USU
Uniformed Services University

COVID-19 PALLIATIVE CARE TOOLKIT

Biobehavioral Framework

Practical Resources to Aid the Delivery of Palliative Care During the COVID-19 Pandemic

Resource Only/Not a Substitute for Clinical Judgment

Brought to you by:
TriService Nursing Research Program

The opinions and assertions expressed herein are those of the author(s) and do not necessarily reflect the official policy or position of the Uniformed Services University or the Department of Defense. None of the authors, or their family members, have a financial interest in any commercial product, service, or organization providing financial support for this research. This work was prepared by a military or civilian employee of the US Government as part of the individual's official duties and therefore is in the public domain and does not possess copyright protection (public domain information may be freely distributed and copied; however, as a courtesy it is requested that the Uniformed Services University and the author be given an appropriate acknowledgement).

TABLE OF CONTENTS

Acknowledgment 2

Introduction 3

About the Toolkit Use 4

Palliative Care 101 5

- Palliative Care vs Hospice vs End of Life Care 6
- COVID-19 Palliative Care Approach 7

Communication 8

- Communication Guide and Strategies 8
- Conversation Guide and Scripts 9

Symptom Management 10

- Shortness of Breath 10
- Respiratory Secretions 10
- Anxiety 10
- Delirium 10
- Constipation 10
- Nausea 10

Pain Management 11

- PCA Pump Management 12

Support for Caregivers 13

- Coping 14
- Guilt 14
- Blame and Anger 14
- Spirituality 15
- Grief 17
- Bereavement 18

Mobile Applications 19

Additional Resources 20

References 21

ACKNOWLEDGMENT

The COVID-19 Palliative Care Toolkit was developed by the Biobehavioral Research Interest Group and Evidence-Based Practice Facilitators, TriService Nursing Research Program, September 2020

Lt Col Laurie Migliore USAF, NC, PhD, RN; Lt Col Sarah Huffman, USAF, NC, PhD, RN; Capt Erin Repko, USAF, NC, MSN; Ceferina Brackett, RN, BSN; Rebecca Heyne, PhD, DNP, MBA, RN; LeAnne Lovett-Floom, DNP, MSN, PHN-BC

This Toolkit does not supersede DoD Policy.

The toolkit contents include the best information available at the time of publication. It is designed to provide basic palliative care information for frontline staff who do not routinely provide palliative care. It is not intended to define a standard of care and should not be interpreted as prescribing an exclusive course of management. Variations in practice will inevitably and appropriately occur when clinicians consider the needs of individual patients, available resources, and limitations unique to an institution or type of practice. Every healthcare professional making use of this toolkit is responsible for evaluating the appropriateness of applying it in the setting of any clinical situation.

Acknowledgments:
We want to thank the following professional organizations and subject matter experts for their support, input, and resources:

- Center to Advance Palliative Care (CAPC)
- Respecting Choices
- Vital Talk
- Col Stephen Hernandez, PhD, RN
- Kristin Callaghan, MSN, APRN, FNP-C, MBA
- Linda Gowenlock, MSN, MPH, ACNS-BC, CCNS, ACHPN
- Diane A. Faran, MD, FAAHPM, Palliative Medicine Consultant

Funding for this project was provided by the TriService Nursing Research Program
For further information about this toolkit, please contact: Ceferina Brackett, RN, BSN.
Phone: (707) 718-8754; ceferina.d.brackett.ctr@mail.mil

INTRODUCTION

Greetings COVID Warriors!

Our toolkit is based upon the best evidence available and the palliative care information specific to COVID-19 available at the time of publication. A group of nursing professional experts within evidence-based practice and palliative care collaborated on this project. A biobehavioral framework and top recommendations from scientific literature were utilized to extrapolate the tools and resources for rapid integration into clinical care.

Products included in this toolkit were specifically selected from professional palliative organizations for ease of use and to address the most common biopsychosocial needs of COVID-19 patients, families, and healthcare workers. The biobehavioral framework aligns well within the foundational philosophy of palliative care to alleviate suffering and improve quality of life physically, mentally, spiritually, culturally, socially, ethically, and legally throughout the COVID-19 patient/family experience.

The ultimate goal for this toolkit is to **prepare and support frontline workers in addressing unique COVID-19 palliative care challenges** related to physical and social isolation; limited access to "in-person/face-to-face" supports (family, chaplains, therapists); the unpredictable rapid change of a patient's clinical course; and the complex decision making and conversations required in our evolving healthcare delivery system during the COVID-19 pandemic.

About the Toolkit Use

Current operational standards of care will determine how you utilize and implement the palliative care toolkit. Under conventional clinical standards of care, you may have ample time to train staff on the toolkit contents and conduct simulated difficult conversations. A just-in-time review and use of select tools may be more appropriate when operating under crisis standards of care.

Situational Standards of Care: DODI 6200.03 allows for establishment of Crisis Standards of Care within the DoD. Additionally, standards may also be established by local or state government. Your facility will communicate your current operational standards of care to facility staff.

Conventional Standards of Care: Normal daily standard of care.

