



The challenges of providing end-of-life support in care homes during the COVID-19 pandemic, and opportunities for the future: An international perspective

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Corrections and comments are welcome at info@itccovid.org. This document was last updated on 9 June 2020 and may be subject to revision.

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Please note that this 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).

Summary points

- Palliative care has a vital role to play in the response to COVID-19, for relieving pain and other symptoms associated with the condition, particularly breathlessness; for providing emotional and spiritual support; and to ensure dignity in dying.
- There is evidence from media reports that some older people, who died in care homes during the pandemic, did so without adequate basic care, including palliative care. However, the proportion of people of those who died, or continue to die, in care homes with insufficient palliative care is unknown.
- In this paper, we summarise some of the challenges experienced in North America, Europe and Australia during the COVID-19 pandemic with regards to palliative care provision in care homes. We consider these in the context of long-standing challenges with systems of palliative care provision and care home services, highlighting opportunities for change.
- Most countries have focused measures in care homes on the prevention or control of Covid-19 infection rather than on the provision of palliative care, with most care homes poorly-prepared and positioned to provide effective palliative care to their residents.
- Most countries have developed various guidance documents for health and social care staff on palliative care. However, in many countries, guidance is not setting-specific. It is also often patchy in its coverage or inconsistent, and details about how to operationalise recommendations is commonly lacking.
- Lack of personal protective equipment for staff and visitors and shortages of palliative care medications have been major barriers to ensuring effective palliative care and a good quality of death for care home residents.
- The COVID-19 crisis has exposed the weaknesses of many health and social care systems, including the underfunding and understaffing of care homes and palliative care provision. There were already calls in most countries, prior to the current crisis, to scale measures that ensure high quality palliative care in care home settings. Once the acute phase of this crisis has passed, countries should revisit these recommendations, which include training curricula for care home staff that include 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 contractual arrangements between specialist palliative care providers and care homes.

1. Palliative care in the pandemic

In pandemics, the resources of health and social care systems tend to be steered towards preventing new infections, and towards providing life-saving treatment and care for those infected.¹ Less focus is given to 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, relieved of pain and other symptoms, 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.² This includes people living in long-term care facilities such as care homes and hospices. Additionally, calls have made for prioritising people with dementia,³ who comprise a large proportion of care home residents and are a particularly vulnerable population during this pandemic.

However, it is clear from countries that have been particularly hard-hit by the pandemic, that this has not always been achieved. In some cases, people living in care homes have died without access to even basic care, including palliative care, due to abandonment of care facilities. An investigation into deaths in a French care home affected by COVID-19, showed that people were left alone in their rooms without any help or assistance for several days before dying from hypovolemic shock.⁴ The same investigation showed that general practitioners had stopped their physical examination visits days before people died. In Spain, the media reported widely on a number of care home residents who were left abandoned and found dying or dead in their beds.⁵ Similar situations occurred in care homes in the province of Québec in Canada, where people were left dehydrated and undernourished.⁶ In an open letter to the U.K. Secretary of Health and Social Care, Alzheimer's U.K. 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."*⁷ In many of the Western countries affected by the crisis, legal enquiries have been made into care home deaths during the COVID-19 pandemic.^{8 9}

¹ [https://www.jpsmjournals.com/article/S0885-3924\(09\)01143-9/fulltext](https://www.jpsmjournals.com/article/S0885-3924(09)01143-9/fulltext)

² <https://smw.ch/article/doi/smw.2020.20233>

³ 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.

