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URGENT CALL TO ACTION – RECOMMENDATIONS TO MITIGATE CRISIS OF PROLONGED ISOLATION IN LONG TERM CARE FACILITIES

Introduction

A new crisis is building in long term care (LTC) facilities: the dire consequences of prolonged social isolation. This crisis is not unique to Pennsylvania, it is occurring nationally and internationally. Canada's LTC facilities were severely impacted by COVID-19 but newly issued evidence-informed guidance is directed to reopening facilities, recognizing residents have endured potentially irreversible physical, functional, cognitive, and mental health decline.[1] Pennsylvania and the federal government must do the same and take action to address the crisis caused by prolonged social isolation and avoid full lockdowns.

There is a moral and health imperative to restore essential care and oversight for the wellbeing of residents. When the COVID-19 pandemic began there was a sense of urgency to lockdown LTC facilities to reduce the risk of the lethal virus entering facilities. The grim reality of the insidious nature of COVID-19 highlights the challenges of balancing person-centered care with public health infection control in LTC settings. Now that we know more, the adverse outcomes caused by the lockdown of facilities must be mitigated in a way that keeps people safe through adhering to stringent rules while creating a measured approach to prevent residents suffering from the consequences of isolation.

Time is of the essence to prevent further collateral damage inflicted upon residents. It is vital to plan and implement a response that is safe, comprehensive, equitable, and sustainable, and that builds upon the growing knowledge around COVID-19.

[1] Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Long-Term Care Homes to Family Caregivers and Visitors during the COVID-19 Pandemic at https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5f0f2678f205304ab1e695be/1594828410565/%27NIA+LTC+Visitor+Guidance+Document.pdf

Background

LTC facilities are people's homes, not simply medical environments. Mandated isolation practices mean there has been little, if any, oversight, or accountability. LTC residents experience a range of physical and/or cognitive decline, and many depend upon essential caregivers, family and friends who provide needed care and oversight. They also depend on frequent visits from family and friends for companionship and to support their emotional wellbeing.

> "Without these visits, residents may feel increasingly lonely, abandoned, and despondent. That's a medical problem in its own right, leading to depression, weight loss, and disruptive behavior. As troubling, family visits are a crucial procedure for monitoring quality of care. With visits curtailed and staff absenteeism rising, the quality of care – already low in many facilities – is likely to decline further. And we will have only limited visibility into the full scope of the problem."[2]

Clear guidance is needed to allow each LTC facility to resume and sustain communal activities and allow residents to leave their rooms. The process should involve communicating with residents to hear their input. Essential caregivers who support care in LTC facilities are not simply "visitors" who are potential carriers of a lethal virus and need to be kept out but rather caregivers, as essential as employed staff. With staffing shortages at LTC facilities during the best of times, if essential caregivers could reenter facilities following strict safety precautions, they could resume providing care. Lives would be saved, and functional or cognitive decline lessened. Most importantly, it would reaffirm that residents' mental and physical health, wellbeing, and dignity are valued.

Necessary Immediate Actions

Pennsylvania and the federal government must take the following actions to create and implement a plan to mitigate the adverse consequences of social isolation:

1. Restore essential caregivers to support resident care needs
2. Facilitate ongoing meaningful engagement of residents, families, and their advocates
3. Create and implement safe, sustainable visitation guidance
4. Expand and promote compassionate care visits
5. Increase access to technology and training for self-management
6. Resume safe, sustainable communal activities and social engagement within LTC facilities
7. Address staff related needs
8. Establish an ongoing testing strategy
9. Ensure adequate supply of PPE and training in its use
10. Collect and report data about the reopening LTC facilities

[2] William Gardner, David States & Nicholas Bagley (2020) The Coronavirus and the Risks to the Elderly in Long-Term Care, Journal of Aging & Social Policy, 32:4-5, 310-315, DOI: 10.1080/08959420.2020.1750543

1. Restore essential caregivers to support resident care needs

Mandated isolation of LTC residents is causing great human suffering resulting in loneliness, depression, anxiety, neglect, loss of dignity and loss of life such as by failure to thrive. Residents in homes that are understaffed have not received basic care that their families routinely provided. Quality of care is diminished for residents without regular visitors who can provide critical oversight.[3] A French study found that there were more deaths associated with isolation than COVID-19 at facilities that lacked adequate staffing.[4]

