

UCHSC CHA/PA Hospice Rotation

Rotation Overview:

The CHA/PA Hospice Rotation will provide you an introduction to the care of persons with terminal illness. The course will highlight principles of hospice and palliative care through experiences with patients, families and providers in inpatient and community-based hospice settings. Interactive sessions with course facilitators will highlight key aspects of hospice care, advance directives, and childhood bereavement.

Rationale:

Despite rapid advances in health technology during the past 40 years, medical care for patients with chronic and advanced illness remains woefully inadequate. Studies have demonstrated prominent deficiencies that include:

- Frequent patient distress from pain and other symptoms
- High financial burden and lack of support for family caregivers
- Frequent miscommunication around prognosis and goals of care
- Insufficient end-of-life care education for professional providers

Hospice and palliative care offer a patient- and family-oriented approach to care for persons with advanced illness and their families. This care has been shown to improve patient and family satisfaction, reduce pain and distressing symptoms, relieve family burden and reduce overall medical costs. This rotation will introduce you to the essential principles of hospice and palliative care and provide you an opportunity to spend time with dying patients and their families. The rotation will also provide you the opportunity to explore your own end-of-life beliefs and values, and process normal human reactions and emotions when talking with and caring for dying patients.

Rotation Objectives:

Following rotation completion, participants will demonstrate improved understanding of:

- Approaches to care for patients with advanced illness
- Core philosophical principles of hospice and palliative care
- The Hospice Medicare Benefit
- Normal childhood development around death and dying

Participants will gain experience:

- Communicating with terminally ill patients and their families
- Working with the hospice interdisciplinary team in multiple settings
- Completing your own advance directives
- Reflecting upon (and writing about) personal and professional interactions in caring for terminally ill patients

Structure:

The rotation includes the following six core features.

1. Introductory Session: Hospice and Palliative Care Rotation
2. One-day Community (Home or Nursing Home) Hospice Experience
3. Follow-up Community Hospice Visit

4. Inpatient Hospice Experience
5. Additional Community-based Shadow Experience
6. Final Day: Journal Debriefing and Summary Wrap-up Session

Each of these core experiences is described in detail in the following section.

1. Introductory Session: Hospice and Palliative Care Rotation

Overview: This half-day session will provide you an overview of the course, and an introduction to advance directives, the Medicare Hospice Benefit, and bereavement.

Agenda

- 8:00-8:20 Introductions and Overview
- 8:20-8:50 Advance Care Planning and the “Five Wishes”
- 8:50-9:00 Break
- 9:00-9:50 Hospice 101
- 9:50-10:00 Break
- 10:00-10:30 Bereavement Exercise
- 10:30-11:30 Childhood Bereavement

Goals for the session:

By the end of the session, you will:

- Describe the course structure and objectives
- Describe common features of advance directives and the “Five Wishes”
- Define “hospice” and explain key features of the Medicare Hospice Benefit
- Describe normal stages of childhood development around death and dying

Assignments:

1) Read handouts and articles:

- NHPCO. What is Hospice and Palliative Care?
- Morrison S et al. Palliative Care, NEJM, 2004.
- Kinzbrunner BM. The Medicare Hospice Benefit. AAHPM Bulletin, 2001.
- Aasen N. Dialing Up Words of Permission: Dialing Down Words that Push.
- Bennett L. My Assistance to You

2) Complete “Five Wishes” for yourself prior to the last session. During the month, write a journal entry that describes the challenges of completing your own advance directives. What was difficult about the exercise? Are you sure of your preferences? Do others know of your preferences?

Logistics:

- Meet at The Denver Hospice (TDH), 501 S. Cherry St., 7th floor, at 8 AM for the Introductory Session.

2. One-day Community (Home or Nursing Home) Hospice Experience (TDH)

Overview: This one-day hospice experience will introduce you to hospice care through a community-based clinical experience. You will shadow a hospice nurse, social worker or chaplain to observe hospice providers interacting with and caring for terminally ill patients and families.

Goals for the day:

After completing this one-day clinical experience, you will:

- Demonstrate improved understanding of home- and nursing home-based hospice care, including the interdisciplinary team approach to the care of terminally ill patients and their families.
- Explore your own thoughts, values and beliefs around hospice care and the care of dying patients.