⁴ [https://www.jamda.com/article/S1525-8610\(20\)30354-6/pdf](https://www.jamda.com/article/S1525-8610(20)30354-6/pdf)

⁵ <https://www.bbc.co.uk/news/world-europe-52014023>

⁶ <https://www.msn.com/de-at/news/other/31-senioren-in-kanada-tot-pfleger-kamen-aus-angst-vor-corona-nicht/ar-BB12QiDh#image=1>

⁷ <https://www.alzheimers.org.uk/news/2020-04-14/our-letter-secretary-state-health-and-social-care>

⁸ <https://www.nzz.ch/international/coronavirus-in-italien-spitaeler-und-altersheime-als-todeszone-ld.1551236>

⁹ 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

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 called supportive care and is a part of end-of-life care. It is aimed at improving quality rather than quantity of life, although 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 Advance care planning is an important part of end-of-life care and refers to a process where people who reach the end-of-life, together with their (family) carers, discuss with health and social care professionals their preferences for future care and treatment (e.g. whether they wish to receive life-prolonging treatments in certain circumstances), and who will speak for them if they are unable to speak for themselves. Documents and legal provisions for advance care planning include advance directives, advance statements and power of attorney.¹²

In this document we highlight some of the challenges experienced in countries or states in North America, Europe, and Australia during the COVID-19 pandemic with regards to palliative care provision, with a particular focus on care homes and hospices. We consider these in the context of historic challenges with systems of palliative care and care home services, highlighting opportunities for changes.

2. Main challenges

Lack of personal protective equipment and medication

Insufficient and delayed supply of personal protective equipment and medication presented major challenges for care homes in many of the countries most strongly affected by the pandemic including UK, Italy, Spain, France, U.S. and Canada.^{13 14}

Medication shortage

Stockpiling medication for managing pain towards the end-of-life by health services was an issue discussed for care homes in Canada, U.K. and U.S., resulting in shortages of morphine and other medications reported primarily for Canada and U.S.^{15 1617} The lack of medication was also reported as a major challenge for meeting palliative care needs in Italy.^{18 19} Globally, the lack of

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://itccovid.org/2020/03/31/covid19-proving-palliative-care-for-the-many/>

¹³ <https://www.ft.com/content/574ca84a-e735-4e42-8faf-62c641953efc>

¹⁴ <https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M>

¹⁵ <https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M>

¹⁶ <https://medicaring.org/2020/03/28/pragmatists-advice/>

¹⁷ <https://www.nytimes.com/2020/04/02/health/coronavirus-drug-shortages.html>

¹⁸ <https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf>

¹⁹ [https://www.jpsmjournal.com/article/S0885-3924\(20\)30182-2/fulltext?mobileUi=0](https://www.jpsmjournal.com/article/S0885-3924(20)30182-2/fulltext?mobileUi=0)

availability and limited access to essential medication for palliative care patients during this pandemic has been highlighted as a major issue and threat to human rights violation.²⁰

In England, national bodies such as the national Health Technology Assessment body (National Institute for Health and Care Excellence; NICE) responded to anticipated shortages by advising 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'.²¹ NICE also advises that in case of staff shortages, different medications might need to be prescribed that can be administered by carers or family members.²² Detailed guidance on alternative drugs has been also provided nationally.²³ At the same time, care home managers were advised by the British Geriatrics Society to work with General Practitioners (GPs) and pharmacists, and for them to hold stock of anticipatory medication to meet care homes' palliative care needs²⁴. However, in practice, this has not always been feasible due to a lack of stock and challenges in the supply chain. The government introduced a medicines re-use 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.²⁵ However, since this requires supervision from a registered healthcare professional, who needs to check the suitability for re-use, it is not clear whether this has been always feasible for care homes.

In the U.S., guidance for hospice workers and health care staff in nursing homes by the Centers from Medicare and Medicaid (CMS), National Hospice and Palliative Care Organization (NHPCO) and The Society for Post-Acute and Long-Term Care Medicine did not provide any guidance on stockpiling. However, pragmatic guidance shared within online communities advised care homes to hold stock, and also be looking out for anticipated legal changes that would allow care homes to re-use medication such as opioids of people who no-longer needed it because they died.²⁶ Although not specifically addressing care homes, CVS pharmacy, a large retailer of pharmaceuticals advised against stockpiling medication to prevent further exacerbate supply problems and shortages.²⁷ Whilst guidance by University of Maryland School of Pharmacy set out detailed recommendations on optimising medication management, they do not cover strategies for possible medication shortages to use.²⁸

In Europe, although medicine shortages are dealt with at national level, the European Medicines Association has taken on the role of a central coordinator during the pandemic and

