

ASPR TRACIE Technical Assistance Request

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Response Date: July 2, 2020

Type of TA Request: Complex

Request:

ASPR TRACIE received a request for information on palliative care during the COVID-19 pandemic.

Response:

The ASPR TRACIE Team reviewed material on our [Novel Coronavirus Resources](#) page and searched for additional resources. Section I of this response includes general considerations related to the delivery of specialized care by providers and teams to individuals with serious illnesses to manage their symptoms, determine their care goals, and coordinate their medical, behavioral health, and social supports. Section II includes links to resources from palliative care patient and provider organizations and federal agencies to guide provision of palliative care during the COVID-19 pandemic. Section III offers articles focused on specific aspects of palliative care.

Please refer to CDC's [Coronavirus Disease 2019 webpage](#) for the most up-to-date clinical guidance on COVID-19 outbreak management.

I. Considerations

[Palliative care](#) is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment in any care environment.

Surge Considerations:

- Expect a surge of COVID-19 cases in your community to be accompanied by a surge in need for palliative care services. One health system reported a [seven-fold increase](#) in the number of requests for palliative care consultations. Some providers will become overwhelmed and may not have time to make palliative care referrals. Palliative care

teams should consider proactively rounding to provide palliative care services in the emergency department and critical care areas.

- Communicate with stakeholders and other providers in both inpatient and outpatient settings. Make them aware of your organization's capabilities and capacity.
- Ensure availability of adequate supplies of medication for pain management and those for shortness of breath, anxiety and other symptom management. Maintain situational awareness of medication shortages. Discuss with palliative care team plans for use of alternative pain medication should it become necessary. Stay in contact with suppliers and identify possible new vendors.
- Consider establishing a dedicated comfort care unit for COVID-19 patients unlikely to survive. Consider a Palliative Care Consult Team, inpatient and outpatient, for COVID-19 patients only. Expertise in comfort measures, transitional options, and settings for care are critical support systems necessary in all healthcare settings.
- Remember to account for the needs of existing palliative care patients who are not infected with COVID-19. Consider infection prevention measures to protect them from COVID-19 transmission (e.g., conduct consultations via telemedicine, use mail order or delivery options for medications), provide guidance on when to seek in-person care, identify hospice agencies accepting referrals, and address behavioral health concerns associated with perceived higher risk.

Patient Considerations:

- Understand the characteristics of patients at greatest risk of severe COVID-19 illness, including advanced age and those with multiple comorbidities, experiencing access to care issues, or living in environments with increased exposure risk. There is considerable overlap between known COVID-19 risk factors and the characteristics of those who typically receive palliative care.
- Recognize that patients with COVID-19 may experience physical, psychological, social, and/or spiritual symptoms and suffering. Individuals with pre-existing serious illness like advanced cancer, advanced organ failure (heart, lung, liver, kidney), dementia, or frailty may be at higher risk for unmet needs across these domains. Suffering can be amplified by isolation and separation from loved ones during hospitalizations or facility stays where visitation is prohibited for infection control purposes.
- Assess patients with moderate to critical COVID-19 infection or pre-existing serious illness for unmet needs across physical, psychological, social, and spiritual domains. Access specialist palliative care teams for needs not readily met by frontline clinicians.
- Engage patients and their loved ones in discussions about goals of care, end of life wishes, and management of pain and symptoms early in the treatment course. While palliative care plans are usually developed over time through ongoing discussions with patients with serious illness and their loved ones, some COVID-19 patients may deteriorate rapidly and require interventions that make communication difficult, if not impossible. Patients in generally good health prior to COVID-19 infection may not have completed advance directives or discussed their wishes with their clinicians or loved ones.

Operational Considerations:

