VCU Palliative Care ECHO*

November 14, 2019

Existential and Spiritual Assessment

*ECHO: Extension of Community Healthcare Outcomes

Continuing Medical Education

November 14, 2019| 12:00 PM | teleECHO Conference

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The following Planning Committee and Presenting Faculty Members report having no relevant financial relationships:

Jason Callahan, M.Div.
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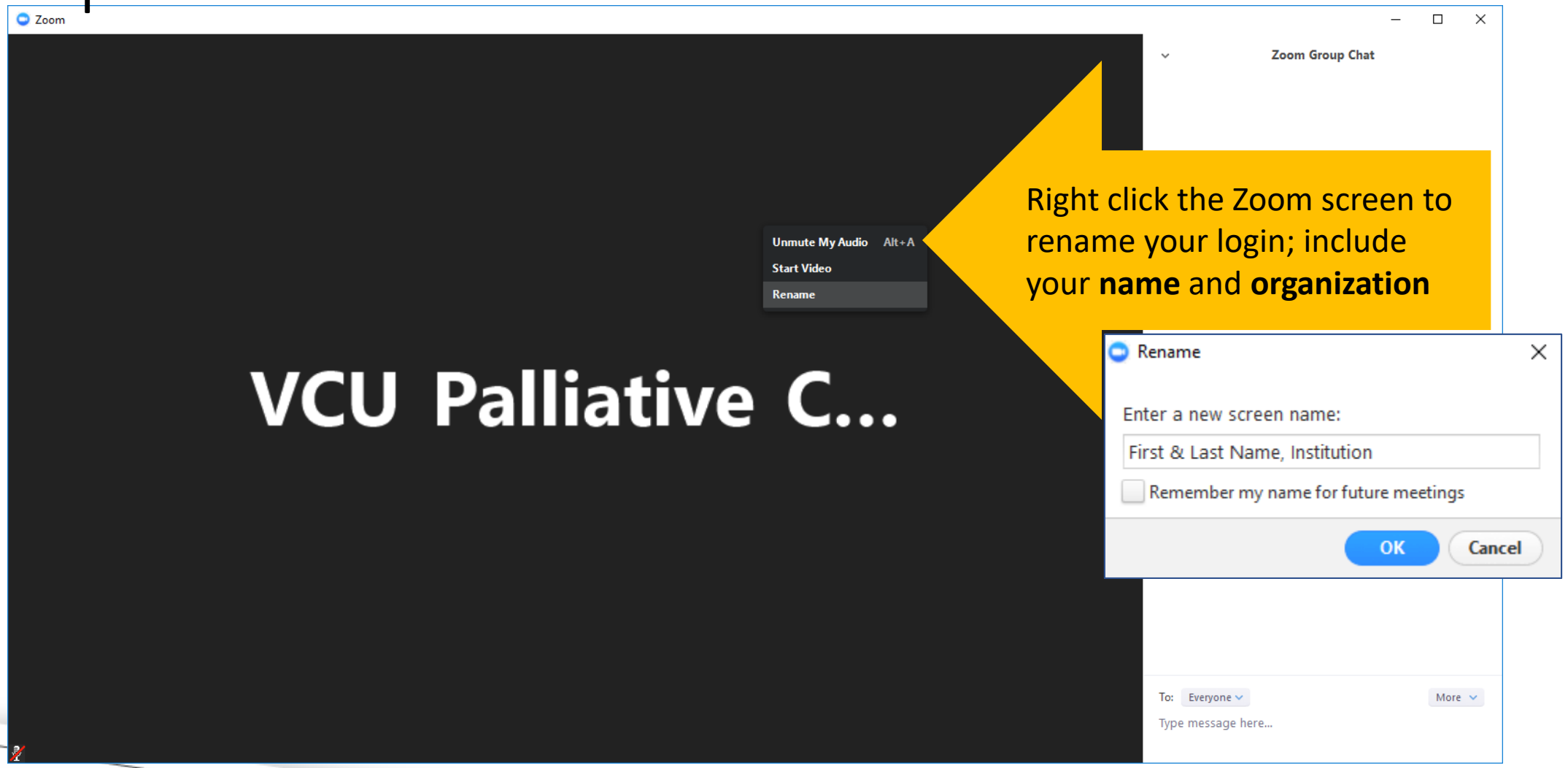
Helpful Reminders



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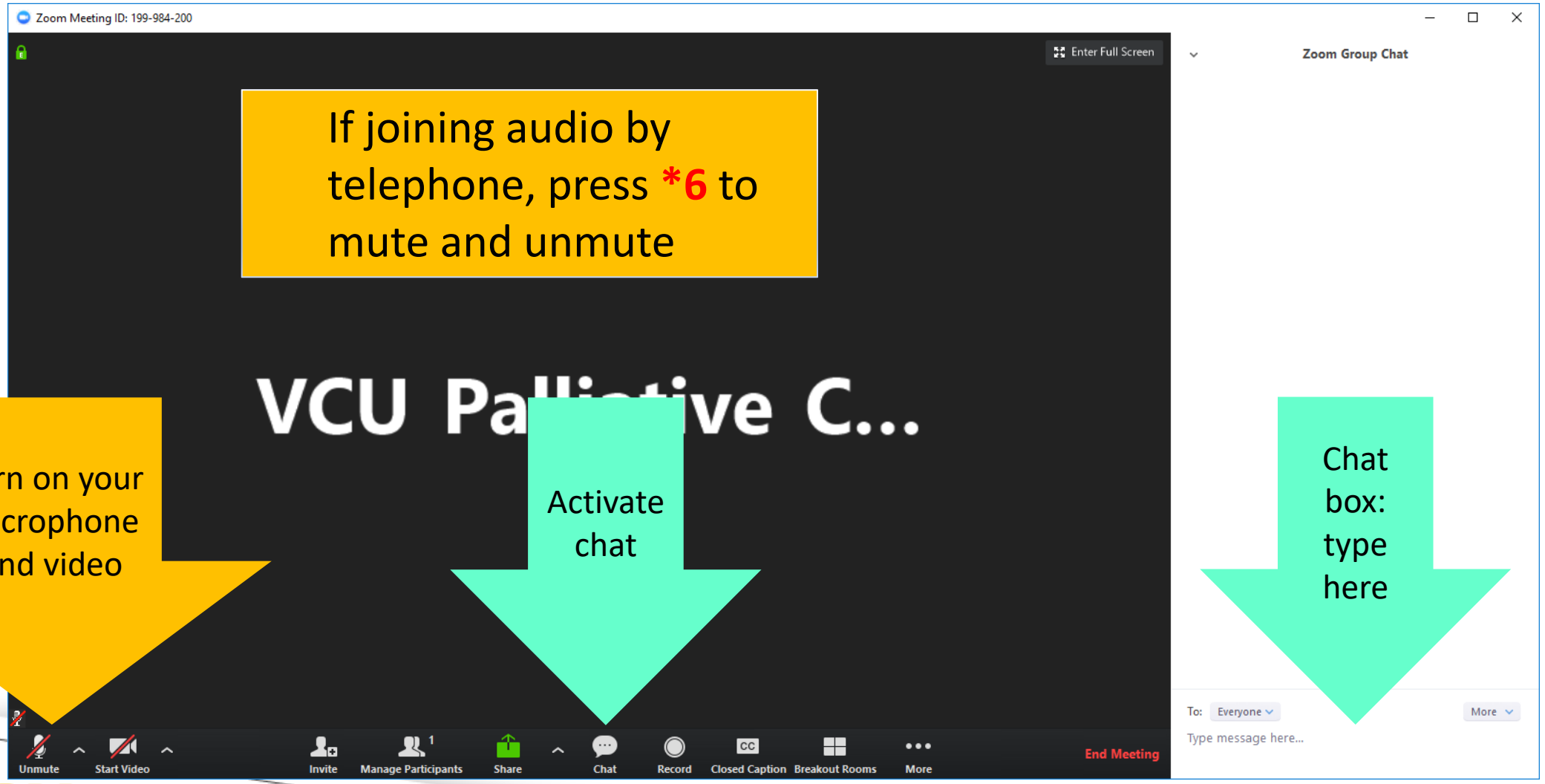


What to Expect

I. Didactic Presentation
   20 minutes + Q&A

II. Case Discussions
   - Case Presentation
     5 min.
   - Clarifying questions from spokes, then hub
     2 min. each
   - Recommendations from spokes, then hub
     2 min. each
   - Summary (hub)
     5 min.

III. Closing and Questions

- Bi-weekly tele-ECHO sessions (1.5 hours)
- Didactic presentations developed by inter-professional experts in palliative care
- Website: www.vcuhealth.org/pcecho
- Email: pcecho@vcuhealth.org

Let's get started!

Introductions

VCU Team	
Clinical Directors	Egidio Del Fabbro, MD VCU Palliative Care Chair and Program Director Danielle Noreika, MD, FACP, FAAHPM Medical Director/Fellowship Director VCU Palliative Care
Clinical Experts	Candace Blades, JD, RN – Advance Care Planning Coordinator Brian Cassel, PhD – Palliative Care Outcomes Researcher Jason Callahan, MDiv – Palliative Care Specialty Certified Felicia Hope Coley, RN Diane Kane, LCSW – Palliative Care Specialty Certified Tamara Orr, PhD, LCP – Clinical Psychologist
Support Staff Program Manager Telemedicine Practice Administrator IT Support	 Teri Dulong-Rae & Bhakti Dave, MPH David Collins, MHA Frank Green

Existential and Spiritual Assessments

Presented by Jason Callahan, MDiv, MS, BCC

Palliative Care Chaplain

VCU Health

Objectives

- Identify existential distress in patients, families and caregivers.
- Select appropriate interventions in addressing existential distress.
- Discuss grief and bereavement issues.

Common Sources of Spiritual Distress

- Guilt, shame or forgiveness issues 54%
- Broken or damaged relationship with faith tradition or community 53%
- Lack of a sense of meaning 45%
- Loss of usual source of religious or spiritual coping or well-being 44%
- One or more life events that are unresolved 44%
- Close relationship is broken or damaged or disappointing 43%
- Anxiety about afterlife 42%
- Loss of hope or the ability to reframe hope 37%
- Loss of a sense of dignity 33%
- Broken relationship with divine 26%
- Loss of confidence in a religious belief: questioning 25%
- Shaken world view or concept of the divine 15%
- Need for sense of legacy 14%
- Other 13%
- Addiction-related issues 9%
- Abuse-related issues 4%

***Source**: The National Hospice and Palliative Care Organization's Hospice Care in America Report (2013)*

Existential, Spiritual, and Religious needs

- A key element of working with issues of spirituality or existential awareness is to address how people find meaning in their lives. This may be especially true when facing illness, suffering, or death. Palliative care providers continually encounter patients and their loved ones in their times of greatest pain, vulnerability, and confusion as well as at times of ineffable joy and connection to something greater than themselves.
- As practitioners of whole-person care, it is incumbent upon practitioners to attend to patients' needs in body, mind, and spirit. Whole-person palliative care includes care for the spiritual and existential distress of patients and those who love them.
- The Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project, 2013) include standards for spiritual screening as part of the whole person assessment of patients' needs and resources. The guidelines also affirm the role of board certified chaplains in the provision of a quality palliative care service.

Chaplains as Facilitators of Spiritual Care for the Palliative Care Team

- Chaplains do not own spirituality in the practice of palliative care. Each health care discipline has its own rich history of incorporating spirituality into professional practice. As spiritual care experts, chaplains support the spiritual care provided by the other members of the team and address higher level spiritual care needs with expertise gained through graduate level education and chaplaincy training.
- As spiritual care experts, in addition to the spiritual care provided to patients and loved ones, chaplains provide spiritual care to the interdisciplinary care team in order to support their personal and professional well-being and to encourage compassion, sensitivity, and awareness of the spiritual dimension of palliative care.