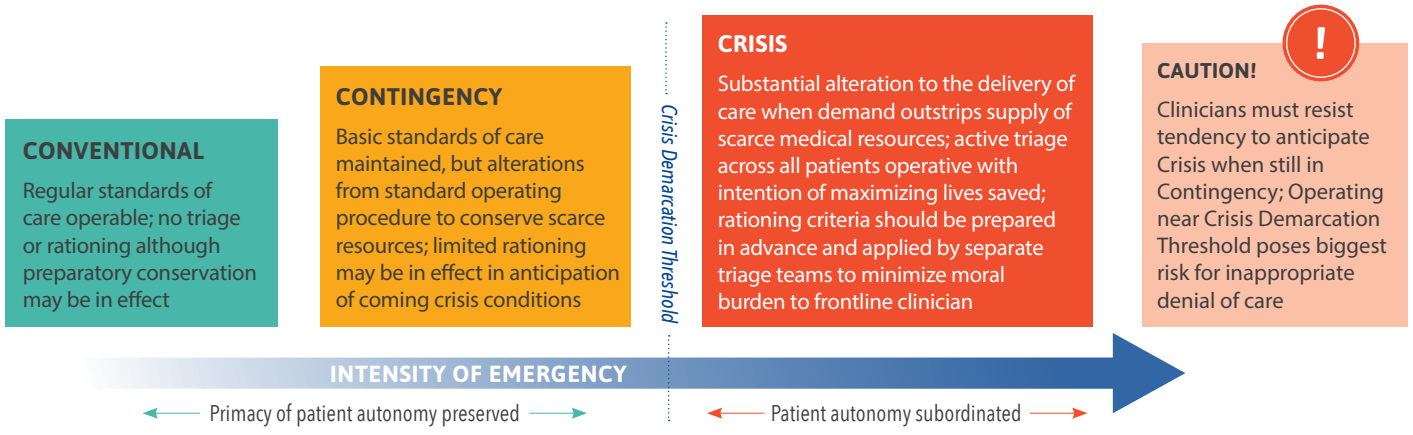
Contingency Standards of Care: Normal standards but with expanded roles, responsibilities and resource conservation.

Crisis Standards of Care: Public health emergencies and surge requirements such as:

- Formally declared by authorities for a sustained period
- Overwhelmed response capacity, capability, resources and providers
- Substantial change in usual healthcare operations
- Not optional - forced by an emerging situation
    - Increased patient load
    - Alternate patient care delivery locations
    - Expanded scope of practice
    - Modified practices permitted (monitoring, documentation, equipment)
    - Limiting and rationing resources; recycle/reuse/extended use
    - Enables legal and regulatory protections for healthcare workers

Phased standards of care with general guidelines for the continuum of standards are illustrated below. Facilities will typically establish specific indicators or triggers (% beds available, # ventilators, # isolation rooms, staffing ratios, etc.) for determining transitions between care standards.

CENTRAL ILLUSTRATION: Framework for Understanding Standards of Care Implications During Pandemic Conditions



Kirkpatrick, J.N. et al. J Am Coll Cardiol. 2020;76(1):85-92.

PALLIATIVE CARE 101

What is Palliative Care?

Palliative care is an interdisciplinary specialty that focuses on meeting the needs, priorities, and goals of seriously ill patients, families, and caregivers. Those needs often consist of strategies to alleviate pain, symptom management, stress, and improve overall quality of life. Palliative care embraces a holistic approach by viewing a patient as more than just a person but a human being consisting of physical, psychosocial, spiritual, and cultural needs.

When is Palliative Care Appropriate?

Palliative care is appropriate for any age and at any stage of serious illness.

Who is Palliative Care For?

All **seriously ill people** with life altering illnesses such as cancer, end-stage lung disease, HIV, renal failure, liver failure, and more.

Seriously ill COVID-19 Patients

- Individuals hospitalized to manage COVID-19 symptoms
- Individuals in home care for COVID-19 symptom management

Principles and palliative care best practices will benefit seriously ill COVID-19 patients regardless of age or clinical setting by identifying the needs and priorities of patients and families.

Who Provides Palliative Care?

- Interdisciplinary teams with palliative care certified professionals, doctors,nurses, social workers, chaplains,psychological specialists, and all healthcare workers caring for the seriously ill.
- Not all hospitals have palliative care departments and specialists, but all clinicians are called on to provide generalist palliative care.
- Frontline staff (ER, ICU, COVID-19units) will be the primary deliverers of palliative care.
- Palliative care experts are available for just in time coaching and assisting with managing complex cases.

Difference of Palliative Care, Hospice Care, and End of Life Care

	PALLIATIVE CARE	HOSPICE CARE	END OF LIFE CARE
Provides patient/family/caregiver support	✓	✓	✓
Symptom Relief	✓	✓	✓
Comfort Care	✓	✓	✓
Curative Care	✓		
Any stage or phase of serious illness	✓		
Requires prognosis of 6 months or less		✓	
Focus on impending death and days after death			✓

Palliative Care Assessment and Planning

- Identify important and priority issues for patients and families
  - Physical, Emotional, Social, Spiritual, Cultural, Ethical, Legal
  - Survival
  - Health maintenance
  - Treatment options
- Recognize what is possible
- Patient/family shared decision-making
- Interdisciplinary approach to planning
- Continual assessment/re-assessment
- Modify care plans as needed
- Pandemic processes may compress and/or expedite end of life care

Palliative Care Goals

- Improve quality of life
- Pain and symptom relief
- Fewer hospitalization and emergency room visits
- Support for patients, families, and caregivers
- Shared decision-making

DoD Palliative Care Teams

- **Walter Reed National Military Center Palliative Medicine**
- **Brooke Army Medical Center Palliative Care**
- **Madigan Army Medical Center Palliative Care**