²⁰ [https://www.jpsmjournals.com/article/S0885-3924\(20\)30375-4/fulltext#cebib0010](https://www.jpsmjournals.com/article/S0885-3924(20)30375-4/fulltext#cebib0010)

²¹ <https://www.nice.org.uk/guidance/ng163/chapter/9-Prescribing-anticipatory-medicines-for-patients-with-COVID-19>

²² Ibid

²³ <https://apmonline.org/wp-content/uploads/2020/04/priority-meds-for-end-of-life-care-290420-final-2.pdf>

²⁴ <https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes>

²⁵ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881838/medicines-reuse-in-care-homes.pdf

²⁶ <https://medicaring.org/2020/03/28/pragmatists-advice/>

²⁷ <https://www.nytimes.com/2020/04/02/health/coronavirus-drug-shortages.html>

²⁸ https://www.pharmacy.umaryland.edu/media/SOP/wwwpharmacyumarylandedu/centers/lamy/covid19-med-mgmt/complete-implementation-guide_042420.pdf

agreed measures to support the availability of medicines.²⁹ However, to what extent such measures were timely enough to prevent medication shortages in all European is less clear. At least for some regions in Italy, there is preliminary evidence that medication shortage presented a major barrier towards providing adequate palliative care.^{30 31} There was only limited evidence that lack of palliative care medication such as opioids and morphine has been an issue for many European countries³² Although there was no evidence of supply problems, guidance from the Swiss association for palliative care (palliative ch) set out that all pharmacological measures must be adapted to what is feasible in each setting.³³ Overall, there appeared to be no guidance for continental European countries on how to deal with medication shortages in care homes or more generally.

Personal protective equipment

A lack of personal protective equipment was reported a major challenge for care homes in many countries, most evidently the U.S., Canada, U.K., Italy and Spain.^{34 35 36}

U.S. care homes widely report insufficient availability of personal protective equipment.³⁷ The lack of personal protective equipment has been, in addition to lack of medication and lack of setting-specific guidance, identified in Italy and in other countries as one the most challenging problems affecting care homes' ability to respond effectively to the crisis, and to ensure effective palliative care provision.^{38 39} In Spain, the lack of personal protective equipment has also, on occasion, prevented the collection of bodies.⁴⁰

In the U.S., the lack of personal protective equipment, together with staff shortages led to discussions among palliative care professionals to introduce guidelines that allow staff to potentially deviate from usual life-saving procedures and the stated end-of-life care wishes of patients, if necessary, to protect nurses and doctors from becoming infected.⁴¹

Similar to the situation in U.K., Europe and the U.S., Canadian care homes also reported not have enough personal protective equipment or palliative medications, along with staff shortages and lack of appropriate staff training (reported on 7th April).⁴²

²⁹ <https://www.ema.europa.eu/en/news/eu-authorities-agree-new-measures-support-availability-medicines-used-covid-19-pandemic>

³⁰ <https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf>

³¹ [https://www.jpsmjournals.com/article/S0885-3924\(20\)30182-2/fulltext?mobileUi=0](https://www.jpsmjournals.com/article/S0885-3924(20)30182-2/fulltext?mobileUi=0)

³² [https://www.jpsmjournals.com/article/S0885-3924\(20\)30375-4/fulltext](https://www.jpsmjournals.com/article/S0885-3924(20)30375-4/fulltext)

³³ <https://www.ncbi.nlm.nih.gov/pubmed/32208497>

³⁴ <https://medicaring.org/2020/03/28/pragmatists-advice/>

³⁵ <https://www.bbc.co.uk/news/world-europe-52014023>

³⁶ <https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M>

³⁷ <https://medicaring.org/2020/03/28/pragmatists-advice/>

³⁸ <https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf>

³⁹ [https://www.jpsmjournals.com/article/S0885-3924\(20\)30182-2/fulltext?mobileUi=0](https://www.jpsmjournals.com/article/S0885-3924(20)30182-2/fulltext?mobileUi=0)