Assessing and Responding to Spiritual Distress

- As specialists on the palliative care team, palliative care chaplains guide and facilitate the spiritual care provided to patients, their loved ones and the other members of the interdisciplinary team. In coordinating spiritual care for patients and their loved ones, chaplains may encourage the team to utilize a tool to identify spiritual distress. Such tools can be used by all members of the palliative care team to identify the spiritual needs and resources of patients and their loved ones. Numerous tools are available to assist providers in screening for possible spiritual distress.

Generalist and Specialist Assessments

- As the clinical professional who is primarily responsible for spiritual assessment and intervention, a board-certified professional chaplain is a highly valued member of the palliative care team. In addition to their role with patients and families, chaplains serve to help educate their teams regarding the spiritual, religious and existential issues that affect their patients' lives, and help to facilitate discussions that engage other team members in understanding and exploring these areas. This opportunity for self-exploration and insight is extremely important for teams who work with suffering and existential distress.
- While physicians and nurses on the palliative care team may hesitate to address issues of religiosity, or the spiritual and existential distress of their patients, they can become competent providers of "generalist" level care, identifying when patients are experiencing these higher order needs and effectively responding to basic requests.
- Social workers are trained to assess and provide interventions for spiritual and existential distress, but often lack the specialized skills and training of the chaplain, especially as it relates to specific issues of spirituality, religion or existential concerns. Referrals to the palliative care team chaplain, when available, for more specialized, in-depth assessment and intervention is a critical part of the whole-person care provided by a palliative care team

SDAT

- One tool that has been validated through research studies is the **Spiritual Distress Assessment Tool (SDAT)**.
- The SDAT can be utilized by all members of the interdisciplinary team to identify sources of spiritual distress. If a patient is assessed to have spiritual distress, a referral to the palliative care team chaplain is an appropriate next step.
- When practitioners are listening at deeper levels for the meaning and coping strategies that patients and loved ones have developed, they may find kernels of information that shed light on spirituality and existential coping. This information provides an opening for deeper assessment, either in the moment or in referral to a chaplain as the clinician specialized in spiritual care. Practitioners of all disciplines need to be prepared and have a level of comfort with moving into these conversations. This requires being proactive and self-aware in their limitations and opportunities for growth. Palliative care chaplains support the team in developing the capacity to assess patients and their loved ones for spiritual distress and spiritual resource.

Models of Spiritual Care Assessment

- Spiritual assessment is required as part of an overall patient assessment by the Joint Commission and an ability to formulate and utilize spiritual assessments is one of the common standards of professional chaplaincy certified bodies.
- “Spiritual assessment” is a broad term that refers to many types of assessments that are conducted by chaplains as well as other members of the interdisciplinary team.
- **Spiritual assessment can refer to:**
  - Spiritual screening
  - Spiritual history
  - Spiritual distress
- In-depth spiritual assessment conducted by a professional chaplain. Spiritual assessment is an in-depth process of connecting with the patient’s care team, conducting an in-depth review of the patient’s medical record and engaging the patient and their loved ones to determine spiritual care needs and resources in order to develop a care plan.

Spiritual Screening

- A spiritual screen is a brief tool that includes just one or two questions often asked of a patient and their loved ones upon admission. Spiritual screens determine a patient's religious affiliation and whether the patient has special religious and/or cultural needs, such as dietary restrictions, blood products or gender preferences in regard to their providers.
- A spiritual screen obtains demographic information that rarely changes in the course of a patient's admission. Spiritual screens may not always represent the patient's preferences accurately and will need to be confirmed by a member of the palliative care team – ideally the palliative care chaplain.

Spiritual History

- A spiritual history is a more in-depth tool used by interdisciplinary clinicians to assess the ways in which a patient's spiritual and/or religious history impacts their medical care. Spiritual histories, in contrast to spiritual screens, are dynamic and may change during the course of a patient's hospitalization. A spiritual history assesses the ways in which one's beliefs, values, and participation in a spiritual or religious community impacts medical decision-making.
- Spiritual histories are used by physicians, nurses, social workers and chaplains to engage beliefs and values that contribute to positive and negative religious coping in relationship to illness. Spiritual history tools tend to be brief with easy to memorize acronyms. Many of the tools were developed by physicians or other clinicians interested in developing the spiritual dimension of their clinical work. The authors of these tools developed these methods to encourage their colleagues to address the spiritual dimension of care

In-Depth Spiritual Assessment

- Unlike spiritual screening, history and distress tools, full spiritual assessments are completed by a qualified chaplain and are more in-depth approaches to addressing the patient and loved ones' spiritual needs and concerns. Unlike spiritual histories and spiritual screenings, spiritual assessment is not a scripted or standard set of questions asked in the same way each time.
- Assessing the spiritual needs and resources of patients and loved ones is an evolving relational dialogue that should be engaged by a professional chaplain (Handzo et al., 2012) or a closely supervised chaplaincy student. Competent palliative care chaplains use spiritual assessment tools to create consistency across the spiritual care service and to ensure an approach to care that holds the chaplain accountable to a thoughtful methodology.
- Spiritual assessment is complex and requires specialized understanding of spiritual needs and resources, positive and negative coping, and particular knowledge of spiritual and religious traditions. Spiritual assessment is important to the overall palliative care plan because it guides the care plan and interventions, allows for quality communication with colleagues, and provides an opportunity to identify and evaluate outcomes.
- While spiritual assessments are essential to competent palliative care chaplaincy, as George Fitchett, a leader in the field of professional chaplaincy, has noted, spiritual assessments are not well tested through empirical study, leaving opportunity for chaplain researchers to strengthen the evidence base for the assessment tools they draw from (Fitchett, 2014).
- The spiritual assessment tools that follow represent prominent models in the field of spiritual care.

The 7 x 7 Spiritual Needs Assessment Model (Fitchett, 2002)

- The 7 x 7 model takes a “functional” approach to assessment, meaning that it is concerned with:
- How a person finds meaning and purpose in life and,
- The behavior, emotions, relationships and practices associated with that meaning and purpose.
- Fitchett contrasts his functional approach to spiritual assessment with what he calls a “substantive” approach. While a functional approach is pragmatic in considering how beliefs, values, and practices function in the life of the patient, a substantive approach asks whether or not a person holds a particular substantial belief such as a belief in reincarnation or a belief in God. Fitchett argues that, in a spiritually pluralistic context such as a public hospital, the functional approach to spiritual assessment is more inclusive of diverse beliefs and practices than a substantive model of spiritual assessment.
- The 7 x 7 model is based on an interdisciplinary approach to spiritual assessment. Fitchett views spiritual assessment as one of seven primary dimensions of the holistic assessment of a patient’s overall needs and resources.

The 7 x 7 Spiritual Needs Assessment Model (Fitchett, 2002)

7 Dimensions of a Holistic Assessment

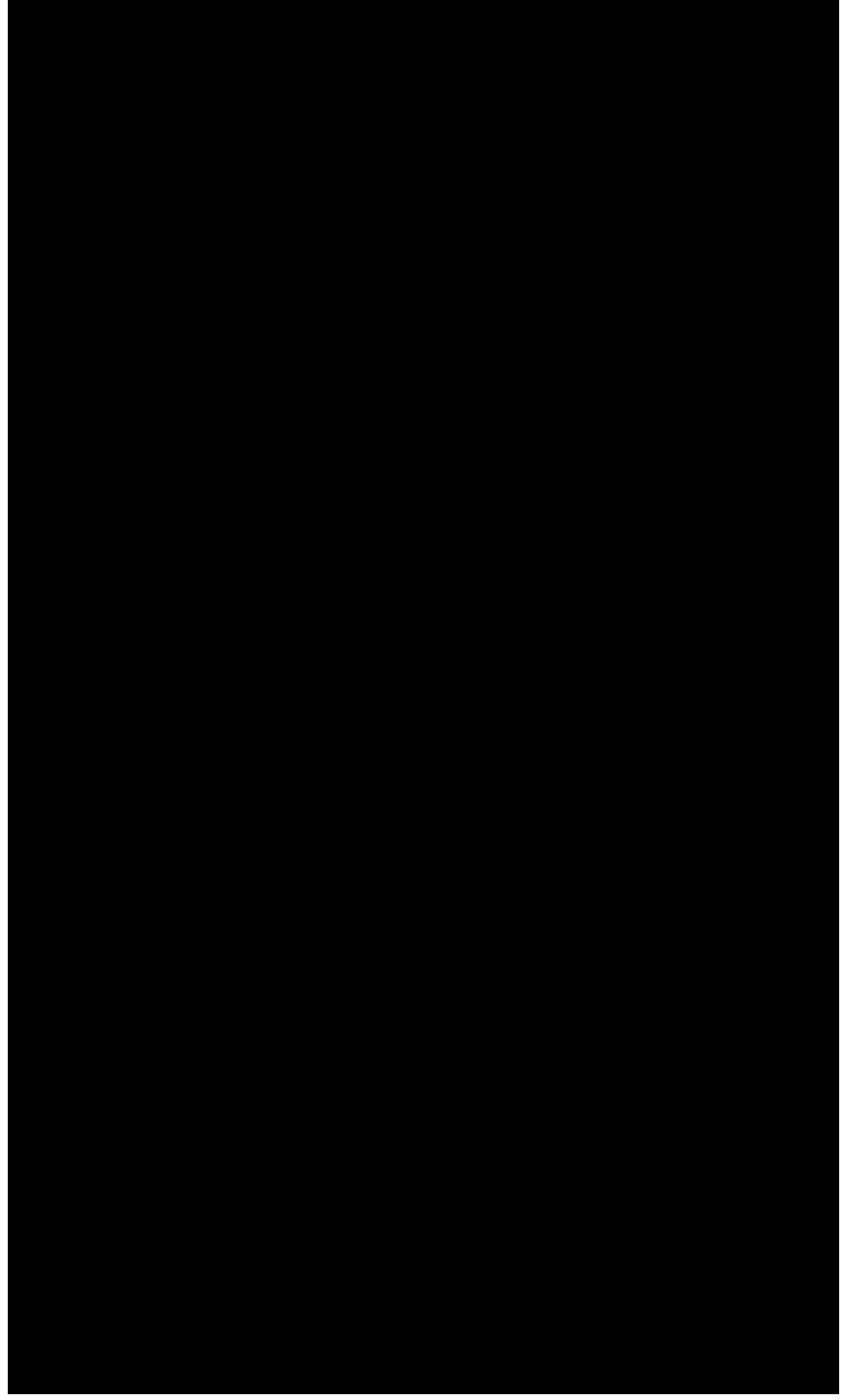
- Medical (Biological)
- Psychological
- Family Systems
- Psycho-Social
- Ethnic, Racial, Cultural
- Social Issues
- Spiritual

7 Dimensions of a Person's Spiritual Life

- **Beliefs and Meaning**: What beliefs does the person have which give meaning and purpose to their life? What major symbols reflect or express meaning for this person? What is the person's story? Do any current problems have a specific meaning or alter established meaning? Is the person presently or have they in the past been affiliated with a formal system of belief?
- **Vocation and Obligations**: Do the persons' beliefs and sense of meaning in life create a sense of duty, vocation, calling or moral obligation? Will any current problems cause conflict or compromise in their perception of their ability to fulfill these duties? Are any current problems viewed as a sacrifice or atonement or otherwise essential to this person's sense of duty?
- **Experience and Emotions**: What direct contacts with the sacred, divine, or demonic has the person had? What emotions or moods are predominantly associated with these contacts and with the person's beliefs, meaning in life and associated sense of vocation?
- **Courage and Growth**: Must the meaning of new experiences, including any current problems, be fit into existing beliefs and symbols? Can the person let go of existing beliefs and symbols in order to allow new ones to emerge?
- **Ritual and Practice**: What are the rituals and practices associated with the person's beliefs and meaning in life? Will current problems, if any, cause a change in the rituals or practices they feel they require or in their ability to perform or participate in those which are important to them?
- **Community**: Is the person part of one or more, formal or informal, communities of shared belief, meaning in life, ritual or practice? What is the style of the person's participation in these communities?
- **Authority and Guidance**: Where does the person find the authority for their beliefs, meaning in life, for their vocation, their rituals, and practices? When faced with doubt, confusion, tragedy or conflict where do they look for guidance? To what extent does the person look within or without for guidance? (Fitchett, 2002).