Palliative Care Referral

- Patients already followed by palliative care
- Symptoms refractory to palliative symptom protocols
- On ventilatory support
- Difficult-to-control emotional distress
- Patient, family, or physician uncertainty regarding prognosis
- Patient, family, or physician uncertainty regarding non-beneficial treatment options
- Patient or family psychological or spiritual/existential distress
- Patient or family request

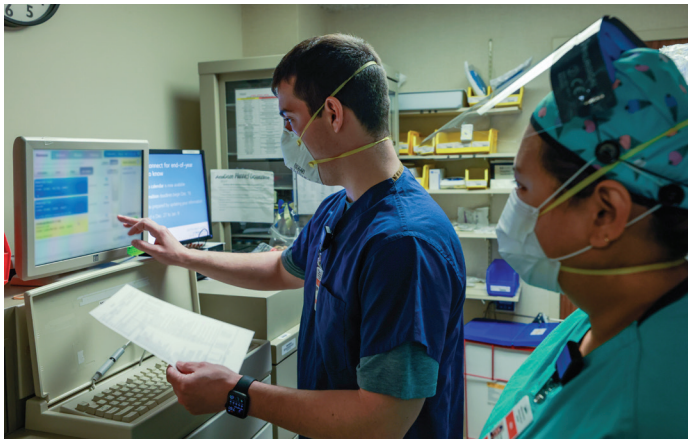
Content adapted from CAPC

COVID-19 Palliative Care Approach: Using 3 Questions

1. Who is this person?
Medically? Functionally? Psychosocially? Spiritually?

2. What is important?
Medically? Functionally? Psychosocially? Spiritually?

3. What is possible?
Medically? Functionally? Psychosocially? Spiritually?



MEDICALLY	• COVID-19 diagnosis, symptoms, and severity • COVID-19 exposure/contacts • Comorbidities, age • Treatments • Clinical course • Prognosis • Medical decision-making • Intubation risk/preference • CODE STATUS
FUNCTIONALITY	• Baseline functional status • Current functional status • Rehab potential • Decision making capacity • History of dementia, delirium, depression • History of anxiety, claustrophobia, PTSD • Caregiving needs • Caregiving resources
PSYCHOSOCIALLY	• Family structure/Household members • Surrogate/POA • COVID-19 assumptions and beliefs • Expectations/Fears • Priorities — what is most important? • Support system • Stressors/Conflicts/Estrangement • Home Environment
SPIRITUALLY	**F**aith **I**mportance **C**hurch/Community **A**ssessment/Action • COVID-19 narrative (making meaning) • Ritual adapted to COVID-19 times • Reconciliation with self, family, faith, and more.

Source: Palliative Care Team, October 2020 Madigan Army Medical Center

COMMUNICATION

Communication Strategies

To prevent harmful misunderstandings, it is important to standardize communication with the family.

1. Get team on same page (see 'Getting on Same Page' illustration below).
2. Identify family POC with contact numbers in the chart and posted in the room.
3. Identify a team "communication lead" responsible for ensuring regular contact with family.
4. Utilize time windows to mitigate family anxiety about missed phone calls (i.e., call between 2-4 pm every day).
5. Be explicit in your updates as well as in your expressions of empathy and commitment to care.
6. When giving information, build in intentional pauses to allow for processing of information. For example, *"I will stop now to give you time for things to sink in. Let me know when you are ready to continue."*
7. Be vigilant about identifying misconceptions and address them directly.
8. Clarify and revise goals and plans based on patient preferences, values, and priorities.

Getting on the Same Page

Getting on the SAME PAGE can help us clarify a plan by considering 'what is possible?'

Getting on the SAME PAGE can help us clarify our messages to families.

It's a chance to make sure all staff members are on the SAME PAGE when communicating with families.

BEFORE talking with families, consider:

1. Where have we been?
- Review/update regarding hospital course
- Consider big picture of this admission as well as overall illness trajectory

2. Where are we now?
- What is being done (monitoring, testing, therapies, consults, etc.)?
- Consider short term prognosis for survival, as well as quality of life, caregiving needs, etc.
- Use all of this to inform possibilities for ongoing care here and after discharge

3. Where are we going?
- Consider patient/family values, preferences, and priorities to inform clinical goals
- Consider patient/family expectations and stressors
- Consider staff expectations and stressors
- Emphasize level of fluidity and uncertainty

To Clarify Our Message, Ask Yourself...

1. What are our boundaries and limitations (acknowledge them out loud to ourselves and family)?
2. What does "best care" look like in a "not the best" situation (be specific and speak simply)?
3. What is our message to patient/family (keep it simple)?
4. Who is best to deliver the message and how can rest of team best reinforce it?
5. Is our message unified and consistent (across shifts, team changes, consultants, etc.)?

Source: Palliative Care Team, October 2020 Madigan Army Medical Center

Communication During COVID-19 Times:

- With families no longer at the bedside, they are removed from the physical reality of the patient's condition.
- Patients and families are often receiving multiple messages from news outlets and social media.
- They may believe the healthcare system is ill-equipped or running out of resources.
- They may believe they are being dealt with in a biased fashion.
- Serious effort must be given to create clear, consistent processes for communication.
- Communication breakdowns have potential to tarnish all the outstanding work that goes into patient care.