⁴⁰ <https://www.bbc.co.uk/news/world-europe-52014023>

⁴¹ <https://ltccovid.org/category/end-of-life-care/>

⁴² <https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M>

Communication about end-of-life

In many countries, including the U.S. and U.K., care homes have been advised to initiate advance care planning discussions as early as possible and as a matter of urgency.⁴³ In most countries, guidance stated that advance care plans should be taken into account when making decisions about whether to refer a person to hospital in emergency situations for life-prolonging treatments.⁴⁴ Whilst guidance in some countries specifically highlighted the importance of providing advance care planning as a personal process, there has been limited guidance about how this can be realised in situations where there are pressures on staff time and 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).⁴⁵

In the U.S., advice shared by professional networks and palliative care communities has been to carry out these discussions before people become unwell, to ensure that people understand the risk and burdens of hospitalisations in advance.⁴⁶

The U.K. Health Secretary stated on 15th April that it would be unacceptable for treatment-limiting advanced care plans, including 'do not attempt to resuscitate' orders, to be completed without a personalised process. This would need to involve communicating decisions taken by a doctor about appropriate treatment options, and discussing options for treatment with the person undertaking advance care planning, or where capacity is lacking, their surrogate.

Regional health authorities in Ontario and other provinces have emphasised the importance of advance care planning, and made recommendations that focus on the importance of palliative care for the frail elderly.^{47 48}

Visitation during end-of-life

Care homes in most countries have made some in-principle exceptions to their visitation restrictions for end-of-life situations,⁴⁹ but there is evidence from some countries that this might not always have been possible to implement fully.

Guidance from the U.S., for example, suggests that visitors should still be allowed to visit the care home in end-of-life situations but be limited to a specific room.⁵⁰ The guidance also states that hospice workers be allowed to enter facilities⁵¹. However, frontline social workers working in hospice and palliative care report that they are struggling to respond to frequently changing

⁴³ Ibid

⁴⁴ [https://www.jpsmjjournal.com/article/S0885-3924\(20\)30372-9/fulltext](https://www.jpsmjjournal.com/article/S0885-3924(20)30372-9/fulltext)

⁴⁵ [https://www.jpsmjjournal.com/article/S0885-3924\(20\)30372-9/fulltext](https://www.jpsmjjournal.com/article/S0885-3924(20)30372-9/fulltext)

⁴⁶ <https://medicaring.org/2020/03/28/pragmatists-advice/>

⁴⁷ https://www.ontario.ca/page/covid-19-action-plan-long-term-care-homes?_ga=2.89700955.1139230179.1587042009-1793468587.1583765728

⁴⁸ <https://www.speakupontario.ca/>

⁴⁹ [https://www.jpsmjjournal.com/article/S0885-3924\(20\)30372-9/fulltext](https://www.jpsmjjournal.com/article/S0885-3924(20)30372-9/fulltext)

⁵⁰ https://www.nhpco.org/wp-content/uploads/Nursing_Home_Guidance_Hospice_Workers.pdf

⁵¹ Ibid

and inconsistent hospital visitation policies, and that they lack guidance on how to enter facilities without putting themselves or others at risk.⁵²

The U.K. Health Secretary 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 level could not necessarily be kept, in practice.⁵³

State-level guidance for Victoria (Australia) sets out that palliative care physicians or other palliative care workers are allowed to visit care homes.⁵⁴

Canadian guidance, last updated on 8th April, states that essential volunteers and visitors are still allowed to enter the care home, which includes those providing end-of-life support.⁵⁵ However, they have to be trained in the use of personal protective equipment⁵⁶ leaving it unclear how this could be realised in care homes without sufficient personal protective equipment.