Emerging Models of Spiritual Assessment

- **Palliative Care Spiritual Assessment (Fitchett et al., 2017)**
  - The palliative care spiritual assessment tool is based on the SDAT spiritual distress tool and informed by Pargament's spiritual and religious struggles research (R/s Struggles), and Steinhauser and colleagues' work on the QUAL-E quality of life scale (Steinhauser, et al., 2004).
  - The Palliative Care Spiritual Assessment tool has not yet been published and continues to evolve. The authors encourage chaplains in the field of palliative care to utilize and adapt the tool. The template is a work in progress and the authors believe that the basic format can serve as a format for other specialties within the field of chaplaincy. Next steps for the research team include testing the validity, reliability, and clinical usefulness of this palliative care assessment and the forming of teams to develop similar assessment templates for other clinical contexts (Fitchett, APC Conference 2017).



Pediatric Spiritual Care Assessment

- Pediatric patients in palliative care have unique needs that require thoughtful assessment and intervention. A central consideration for pediatric spiritual assessment is the developmental age of the patient and their understanding of illness and death. Other considerations that make palliative care chaplaincy unique include caring for very young patients who may not be able to speak and the potential ethical dilemmas that arise when developing a palliative care plan for minors under the legal age of consent. It is important for the team to allow a child to participate as much as possible in their decision-making in consideration of the child's level of understanding of the medical information and potential treatment outcomes. In some cases the process of determining when to withhold or withdraw treatment can become complex if a child’s wishes differ from those of their parents, guardians, or physicians.

Developing the Spiritual Care Plan

- The process of utilizing and documenting a spiritual care assessment is an important dimension of full circle spiritual care. For the palliative care chaplain, as an advanced spiritual care practitioner, assessment forms the foundation for the chaplain's contribution to the overall palliative care plan.
- Based on the assessment of needs, resources and distress, a simple and clearly stated spiritual care plan is then developed.
- **The palliative care chaplain's care plan will contribute to the patient's over-all palliative care plan of care and goals and should include the following:**
  - A plan for supporting the patient's spiritual needs, resources and distress as each impacts the patient's **medical decision-making** process.
  - A strategy for addressing spiritual needs, resources and distress in light of the patient's **quality of life** both now and as the patient looks ahead to the future.
  - A plan for supporting positive spiritual coping and addressing any **spiritual distress** that may negatively impact the patient's coping with chronic or serious illness.
  - Strategies for addressing the spiritual, religious and **existential needs** of patients and loved ones who are facing a terminal diagnosis.
  - A plan for supporting appropriate **spiritual practices** that may help the patient adjust to change and loss.
  - Specific strategies for addressing the spiritual dimension of **physical, emotional or psychological pain and suffering** as a result of serious or chronic illness.

Spiritual Care Interventions

- Spiritual care interventions are the heart of full circle palliative care chaplaincy. With thoughtful spiritual care interventions, chaplains mediate hope, cultivate compassion and bring healing and reconciliation to places of brokenness and fractured meaning in the lives of patients and their loved ones.
- With serious illness, previous assumptions about the world can begin to unravel as patients question the meaning of their illness. Spiritual care interventions in the context of palliative care and hospice address the deepest struggles of the human condition. Spiritual Care Interventions flow out of the spiritual care assessment and care plan. Well-constructed interventions are co-created in the relationship with the patient, her loved ones, and the other palliative care clinicians as a collaborative team. Interventions may be active, such as facilitating a spiritual care practice, or more receptive, as when a palliative care chaplain provides a silent and compassionate presence to a grieving patient
- Just as the other healthcare professionals rely on care plans, it is important for the chaplain to have a clear sense of how to proceed with a patient, based on a skilled assessment of needs and resources. Once a plan is constructed from the palliative care team’s interdisciplinary care plan and the specific spiritual care plan, the chaplain provides interventions based on evidence-based practice and the chaplain's own gained experience as a reflective practitioner. The palliative care chaplain then assesses interventions to observe whether or not a particular intervention is accomplishing a desired outcome.

Foundational Interventions

- Palliative care chaplains draw from foundational spiritual care interventions that include skills that beginning chaplains will learn to embody in their practice. Foundational chaplaincy interventions reflect the values of professional spiritual care and establish a basis for more complex care to take place.
- **Foundational interventions include:**
  - Reflective listening
  - A nonjudgmental regard for cultural and religious difference
  - Appropriate use of self-disclosure
  - Rapport building
  - Empathy
  - The ability to be present to silence without filling the space with words
- More **complex interventions** will build on these foundational skills.

Providing Interdisciplinary Spiritual and Existential Care

- **Listening for Religious, Spiritual, and Existential Distress**
  - Many providers assume that patients express spiritual and existential distress using specific religious or spiritual words such as God, faith, prayer, sin, karma or other similar terms.
  - While this may be true for some, many patients also express spiritual and existential distress through language that seems more commonplace and may be misunderstood. A patient may wonder aloud, “How in the world am I going to make it through this? They may speak about feeling “useless,” “hopeless,” or questioning what they did to “deserve this” illness.

Interdisciplinary Interventions for Suffering

Examples of Interventions to Address Suffering

- Pain and symptom management
- Life review
- Support for medical decision-making
- Integrative therapies
- Spiritual support
- Ethical decision-making
- Family counseling
- Addiction support
- Dignity therapy
- Mindfulness
- Guided imagery
- Art or music therapy

Spiritual Care as Meaning-Making

- The practice of chaplaincy is an art of meaning-making. When patients and their loved ones face serious illness, the fabric of meaning which brings life purpose and a sense of coherence may become fractured and frayed. Meaning-making interventions require that the chaplain maintains an openness to unforeseen possibilities in allowing the care seeker to explore their own world of meaning. What is meaningful to the chaplain may not have resonance with the care seeker. The palliative care chaplain provides a nonjudgmental transitional space for new meaning to emerge in often new and surprising ways in the context of loving support.

Meaning-Making Interventions

- **Deep listening**: Deep listening provides the foundation for the reweaving of meaning. Deep and reflective listening allows the patient to listen to the voice of inner intuition and insight that often holds the answers to the challenges of adjusting to profound change and loss. Simply allowing space and time for the patient to listen to herself is a profound act of caring.

- **Spiritual and emotional support and counseling**: Although chaplains are not licensed counselors, counseling skills such as empathy, unconditional positive regard, restating, cognitive reframing, narrative counseling, and motivational interviewing can help a patient clarify and engage their experience with a greater sense of empowerment.

- **Life review**: Life review invites the patient and their loved ones to reflect on the past in order to weave themes from the past into a new sense of meaning in the present. Life review is helpful for people at the end of their lives because it invites a reflection on the joys, losses, important relationships and accomplishments so that the patient can experience gratitude, forgiveness, and acceptance of the past. Life review also provides an opportunity for patients to share their legacy and wisdom with one willing to receive insights and life lessons learned through experience.

- **Dignity therapy**: Dignity therapy was developed by a psychiatrist named Harvey Chochinov. In his work with the dying, Chochinov recognized that many people suffer at the end of life from a sense that their lives did not matter and their existence will be forgotten. In response to this existential lack of meaning, Chochinov developed a tool for recording patients' legacy and life story to be passed on to relatives, loved ones and others the patient would like to be remembered by.

Prayer, Meditation, Ritual, & Other Mind/Body Interventions to Alleviate Spiritual and Existential Suffering

- Palliative care chaplains bring a holistic view of health to the palliative care interdisciplinary team through utilizing mind- body interventions for complex symptom management. While the field of chaplaincy has traditionally relied on psychological and theological sources of assessment and intervention, there is an increasing recognition of the importance of attending to the body as well as the mind and spirit as a source of care and support. Interventions that draw out the body's natural wisdom and healing can activate the parasympathetic nervous system and calm the patient's body, mind, and spirit.

More Complex Palliative Care Chaplaincy Interventions

- Identifying and addressing ethical dilemmas and conflicts.
- Assisting the interdisciplinary team in assessing for decisional capacity.
- Helping to establish surrogate decision-makers for non-decisional patients who are unbefriended or have complex family dynamics.
- Facilitating a family meeting
- Providing mind-body interventions to support pain management
- Utilizing Dignity Therapy
- Teaching the team about specific cultural beliefs and values as they influence medical decision-making
- Providing emotional and spiritual support for complex grief
- Working with addiction
- Collaborating with the patient's spiritual advisor or religious leader for complex medical decision-making

Ethical Wills

- Like dignity therapy, an ethical will is a way of capturing one's legacy and passing on one's values and one's legacy to future generations. One way of thinking of an ethical will is as a love letter to the patient's loved ones. Every ethical will is as unique as the person writing it. Ethical wills may contain blessings, personal and spiritual values, and end of life wishes.
- **Ethical wills may also contain:**
  - Important personal values and beliefs
  - Spiritual values
  - Hopes and blessings for future generations
  - Life's lessons
  - Love
  - Forgiving others and asking for forgiveness

Family Systems Interventions

- Family systems theory provides a helpful way for engaging family dynamics as they unfold for patients with a serious illness. Family systems interventions will often take place in initial or ongoing palliative care consultations with multiple family members and team members present. In engaging the family systems of patients, their loved ones and the interdisciplinary team, competent chaplains can cultivate self-awareness of the chaplain's own role(s) within the system as such roles are activated in patient care encounters and family meetings.
- **Family systems intervention may include:**
  - Bringing attention to family dynamics in a compassionate way to encourage more awareness and flexibility with dynamics as they impact patient well-being.
  - Engaging patients and loved ones in a way that allows for the care seeker’s full personhood to be honored in spite of their prescribed role in the family system. For example, approaching a patient who is seen as the “black sheep” or addicted person in the family with a deep appreciation for the aspects of heroism, bravery, and overcoming challenges that make up their life story.
  - Addressing distress that may happen as a result of changes in the family system such as when the matriarch of the family becomes ill and is no longer able to serve as the family organizer and spiritual advisor.
  - Other interventions that take the family as a complex system into account, rather than over-focusing on the individual as the locus of imbalances, problems, and strengths.

Physical Pain and Stress Management

- As part of the palliative care team, chaplains are responsible for assessing their patient’s experience of physical pain. At the beginning of each patient encounter, chaplains should take the time to assess physical pain through asking decisional patients to rate their pain on a pain scale. With decisional and non-decisional patients, noticing affective signs of pain including a furrowing brow, clenching hands, groaning, moving in bed, or pursed lips are effective ways of assessing pain and reporting any concerns regarding pain management to the care team for immediate follow-up
- In a holistic view of health, spirituality cannot be separated from one's physical, psychological and emotional experience. Spiritual beliefs, values, experiences, hopes, and fears are held in the body and are interconnected with a patient's experience of physical disease processes and symptoms, including physical pain and stress.
- Spirituality can serve as a resource for addressing pain when traditional methods of pain management are limited in their capacity to provide relief from suffering.