Assignments:

1. Read articles:
 - Gabriel BA. "Ross' Story: One Man's Triumphant Journey Through Life and Death"
 - von Gunten CF. Discussing Hospice Care. JCO, 2003.
2. Complete post-test and evaluation of one-day experience.
3. During or after completion of the one-day experience, write a journal entry about this introductory clinical experience. The journal entry can focus on one or more of the patients that you observed and/or on how this experience has impacted you as a person or health care provider. Some questions you may want to consider in thinking through the content of your journal entries:

How would you describe "hospice" to a friend, patient or family member?

What patients might most benefit from hospice care at the end of life? Who might not?

What is the role of the family in hospice care?

How do we talk with patients and families about prognosis?

How will you decide when a patient is "sick enough" for hospice? What if you are wrong?

How will you talk with a patient about hospice and/or palliative care services?

What is "quality of life" or "suffering" for a terminally ill patient?

What is "hope" for someone who is dying?

Can we help patients and families reframe hope at the end of life? If so, how?

Describe the hospice interdisciplinary care team (IDT).

Why does hospice utilize a team approach to care at the end of life?

Logistics:

- Susan Anderson will pair you with a hospice nurse, chaplain or social worker. She will contact you and provide information on time/location to meet your preceptor. Bring your syllabus with you as there may be opportunity for reading throughout the day.
- Please return to TDH **no later than 3:30 p.m.** for the debriefing session with Dr. Johnson (or other provider).
- No white coats; professional attire. Please wear your nametag throughout the day.
- If any problems arise during the day, please contact Susan Anderson at 303.398.6326, Cheryl Siefert at 303.780.4676, or Judy Kadlec-Fuller at 303.398.6259.

3. Follow-up Community Hospice Visit

Overview: During the two week period following your introductory hospice experience, you will revisit one of the patients and/or families on a follow-up experience.

Goals for the experience:

After completing the follow-up visit, you will:

- Describe the hospice interdisciplinary team and provide a rationale for team-based care for patients with chronic and life-limiting illness.
- Describe the emotional challenges and opportunities in the patient-provider *relationship*, especially as it pertains to the end of life.

Assignment:

1. Read article:
 - Bedell S et al. The Doctor's Letter of Condolence. NEJM, 2001.
2. Write a journal entry about the follow-up clinical experience. Again, assess both the clinical and personal aspects of the experience. For example, describe what struck you about the follow-up visit – what will you remember? If you visited this patient with a person from a different discipline, describe what was different. What was it like to see this patient (and/or family) a second time? Contemplate the opportunities and challenges in developing relationship with our patients and their families. Imagine saying good-bye to your patients/families. If you choose, write about your emotions – what did you think about during the visit? What additional thoughts were triggered by the follow-up visit?

Logistics:

- At the debriefing session of your initial hospice visit (Core Experience 2), you will identify a patient and/or family for which you would like a follow-up visit. Susan Anderson will provide you with contact information for the hospice team that provides care for your selected patient. During the 2-week period following this initial visit, Susan Anderson will schedule you with a team member to re-visit your patient/family at least once. These visits will typically last about 1 to 2 hours (not accounting for drive time). Other points:
 - If possible, shadow a different provider for the follow-up experience (e.g., if you followed an RN for the first visit, shadow a social worker or chaplain for the follow-up visit).
 - You may, if you would like, visit your patient/family more than once. All visits MUST be chaperoned by a hospice provider. Talk with a team member to let them know your preferences re: additional visits.

4. Inpatient Hospice Experience

Overview: During the hospice rotation, you will visit an inpatient hospice facility at The Denver Hospice. Patients are sometimes moved to the inpatient setting when end-of-life symptoms are not adequately controlled or home support is lacking.

Goals for the experience:

After completing the inpatient hospice experience, you will:

- Describe common physiologic features of the dying process
- Describe challenges in managing pain and other distressing symptoms in patients with advanced illness

Assignment:

1. Read articles:
 - Portenoy R. Myths about Controlling Pain. Mayday Fund, 2000.
 - Plonk et al. Terminal Care: The Last Weeks of Life. J Pall Med, 2005.
 - Eddy DM. A Conversation with My Mother. JAMA, 1994.

- Write a journal entry about the inpatient hospice experience. How was this different than your home or nursing home visit? Consider what you saw, heard, smelled, and/or felt during the experience. Reflect, again, on the concept of a “good death.” Describe your thoughts, perceptions and emotions.