Source: Palliative Care Team, October 2020 Madigan Army Medical Center

Difficult Conversations and Scripts for Communicating with Patients and Families

WHAT THE PATIENT/ FAMILY SAYS	WHAT YOU MAY SAY
Admitting a Patient	
How bad is this?	From the information I have now and from my exam, your situation is serious enough that you should be in the hospital. ***We will know more in the coming hours to days***, and we will update you. Who else should know about your/ their situation and how will they know?
Is my grandfather going to make it?	***I imagine you are scared***. Here's what I can say: because he is 90, and is already dealing with other illnesses, ***I worry that he is at risk of dying if this worsens in the hospital. While it is too soon to say for certain, what worries you most about that?***
Are you saying that no one can visit me?	I know it is hard to not have visitors. The risk of spreading the virus to other vulnerable people is so high that ***they and those they contact will be in more danger if they come into the hospital.*** I wish things were different.
How can you not let me in for a visit?	The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. We can help you be in contact electronically. ***I wish I could let you visit, because I know it's important, but it is not possible now.***
When things are not going well, goals of care discussion, code status discussions	
I want everything possible. I want to live.	We are doing everything we can. This is a tough and scary situation for many of us. Could we step back for a moment so I can learn more about you? ***What do I need to know about you to do a better job taking care of you?***
I don't think my grandfather would have wanted this.	Well, let's pause and talk about your concern. ***Can you tell me what we should know to take the best care of him?***
I don't want to end up being a vegetable or on a machine.	Thank you, it is very important for me to know that. ***Can you say more about what you mean?***
I am not sure what my grandfather wanted – we never spoke about it.	You know, many people find themselves in the same boat. This is a hard situation. To be honest, given his overall condition now, I worry that further treatments may not be successful in preventing him from dying. ***In a situation like that, I have recommended that we allow a natural death***. That could be hard to hear. What do you think?
When coping needs to be boosted, or emotions are running high	
I'm scared	This is such a tough situation. ***I think anyone would be scared***. Could you share more with me?
I need some hope	Tell me about the things you are hoping for? ***I want to understand more.***
You people are incompetent!	I can see you are not happy with things. ***I am willing to do what is in my power to improve things for you.*** What could I do that would help?
I want to talk to your boss.	I can see you are frustrated. ***I will ask my boss to come by as soon as they can. Please realize that they are juggling many things right now.***
Do I need to say my goodbyes?	I'm hoping that's not the case and I worry time could indeed be short. ***What is most pressing on your mind?***

Source: Content adapted from VitalTalk

SYMPTOM MANAGEMENT (End of Life Care)

Symptom management should be individualized and patient centered. This serves as a guideline only for common symptoms at the end-of-life care. Please follow your local policy and procedures.

SYMPTOMS	PHARMACOLOGICAL INTERVENTION	NONPHARMACOLOGICAL	RECOMMENDATION
Shortness of Breath	**Morphine Sulfate PO** 15 mg ½-1 tablet every 3 hours PRN. **OR** **Morphine Sulfate IV** 5 mg IV or SQ every 1-hour PRN. (SQ/IV can be given as frequent as every 30 minutes PRN)	• Positioning • Cool room temperatures • Remove restrictive clothing • Bedside relaxation techniques such as breathing exercises	Assess the underlying condition. Treatment goals are: • Minimal use of accessory muscle, nasal flaring, and retractions • Patient comfort.
Respiratory Secretions (Congestions Near End of Life)	**Glycopyrolate** 0.4 mg SQ/IV every 4 hours PRN. **Furosemide** 20 mg SQ/IV q2h PRN	• Limit suction • Reduce or stop saline infusions	• During end of life, pharyngeal secretions are normal.
Anxiety	**Lorazepam PO/IV** 0.5 – 1 mg PO/ IV every 1-4-hour PRN. **Midazolam IV** 1-4 mg SQ/IV every 30 minutes PRN. For severe anxiety or shortness of breath.	• Breathing exercises • Minimize noise and light • Music therapy • Acupressure • Cool room	Dyspnea often induces anxiety. Treat dyspnea with opioids as first line of treatment. • Lorazepam and Midazolam can be helpful as adjuncts
Delirium	**Haloperidol PO** 0.5 mg PO every 4 hours PRN. **Haloperidol IV** 0.5 – 1 mg IV every 4 hours PRN. Titrate dose in 0.5 mg increment. **Olanzapine PO** 2.5- 5 mg PO at bedtime and every 8 hours PRN.	• Music therapy • Reorientation • Massage • Short and direct communication	Treat underlying cause for delirium. • Avoid benzodiazepines
Constipation	**Senna PO** 8.6 mg PO daily **Enema** PRN if unable to tolerate PO.	• Increase fluids orally, if tolerated • Warm prune juice	Constipation is a common side effect of opioid use. • Establish bowel regimen
***Nausea**	**Metoclopramide PO** 10 mg every 6 hours around the clock **Ondansetron PO** 4mg every 8 hours, increase to 8 mg if no relief from starting dosage. **Metoclopramide IV** 5 mg/ml give 1 ml every 6 hours around the clock. **Ondansetron IV** 0.15 mg/kg IV every 8 hours.	• Aromatherapy • Acupressure	Treat underlying cause. • If its opioid-induced nausea, give anti-nausea medication 30 minutes before opioids
Pain	**Morphine Sulfate PO** 15 mg ½-1 tablet every 3 hours PRN. **OR** **Morphine Sulfate IV** 5 mg IV or SQ every 1-hour PRN. (SQ/IV can be given as frequent as every 30 minutes PRN)	In conjunction with opioid therapy: • Relaxation techniques • Breathing exercises • Meditation • Distraction • Acupressure • Mindfulness	Pain is subjective. Re-assess pain after every intervention. The goal is to make the patient comfortable.