Physical Pain and Stress Management

- **The following interventions may positively influence a patient's experience of intractable and refractory pain and stress and should be utilized only after patients have received a full pain management assessment and care plan from the medical providers on the team:**
  - **Guided imagery and visualization** can help patients learn to work with the pain as an ally instead of an enemy, leading to a greater sense of empowerment and a reduction in the suffering associated with pain.
  - **Meditation** can impact the subjective experience of pain through influencing the parts of the brain that process pain and attribute emotions to the experience of pain. In empirical studies, areas of brain function that influence pain were significantly altered through the practice of meditation. The patients' experience of pain was significantly improved.
  - **Mindfulness** as an intervention for physical pain can be introduced to patients from any spiritual or religious background and is best introduced in a non-religious manner with patients who do not identify as Buddhist.

Mind-Body Interventions for Symptom Management

- Mindful self-compassion
- Body scanning
- Aromatherapy (if approved by your institution and PC team)
- Grounding practices
- Relaxation techniques
- Yogic breathing
- Appropriate use of touch
- And many more…

Spiritual Counseling

- Though chaplains are not licensed counselors, chaplains draw on counseling techniques to support patients toward healthy and positive coping strategies in relationship to pain. Spiritual and religious beliefs can significantly impact the patient's experience of their pain.
- As was noted above, examples of spiritual counseling techniques include deep listening, life review, family systems interventions, cognitive behavioral interventions, motivational interviewing, reframing, engaging stages of change, spiritually integrated counseling and many other techniques based on the chaplain's utilization of particular theories from the behavioral sciences. Counseling techniques can be drawn upon to help empower patients in relationship to their experience of illness and pain.

Grief and Emotional Distress

- Beginning chaplains learn the art of listening and companioning those who are facing loss and change. Advanced palliative care chaplains learn to assess and engage complex grief with more refined interventions. As has already been addressed previously in this course, grief may be complex in nature.
- **Grief and Mental Health**
  - In providing support for grief and loss, it is important to recognize when care seekers have an underlying mental health challenge, personality disorder or addiction history. Grief for such care seekers can be exacerbated by existing mental health conditions. These patients may need the support of a psychiatrist as they navigate their experience of grief and bereavement

Disenfranchised Grief	
Example	A young homeless man is admitted to the palliative care service to manage the progression of HIV/AIDS. He is isolated from his family and home community who condemn his gay lifestyle and refuse to visit him in the hospital. The young man is a former evangelical youth leader who left his church community and his family to move in with a gay partner who financially took advantage of him and left him without resources or a home.
Intervention	Validation of grief, loss, and feelings of anger and betrayal; spiritual counseling to allow space for spiritual and religious meaning-making; exploration of forgiveness of self and other in light of betrayal by religious leaders and his community of faith; referral to social work for housing and resources.
Anticipatory Grief	
Example	A woman in her 30s with four children is given the devastating diagnosis of advanced metastatic breast cancer and anticipates a difficult course of treatment that is unlikely to prevent her death. She practices yoga and mindfulness meditation daily.
Intervention	Provide guidance to the patient and her husband about age appropriate spiritual and emotional support for her children; encourage spiritual practices from the Buddhist/Yoga tradition to strengthen positive coping with fear about treatment and anticipated losses; deep listening to offer patient a space to grieve and begin to clarify her goals regarding balancing quality of life and her treatment plan.
Complicated Grief	
Example	A 70-year-old woman is dying of advanced COPD and will soon be admitted to hospice. Six months before her diagnosis, one of her sons was imprisoned for murdering his wife and two children. This patient belongs to a 12-step program. She serves as a sponsor for younger women struggling with alcoholism.
Intervention	Provide emotional and spiritual support for multiple losses; encourage a deeper connection to a higher power; suggest ritual or collage/memorial board to honor each individual loss and its impact; develop quality of life goals that will help maintain patient's connection to her 12-step community once she is home bound.
Ambiguous Grief	
Example	A 55-year-old man is grieving the loss of his wife who is imminently dying after a 20-year struggle with Multiple Sclerosis. He was his wife's primary caregiver for many years. This patient's husband feels guilty about the sense of relief and liberation he feels as he must say goodbye to his beloved life partner. He is an avid hiker and finds a deep sense of peace and greater connection in the natural world.
Intervention	Validate and normalize ambiguous nature of grief; encourage healing connection to the natural world; invite an honoring of all dimensions of this caregiver's experience as equally valuable; encourage self-compassion practice; facilitate a healthy and loving goodbye between the patient and her husband; allow husband time to share his feelings of relief apart from his wife.

Addressing Complicated, Disenfranchised, Anticipatory and Ambiguous Grief

- In addition to assessing positive and negative coping, chaplains are trained to engage grief and loss through deep listening, the gift of presence, and simply witnessing the natural unfolding of painful emotions. Yet, the experience of grief is rarely straightforward and simple and many people will experience grief in complex ways. The role of the palliative care chaplain as an advanced spiritual care practitioner is to help the team identify complex grieving and respond with appropriate interventions.
- When considering complex grieving it is important to consider cultural differences that exist in the ways that people grieve. Certain regional and family cultures value emotional expressiveness, for example, while others may grieve in a more reserved and private manner. The goal of assessing coping is to consider values, beliefs, and practices as they are active in the patient's context and not apart from it. There is always a temptation to define those who cope in a way that is similar to our own as coping in a healthy way, while those whose practices may differ are defined as problematic. Cultural humility will be discussed further throughout the course.

Bereavement

- Forms and book

Resources

- Arnold, S., Herrick, L., Pankratz, V., Mueller, P. (2006). Spiritual well-being, emotional distress, and perception of health after a myocardial infarction. I*nternet J Adv Nurs Pract* 9:1
- Cassell, E. (1995). Pain and Suffering, Encyclopedia of Bioethics 4:1897-1905 (1995)
- Cummings, J. & Pargament, K. (2010). Medicine for the Spirit: Religious Coping in Individuals with Medical Conditions, *Journal of Religions*, 1, 28-53: doi 10.3390/rel1010028
- Edmondson D., Park C., Blank T., Fenster J., Mills M. (2008). Deconstructing spiritual wellbeing: existential wellbeing and HRQOL in cancer survivors. *Psychooncology*. 17:161
- Fitchett, G. (2002). *Assessing Spiritual Needs: A Guide for Caregivers*. Academic Renewal Press, Lima, Ohio
- Monod S., Rochat E., Bula C., Spencer B. (2010). The Spiritual Needs Model: Spirituality Assessment in the Geriatric Hospital Setting. *J Religion Spirituality Aging*. 22: 271-282. 10.1080/15528030.2010.509987.
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., et al. (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. DOI:10.1089=jpm.20
- Swinton, J. (2012). Oxford Textbook of Spirituality in Healthcare. *Healthcare Spirituality: A Question of Knowledge*, Oxford University Press, 99-104

Questions and Discussion

Patient History

Presented by Paul Zelensky, MD

Hospice and Palliative Medicine Fellow

How Can Spiritual and Social Dilemmas be Actively Addressed by IDT Staff?

Brief History of Serious Illness and Other Comorbid Disorders

70 y/o male with history of Stage IV lung adenocarcinoma, HTN, DM, bronchitis, CKD 4, BPH, spinal metastasis with large sacral ulceration who was seen by home hospice, who came to VCUHS 3 months after diagnosis. was found to have large amounts of bloody drainage from sacral wound. Patient was seen by ortho but had declined further surgical intervention and was transferred to the palliative care unit for end of life care. In the palliative unit he was started on medications for delirium and pain; and started to decline slowly, and lost his ability to swallow. Patient was evaluated and accepted to inpatient hospice [approx. two weeks later], where he continue to receive full IDT support, and medications for pain and delirium subcutaneously [Two days later,] he passed away peacefully with his best friend […] at his side […] An autopsy was offered by patient's family declined.

Pertinent Physical Exam, Lab, or Imaging Findings, Including Assessment of Functional Status:

- Patient bed bound, large open ulceration to sacrum.
- Paraplegic

Patient Social and Spiritual History

- Patient married, had adult children from previous marriage.
- Identified with Methodist church.
- Patient had complicated relationship with adult children, who were threatening patient and current wife due to questions regarding anticipated inheritance.
- Patient frequently had tearful encounters, endorsed feeling guilt about his life and actions.

Patient Symptom Assessment

- Agitation
- Depression
- Anxiety

Patient Advance Care Planning Documents:

Advance Directive, Durable DNR

Case presentation
Sarah West, MD

Brief history
This is a 27 yo F with metastatic chondroblastic osteosarcoma s/p multiple orthopedic procedures, including most recent thoracic tumor debulking w/extension of T4 laminectomy, neurogenic bladder/bowel, recurrent UTIs, asthma, and PE who was admitted to Orthopedic Surgery from the ED for increasing back pain found to be in shock.

Current meds and therapies
Antibiotics, high-flow oxygen, therapeutic Lovenox, (Erdafitinib in view of FGFR mutation,
Morphine 30 SR every 8 hours, dilaudid 1 q3h, oxy 20 q3h, lidocaine patch, gabapentin 300 at bedtime

Pain
Agitation
Anorexia
Anxiety
Has advance directive

Accessing CME and CEU Credits

Claim CME / CEU at www.vcuhealth.org/pcecho

VCU Health Palliative Care ECHO

Our VCU Health Palliative Care ECHO program partners with community practices caring for patients with serious illness and applies our interdisciplinary care team - a mix of physicians, nurses, social workers, psychologists, chaplains and more - to provide patient care support and education throughout Virginia.

We have a long-standing palliative care program with an inpatient unit, consult service and supportive care clinic to provide serious illness care. Many communities in Virginia do not have access to palliative care and we're here to help.

- View Palliative Care ECHO sessions (CME/CEU available).
- Register now for an upcoming clinic.
- Submit a case study (registered participants only).
- Live Session Participants: Claim CME/CEU.

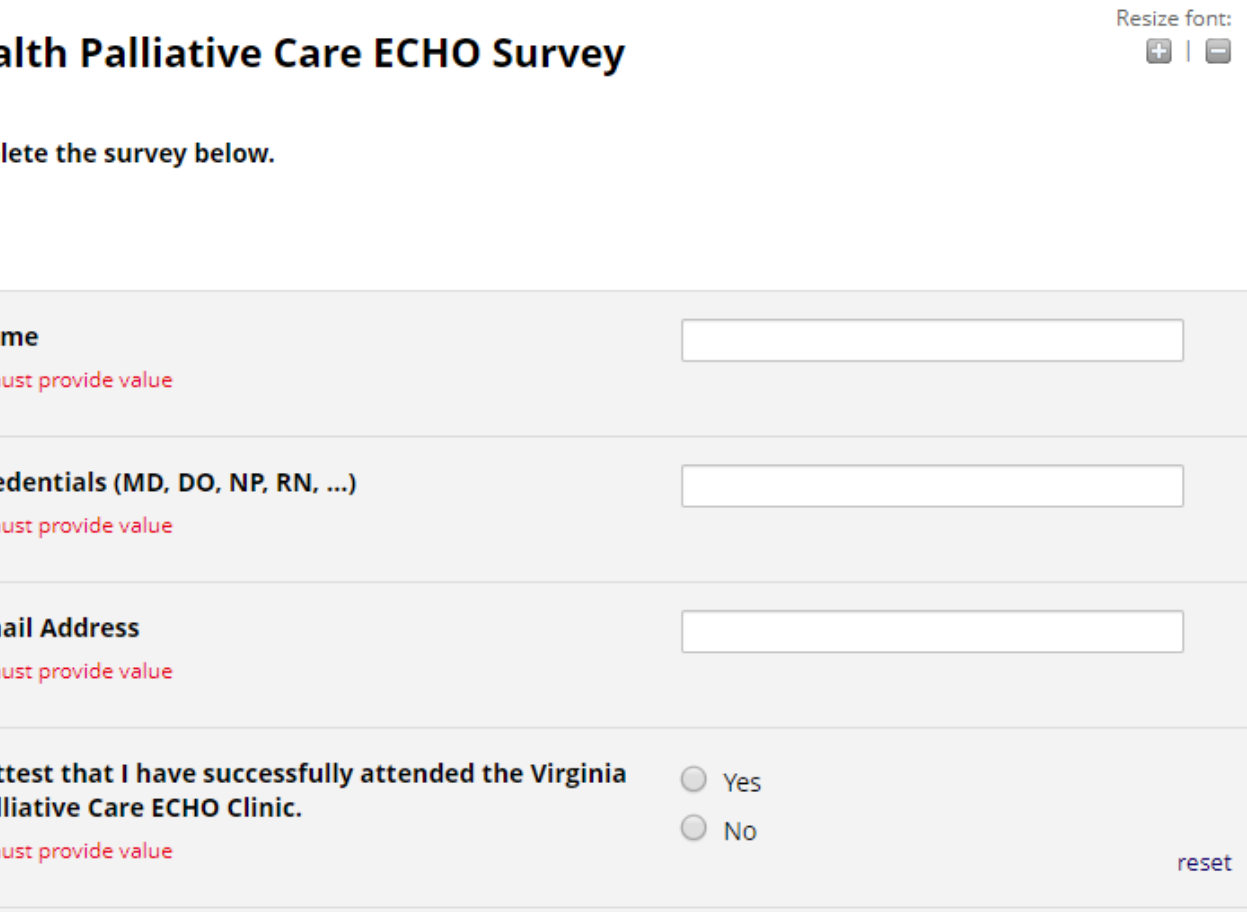
Contact us for more information or help with any questions about our program.