Logistics:

- Your orientation schedule includes a ½-day Inpatient Hospice Experience. If this experience is not listed at orientation, contact Susan Anderson to finalize details for the inpatient facility visit.
- The address for TDH inpatient facility is 3399 S. Eagle St., Aurora, CO 80014. Their phone number is 303.418.3000. A map showing the facility is included in the packet.
- Dress professionally; no white coats. Wear your nametag.
- During the experience, you will shadow a NP, MD and/or other providers. Feel free to ask these providers questions.
- You may be paired with one or more of your classmates for this half-day experience. Share your thoughts and perceptions with one another during the day.

5. Additional Community-based Shadow Experience

Overview: During the month, you will have the opportunity to shadow a provider (either MD or PA) or an alternative therapist. This will broaden your experience by providing you a unique, additional opportunity 1) to work with a hospice-trained MD or a PA colleague and, 2) to experience alternative therapies used in hospice care.

Goals for the experience:

After completing this additional clinical experience, you will:

- Recognize variations (philosophical and practical) amongst hospice organizations
- Describe roles and career opportunities for physician assistants in hospice and palliative care
- Discuss death and dying in the lives of children

Assignment:

- Read articles:
 - Christ G and Christ A. Current Approaches to Helping Children Cope with a Parent's Terminal Illness.
 - Hurwitz, C et al. Caring for the Child With Cancer at the Close of Life
 - Truog, R et al. Sudden Traumatic Death in Children
- Write a journal entry about your experience. Describe your interactions with your MD/PA preceptors – describe something you learned from these professionals – and the alternative therapists. Share emotions and observations.

Logistics:

- Your schedule includes a 3-4 hour Hospice Shadowing Experience with **either** 1) a Kaiser Permanente palliative care doctor, 2) a Denver Hospice Pathways (palliative care) PA, **or** 3) a Denver Hospice music therapist during their home visits with patients. You will experience the music therapist using songs and guitar music to help calm the patient and make his/her breathing easier. The therapist may also use comfort touch or guided imagery to help the patient.

- Susan Anderson will finalize details for this additional community-based experience.
- Dress professionally; no white coats. Wear your nametag.
- Ask questions of your preceptors to highlight similarities and differences between roles and career opportunities for PAs.
- You may be paired with one or more of your classmates for this half-day experience. Share your thoughts and perceptions with one another during the day.

6. Final Day: Journal Debriefing and Summary Wrap-up Session

Overview: During this final session, you will debrief the core features and observations of the month with Dr. Johnson and your classmates. As part of this process, you will share a journal entry with your colleagues. The group will also review the “Five Wishes” exercise and provide feedback regarding the least and most helpful aspects of the course.

Goals for the experience:

After completing the final debriefing session, you will:

- Describe at least 3 memorable experiences from this hospice rotation
- Describe the challenges and opportunities you observed in completing your own advance directives
- Provide feedback to course facilitators and complete the course evaluation

Assignment:

1. Read articles:
 - Finish all articles in the syllabus prior to the last session
2. Choose a journal entry to share with the group. While any entry is acceptable, consider entries of special importance or meaning where willing/possible.

Logistics:

- Meet at TDH at 8 AM. Bring your journals and your “Five Wishes” to this session.

Commonly Asked Questions:

- *What if my visits/experiences coincide with lectures or other program commitments?* DO NOT schedule or participate in visits (even “emergency” visits) during required CHA/PA Program class time – you are required to attend all scheduled lectures. Contact Susan Anderson with a conflict – she will arrange make-up visits/experiences in the event of unexpected absences. Completion of all six elements is required to pass this course.
- *Can I visit my patient/family without the supervision of an interdisciplinary team member?* No, please DO NOT visit patients or families without the presence of one of a hospice provider – both for the protection of you and your patient/family.
- *Can I share information about my patient/family with others?* Remember that beyond the debriefing sessions, all information regarding patients (and their families) MUST remain confidential.
- *What if my community patient dies before I have a chance to participate in a follow-up visit?* If your follow-up patient (the one whom you identify after the initial one-day experience) dies before you have a chance to revisit, please notify Susan Anderson at 303.398.6326. You will have 2 choices: 1) to attend the funeral of this patient (if appropriate), or 2) to follow-up with one of the other patients that you met during the original one-day experience.