*Source: Content adapted from DOD COVID-19 Practice Management Guide V. 10-16-20 | *Source: CAPC*

PAIN MANAGEMENT (Opioid Intermittent Dosing)

To address pain effectively, consider adjusting the dosing for patients already taking opioids, the elderly, frail, and opioid naïve patients. This table provides opioid intermittent dosing to relieve pain and/or shortness of breath for adults.

OPIOID DOSING TO RELIEVE SHORTNESS OF BREATH AND PAIN IN ADULTS	
DOSING FOR OPIOID NAÏVE PATIENT **(Patient *NOT* on opioid therapy) *(For frail, elderly patients, begin at low end of any range)***	
Morphine	• 15 mg tablet ½ to 1 tab PO q 3 hours PRN for pain **OR** • 5 mg SQ/IV q1H PRN shortness of breath (SQ/IV can be given as frequently as q30min PRN)
Hydromorphone	• 2 mg tablet ½ to 1 tab PO q 3 hours PRN for pain **OR** • 0.4-0.8 mg SQ/IV q1H PRN shortness of breath (SQ/IV can be given as frequently as q30min PRN) If more than 6 PRN doses of opioid in 24 hours: • Consider a basal opioid such as MS Contin 15 mg PO BID.
If patient unable to make needs known, consider SCHEDULED dosing of the immediate release opioid (q4H or 6H for frail elderly) AND continue PRN dose.	
	TITRATE UP AS NEEDED for relief of dyspnea and/or pain.
DOSING FOR PATIENTS *ALREADY* TAKING OPIOIDS	
Applies to any opioid	• Continue previous opioid, consider increasing dose by 25% • To manage breakthrough symptoms: Start PRN opioid at 10% of total daily (24 hour) opioid dose • PRN q1H for PO and q30mins for SQ/IV

Source: Content adapted from DOD COVID-19 Practice Management Guide V. 10-16-20

PAIN MANAGEMENT (PCA Use)

PCA INFUSION DOSING: FOR ALERT PATIENT WHO NEED IV OPIOIDS (UNABLE TO TAKE PO OR WITH SEVERE SYMPTOMS.		
Opioid	**Bolus Dose**	**Basal Rate**
Morphine	1.5 mg q10mins	1-2 mg/hour
Hydromorphone	0.2 mg q10mins	0.1 – 0.3 mg/hour
Fentanyl	20 micrograms q10mins	10-25 micrograms/hour

- Titrate the basal rate and bolus dose to effect.
- If using more than 1 rescue dose/hour, increase the basal rate for improved symptom control.

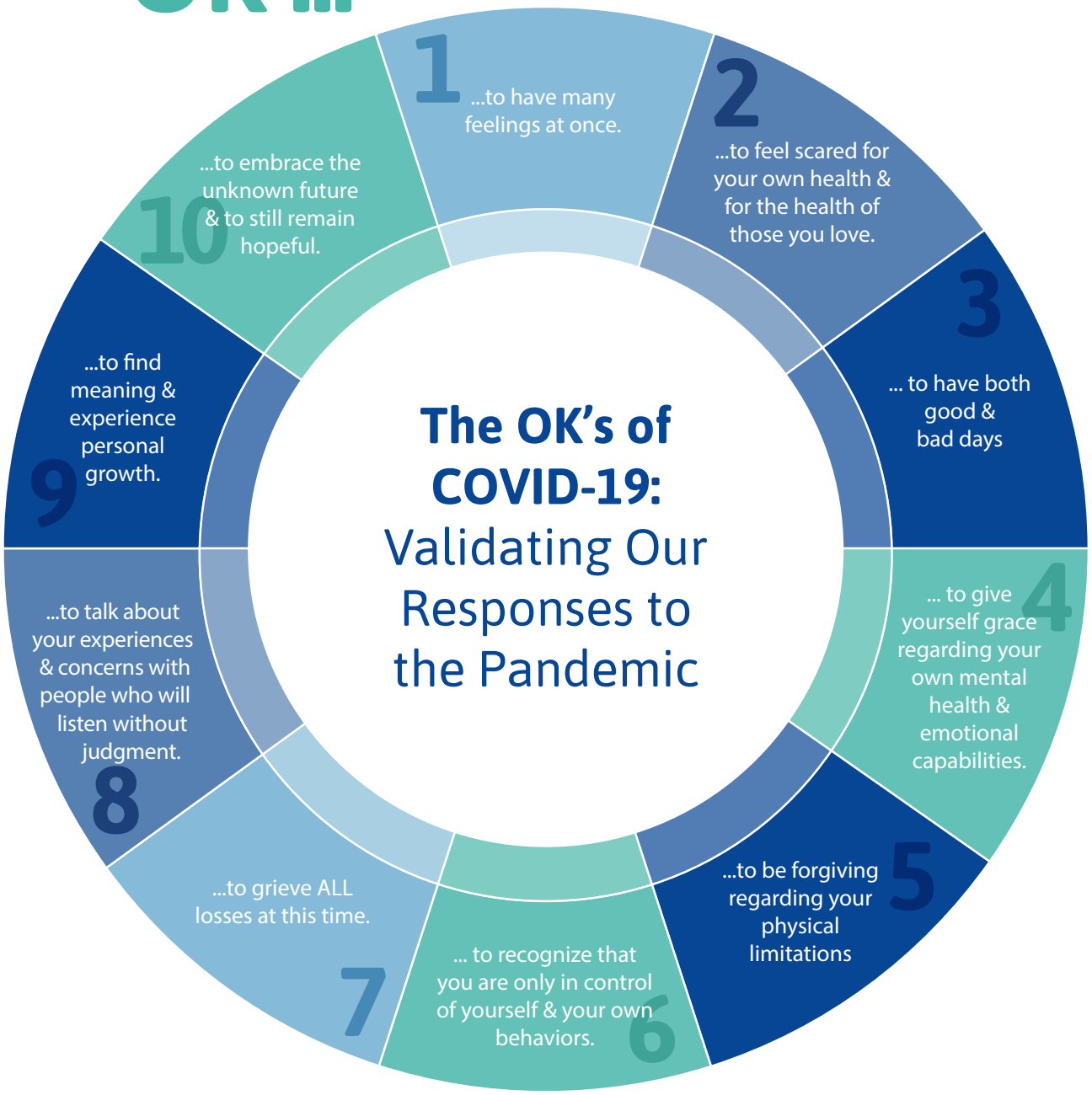
PCA Infusion Pump Strategy for Patient ALREADY Taking Opioids