About Palliative Care

Telehealth
About Telehealth at VCU Health
For Patients
For Providers
Virginia Opioid Addiction ECHO
VCU Health Palliative Care ECHO
Curriculum
Register Now!
Submit Your Case Study
Virginia Sickle Cell Disease ECHO
Telehealth Programs

Project ECHO
Virginia Commonwealth University

Submit your evaluation to claim your CME



Resize font:

VCU Health Palliative Care ECHO Survey

Please complete the survey below.

Thank you!

Name
* must provide value

Credentials (MD, DO, NP, RN, ...)
* must provide value

Email Address
* must provide value

I attest that I have successfully attended the Virginia Palliative Care ECHO Clinic.
* must provide value

- Yes
- No

reset

View recorded sessions at www.vcuhealth.org/pcecho

VCU Health Palliative Care ECHO

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Contact us for more information or help with any questions about our program.

About Palliative Care

Project ECHO
Virginia Commonwealth University

Curriculum

Register now for an upcoming clinic on palliative care.

Upcoming Clinics

Mindfulness and Provider Self Care

June 13, 2019

Previous Clinics

Introduction to Palliative and Supportive Care

Feb. 14, 2019

View session for CME

Presented by Danielle Noreika, MD

Learning Objectives:

- Define palliative care and differentiate from hospice.
- Describe reasons for referral to palliative care.
- Describe basic structure of palliative care team.

Telehealth

About Telehealth at VCU Health
For Patients
For Providers
Virginia Opioid Addiction ECHO
VCU Health Palliative Care ECHO
Curriculum
Register Now!
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Telehealth Programs

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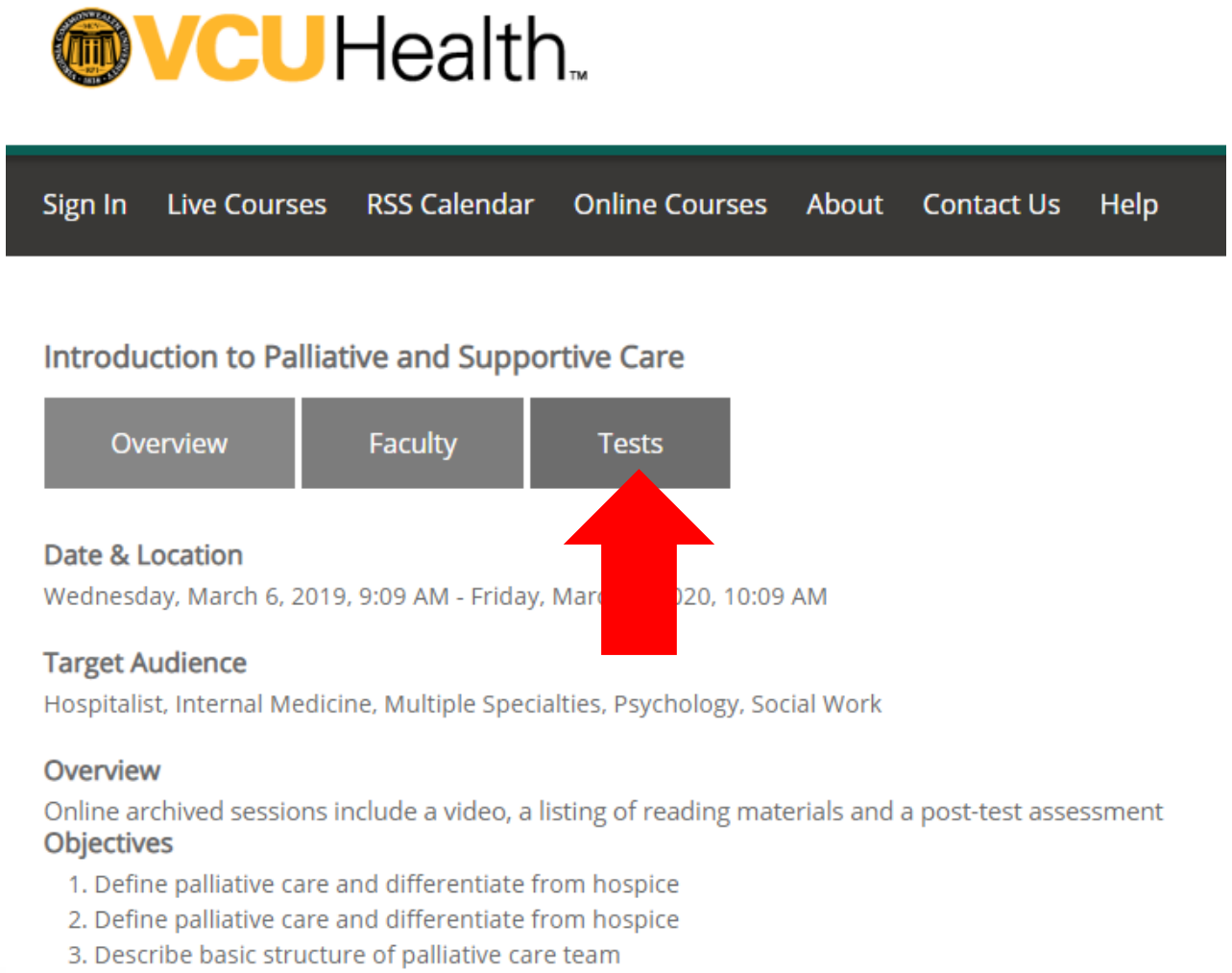
VCU

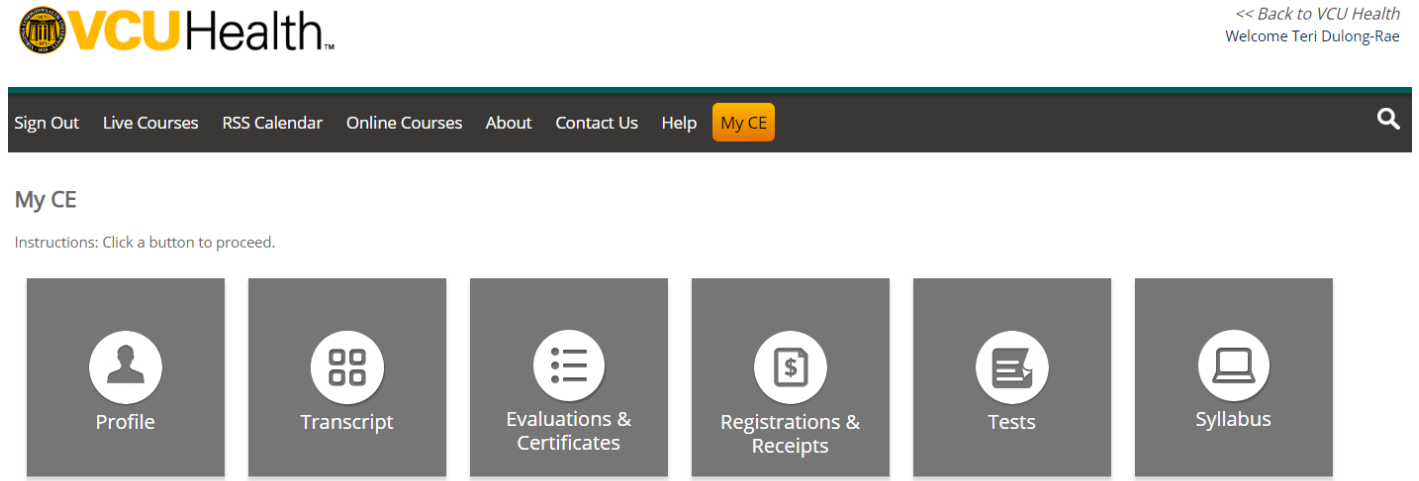
View previously recorded ECHOs for CME

Click “Tests” to view video of the session and take a short quiz for continuing education credit



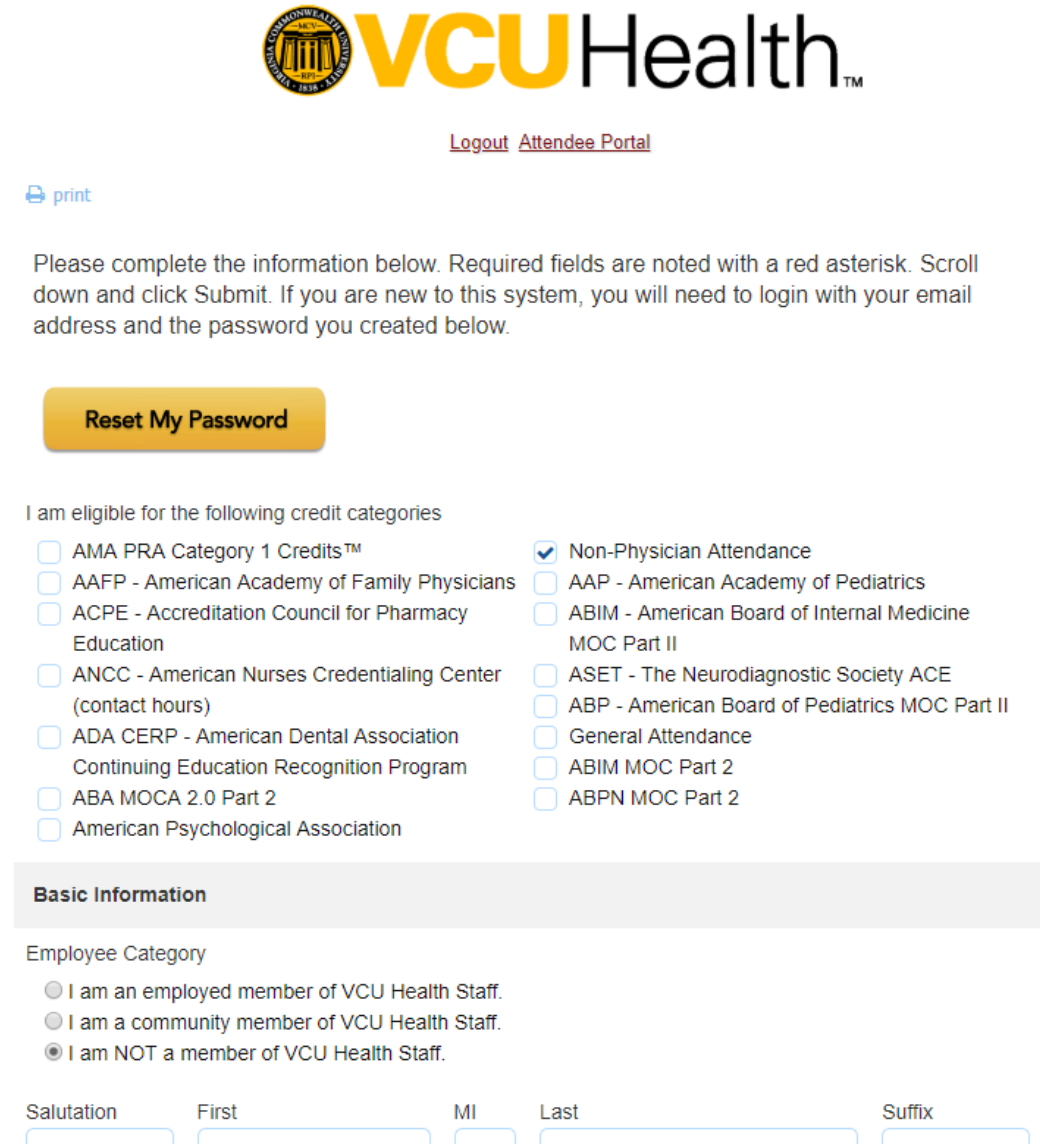
View your CME/CEU transcript

- Go to vcu.cloud-cme.com and click “My CE”
- Log in with the email you used to register for our ECHO session



View your CME/CEU transcript

If you have never logged in before, you may be prompted to enter more information before you can view your transcript



THANK YOU!