Re-organisation of care

Some countries reorganised care in an attempt to increase access to palliative care for people dying from COVID-19 or other causes in care homes, or in their own homes.⁵⁷ This included access to specialist palliative care teams, GPs and other community staff.⁵⁸

In the U.K., care home staff have been advised by the British Geriatrics Society to work with specialist palliative care teams (where those are available), community healthcare staff and community geriatricians.⁵⁹ This includes working together on reviewing advance care plans as a matter of urgency. The importance of close collaboration between GPs and care homes is emphasised in order to achieve continuity of care for those with end-of-life care needs.⁶⁰

The Australian government has developed plans for specialist palliative care providers, in order to reduce face-to-face consultations and focus instead on providing advice and guidance to generalist practitioners looking after patients with COVID-19.⁶¹ Plans also exist to optimise the role of telehealth, including improved access to smart phones for community palliative care nurses. Changes have also been made to the reimbursement system to allow for palliative care provision via telehealth technology; as of 13th March, the Medicare Benefits Schedule includes new telehealth items. This supports plans by the Australian COVID-19 Palliative Care Working

⁵² <https://swhpn.memberclicks.net/assets/Allie%20Shukraft%20COVID19.mp4>

⁵³ <https://www.theguardian.com/world/2020/apr/15/families-to-be-allowed-to-say-goodbye-to-dying-relatives-in-care-homes>

⁵⁴ <https://www.dhhs.vic.gov.au/aged-care-sector-coronavirus-disease-covid-19>

⁵⁵ <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/prevent-control-covid-19-long-term-care-homes.html>

⁵⁶ <https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/prevent-control-covid-19-long-term-care-homes.html>

⁵⁷ <https://itccovid.org/2020/03/31/covid19-proving-palliative-care-for-the-many/>

⁵⁸ <https://itccovid.org/2020/03/31/covid19-proving-palliative-care-for-the-many/>

⁵⁹ <https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes>

⁶⁰ Ibid

⁶¹ <https://insightplus.mja.com.au/2020/11/integrating-palliative-care-into-covid-19-planning/>

Group (ACPCWG) to increase the use of telehealth free of charge to people with palliative care needs.⁶²

State-specific guidance in the U.S., including from Missouri,⁶³ sets out that care homes should work with hospice agencies to ensure that residents' needs are met. 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, there have been obstacles to its realisation because of reimbursement problems for telehealth.⁶⁴

In some regions in Italy, special palliative care teams reorganised themselves quickly during the peak of the pandemic by creating networks of hospice care providers and shifting staff from hospice inpatient to home care services.^{65 66} They used case conferences to decide where to prioritise resources (e.g. by deciding who to prioritise for support after hospital discharge). Palliative care teams also shared information about palliative care symptom management with health and social care professionals, and developed clinical and care pathways and referrals forms for ensuring access to palliative care.^{67 68} In Europe, some countries have started to implement additional technological platforms to ensure that the health needs of those with serious illness are met while reducing risk of Covid-19 infection.⁶⁹

Supporting care home staff

Staff shortages and lack of support for staff in care homes were identified as major challenges in dealing with the crisis in many countries, including U.K., U.S., Canada, and Italy.^{70 71 72} In most countries, a large number of palliative care guidance documents have been published in response to the pandemic in an attempt to support health and social care staff in various settings.⁷³ In addition, some countries developed setting-specific guidance on providing palliative care in care homes, hospices or in a person's own home. In the U.S. this includes guidance by the Social Work Hospice and Palliative Care Network. In the U.K. the British Geriatrics Society developed specific guidance and recommendations for care home staff and healthcare staff working with care homes to support them through the pandemic. However, guidance tends only to address certain aspects of palliative care (such as visitations, advance care planning⁷⁴ or medication⁷⁵), to only make a few recommendations and provides almost no

⁶² https://www.health.qld.gov.au/__data/assets/pdf_file/0040/947965/2020-0317-Covid19-PCA-statement.pdf

⁶³ <https://health.mo.gov/safety/homecare/pdf/guidance-hospice-care-ltc-facilities.pdf>

⁶⁴ <https://www.forbes.com/sites/nextavenue/2020/04/10/hospice-demanded-but-threatened-by-covid-19/#cf691e37e265>

⁶⁵ <https://ltccovid.org/2020/03/31/covid19-proving-palliative-care-for-the-many/>