- For patients on chronic opioid therapy, rotate their long-acting medication into the basal rate of your PCA. Titrate to effect.
- Bolus doses may be given q10 to 15min PRN; if the patient is NOT able to use the button, add a nurse administered bolus order of 5 mg IV q 2-hour prn for morphine PCAs and 0.8 mg IV q 2-hour prn for hydromorphone PCAs.
- Example titration: You start a morphine PCA at 1 mg/hour basal rate with 1 mg q 15 minutes rescue. The patient presses the button every 15 minutes and says he "feels nothing" and continues to be short of breath. Increase the rescue dose to 2 mg and reassess.
- Adjust bolus doses to 50-100% of new continuous infusion rate (e.g., Bolus dose of 2-4 mg q15min PRN for new rate of 4mg/h).
- New rate can be reassessed for adjustment again in 3-4 hours.

Source: Content adapted from DOD COVID-19 Practice Management Guide V. 10-16-20

SUPPORT FOR CAREGIVERS

It is OK ...



Source: Home Nursing Agency Blog (The Ok's of COVID-19: Validating our Responses to the Pandemic)

Clinicians and families experience challenges in processing their thoughts and emotions during a crisis and difficult situations. These emotions and thoughts are normal. Here are examples of helpful thoughts to use during those situations.

COMMON UNHELPFUL THOUGHTS	HOW YOU MAY FEEL	ALTERNATE HELPFUL THOUGHTS	HOW YOU'LL FEEL
TOPIC: COPING			
• I should be coping better.	• Helpless • Useless • Scared	• I got here today, so I'm coping a bit. • Talking to a friend, mentor, or counselor might help me cope better. • Most people are struggling to cope in this new context. We're all doing the best we can. • I can use this time to strengthen my skills/faith/values/practice.	• Less scared • More hopeful • Less helpless • Stronger • Capable • Open to getting support or help
• Other people deal with this better than I do, so what is wrong with me? • Only weak people react the way I do.	• Worthless	• Most people react this way for a while. • My reaction shows the challenge I'm going through, not how weak I am.	• Reassured • Capable • Stronger
TOPIC: GUILT			
• I should have prevented this. • I should have done something differently. • I am disappointed in myself.	• Guilty • Worthless or blameworthy • Frustrated • Upset	• Nobody could have prevented this. • I can't always protect myself or others. • I did the best I could, given that: I was exhausted; I was dealing with a lot; I was operating with limited resources; I was pressed for time, etc. • There are many things I'm grateful for, so I'll focus on those instead of what is bothering me.	• Self-accepting • Worthy • Like you aren't to blame
TOPIC: BLAME AND ANGER			
• It's unfair.	• Angry • Vengeful	• This could have happened to someone else. • Sometimes bad things happen to good people. • It might be unfair but, if I continue to be angry, it is getting in the way of my bigger priorities (e.g., helping my children feel safe etc). • There are many things I'm grateful for, so I'll focus on those instead of what is bothering me. • I can use this time to strengthen my faith/values/practice.	• Understanding • Realistic • Accepting

Source: U.S. Department of Veteran Affairs, National Center for PTSD

SPIRITUALITY

North American Definition of Spirituality:

"Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience connectedness to the moment, to self, to others, to nature and to the significant or sacred." (Puchalski et. al, 2009)

Spirituality allows individuals to find purpose, meaning, transcendence and relationship and is typically rooted in beliefs, doctrine, and practices.

Helpful Tips in Addressing Patient's Spiritual Needs:

1. Assess spiritual need with the understanding that the spiritual dimension of a person's life is an avenue for compassionate caregiving.
2. Provide basic spiritual support
   - Empathic listening
   - Compassionate presence
   - Inquiry about spiritual beliefs, values, & practices
   - Reflective listening, query about important life events
   - Life review, listening to the patient's story
   - Breathing practice or contemplation
   - Support patient's sources of spiritual strength
   - Continued presence and follow-up
   - Open-ended questions to elicit feelings
3. Refer to spiritual care provider when appropriate.