- Monitor updates from the [Centers for Medicare and Medicaid Services \(CMS\)](#) and [state health departments or governors](#) that provide waivers and guidance for palliative care services and providers. Examples of modifications to requirements include nursing supervisory visits, agency communication with patients via telehealth, physician use of telehealth for home ‘face-to-face’ visits, expansion of testing options in homes and communities, putting ‘Patients over Paperwork’ to reduce non-essential audit requirements, modifications in staff training, and assessment requirements.
- Recognize that members of your palliative care team may be the conduit between patients and their loved ones. Restrictive inpatient visitation policies intended to reduce COVID-19 transmission may prevent or limit the number of loved ones able to be physically present with the patient. Ensure there are staff available to provide some physical and emotional support that would otherwise be provided by family and friends.
- Prepare for limitations in the ability to provide support through extended physical presence, hand-holding, and similar forms of comfort. Consider how this affects patients who may feel isolated or forgotten, loved ones who may feel guilt or anger for not being allowed to be with the patient, and providers whose usual support roles are altered by the pandemic.
- Recognize that personal protective equipment (PPE) use during a face-to-face visit is a barrier to communication. Patients and family may have a difficult time understanding what providers say as words may be muffled and facial expressions are hidden behind masks.
- Schedule outpatient visits in a manner that minimizes risk. Consider scheduling COVID-19 home visits at the end of the day to minimize risk of transmission to non-COVID-19 patient households. Explore developing teams that serve only COVID-19 suspected or positive clients, travelling to their homes or facility settings.
- Provide consistent and frequent messaging to patients, their loved ones, and the palliative care team especially on good hygiene practices and safety. Pledging vigilance and adherence to local, state, and federal guidelines and regulations is paramount to allay anxiety.

Telehealth and Virtual Medical Care Considerations:

- Adapt telemedicine capabilities to both inpatient and outpatient settings to reduce provider exposures and preserve PPE. Technology can be of significant help to the palliative care team when acting as a conduit on the patient’s behalf and providing care in both the inpatient and outpatient setting.
- Assess patients in the community for access and ability to use technology, especially tele-palliative care. Some patients may find technology especially challenging. Others may not have the resources for internet charges and hardware such as tablets and smart phones.
- Use telehealth solutions to break down barriers to care. Universal masking requirements inhibit communication in many ways, some of them unexpected. Mask use may prevent

seniors with hearing difficulties from reading their provider's lips to aid their understanding. Initiating home visits on a video call while the provider is in his or her car without a mask may allow the provider and patient to exchange essential information before entering the home.

- Consider the use of virtual medical care to increase your palliative care capacity by engaging providers from less affected geographic areas remotely. One health system used [remote consultants](#) to engage with loved ones about clarification of goals of care of high-complexity patients unable to communicate with clinicians.

Staffing Considerations:

- Consider staffing needs in light of changes affecting the community at large. Aside from changes in patient acuity, staffing models may need to respond to community and provider issues in emerging COVID-19 hot spots such as school closures and child care arrangements affecting staff, requests for leave of absence, staff with risk factors for severe COVID-19 illness, and provider and patient anxiety about possible exposures.
- Expect high healthcare workforce demand to continue. This is in part because of the increased complexity of patients, but also because of the limitations some jurisdictions have placed on the type of providers allowed into nursing and assisted living facilities, limiting access of home health aides, social workers, spiritual counselors, and therapists.
- Leverage the availability of experienced palliative care providers whose usual work settings are in non-clinical settings or in specialty clinical areas that may be experiencing decreased volume during the COVID-19 response. This include staff underutilized due to patients' concerns about in-home visits or facility access restrictions (e.g., reassign chaplaincy staff to provide support to workforce or bereavement services to community partners).
- Ensure behavioral health support for providers, both palliative care providers who are managing increased caseloads or operating under modified procedures and non-palliative care providers who have taken on new or increased palliative care responsibilities during the pandemic. Consider inspirational messaging and communications for all staff on a regular basis especially from leadership. Explore creation of a team dedicated to workforce resiliency and well-being.

II. Operational Resources

American Health Care Association, National Center for Assisted Living, and National Hospice and Palliative Care Organization. (2020). [Guidance on the Role of Hospice Services in LTC Facilities During COVID-19 Pandemic](#).

This joint document from associations representing the long-term care (LTC) and hospice communities provides guidance on the risk-benefit analysis between implementing strong infection prevention measures and the best interests of LTC residents.

Center to Advance Palliative Care. (2020). [COVID-19 Response Resources Toolkit](#).

This toolkit includes a variety of resources to support the delivery of palliative care during the COVID-19 pandemic. Resources include: communication scripts, symptom management protocols, care team tools and telehealth tools, resilience support, policy trackers, links to guidance, and information for specific settings and populations.

Centers for Medicare & Medicaid Services. (2020). [Coronavirus \(COVID-19\) Partner Toolkit](#). U.S. Department of Health and Human Services.

This toolkit includes links to register for upcoming stakeholder engagement sessions hosted by CMS; communications resources; CMS guidance; and information and resources for specific populations, provider types, and care settings.