State and federal governments need to understand the difference between a visitor and an essential caregiver (family/informal caregiver) who provides care and supports vital aspects of health. Essential caregivers provide life sustaining support to residents in LTC facilities and are considered part of the care team.[5] If requirements for training can be waived to allow direct care workers to help meet staffing needs, surely essential caregivers who know their loved ones and know what changes are of concern, who know how to get them to eat, can be allowed to enter the facility with precautions to provide needed care, timely detection of changes in health, and advocacy for their loved ones.

Essential caregivers serve a vital role in supplementing care caused by staffing deficiencies. Even when staffing levels are sufficient to provide adequate care, staff could never substitute for the love and care provided by a family member or friend. Pennsylvania and the federal government must immediately restore and mandate access to facilities for essential caregivers to resume their vital roles following the same precautions required of staff. Policies could limit to one essential caregiver at a time along with other safety precautions that staff must follow. Minnesota's policies for essential caregivers could be used as a model.[6]

2. Facilitate ongoing meaningful engagement of residents, families, and their advocates

Government and facilities must acknowledge the civil rights of residents and avoid paternalistic policies. The Pennsylvania Departments of Health and Human Services need to be transparent with their plan around COVID-19 and LTC facilities, and must engage residents, families, and advocates in a meaningful way in the planning process including in developing policies around visitation. The concerns of residents must be heard and

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[3] Grabowski DC, Mitchell SL. Family oversight and the quality of nursing home care for residents with advanced dementia. Med Care. 2009;47(5):568-574. DOI: 10.1097/MLR.0b013e318195fce7

[4] Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2)-Related Deaths in French Long-Term Care Facilities: The "Confinement Disease" Is Probably More Deleterious Than the Coronavirus Disease-2019 (COVID-19) Itself DOI: https://doi.org/10.1016/j.jamda.2020.04.023

[5] *The Journals of Gerontology: Series B*, Volume 73, Issue 4, May 2018, Pages e13–e23, https://doi.org/10.1093/geronb/gbx184

[6] Minnesota Department of Health - Essential Caregiver Guidance for Long-term Care Facilities at https://www.health.state.mn.us/diseases/coronavirus/hcp/ltccaregiver.pdf

considered in this process. Residents must have some control during the last chapter of their lives and have a basic right not to die alone or live without meaningful contact with those they love. Families are also becoming increasingly frustrated because they have not seen their loved ones in-person in months and are worried about the impact of isolation. Policies need to avoid future full lockdowns and be developed to break the negative consequences of strict isolation while focusing on public health.

Residents, families, and their advocates have been frustrated by the lack of communication and engagement from government related to COVID-19. Facilities vary in their ability to communicate information to residents and all are constrained when there is no or conflicting guidance. Residents, families, and their advocates must be kept informed about what is happening.

LTC residents with limited English proficiency face additional barriers during the pandemic such as the lack of access to translated information that may result in misinformation and exacerbating threats to their health and wellbeing.

Some residents tell us that they feel as if they are in prison. Care plans should be discussed with residents and families and updated to reflect how wellbeing, mental health, social connection, and limitations on mobility are being supported during isolation. Residents with dementia may have a worsening in their cognition requiring a new person-centered care plan.

Residents should be engaged, educated, and supported in practicing infection control, including the importance of washing hands and wearing a mask, if possible.

The Long-Term Care Ombudsman Program (LTCOP) including local programs need to be kept informed about government plans and actions in specific facilities and should be consulted for feedback about what they hear and encounter in their work.

3. Ensure Safe and Sustainable Visitation Policies

A group of experts wrote an opinion in The Washington Post, *Continued bans on nursing home visitors are unhealthy and unethical,* describing the need to safely reopen LTC facilities to visitors.[7] The Pennsylvania Departments of Health and Human Services' visitation guidance needs to be updated as it fails to consider the resident's and family's point of view nor does it follow a person-centered care approach as required by federal nursing facility regulations. Federal regulation ensures the right of nursing home residents to have visitors. Guidance needs to include necessary steps to facilitate visits to the greatest extent possible to restore that right using all needed precautions to prevent infections. Visitor policies should balance the protection of residents from the virus with their need for family and connection.