⁶⁶ <https://eapcnet.wordpress.com/2020/03/22/from-the-front-line-palliative-care-in-bologna-during-the-covid-19-crisis/>

⁶⁷ <https://ltccovid.org/2020/03/31/covid19-proving-palliative-care-for-the-many/>

⁶⁸ <https://eapcnet.wordpress.com/2020/03/22/from-the-front-line-palliative-care-in-bologna-during-the-covid-19-crisis/>

⁶⁹ <https://www.esmo.org/oncology-news/improving-telemedicine-helps-to-minimise-risks-for-cancer-patients>

⁷⁰ <https://www.reuters.com/article/us-health-coronavirus-canada-seniors-idUSKBN21P35M>

⁷¹ <https://ltccovid.org/category/end-of-life-care/>

⁷² http://www.ipcrc.net/pdfs/media_watch/Suppl.2020.03.30.m.w.n659.pdf

⁷³ [https://www.jpmsjournal.com/article/S0885-3924\(20\)30372-9/fulltext](https://www.jpmsjournal.com/article/S0885-3924(20)30372-9/fulltext)

⁷⁴ <https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response>

⁷⁵ <https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response>

detail on how to operationalise these recommendations.^{76 77} There are various websites that collate various guidance, research, toolkits and other resources on various aspects of providing palliative care during this pandemic.^{78 79 80}

The experiences from at least some regions in Italy also highlighted that staff training was not only an issue for health and social care staff who needed to be trained in palliative care provision, but that there was also a need for COVID-19-related training for specialist palliative care staff, who needed information about how to keep themselves and others protected.⁸¹

In the U.K. multi-professional support networks are seen by the British Geriatrics Society to have an important role in supporting care home staff through the current crisis. The British Geriatrics Society guidance refers to a national COVID-19 online care home community of practice, emerging as the initiative of a leading geriatrician and organised via Whatsapp, which care home staff are encouraged to join.⁸² It also refers to a Facebook page hosted by the Queens Nursing Institute specifically to support care home registered nurses.⁸³

In Australia, 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).^{84 85} 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.⁸⁶ Some state governments (of regions most strongly affected by the virus) have published additional guidance, some of which is setting specific. For example, the State of Victoria published their COVID-19 plan for the aged care sector.^{87 88}

3. Wider system issues and opportunities for long-term changes

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, prior to the current crisis, to implement measures that ensure high quality palliative care in care home settings, including during potential epidemics or pandemics. In a recent journal article on the palliative care situation in Ontario, the authors predict that, as Covid-19 infections increase, care homes will be highly understaffed and have undersupply of palliative

⁷⁶ [https://www.jpsmjournal.com/article/S0885-3924\(20\)30372-9/fulltext](https://www.jpsmjournal.com/article/S0885-3924(20)30372-9/fulltext)

⁷⁷ <https://ltccovid.org/wp-content/uploads/2020/05/Palliative-care-in-care-homes-and-COVID-1-May-2020.pdf>

⁷⁸ <https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response>

⁷⁹ <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/covid-19#covid-19>

⁸⁰ <https://www.speakupontario.ca/>

⁸¹ <https://www.medrxiv.org/content/10.1101/2020.03.18.20038448v1.full.pdf>

⁸² Ibid

⁸³ Ibid

⁸⁴ https://www.health.qld.gov.au/__data/assets/pdf_file/0040/947965/2020-0317-Covid19-PCA-statement.pdf

⁸⁵ <https://palliativecare.org.au/covid-19-updates>

⁸⁶ <https://www.caresearch.com.au/caresearch/tabid/5982/Default.aspx>

⁸⁷ <https://www.dhhs.vic.gov.au/recognising-and-responding-at-the-end-of-life-COVID-19>

⁸⁸ <https://www.dhhs.vic.gov.au/recognising-and-responding-at-the-end-of-life-COVID-19>

care medication and personal protective equipment, and make a series of recommendations to avert a crisis similar to that witnessed in Italy.⁸⁹ In most countries, palliative care and care home services are chronically underfunded. Common challenges in care home provision include high staff turnover, recruitment challenges (due to low pay and limited opportunities for training, development and career progression), and lack of legislation or regulation.⁹⁰