GeriPal. (2020). [COVID-19 Resources](#). A Geriatrics and Palliative Care Blog

This collection of resources includes numerous podcasts on palliative care and related issues specific to COVID-19 considerations.

Home Care Alliance of Massachusetts. (2020). [Guidance for Home Health and Hospice Agencies on Admissions from Hospitals Related to COVID-19](#).

This document provides a set of reference resources for home health agencies to use in formulating and updating their policies, procedures, and capabilities. It includes guidance on screening and acceptance criteria, home visit considerations, patient education and reassurance, and hospice inpatient unit considerations.

Hospice and Palliative Nurses Association. (2020). [HPNA Primary Palliative Nursing for Patients with COVID-19](#).

This resource page includes patient care guides focused on various aspects of palliative care for COVID-19 patients.

National Academies of Sciences, Engineering, and Medicine. (2020). [Innovative Hospital-based Palliative Care Responses to the COVID-19 Pandemic: Perspectives from Program Leaders of Two Large Hospitals](#).

This page includes a video and meeting materials from a June 5, 2020 webinar featuring lessons learned by palliative care teams of two hard-hit health systems.

National Association for Home Care and Hospice. (2020). [COVID-19 Frequently Asked Questions](#).

This page contains COVID-19 frequently asked questions on issues including PPE, telehealth, testing, home health and hospice care in nursing homes and assisted living,

quality reporting, assessment, homebound patients, death in the home, and employee return to work.

National Coalition for Hospice and Palliative Care. (2020). [COVID-19 Resources](#).

This page includes numerous resources to support hospice and palliative care providers. It includes links to organizations with additional COVID-19 resources, news articles, advocacy materials, and links to other resources.

National Coalition for Hospice and Palliative Care. (2020). [Four Essential Elements of Palliative Care in COVID-19 Pandemic Response](#).

The National Coalition for Hospice and Palliative Care developed a concise table to guide clinicians taking care of COVID-19 patients in an acute care setting. The Coalition submitted the table to the National Institutes of Health as an update to their [COVID-19 Treatment Guidelines](#).

National Consensus Project for Quality Palliative Care. (2018). [Clinical Practice Guidelines for Quality Palliative Care, 4th Edition](#). National Coalition for Hospice and Palliative Care.

The National Consensus Project for Quality Palliative Care (NCP) developed comprehensive Guidelines that have been endorsed by over 90 organizations. The NCP guidelines provide evidence-based recommendations for both specialist and non-specialist palliative care clinicians working in all health care settings to optimize quality of life for patients with serious illness from diagnosis through end-of-life.

National Hospice and Palliative Care Organization. (2020). [COVID-19 Information](#).

This page includes a variety of resources to support hospice and palliative care providers. It includes members-only resources, webinar recordings, COVID-19 tools and information, legislative and regulatory information, and links to additional information for various audiences.

Pallimed. (2020). [COVID-19 Pandemic Resources](#). A Hospice and Palliative Medicine Blog.

This collection includes numerous resources on palliative care and related issues specific to COVID-19 considerations.

VitalTalk. (2020). [COVID Ready Communication Playbook](#).

This playbook offers communications tips to help healthcare providers respond to questions from patients and their loved ones about COVID-19. [Available in additional languages](#).

III. Literature

Bajwah, S., Wilcock, A., Towers, R., et al. (2020). [Managing the Supportive Care Needs of Those Affected by COVID-19](#). European Respiratory Journal.

The authors describe the importance of supportive care – including symptom management, psychological support, communications, and spiritual care – for COVID-19 patients with severe illness and high risk of death. The article includes links to downloadable Word leaflets that may be customized for communications with patients' loved ones.

Curtis, J., Kross, E., and Stapleton, R. (2020). [The Importance of Addressing Advance Care Planning and Decisions About Do-Not-Resuscitate Orders During Novel Coronavirus 2019 \(COVID-19\)](#). Journal of the American Medical Association. 323(18):1771-1772.

The authors identify various reasons that providing goal-concordant care is of heightened importance during the COVID-19 pandemic. They include an informed assent framework to guide discussions between clinicians and patients and their loved ones about cardiopulmonary resuscitation.

deLima Thomas, J., Leiter, R., Abrahm, J., et al. (2020). [Development of Palliative Care Toolkit for the COVID-19 Pandemic](#). Journal of Pain and Symptom Management.