- *Can I stay in contact my community patient/family?* An important aspect of this rotation centers on “closure” – both from a professional and personal perspective. If interested, Susan Anderson can keep you apprised of the status of your patient and family. Course facilitators generally do *not* recommend ongoing contact with patients and families after completion of this rotation. In the event you choose to make further visits/contact, please contact Dr. Johnson to discuss options.

General Suggestions on Journal Writing:

Throughout this rotation, you will record your hospice experience through written narrative. Through your journal – a required aspect of this rotation – you should capture personal reflections on a variety of topics including:

- Patient and family stories of illness
- Patient and family perspectives on suffering, spirituality, hope and fear
- Professional provider’s clinical and emotional responses to dying patients
- Your own emotional reactions to death and dying

Unlike a “locked,” private diary, keep in mind that you will be asked to share one or more of your journal entries with your fellow classmates and the course facilitators. While you will not be “graded” on your journal narrative, you will be asked to rewrite poorly written or overly brief entries. You should plan on journaling a minimum of once per week (capturing highlights of required experiences) and more often as desired and appropriate.

Some tips for journaling:

- 1) Recognize that you are free to write about anything you choose (as long as it pertains to the experience). While the “Assignments” sections (above) provide *suggestions*, feel free to deviate from these suggestions as desired. Poetry, drawings, or other creative or unique entries are encouraged.
- 2) Think broadly: consider framing one or more journal entries around the following questions:
 - *How did different interdisciplinary team members interact differently w/ your patient/ family?*
 - *What are sources of “suffering” for your patient and their family?*
 - *How might your patient and family describe “hope?”*
 - *How will this experience affect the way in which you practice medicine?*
 - *How has this experience affected you as a person?*
- 3) Be mindful: describe both the experience and your own reactions to the experience.
- 4) Be creative: if “stuck”, start by describing the experience using your senses: What did you see? Smell? Hear? Feel? Does the experience trigger memories?
- 5) Be candid: don’t seek a “right” answer – rather, seek understanding through honest description, even if these descriptions drift into uncomfortable or unfamiliar territory.
- 6) Have fun: don’t fret over your writing – we all struggle with words. Don’t be afraid to capture humorous or lighthearted moments.

Suggestions on Self Care:

This rotation provides you an ideal opportunity to explore “mindful” practice – active reflection on your actions and emotional reactions during patient and family interactions (please read the 1999 JAMA article “Mindful Practice” provided to you at the introductory session). While caring for persons with terminal illness can provide great personal satisfaction and meaning, these experiences are often emotionally and psychologically challenging. Learning to manage these emotions – rather than suppressing difficult feelings or avoiding engaging in meaningful relationships – is an important aspect of this rotation. Development of such skills will lead to more effective and compassionate care for your future patients and their families, whether dying or not, and result in your own greater personal satisfaction as a health care provider. Your journal writing and group debriefing sessions will provide you an opportunity to actively “process” the hospice experience. Know that additional support is directly available through course facilitators and personnel at The Denver Hospice. Please utilize this support at any time by calling Susan Anderson at 303.398.6326, Cheryl Siefert at 303.708.4676, Judy Kadlec-Fuller at 303.398.6259, or Daniel Johnson at 303.636.3304.

Rotation Syllabus:

During this four-week rotation, you are required to read all of the articles and reading materials (for references, see chapter cover pages) contained in the course syllabus. Writings include both technical articles and narrative prose. The syllabus is divided into three chapters and includes information on the following topics:

Chapter 1: Hospice and Palliative Care

This chapter provides basic information regarding hospice and palliative care including:

- Definitions of hospice and palliative care
- Myths of hospice
- Patient narratives of hospice care
- The Medicare Hospice Benefit

Chapter 2: Pediatric Palliative Care

During this rotation, consider the challenges in providing care to terminally ill children. Readings in this chapter include:

- Definitions of pediatric palliative care
- Challenges in caring for children with terminal illness
- Children's grief and bereavement

Chapter 3: Other Resources

Chapter three contains information and narrative about a variety of essential topics in palliative care including:

- Myths about controlling pain
- Physiology and psychology of dying
- End-of-life communication
- Writing a letter of condolence
- Cultural competency in end-of-life care