Even in the U.K., which is ranked highest in the world in quality of death due its advanced hospice network and statutory involvement in end-of-life care⁹¹, it has been estimated that only about three-quarters of those who need palliative care in the population as a whole receive it, with around half receiving specialist palliative care and a further 25% thought to receive palliative care from generalist providers such as general practitioners and care home staff, although the levels in care homes specifically are unknown.⁹² In the U.S., about 60% of hospitals offer specialist palliative care but provision in care homes is much lower⁹³ and many hospices are overburdened according to the National Hospice and Palliative Care Organization.⁹⁴ In Canada and Australia, about 3% to 4% of care home residents receive specialist palliative care.⁹⁵ ⁹⁶ 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.⁹⁷ These figures, however, are difficult to interpret as data is often only available for specialist palliative care and many care homes will offer some forms of care that are palliative in nature, especially in nursing homes, and there may be variation in what types of care and treatment are provided by specialist and generalist providers respectively. Nonetheless, the evidence suggests potentially large unmet need.⁹⁸

Over the past decades, researchers, practitioners and national associations have called for implementing or scaling the following measures to improve palliative care provision:

- National and regional policies, programmes and guidelines to support the provision of palliative care in care homes⁹⁹ ¹⁰⁰

⁸⁹ <https://www.cmaj.ca/content/192/15/E400>

⁹⁰ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)30822-9/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30822-9/fulltext)

⁹¹ <https://eiuperspectives.economist.com/healthcare/2015-quality-death-index>

⁹² <https://www.pssru.ac.uk/pub/4962.pdf>

⁹³ <https://uk.reuters.com/article/us-health-palliative-nursing-homes/nursing-home-residents-eligible-for-palliative-care-often-dont-get-it-idUKKBN1DL28S>

⁹⁴ <https://www.forbes.com/sites/nextavenue/2020/04/10/hospice-demanded-but-threatened-by-covid-19/#cf691e37e265>

⁹⁵ <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0480-z>

⁹⁶ <https://onlinelibrary.wiley.com/doi/epdf/10.1111/ajag.12480>

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https://www.eapcnet.eu/Portals/0/adam/Content/xwkGGSw2ykCLpHNMPZRxA/Text/WP1_EAPC%20report%20Feb_25_2016.pdf

⁹⁸ <https://uk.reuters.com/article/us-health-palliative-nursing-homes/nursing-home-residents-eligible-for-palliative-care-often-dont-get-it-idUKKBN1DL28S>

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

¹⁰⁰ <https://palliativecare.org.au/palliative-care-in-aged-care>

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- Harmonisation of payment and regulation standards to include palliative care¹⁰¹
- Contracts between care homes and hospice agencies or other external palliative care providers¹⁰²
- Palliative care as part of the training curriculum for care home staff¹⁰³
- Palliative care core competencies for care home staff¹⁰⁴
- On-the-job training tools and educational and professional development¹⁰⁵
- Introduction of palliative care standards into quality monitoring of care homes^{106 107}
- Palliative care data in care homes as part of national minimum data sets and reporting^{108 109}

These, and other emerging, recommendations need to be revisited with urgency as we emerge from the current Covid-19 public health crisis, alongside investing in palliative care training and services and implementing measures to improve financial stability and the quality and sustainability of staffing in care homes, so that these sectors are better able to engage with needed developments.

¹⁰¹ http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf

¹⁰² <http://endoflifecareambitions.org.uk/wp-content/uploads/2017/08/Care-Homes-Survey-Report-August-2017.pdf>

¹⁰³ <https://palliativecare.org.au/palliative-care-in-aged-care>

¹⁰⁴ <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>

¹⁰⁵ http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf

¹⁰⁶ <https://nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf>

¹⁰⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5754324/>

¹⁰⁸ http://assistenza.cottolengo.org/doc/ICare/PALLIATIVECARE_PC_NursingHome.pdf

¹⁰⁹ <https://palliativecare.org.au/palliative-care-in-aged-care>