Source: Palliative Care Team, October 2020
Madigan Army Medical Center

Photo Source: iStock

Spirituality is Described in Terms of:

- **Indicator of our humanity**
- **Our core, beliefs, values**
- **Our inner being**
- **The divine, Holy One, Spirit**
- **Found within or beyond**

Assessing Patient's Faith or Belief Using FICA:

F — FAITH AND BELIEF
- "Do you consider yourself of any particular faith?"
- If no, you could ask, "What gives your life meaning?"

I — IMPORTANCE
- "What importance does your faith have in your life?"

C — COMMUNITY
- "Are you part of a spiritual or religious community?"

A — ACTION
- Ask yourself, "What are next steps?"
- "Who can I partner with?"

Palliative care strives to provide spiritual support for patients as indicated by their preferences, needs, and goals of care.

GRIEF

What is Grief?

Grief is an **experience** not a process.

Grief is not a single emotion.

Grief symptoms can manifest physically, emotionally, and mentally.

Helpful Tips in Addressing Patient's Spiritual Needs:

Our individual grief experience is shaped by a myriad of factors:

- The relationship we had with the person who died
- The cause of death
- Our society and cultural background
- Our personality and coping style
- Our past experiences with loss
- Our support networks
- Our religious or spiritual beliefs and customs

Source: Palliative Care Team, October 2020 Madigan Army Medical Center

Source: Kübler-Ross, E., & Kessler, D. (2009). The five stages of grief. In Library of Congress Catalogin in Publication Data (Ed.), On grief and grieving (pp. 7-30)

How to Support a Grieving Patient and Families?

Support, NOT Comfort

- Grievers need support, not fixing.
- It's human nature to want to alleviate someone else's pain, but grief doesn't work that way. There is nothing we can do to take away the pain.
- Instead, we can acknowledge the pain and help to hold them up. Supporters can be part of their foundation as they learn how to carry their grief forward.

Empathethic Listening

- Your job as grief support person is NOT to make the grieving person feel better, it's to make the grieving person **feel heard**.

Individualized Support

- Grief support is not one size fits all. The support you give to one griever may not work for another.
- Grief is individual, and grief support should be tailored to everyone's needs.

Grief is the container that holds all the emotions felt as a result of loss.

5 Stages of Grief

BEREAVEMENT

Table 8. Evidence-Based Recommendations for Mitigating Poor Bereavement Outcomes in Relatives

BEFORE a Patient's Death

- Early advance care planning discussions and parallel planning with patients and families.
- Timely, proactive, and sensitive information provision and communication with families, guided by the VALUE mnemonic: value and appreciate what family members say; acknowledge family members' emotions; listen to their concerns; understand who the patient was in active life by asking questions; elicit questions from family members.
- Where possible, assign a specific contact person for each patient to help ensure continuity of care and timely communication with families before and after death.
- Follow expert guidance on tele-communication and communication with PPE.
- Specialist palliative care collaboration, referral, and advice; use triage and remote communication where needed.
- Optimize symptom management.
- Where possible, allow and facilitate a family member to visit a deteriorating patient.
- Facilitate virtual communication using smartphones, tablet computers, and other technology. Enlist donations to source tablets, smartphones, and charging devices (patients are often admitted to hospital with their phones but not chargers). Dedicated equipment with appropriate applications can then be loaned to patients and families in COVID-19 areas.
- To avoid distress, be cautious about virtual communication when a patient is actively dying.
- Ensure patients and families have access to emotional, psychological, and spiritual support, including access to chaplaincy.

AFTER a Patient's Death

- Some families may want mementos or keepsakes (e.g., locks of hair, handprints, etc.). Local practice may vary; in the U.K., these can be taken at the time of care after death, but not at a later date, placed in a sealed bag and not opened before seven days.
- Ensure an involved clinician is available postmortem to speak and listen to family members, discuss what happened, and answer questions via telephone.
- Identify relatives who may be at particular risk of poor bereavement outcomes (e.g., due to social isolation) for enhanced follow-up and support.
- Enlist the support of allied health professionals from other specialties within the hospital, whose workload may have decreased during the pandemic, to help provide psychosocial support to bereaved families.
- Create a COVID-19 bereavement leaflet which signposts relatives to local bereavement support services available via e-mail, telephone, mobile apps, web forums, web chats, and virtual peer support, and where to get faith-specific advice. These should be given to the family as soon as possible after the patient's death.
- Send a personalized condolence letter. The best timing of a condolence letter is not currently known; however, it should be personalized, not make commitments that cannot be met, and include information regarding further support.
- If needed, provide a list of local support services which may be able to provide practical help and support to people who are suddenly vulnerable due to a bereavement and may be self-isolating.
- Provide up-to-date information and guidance on arranging a funeral or other religious ceremony and registering a death, with suggestions and resources for future ceremonies. Funeral poverty may be a concern for many relatives, so signposting toward organizations who can advise on this issue may be helpful.
- **Consider providing bereavement support evenings and/or culturally sensitive bereavement services for relatives after the immediate crisis.**

Source: Bereavement Support on the Frontline of COVID-19

MOBILE APPLICATIONS

COVID Coach

For managing the stressors associated to the COVID-19 pandemic.