[7] https://www.washingtonpost.com/opinions/2020/07/13/residents-good-nursing-homes-should-consider-re-allowing-visitors/

Several states and countries have successfully restored visitation. Australia has adopted reasonable procedures to allow for visits and reduce isolation while maintaining infection control standards.[8]

A recent small-scale study in the Netherlands shows it is possible to allow visitors in LTC facilities with precautions, even facilities with active cases of Covid-19. The study demonstrated a significant increase in resident wellbeing with no additional cases of COVID-19. The results of this study led the Dutch government to model study guidelines to reopen nursing facilities to visitors throughout the country.[9]

Understanding that fewer people in facilities means fewer chances for the virus to enter and spread, restrictions could be considered such as limiting the visitors a resident can receive at any one time (e.g. one or two); limiting the number of different visitors a resident can receive a week (e.g. one or two); limiting the length of visits; limiting the number of visitors in the care home at any one time; and, limiting entry points and movement throughout the building. Infection control best practices used by staff could be implemented for visitors such as requiring all visitors to be masked, screened before entering, and instructed on policies such as hand sanitizing. If possible, a well-ventilated room could be designated for visitation and sanitized between visits.

In addition to visits within the facility, outdoor visits should be encouraged and facilitated whenever possible as meeting outdoors adds additional safety measures. Weather permitting, these visits could provide needed contact and socialization for residents.

Along with Pennsylvania publicizing policies, clear communication of visitation policies and rights should be posted at entry points, posted on websites, and shared with residents, families, and others. Communication should be available in accessible formats.

4. Ensure and Promote Expanded Compassionate Care Visitation

Pennsylvania's and CMS' guidance allows for "compassionate care" visits that go beyond end-of-life situations. Some examples are provided in CMS' Frequently Asked Questions (FAQs) on Nursing Home Visitation released in June.[10] However, these visits have mostly been interpreted to allow visits only when a resident is believed to be within the very last hours of life, if allowed at all. Residents are dying alone without the opportunity for loved ones to have closure and say good-bye.

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[8] COTA's Australia's Industry Code for Visiting Residential Aged Care Homes During COVID-19 at https://www.cota.org.au/policy/aged-care-reform/agedcarevisitors/

[9] Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being at https://www.jamda.com/article/S1525-8610(20)30526-0/pdf

[10] CMS Frequently Asked Questions (FAQs) on Nursing Home Visitation at https://www.cms.gov/files/document/covid-visitation-nursing-home-residents.pdf

Residents in LTC facilities that are understaffed have not received basic care that their essential caregivers routinely provided which lessens the probability of "compassionate care" being provided.

> "Compassion involves demonstrating characteristics such as empathy, sensitivity, kindness and warmth–and when these are lacking, all too frequently one of the factors that underpins poor care is an attitude to care that is task based rather than person centered care. Task based care is frequently impersonal and not what people want. Instead they want to be treated with respect, dignity and compassion, attributes that cost nothing."[11]

Residents who depended on loved ones to assist with meals have lost significant weight and, in some cases died, when overwhelmed staff do not have the time or ability to persuade them to eat as their essential caregivers always had. Some residents with cognitive or mental health impairments have become increasingly agitated without the in-person support of their essential caregivers, at times causing an increased need for medication. One example of this plight is a resident with dementia whose essential caregivers visited 50 hours a week before the lockdown started in March. They continue to be denied a compassionate care visit despite their mother's now being withdrawn and barely communicative, not eating - causing about a 30-pound weight loss and need for IV fluids and developing a pressure ulcer. They fear she has reached a point where she will never recover anywhere near her previous functional and cognitive abilities when they provided care and support.

Regulators need to provide additional support and guidance around compassionate care visits to enforce that end-of-life is only one example of these visits and that end-of-life goes beyond the last few hours of life. A final adverse decision should not be left to individual facilities. A formal expedited appeal system needs to be offered for when facilities are denying accommodating these visits.

