available guidance on communication with those dying and their families, and on advance care planning.[83]

The experiences from at least some regions in Italy have shown that specialist palliative care staff in hospices were not always sufficiently informed about the risk of COVID-19 infection, how to deal with this when looking after patients, and how to protect themselves.[84] In Spain, on 24th March, it was reported that care residents were left abandoned, dying or dead in their beds as care home staff were unable to cope with the situation.[85] In many European countries legal enquiries are made into care home deaths during COVID-19.[86] [87]

The experience in Italy, also highlighted the importance of case conferences and similar multi-disciplinary team discussions so that providers can collectively decide, effectively and quickly, where and how to focus their limited resources.[88] Some palliative care teams also organised a 24-hour hotline, which provided advice for all people reaching end of life and their families, hospitals and care homes.

Access to personal protective equipment, testing and medication

The lack of personal protective equipment in addition to lack of medication and lack of setting-specific guidance were identified as the most challenging problems affecting care homes' ability to respond effectively to the crisis, and to ensure effective palliative care provision. [89] [90] The lack of equipment in Spain prevented the collection of bodies. [91]

In German speaking countries (Austria, Germany and Switzerland) guidance from the professional body for geriatricians published guidance that all pharmacological measures must be adapted to what is feasible in each setting.[92] For example they state that prescriptions should be made in advance and it must be ensured that drugs together with the equipment required for their administration is available on site.[93] Supply problems are not mentioned.

Telehealth

Some countries have started to implement additional technological platforms to ensure that health needs of those with serious illness are met while reducing risk of Covid-19 infection.[94]

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[82] https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response
[83] https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response
[84] https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf
[85] https://www.bbc.co.uk/news/world-europe-52014023
[86] https://www.nzz.ch/international/coronavirus-in-italien-spitaeler-und-altersheime-als-todeszone-ld.1551236
[87] https://www.focus.de/panorama/welt/jetzt-23-tote-in-pflegeheim-schon-23-covid-tote-in-wolfsburger-altenheim-anwalt-legt-nach-und-beantragt-beweissicherung_id_11839932.html
[88] Ibid
[89] https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf
[90] https://www.jpsmjournal.com/article/S0885-3924(20)30182-2/fulltext?mobileUi=0
[91] https://www.bbc.co.uk/news/world-europe-52014023
[92] https://www.ncbi.nlm.nih.gov/pubmed/32208497
[93] https://smw.ch/article/doi/smw.2020.20235
[94] https://www.esmo.org/oncology-news/improving-telemedicine-helps-to-minimise-risks-for-cancer-patients

4.5. Canada

Supporting care home staff

In addition to various guidance and resources on palliative care in response to COVID-19 for health and social care professionals[95], federal government published and implemented new guidance for care home staff to manage COVID-19.[96] The guidance, which was last updated on 8th April, states that essential volunteers and visitors are still allowed to enter the care home, which includes end of life support. However, they have to be trained in the use of personal protective equipment. Regional health authorities in Ontario and other provinces have emphasised the importance of advance care planning, and made recommendations to focus on palliative care for the frail elderly. A taskforce of the Alzheimer Society of Canada recommends that persons with dementia who are unable to receive life-sustaining care because of the pandemic should receive good quality palliative care. [97]

On 18th April newspapers reported that – similar to situations in some European countries - a care home in the province of Québec was abandoned by care home staff, who were unable to cope with the situation. It is report that people had been left dehydrated and undernutritioned. [98]

Access to personal protective equipment, testing and medication

Similar to the situation in UK, Europe and the U.S., care homes also do not have enough personal protective equipment or palliative medications, and staff lack appropriate training and are in shortage (reported on 7th April).[99] Lack of testing in care homes has been also well documented.[100] In a recent journal article on the palliative care situation in Ontario during this pandemic authors predict that care homes will be highly understaffed and have undersupply of palliative care medication and personal protective equipment. [101] Ontarios' government announced on 13th April an investment of $133 million for care homes, which is addition to the

[95] https://www.pallium.ca/pallium-canadas-covid-19-response-resources/
[96] https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/prevent-control-covid-19-long-term-care-homes.html
[97] Smith EE, Couillard P, Fisk JD, Ismail Z, Montero-Odasso M, Robillard JM, Vedel I, Sivananthan S, Gauthier S. Allocating Scarce Resources to Persons with Dementia During a Pandemic. Canadian Geriatrics Journal. 2020: in press.
[98] https://www.msn.com/de-at/news/other/31-senioren-in-kanada-tot-pfleger-kamen-aus-angst-vor-corona-nicht/ar-BB12QiDh#image=1
[99] https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M
[100] https://globalnews.ca/news/6811726/coronavirus-long-term-care-deaths-canada/
[101] https://www.cmaj.ca/content/192/15/E400

$243 million spent on testing, personal protective equipment and infection control in affected care homes.[102]

5. Lessons learnt and calls for action

5.1. Short-term calls for action

- Care homes are under extreme pressure as they deal with preventing or controlling the infection; there is overall limited information on how palliative care is provided in care homes to those dying during this pandemic
- Availability of personal protective equipment, anticipatory and other palliative care medication are essential conditions in order for care home residents to die a dignified death, in which pain and symptoms are controlled, and where they can say goodbyes to their families; many countries are struggling to ensure these conditions are met;
- Clear and consistent guidance is equally important; at the moment there are many guidelines and recommendations (some of which are changing over time); coordinated and comprehensive guidance provided by one responsible body (such as a task force) is largely missing.

5.2. Long-term implications

- The COVID-19 crisis has exposed weaknesses in most health and social care systems, with regards to both care home and palliative care capacities;
- There have been calls in most countries, before the crises, to implement measures that ensure high quality palliative care in care home settings; some measures have been implemented by some countries but not consistently; once the acute phase of the crisis has passed, countries should revisit those recommendations, which include training curriculum for care home staff that includes palliative care; quality standards for palliative care in care homes; national monitoring of quality standards and indicators; national minimum data sets that include palliative care in care homes; and clear contract arrangements between specialist palliative care and care homes;
- In addition, it is likely that many countries will want to develop a palliative care pandemic plan; this should centrally include care homes;
- The importance of advance care planning has become particularly evident during this crisis, and it is likely that many countries, in which the provision of advance care planning is currently patchy, will also want to revisit plans for scaling-up implementation

[102] https://globalnews.ca/news/6811726/coronavirus-long-term-care-deaths-canada/

- In many countries, the pandemic has raised awareness of the staff conditions in care homes such as low pay and unsupported work conditions; it is likely to be important for countries to revisit care providers' wages and employment conditions.