The authors describe the development of a palliative care toolkit made up of a [COVID-19 online resource](#), mobile and desktop web application, one-page guides, pocket cards, and communication skills training videos accompanied by a 24/7 nurse resource line and daily videoconference office hours.

Fausto, J., Hirano, L., Lam, D., et al. (2020). [Creating a Palliative Care Inpatient Response Plan for COVID-19 – The UW Medicine Experience](#). Journal of Pain and Symptom Management.

The authors describe a health system approach across four acute care hospitals, a neighborhood clinic network, and a cancer center for the implementation of conventional, contingency, and crisis palliative care.

Humphreys, J., Schoenherr, L., Elia, G., et al. (2020). [Rapid Implementation of Inpatient Telepalliative Medicine Consultations During COVID-19 Pandemic](#). Journal of Pain and Symptom Management.

The authors describe the adaptation of outpatient and home-based telepalliative care to the inpatient setting to reduce provider exposures and conserve personal protective equipment during COVID-19.

Israilov, S., Krouss, M., Zaurova, M., et al. (2020). [National Outreach of Telepalliative Medicine Volunteers for a New York City Safety Net System COVID-19 Pandemic Response](#). Journal of Pain and Symptom Management.

The authors describe a two-week pilot program to credential and provide electronic health record access to 64 telepalliative medicine volunteers to support five safety net hospitals with no existing telehealth structure and limited palliative care services.

Matzo, M., Powell, T., Surbeck, J., and Erickson-Hurt, C. (2012). [Palliative Care in Disasters](#).

This presentation was given at the Integrated Medical, Public Health, and Response Training Summit. The speakers: shared an overview of palliative care; explained how it fits into Crisis Standards of Care research (and highlighted related ethical considerations during disasters); described a model of palliative care and how it was used in an exercise; and discussed firsthand experience in providing palliative care after disasters struck Haiti and Indonesia.

Mehta, A. and Smith, T. (2020). [Palliative Care for Patients with Cancer in the COVID-19 Era](#). JAMA Oncology.

The authors identify challenges and potential solutions associated with providing palliative care to outpatients, COVID-19-positive inpatients, and COVID-19-negative inpatients.

Mulrow, J., Doherty, C., Bernacki, G., et al. (2020). [Palliative Care Considerations for Patients with Cardiovascular Disease Under COVID-19](#). Cardiology Magazine.

The authors describe the importance of palliative care during the COVID-19 pandemic and identify domains of palliative care for the cardiovascular clinician. Many of the issues they address may also be applied to other medical specialties.

Sun, H., Lee, J., Meyer, B., et al. (2020). [Characteristics and Palliative Care Needs of COVID-19 Patients Receiving Comfort-Directed Care](#). Journal of the American Geriatrics Society. 68(6):1162-1164.

The authors describe the baseline characteristics, end-of-life care needs, and time course from end-of-life decision to death of 30 patients admitted to a palliative care unit established for COVID-19 patients receiving comfort-directed care.

Sutherland, A., Stickland, J., and Wee, B. (2020). [Can Video Consultations Replace Face-to-Face Interviews? Palliative Medicine and the COVID-19 Pandemic: Rapid Review](#). BMJ Supportive and Palliative Care.

The authors completed a rapid review of literature on the use of telemedicine for palliative care. They conclude that while telemedicine cannot completely replace face-to-face visits, it is an acceptable, accessible, and cost-effective approach to provide consultations while limiting exposure risks to providers, patients, and their loved ones.

Tran, D., Lai, S., Salah, R., et al. (2020). [Rapid De-Escalation and Triage of Patients in Community-Based Palliative Care](#). Journal of Pain and Symptom Management.

The authors describe one palliative care and support services team's framework for triage, infection prevention, and safety in the provision of community-based palliative care during the COVID-19 pandemic.

Wallace, C., Wladkowski, S, Gibson, A., and White, P. (2020). [Grief During the COVID-19 Pandemic: Considerations for Palliative Care Providers](#). Journal of Pain and Symptom Management.

The authors identify ways that procedures implemented to address the COVID-19 pandemic affect grief along with recommendations to address these changes. They also identify resources to assist providers in navigating grief.

Zhang, S. (2020). [The Pandemic Broke End-of-Life Care](#). The Atlantic.

This article describes how the delivery of palliative care in one hard-hit hospital was affected by the COVID-19 pandemic. It features first-hand accounts from members of the palliative care team.