Finally, hospice workers are being denied access to some LTC facilities. Government should mandate that hospice workers have full access following all safety protocols.

5. Increase access to technology and training for self-management

Some facilities are doing everything possible to help combat isolation such as setting-up video chats, allowing window visits and assisting residents with using technology, while others fall short. For many LTC facility residents, the telephone and digital technologies have made a big difference in coping by providing an alternate means to connect with family, friends, and those outside of the facility. Unfortunately, other residents are not able to benefit as they do not have access to technology or may have cognitive, functional, or sensory impairments making these communications challenging or inaccessible.

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[11] Haslam, D. "More than kindness". *J of Compassionate Health Care* 2, 6 (2015). https://doi.org/10.1186/s40639-015-0015-2

Government response to COVID-19 should include funding to support these connections. Funding is needed to obtain ADA accessible technology like smartphones or tablets, ensure access to the internet, and help residents learn to use it so they can self-manage communications on these devices. Other residents may need ongoing staff support to make virtual connections. While it is not a substitute for in-person visits, it is a good way to mitigate isolation caused by restrictive visitation policies. And, for those able to self-manage using technology, it has had a positive impact in helping them cope with the adversities they face in isolation.

6. Resume Safe and Sustainable Communal Activities

Residents in LTC facilities have a higher risk from COVID-19 in part because they live in close quarters making recommended physical distancing difficult. As a result, many facilities have taken measures not only restricting visitors but also group activities which can negatively affect the physical and mental health of residents. These restrictions create problems related to lack of social connections with fellow residents, exercise, and recreational activities. Limited opportunities for physical activity may result in weakness and functional decline while breaks in routine and restrictions may cause cognitive decline in people with dementia.

An expert in gerontology at Drexel University who works in three nursing homes in the Philadelphia area expressed concern about the impact of the no visitation policies and residents being mostly confined to their rooms. "I'm seeing a lot of patients with pronounced situational depression," she said - "decreased appetite, decreased energy, a lack of motivation and overall feelings of sadness."[12]

Sustainable strategies need to be implemented and included in guidance to lift restrictive policies with appropriate safety measures in place to meet these needs including ensuring residents can leave their rooms such as for exercise and fresh air. Communal activities such as recreation and dining should resume with safety protocols to help improve health and wellbeing.

7. Address Staff Related Needs

As consumer advocates, we recognize that we owe staff in LTC facilities a tremendous debt of gratitude for their work and dedication in providing care. Like hospital workers, they are making personal sacrifices and putting their safety at risk in providing hands-on care for our loved ones, typically while earning low wages.

LTC facility staff need to have proper training and support such as to ensure effective infection control or when caring for residents with cognitive impairment or challenging behaviors. LTC facilities should follow the recommendations provided by Alzheimer's

[12] For Seniors, COVID-19 Sets Off A Pandemic Of Despair at https://khn.org/news/for-seniors-covid-19-sets-off-a-pandemic-of-despair/

Association to help with best practices in the care of people with Alzheimer's Disease and related disorders.[13]

Funding needs to increase to hire additional staff to ensure there is enough staff to provide needed care, spend time with residents in meaningful activities and exercise, and to compensate for fewer or no visitors, and less group activities. More staff time is also needed to help facilitate both in-person and virtual visits.

Minimum staffing standards need to be established and closely monitored for compliance. A recent study demonstrated that nursing homes with total RN staffing levels under the recommended minimum standard of 0.75 hours per resident day were twice as likely to have residents with COVID-19.[14] In addition, every nursing home must be required to hire a qualified full-time infection preventionist. Even before the Coronavirus, infectious disease killed many residents each year and infection control violations have long been a problem, so this specialist is needed to help address multiple infectious diseases and problems.

Staff should receive increased wages not only for the increased stress and trauma associated with caring for individuals during the pandemic but also as a safety measure. Adequate pay could help limit the number of jobs to one thereby reducing the number of facilities they enter. Workers with multiple jobs should be transparent about where they are employed to quickly limit spread to other facilities should there be an outbreak at one of their workplace sites.

LTC facilities need to compensate employees for sick leave. The lack of paid sick leave can put workers and residents at risk as workers will more likely come to work when they are sick.