We hope to see you at our next ECHO

Bereavement Follow-Up Form (BFF) - Guidelines for Completion

(Updated - March 2017)

A chaplain should be notified of and attend every death. If you find out about a death, to which a chaplain was not called, alert the Attending and/or Faculty Liaison for that floor for follow-up.

PATIENT LABEL	Place patient's sticker on front **ONLY** of the bereavement follow-up form (BFF) – this does NOT replace completing the form
PATIENT NAME	Patient's Name should be confirmed, especially if a trauma or alias. Document nicknames and/or a preferred name.
DATE OF BIRTH	Verify and/or Obtain **date of birth** if trauma or alias (hint: DOB is probably not Jan. 1st)
DATE OF ADMISSION	**Date of admission** is on the sticker
TRANSFER	Bonus: indicate when/where they transferred from
UNIT/BED NUMBER	This is the floor on which the patient died
DIAGNOSIS/CAUSE OF DEATH	When in doubt...check CERNER
MEDICAL RECORD NUMBER (MRN)	
OTHER PERTINENT INFORMATION	Situational factors or family dynamic e.g. ' 'Rapid decline', 'Unexpected', 'Former U.S. Senator', 'Body to be shipped to Lithuania' etc... Check the box if complex situation and reading the medical record would be helpful to the Unit Bereavement Coordinator (UBC).
FUNERAL INFORMATION	If funeral information has not yet been established check off 'TBD' box. If out of town, put name, city, state, phone number. Bonus: if you know the name of the funeral director include that information here.
NEXT OF KIN	Next of kin is the primary bereaved caregiver, not necessarily the MPOA or even a relative. Any family member significantly impacted should be tracked. There is more room on the back under 'Comments / Additional Information Or Comments'.

NEXT OF KIN (CONT'D)	Neighbors, friends, co-workers, and paid caregivers all (may) count. If the family is enormous (i.e. households), identify/recruit and track 'ringleaders' who will have a good sense of how the rest of the family is coping over time. If multiple family live in one household, you can put multiple names/relationships on each line (e.g. Tom & Mary Smith... Son and daughter-in-law).
ADDRESSES	Confirm addresses even if you already have them, **CERNER is often wrong**. Confirm whether there is an apartment number for mailing purposes.
PHONE NUMBERS	Get multiple phone numbers, very few have just one anymore. Indicate which is which. (e.g. '**(C)** 804-123-4567 **(H)** 804-890-1234 **(W)** 804-567-8901'
EMAIL	Bonus: write in email if they have one.
RELATIONSHIP TO DECEASED	This information is CRUCIAL! If you don't know, ask. **Again, don't rely on CERNER.**
FAMILY PRESENT	Include the names and relationships. Include and indicate any family that arrived after death.
CHAPLAIN INVOLVED	Means you attended the call, not that you were present at the actual moment of death. If the body is not yet in the morgue, the answer is 'yes'. If you did not arrive while family was present, indicate that.
FAMILY REACTION TO DEATH	**Helpful information:** 'expected/unexpected', 'peaceful', 'demonstrative', 'angry', 'tearful', 'telling stories', 'laughing', etc. **Unhelpful information:** 'appropriate', 'grieving',
NURSE, M.D. (AT TIME OF DEATH)	Obtain the first and last name of the RN and pronouncing MD. Pronouncing MD and attending MD (as listed in CERNER or on the sticker) are not often the same.
BEREAVEMENT BOOKLET	Tell the RN when you have completed the BFF and delivered the booklet. RN is responsible for confirming this is done for every death.

BEREAVEMENT BOOKLET (CONT'D)	If bereavement booklet is not given to the family, document the date it is expected to be mailed (i.e. the next day the office is open) or why it cannot be mailed.
BEREAVEMENT FOLLOW UP FORM	Original BFF stays on the floor and goes to the Unit Bereavement Coordinator (UBC). Not every clinician knows who (or what) this is. You may have to ask the charge RN or RN manager. Copy of BFF goes in the Death Packet for Decedent Affairs*** (This is new request from Decedent Affairs)*** Copy of the BFF goes on the secretary's desk in the BFF tray in the Pastoral Care Main office. If bereavement booklet is to be mailed, place the copy of the BFF in the booklet. This indicates it is to be mailed.
ADDITIONAL EVENTS/COMMENTS	What does a clinician who does not know the family need to know months later when they call? Remember they may not have access to CERNER notes at that time. Examples: Characteristics of the relationships in the family and with the deceased, history of losses in the family
FOR RESEARCH	FYI: Evidence-based indicators of risk of complicated grief are 1. Death by suicide 2. Pediatric death 3. The degree to which the bereaved are dependent on the deceased for their identity.
DUTY LOG	Every death is logged in the duty log regardless of whether it is a duty call or not. If you are handing off coverage of a death, complete everything on the BFF you can first, especially family reactions etc... Tell the oncoming chaplain exactly what you have left undone. If you do not know/cannot obtain family contact, hunt it down as best you can and file the BFF with any notes/leads for the UBC to follow-up. It is better to file an incomplete form than none at all.
REMEMBER to check on the staff of the unit. Even if they seem fine, they appreciate the check-in.	
PLEASE WRITE LEGIBLY	

Quality Assurance Document – STRICTLY CONFIDENTIAL – Do Not Circulate

Affix Patient Label Here
(Do not place a label on Page 2)

VCU Health™

BEREAVEMENT FOLLOW – UP FORM

PATIENT INFORMATION

PATIENT'S LAST NAME, FIRST	ALIAS/NICKNAME:	SEX:
DATE OF BIRTH:	DATE OF DEATH:	AGE:
DATE OF ADMISSION:	TRANSFERRED / FROM WHICH UNIT:	UNIT/BED NUMBER:
DIAGNOSIS/OR CAUSE OF DEATH:		MEDICAL RECORD NUMBER (MRN):

OTHER PERTINENT INFORMATION: (I.E. PRIMARY LANGUAGE, RELIGIOUS/SPIRITUAL PREFERENCE. ORGAN DONATION?)

☐ SEE MEDICAL RECORD; COMPLEX SITUATION/GRIEF

FUNERAL HOME INFORMATION:

☐ TBD

FAMILY INFORMATION

NEXT OF KIN OR SIGNIFICANT OTHER:

NAME: _____

ADDRESS: _____ APT:_____

_____
CITY STATE ZIP CODE

RELATIONSHIP TO DECEASED: _____

HOME PHONE NUMBER: _____

MOBILE NUMBER: _____

EMAIL: _____

ADDITIONAL NAME (I.E. CHILDREN, SIBLING, PARENTS, ETC.):

NAME: _____

ADDRESS: _____ APT:_____

_____
CITY STATE ZIP CODE

RELATIONSHIP TO DECEASED: _____

HOME PHONE NUMBER: _____

MOBILE NUMBER: _____

EMAIL: _____

BEREAVEMENT BOOKLET GIVEN? ☐ YES ☐ NO TO WHOM? _____

☐ FAMILY DECLINED BOOKLET ☐ FAMILY DECLINED TO PROVIDE CONTACT INFO ☐ FAMILY PRESENT AT TIME OF DEATH ☐ FAMILY DECLINING BEREAVEMENT FOLLOW UP

FAMILY REACTION TO DEATH:

CHAPLAIN INVOLVED? YES ☐ NO ☐ NAME OF CHAPLAIN:

NURSE CARING FOR PATIENT AT TIME OF DEATH:

M.D. (AT TIME OF DEATH):

FORM COMPLETED BY:	DATE:

Original ~ Unit Bereavement Coordinator
Copy to Pastoral Care Office Main 2, Room 2-210; Copy to Decedent Affairs inside Patient's Death Packet

Bereavement Follow Up Contacts

PREVIOUS UNIT NOTIFIED ON:	**BY:**
SYMPATHY CARD SENT ON:	**BY:**
PHONE CALL/ LETTER ON:	**BY:**
LOVELIGHT:	**BY:**
COMMENTS:	
6 WEEKS POST - DEATH CALL/LETTER:	**BY:**
3 MONTHS POST-DEATH PHONE CALL/CARD ON:	**BY:**
6 MONTHS POST-DEATH PHONE CALL/CARD ON:	**BY:**
1 YEAR POST-DEATH PHONE CALL/CARD ON:	**BY:**
BIRTHDAY:	
ADDITIONAL INFORMATION OR COMMENTS:	

Because We Care

Department of Pastoral Care

Helpful Numbers

Hospital Information	***804-828-9000***
Office of Patient Accounting, VCUHealth	***804-281-0610***
Office of Financial Counseling, VCUHealth	***804-828-0966***
MCV Physicians (M.D. Billing Office)	***804-342-1391***
Decedent Affairs	***804-828-1285***
Department of Social Work	***804-828-0212***
Chaplain's Office	***804-828-0928***

Notes

Department of Pastoral Care
Main Hospital, 2 Floor
401 North 12th Street
P.O. Box 980664
Richmond, Virginia 23298-0664

PHONE: 804-828-0928
FAX: 804-828-6974
TDD: 1-800-828-1120

Dear Family Members,

Please accept our deepest sympathy for your loss. While no one can fully comprehend your pain at this time, please know that we are here to listen and to help in whatever ways possible.

We have prepared this packet to answer many of the questions that others who have experienced losses have asked. Some of the materials may notbeeasy for you to read at this time, but as time goes by, we hope the materials will assist you in the long and difficult journey of grief.

While written materials may provide assistance, they are no substitute for human contact. You may wish to be alone at times, but at other times the comfort of family, friends, and others who have faced losses can be very helpful.

Our thoughts and prayers are with you. The staff of the hospital is here to help you in any way we can, both now and over the next difficult months. Please do not hesitate to seek our assistance.

Sincerely and with sympathy,
The Pastoral Care Staff

Understanding Grief

Grief with its many ups and downs lasts far longer than society in general recognizes. There are many factors which determine the length and intensity of grieving, be patient with yourself.

Crying is an acceptable and healthy expression of grief and releases built-up tensions for both women and men. Cry freely as you feel the need.