- Learn ways to improve your well-being during this global pandemic
- Use trackers for mental health and personal goals
- Find tools for coping and self-care

https://www.ptsd.va.gov/appvid/mobile/COVID_coach_app.asp

Insomnia Coach

- Guided, 5-week training plan to help you track and improve sleep
- Sleep coach with tips for sleeping and personal feedback about your sleep
- Interactive sleep diary to help you keep track of daily changes
- 17 tools to help you get your sleep back on track

https://mobile.va.gov/app/insomnia-coach

Mindfulness Coach

Designed to support independent mindfulness practice.

- Mindfulness Training: A stepped training plan that ties together features from each section
- Practice Now: Library of mindfulness exercises
- Track Progress: Assessments and goal tracker
- Build Expertise: Short readings to increase understanding of how mindfulness works

https://mobile.va.gov/app/mindfulness-coach

Covid Coach iOS

Covid Coach Android

Mindfulness Coach iOS

Mindfulness Coach Android

PTSD Coach iOS

PTSD Coach Android

Insomnia Coach iOS

Insomnia Coach Android

Use the above codes to open a link for each app in your preferred app store. Open your smartphone camera and focus on the corresponding code. Alternatively, visit the App Store or Google Play and type the name of the app in the search bar.

ADDITIONAL RESOURCES

SECTION 1: Palliative Care Training

- Center to Advance Palliative Care™ https://www.capc.org/covid-19/
- Respecting Choices® https://respectingchoices.org/covid-19-resources/
- The California State University Shiley Institute for Palliative Care https://csupalliativecare.org/covid-19-resources/
- National Coalition for Hospice and Palliative Care, Clinical Practice Guidelines for Quality Palliative Care https://www.nationalcoalitionhpc.org/ncp/https://www.nationalcoalitionhpc.org/ncp/

SECTION 2: Communication Skills

- Vital Talk, COVID Ready Communication Playbook https://www.vitaltalk.org/wp-content/uploads/VitalTalk_COVID_English.pdf
- Respecting Choices, Proactive Planning Conversations https://respectingchoices.org/covid-19-resources/#planning-conversations
- Center to Advance Palliative Care, Saying Goodbye https://www.capc.org/covid-19/communication/saying-goodbye/

SECTION 3: Symptom Management

- Center to Advance Palliative Care, Crisis Protocols https://www.capc.org/covid-19/symptom-management/crisis-protocols/
- DoD COVID-19 Practice Management Guide https://deployedmedicine.com/market/31/content/1440

SECTION 4: Support for Healthcare Workers

- HHS, Behavioral Health Guidance and Resources, Preventing and Addressing Moral Injury Affecting Healthcare Workers During the COVID-19 Pandemic, https://files.asprtracie.hhs.gov/documents/bh-addressing-moral-injury-for-healthcare-workers.pdf
- Center to Advance Palliative Care, Emotional PPE https://www.capc.org/covid-19/emotional-ppe/
- Resources for Managing Stress. U.S. Department of Veterans Affairs, National Center for PTSD https://www.ptsd.va.gov/covid/index.asp

Support for Patient and Families

- Centers for Disease Control & Prevention, Coping with Stress https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html
- Reducing Stress via Text Messages https://www.myhealth.va.gov/mhv-portal-web/ss20200625-reducing-stress-annie
- Center to Advance Palliative Care, Planning Steps for Patients and Families During the COVID-19 Crisis https://www.capc.org/documents/download/781/

REFERENCES

Center to Advance Palliative Care [Internet]. New York: COVID-19 Response Resources Hub; c2020 [cited 2021 Jan 12]. Available from: https://www.capc.org/covid-19/

National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality PalliativeCare, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. Available from: https://www.nationalcoalitionhpc.org/ncp

Defense Health Agency. (July, 2020). DoD COVID-19 Practice Management Guide. Department of Defense. https://deployedmedicine.com/market/31/content/1440

Kirkpatrick, J. N., Hull, S. C., Fedson, S., Mullen, B., & Goodlin, S. J. (2020). Scarce-Resource Allocation and Patient Triage During the COVID-19 Pandemic: JACC Review Topic of the Week. Journal of the American College of Cardiology, 76(1), 85-92.

National Center for PTSD. (May, 2020). *Coronavirus (COVID-19): Resources for Managing Stress*. U.S. Department of Veterans Affairs. https://www.ptsd.va.gov/

Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., ... & Pugliese, K. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of palliative medicine*, *12*(10), 885-904.

Respecting Choices. (September, 2020). COVID-19 Resources. https://respectingchoices.org/covid-19-resources/

Selman, L. E., Chao, D., Sowden, R., Marshall, S., Chamberlain, C., & Koffman, J. (2020). Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians. *Journal of Pain and Symptom Management*.

Sullivan, G., Ferrell, B., & Twaddle, M. (2019). Clinical Practice Guidelines for Quality Palliative Care: The 4th Edition of the NCP Guidelines (TH360). *Journal of Pain and Symptom Management*, *57*(2), 388-389.

The OK's of COVID-19: Validating our Responses to the Pandemic. (2020, April 22). Retrieved from http://www.homecareinpa.org/blog/2020/04/22/the-oks-of-covid-19-validating-our-responses-to-the-pandemic/

VITAL talk (2020). COVID Ready Communication Playbook. https://www.vitaltalk.org/guides/covid-19-communication-skills/