Finally, LTC facilities and staff should be prioritized the same as hospitals for PPE and testing.

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[13] Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting at https://alz.org/media/Documents/COVID-19-EmergencyTips_LongTermCommunityBasedDementiaCare_AlzheimersAssociation.pdf

[14] Harrington, C., Ross, L., Chapman, S., Halifax, E., Spurlock, B., & Bakerjian, D. (2020). Nurse Staffing and Coronavirus Infections in California Nursing Homes. *Policy, Politics, & Nursing Practice*. https://doi.org/10.1177/1527154420938707

8. Establish an Ongoing Testing Strategy

According to the Centers for Disease Control (CDC), asymptomatic staff are one source of the infection.[15] Ramping up testing of staff, residents and essential visitors is needed to establish baselines, help contain the virus and identify areas of the facility that are safe to reopen.

LTC facilities need to be prioritized for support in testing. Each facility should not be on its own to fund, procure and administer mandated testing. The extensive testing needed to safely reopen LTC facilities will not be met if there is no access to tests or if the cost must be covered by facilities, residents, or staff. The processing of testing of LTC residents and staff must be prioritized at labs to avoid delays in getting results.

Pooling is a cost-efficient way to help to control testing costs and should be considered when the community rate of infection supports this strategy.

9. Ensure Adequate Supply of PPE and Training in its Use

Sufficient Personal Protective Equipment (PPE) is needed for nursing home staff, residents, essential caregivers, and visitors. Research has shown that even when caring for COVID-19 patients in high-risk situations, healthcare providers properly trained and using proper PPE avoided infection.[16]

Procuring a sufficient supply of PPE must include planning for essential caregivers, compassionate care visits and general visitors, if more than masks are needed, to ensure successful reopening of facilities and avoid the restriction of essential caregivers and visitors because of a lack of PPE. Ideally, government could procure and distribute PPE, so each facility is not left on its own (as long as the PPE is of high quality and usable). Otherwise, LTC facilities must receive needed funds for PPE.

Training protocols must be implemented in the proper use of PPE such as donning and doffing. Training must include demonstrated competency in the use of PPE. It is also important that PPE be fitted properly.

10. Collect and Report Data about the Reopening of LTC Facilities

LTC facilities with the support of government health and public health authorities should consistently collect and report data on COVID-19 cases as it relates to reopening. Having data can help inform any changes needed and impact decisions to allow essential caregivers and visitors in facilities as well as lifting restrictions as quickly as possible when COVID-19 community prevalence declines. Data could be used to help compare the impact on resident

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[15] Kimball A, Hatfield KM, Arons M, et al. Asymptomatic and Presymptomatic SARS-CoV-2 Infections in Residents of a Long-Term Care Skilled Nursing Facility — King County, Washington, March 2020. MMWR Morb Mortal Wkly Rep 2020;69:377–381. DOI: http://dx.doi.org/10.15585/mmwr.mm6913e1

[16] Use of personal protective equipment against coronavirus disease 2019 by healthcare professionals in Wuhan, China: cross sectional study, BMJ 2020; 369 doi: https://doi.org/10.1136/bmj.m2195

health and wellbeing of restricting essential caregivers and visitors versus allowing measured access of essential caregivers and visitors in facilities.

The integrity and uniformity of data is important, and it needs to be transparent and publicly shared.

Conclusion

Now is the time to give LTC facilities the support needed to ensure safe in-person visitation throughout the course of the pandemic to restore the health, wellbeing and dignity of residents that only loved ones can provide. With increasing knowledge about COVID-19 and experience implementing safety measures, there is an urgent need to try to balance safety with measures to prevent adverse outcomes caused by prolonged isolation. At the very least, policies must be developed now to ensure equity in care, targeting in-person visitation to LTC residents who are at high risk of adverse outcomes and who are not able to utilize remote means like a telephone to stay connected with families, friends, or their advocates.

The COVID-19 pandemic has necessitated urgency to our advocacy to protect the lives and health of the most vulnerable elder Pennsylvanians. Residents and staff of LTC facilities deserve our focused attention and targeted action to survive and thrive through this pandemic now as well as in the future to ensure we do not repeat this tragedy.

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