There may be times when friends and relatives are uncomfortable around you and do not know what to say. Let them know when it is okay to talk about your loved one. Socializing may be difficult for a while.

Physical reactions to loss may include loss of appetite or over-eating, difficulty sleeping and lack of energy. You may also find it hard to concentrate on your usual activities. Try your best to take care of yourself: eat well, rest and exercise as you are able.

Avoid the use of drugs or alcohol. Medications should only be taken under the supervision of a physician.

Feelings of guilt are very common after a loss. It is normal to look back on the relationship and illness, and feel regret. Take it easy on yourself, forgiveness takes time.

Recognize the individuality of grief. While grief has some common elements, people will grieve differently, responding and coping as individuals. For some people, professional counseling may be helpful; others may seek a support group of persons who have experienced a similar loss which can ease the feelings of isolation and loneliness. If you feel you are having particular difficulty or just want someone to talk with, please call for help.

The feelings of children are often overlooked during this time. It is important for children to know they are loved and included as you go through this grief together.

You may feel you have nothing to live for and would like relief from the intense pain of grief. Be assured that others have had similar feelings. The pain does usually ease, but only with time.

You may want to put off major decisions for a period of time, to give yourself a chance to think more clearly.

Give your faith the opportunity to grow. Questions of faith and feelings of anger or despair are a normal part of grief. For many, faith offers the help to accept the unacceptable.

Suggestions for Helping You and Your Loved Ones

- Draw on your memory of past coping experiences. What you learned could help you now. Remember, there are no rules or timetables for grief. “It is what it is and it takes as long as it takes.” Everyone goes through grief differently, even parents of the same child or siblings of the same parent.
- Learn about grief. Many books and videos are available that might be helpful, especially people writing about their own experiences.
- Realize that other people are often unsure of what to say to you and may say insensitive things. They are usually only trying to be helpful.
- Allow yourself grieving times. Try to declare other times non-grieving times. This way you learn to find at least short periods of peace.
- Learn what you can do when the pain overwhelms you (go to a movie, call a certain friend, go for a walk, clean house, etc.) Have your coping mechanism in reserve for those times.
- Keep on with your life even if the joy seems gone. In time, habit and concentration will take over and you will have increasing moments of relief, even satisfaction. Even if you feel you are only going through the motions, it helps maintain your life structure.
- Be kind to yourself. Pretend you are a friend who needs your help and support. What would you do for them? What would you advise? Then do it.
- Seek out people who have experienced a similar tragedy or can relate to it. It can be good to seek out people in a similar situation who need your help too. Groups can be helpful. Groups are often available for particular losses such as the death of a child, a violent death, or death of a spouse. You may want to investigate groups in your area. Some groups are listed in this resource.
- Be supportive of your family. Invite them in; offer them your support, as you are able. You are still needed. It is easy to want to be protective.

Suggestions for Helping You and Your Loved Ones (continued)

- Remember to give each other space. Be aware of unrealistic expectations of yourself or your loved ones.
- Maintain communication with your partner, sibling, children, and with a friend or pastor who truly cares about you and will listen to you.
- Try not to make major decisions or too many changes early in your grief.
- Nature can be healing. Tune in to the cycles of nature, to the struggles of animals. Absorb the beauty and wonder of the natural world and try to become a part of it. Let yourself flow with the spirit of the universe, you are a part of a greater reality.
- Pets can be a source of peace. If you have a pet, let them help. Animals live one day at a time, accept you as you are, need your care, and are consistently there.
- Continue any sort of creative work. Creativity is renewing of the self.
- Recognize that others may have problems and may be hurting. It may help ease your own pain to offer compassion.
- If you feel, after a while, that counseling or a support group may be helpful, seek out a counselor. It is important to ask for help.
- Remember to appreciate the good moments that you have had and all you still have. Thank people for whatever they contribute.
- Allow yourself to tell your story. It is an important part of healing.
- You may find it helpful to journal or write a letter to your loved one saying goodbye.
- Hold on to hope. With time, work and support, you will survive. It will never be the same, but you can learn again to appreciate life and the people in your life.
- Lastly, remember to be kind to yourself. Think this every day:

"I must be kind and compassionate with myself."

Suggestions for Coping with Holidays

- Holidays and anniversaries are times when people may remember the past and wonder about the future. If therehasbeen adeath inthefamily, emotional wounds are left that can ache during these times of warmth and cheer. Feelings of isolation and loneliness can magnify.
- With planning and forethought, it is possible to get through these times. We hope the following suggestions are as helpful to you as they have been for others.
- Realize this is a new holiday, unlike the holidays of the past.
- ❖ Acknowledge the absence of your loved one, and choose a ritual in remembrance of them – visit the cemetery or memorial site, plant a tree, release balloons, and cry and smile in remembrance.
- Engage in spiritual activities that are comfortable for you.
- ❖ Do things because you want to do them, rather than because your loved one "would have wanted it that way." Do what you are comfortable doing.
- Initiate activity. Plan your own holiday. Make phone calls to your relatives and friends.
- Be gentle with yourself. All wounds take time to heal. Realize you will feel sad at times.
- Take time to identify and take care of your needs. Get adequate rest and exercise. Be aware of the increased accessibility to sugar, caffeine and alcohol during the holiday season, and guard against overuse of these substances.
- Look at the holiday season as the beginning of a new journey, starting a New Year. Enjoy the gifts of the season found in special memories and visits with family and friends.
- ❖ Anniversaries of your loved one's birthday, date of death, or other special occasions can be difficult and bring up many feelings. Plan extra time for quiet and reflection.

Children ~ The Forgotten Grievers

Today psychologists and social workers, clergy and teachers are responding to what many grandparents have learned through the years, that children, like adults, grieve the death and loss of significant people, pets, places and things in their lives. Children experience many of the same emotions as adults, but often do not have the language or skill to name the experience. As a result of children not talking about the loss, we, as a society, have mistakenly assumed that children simply do not grieve to the extent that adults grieve. Research by Alan Wolfelt, Director of the Center for Loss and Life Transition, Elizabeth Kubler-Ross, physician and scholar in the area of death and dying, and Ken Doka, grief specialist and professor, confirm what life teaches us, that children grieve and grieve deeply. Wolfelt reminds us in his work that grief is not so much about understanding as it is about the ability to love. While infants and young children do not have the language capacity to express grief, they certainly have the prerequisite ability of loving and in so doing, grieve when that person or object of loving is no longer present.

Grief responses will be influenced by the developmental stages of children, and as children mature and move from a less mature understanding of death and grief to a more mature understanding their responses will change as well. Children who experience the death of a parent or a sibling will respond to that loss through each of the developmental stages of life, returning to the loss upon each new maturational level. Children demonstrate most significantly that grief is a process, not an event. Babies will often show their sadness through body language and teenagers will often show their sadness through withdrawal or outrageous behavior. Each age of childhood possesses its own ways of responding, but it is not unusual for children to exhibit similar characteristics as adults. For instance, just as adults have difficulty with concentration and completing tasks so do children and teens. Their response will manifest as declining grades in school or more disruptive behavior than usual. It can also manifest as withdrawal from previously enjoyed friends and activities.

Significant loss for children and teens makes them different from many of their friends. They find themselves unable to enjoy familiar and favorite friends and activities. They miss the support that is typically available to them. When a sibling dies or a parent dies, they not only lose the loved one who died, but often the parent or parents who are so devastated themselves that it is difficult to offer their child support. Supporting grieving children and teens requires of us intentional observation and insight into what they are saying to us in words and actions. It is necessary for the adults in their lives to be astute observers of even the subtle changes that may occur. Asking for help from other significant adults

to intuit what a child is feeling is very helpful. No one would ask of a parent to do this alone, for the grief each of us feels at such a time can only dull our ability to recognize the needs of children and teens.

Supporting grieving children is an awesome task and one to be shared by parents, extended family, friends, teachers, coaches and pastors. It will take many adults to offer a grieving child the kind of support that will encourage recognition of support systems and coping skills already in place. If we can offer only one thing to grieving children let it be our willingness to be good and faithful listeners. In listening and validating feelings, we offer children an opportunity to wrestle with a part of life that is inevitable and painful. While adults want to protect children from pain, our ways of protecting rarely offer them relief and reconciliation with their grief.

Practical, helpful ways of supporting grieving children are inclusive. Children are very aware when someone is dying. Opportunities for saying good-bye in their own way will be helpful for later grief reconciliation. Offering children choices about attendance at the visitation or funeral, offering children the opportunity to provide their own ritual of saying good-bye, and involving children in this difficult and painful experience of life reminds them and affirms them as to their place in the family. Around the death of a loved one, children can participate in creating a memory box that gives them a special place for items of remembrance of their loved one. For very young children and infants, memory boxes prepared for them will offer support as they move through their own lives. School age children are very ritual people and are capable and needful of creating rituals – releasing balloons at the funeral, writing a poem to be read, painting a picture to display at the service – for their own processing of grief. Through the gift of supportive adults and creative space children can live with, move into and gradually reconcile their grief and life without their loved one.

Children ~ *the forgotten grievers* ~ need the opportunity to express who they are and who they are becoming as they too experience the death of a loved one and the difficult grief and mourning that follow.

Rev. Dr. Ann Sidney Charlescraft
Chaplain and Bereavement Counselor

Supporting Grieving Children

- Recognize and value the grief of children.
- Validate their feelings.
- Know that children tend to "go in and out" of grief. They will process and dwell on the loss for a little while and then go play. They will repeat this process many times in the course of grief reconciliation.
- Play is one way children make sense of their world and their grief.
- Not all children talk about their grief, yet they grieve.
- Some children do not seem to be affected (but don't be fooled!)
- Grieving children may experience physical reactions:
  - stomach aches
  - concentration problems
  - distraction
  - listlessness
  - loss of appetite
  - increased appetite
  - fatigue
- Developmental age will influence reactions to death/loss.
- Children need clear, honest explanations about death.
- Children will ask questions. They need to hear the story many times as they attempt to understand and reconcile the death of their loved one.
- Adult reactions teach children about death and impact the way children process their own grief.

Adapted from Helping Children Cope with Death,
The Dougy Center. ASC 2010

I know I cannot hold you for long,
Capturing you for my world.
But rest gently with me,
If only for a moment,
That I may treasure the memory
And the beauty of the gift that you are.

Michael Berman, MD
2001

Grief is like a River

by Cynthia G. Kelly

My grief is like a river – I have to let it flow,
but I myself determine just where the banks will go.

Some days the current takes me in waves of guilt and pain, but there are always quiet pools where I can rest again.

I crash on rocks of anger; my faith seems faint indeed, but there are other swimmers who know that what I need are loving hands to hold me when the waters are too swift, and someone kind to listen when I just seem to drift.

Grief's river is a process of relinquishing the past
by swimming in hope's channels I'll reach the shore at last.

Without Remorse

by Tom Clancy

And if I go, while you're still here . . .
know that I live on, vibrating to a different measure,
behind a veil you cannot see through.
You will not see me, so you must have faith.
I wait for the time when we can soar together again,
both aware of each other.
Until then, live your life to its fullest and when you need me,
Just whisper my name in your heart. . .
I will be there.

Funeral and Burial Options

We realize that, at this most difficult of times, it is very difficult to make decisions about the final care of your loved one. It is our sincere hope that the following information will help you make those decisions according to the wishes of your family. If you cannot handle these details yourself, perhaps another family member, friend, chaplain or social worker would be helpful.

If you have decided to have a private burial or cremation, you must now select a funeral home. A full listing is available in the Yellow Pages. Funeral providers will discuss the services they provide as well as the types of funerals and burials available. When you call the funeral home they will ask for the hospital (VCU Medical Center), the doctor's name, the legal next of kin and their phone number.

The funeral home is required by law to tell you exactly what they are charging you for each service before they provide it. The actual cost will be affected by the funeral home you choose, and the type of funeral services and cemetery chosen.

Some considerations include:

Casket: Size and style can alter cost.

Cremation: A casket is not necessary if there is no viewing. There will be crematory and medical examiner fees. If a viewing is desired before the cremation, a casket must be purchased or rented. Cremated remains may be buried, scattered or kept.

Direct Burial: Most funeral homes will allow a private viewing by family members only before a direct burial. Services are usually held at the graveside or in a church.

Viewing/Funeral Home: Funeral homes provide private rooms for families to greet relatives and friends prior to the funeral service. Visitation may be immediately prior to the service or the day/evening before. Services may be held at the funeral home, a church or at the graveside**.**

Cemetery: Fees vary for a plot and the opening/closing of the grave. Cemeteries also vary as to the number of cremations that can be buried in one plot.

Home Burial: Some churches maintain burial land for its members that is free or at a greatly reduced rate. Some areas, particularly rural, allow for home burial. The funeral home will check local ordinances regarding this practice.

Financial Considerations

We understand that the cost of a funeral may be a burden on your family resources. There are funds available through some counties for families that qualify. You would need to contact the Department of Social Services in your city/county to determine if funds are available. We would also suggest that you discuss the cost of the funeral openly with the funeral home. Charges will vary from one funeral home to another and many are willing to make alternative financing arrangements or give special rates for their services. If a funeral home is unwilling to work with you, perhaps another one will.

In addition to initial funeral expenses, there will certainly be other financial concerns you face during this time. You may now be responsible for many areas of financial management with which you are not familiar. There are some helpful numbers on the inside front cover of this booklet.

Others who may be helpful:

Lawyer
Accountant
Minister
Banker
United Way Representative
Department of Social Services
Veteran Affairs in your city/county

Books That May Be Helpful

General Grief Resources

Bozarth, Alla Renee *Life is Goodbye, Life is Hello: Grieving Well Through All Kinds Of Loss*. Hazelden, 1994

Bozarth, Alla Renee *A Journey Through Grief: Gentle, Specific Help to Get You Through the Most Difficult Stages of Grieving*. Hazelden, 1994

Claypool, John. *Tracks of a Fellow Struggler*. Word Publishers, 1974

Doka, Kenneth J. *Living with Grief*. Taylor & Francis, 1998

Doka, Kenneth J. *Grief Is a Journey*. Atria Books, 1999

Doka, Kenneth J. *Living with Grief After Sudden Loss*. Taylor & Francis, 1996

Doka, Kenneth J. & Terry Martin *Men Don't Cry, Women Do: Transcending Gender Stereotypes of Grief (Series in Death, Dying, and Bereavement)*. Routledge, 1999

Jenkins, Bill *What to Do When the Police Leave: A Guide to the First Days of Traumatic Loss*. VBJ Press, 2001

Kubler-Ross, E. *On Death and Dying*. MacMillian, Inc. 1969

Lewis, C. S. *A Grief Observed*. Bantam Books, 1983

Strommen, Maerton & A. Irene *Five Cries of Grief*. Harper, 1993

Rando, Theresa A. *How to Go On Living When Someone You Love Dies*. Bantam, 1988

Tatelbaum, J. *The Courage to Grieve*. Harper & Row, 1980

Westberg, Granger *Good Grief*. Fortress Press, 1971

Death of an Infant

Atlas, Janel C. *They Were Still Born: Personal Stories about Stillbirth*. Rowman & Littlefield Publishers, 2009

Davis, Deborah L. *Empty Cradle, Broken Heart: Surviving the Death Of Your Baby*. Fulcrum Publishing, 2016

Douglas, Ann & Sussman, John R. *Trying Again: A Guide to Pregnancy After Miscarriage, Stillbirth, and Infant Loss*. 1st Edition Taylor Trade Publishing, 2000

Kirk, Paul & Schwiebert, Pat *When Hello Means Goodbye*. Grief Watch, 2012

Kluger-Bell, Kim *Unspeakable Losses.* W.W. Norton, 1998

Nelson, Tim *A Guide for Fathers: When a Baby Dies*. Tim Nelson, 2007

Death of a Child

Day, Sandy *Morning Will Come*. North Carolina: Caleb Cares, 1993

Rando, Theresa A. *Parental Loss of a Child.* Research Press Co., 1986

Schiff, Harriet *The Bereaved Parent*. Penguin Books, 1978

Helping Children Cope

Doka, Kenneth J. *Children Mourning, Mourning Children.* Taylor & Francis, *1995*

Huntley, Theresa *Helping Children Grieve.* Augsburg Books, 2002

Johnson, Joy *Keys to Helping Children Deal with Death and Grief.* Barron's Educational Series, Inc., 1999

LaTour, Kathy *For Those Who Live: Helping Children Cope with the Death of a Brother or Sister.* Centering Corporation, 1991

Schuurman, Donna *Helping Children Cope with Death.* The Dougy Center for Grieving Children, 1997

Temes, Robert *The Empty Place.* New Horizon Press, 1992

Wolfelt, Alan *Helping Children Cope with Grief.* Accelerated Development, 1994

Children's Books

Hanson, Warren *The Next Place.* Waldman House, 1997

Holmes, Margaret M. *Molly's Mom Died: A Child's Book of Hope Through Grief.* Centering Corp., 1999 (older children)

Holmes, Margaret M. *Sam's Dad Died: A Child's Book of Hope Through Grief.* Centering Corp., 1999 (older children)

Karst, Patrice *The Invisible String.* Devorss & Co., 2000 (preschool & elementary age)

Sabin, Ellen *The Healing Book.* Watering Can, 2006 (all ages)

Stickney, Doris *Waterbugs & Dragonflies.* The Pilgrim Press, 1998 (elementary age)

Pet Loss

Anderson, Moira *Coping with Sorrow on the Loss of Your Pet.* Peregrine Press, 1994

Kosins, Martin *Maya's First Rose: Diary of a Very Special Love.* Villard Books, 1992

Peterson, Linda *Surviving the Heartbreak of Choosing Death for Your Pet.* Greentree Publishing, 1997

Quackenbush, Jamie & E. Gravely *When Your Pet Dies.* Simon & Schuster, 1985

Support Resources

Department of Pastoral Care 804-828-0928
Annual Memorial Services – Contact the Department for dates

Bon Secours Hospice
Bereavement Coordinator 804-627-5372

Comfort Zone Camp - www.comfortzonecamp.org/
Grief support for children, teens, and adults 804-377-3430

Compassionate Friends – www.compassionatefriends.org
Support groups for parents, adults, siblings or grandparents who have lost a child.
Chapters through Capital area
Richmond Chapter: 804-458-9000
National Office: 877-969-0010

Full Circle Grief Center – www.fullcirclegc.org 804-912-2947
Support groups for grieving children and their families
Patterson Avenue, Richmond, Virginia

Hospice of Virginia Grief Support Groups
Andrea Skeens, Bereavement Services Coordinator 804-281-0451

LifeNet Donor Family Advocate
Debbie Hutt 757-609-4685

Mothers Support through Grief
Barbara Tyler 804-484-9366

Pet Loss Counseling Resources
The Center for Human-Animal Interaction 804-827-PAWS (827-7297)
VCU School of Medicine

IAMS Pet Loss Support Resource Center 888-332-7738

Practical Things to Consider After a Person Dies in the Hospital

At the time of Death:

- Notify medical professionals, if appropriate, immediate family and close friends
- Notify Power of Attorney of death and end of their responsibilities
- Deal with donation of bodily organs or tissues, as appropriate
- ❖ Make arrangements for the Decedent's Body according to the Coroner's Hospital instructions with Funeral Home or Crematory
- Make arrangements for care of dependents and/or pets

One to three days after Death:

- Find any instructions the Decedent may have made regarding his/her funeral arrangements.
- Compose obituary or death notice and arrange publication
- Determine the primary person(s) responsible for arranging the funeral and to address other concerns: answer the phone, collect mail, officiate at the ceremony, take care of perishable property, find someone to stay at home during the ceremony, provide food for family and friends after the funeral, and cancel services such as food delivery or homecare.
- Complete funeral and burial arrangements.
- ❖ Notify Decedent's employer and/or organizations they belonged to about the death.

One to ten days after Death:

- ❖ Locate Decedent's legal and financial papers: Will, safe deposit box keys & arrangements, trust agreements, marriage agreements, life insurance policies, pension or IRA statements, income tax returns for several years, gift tax returns, marriage, birth, death certificates, divorce papers, military records, computer bookkeeping records, certificates of deposit, bank statements, checkbooks, notes payable or receivable, motor vehicle titles, deeds, mortgages, title policies, leases, stock or bond certificates and statements, bankruptcy filings, partnership or corporate agreements, unpaid bills, health insurance.
- Obtain death certificates, either through Funeral Director or county Vital Records.

Contact:

- ❖ Police to check Decedent's house occasionally, if vacant
- Attorney to assist with transfer of assets, probate issues
- Accountant or tax preparer to determine which tax returns need to be filed
- Investment professional to get information about assets or holdings
- Bank to locate accounts, safe deposit box
- Insurance agent to obtain claim forms
- Social Security to stop monthly check and learn of benefits
- Social Services to learn of benefits
- Veterans Affairs to stop monthly check and learn of benefits
- Applicable pension agencies to stop monthly check and learn of benefits
- Utility companies to change or discontinue service
- Newspaper to stop subscription and/or submit an obituary
- Post office, if necessary, to forward mail
- Any social media accounts to discontinue services

Three to six months after Death:

- Take your time, get good advice and delay making big changes or decisions.

When Death Comes Before – or Soon After – Birth

We want to extend to you our most heartfelt sympathy at this difficult time. The death of a child before or shortly after birth is a traumatic experience. We recognize that you are grieving the loss of so many hopes, wishes, and dreams – still, we cannot imagine the pain you're feeling, and we realize that this experience continues for you even after you leave this hospital. We want to provide you with tools that will aid your healing and recovery – when you're ready. While we understand that no two families react to death in the same way, we offer these resources as potential starting points for your grief journey.

Compassionate Friends: www.compassionatefriends.org
Provides comfort, hope, and support to families experiencing the death of a child with local chapters throughout Virginia and all over the country.

First Candle: www.firstcandle.org/grieving-families/
Support for families affected by SIDS through grief counselors available 24/7 at 1-800-221-7437 as well as closed Facebook groups for online conversations.

Heartbreaking Choice: www.aheartbreakingchoice.com
Resources for those who have undergone a pregnancy termination due to a poor prenatal diagnosis, problems with their own health, or for the health of another fetus (selective reduction).

Mothering Your Heart: www.motheringyourheart.com
Provides space to explore what it means to "mother a child who is not in our arms."

Mothers in Sympathy and Support: www.missfoundation.org
Provides online and local support groups to families experiencing the death of a child.

Pregnancy and Infant Loss Remembrance Day: www.october15th.com
Promotes community education and awareness for families experiencing the death of a child through miscarriage, stillbirth, or neonatal death.

SHARE Pregnancy Loss and Infant Death Support: www.nationalshare.org
Provides support toward positive resolution of grief experienced at the time of, or following the death of a baby.
Tambien en Español: **www.nationalshare.org/share-espanolesperanza/**

Stillbirthday: www.stillbirthday.com
Resources for all walks of loss: early and late miscarriage, stillbirth, infant loss.

National Organizations

First Candle/National SIDS Hotline

1-800-221-7437

Offers crisis counseling, literature, information, and referral for support groups. Focus is on support for families affected by SIDS. Grief counselors available 24/7.

www.firstcandle.org/grieving-families/

Compassionate Friends

PO Box 3696 Oak Brook, IL 60522

1-877-969-0010

Provides education, correspondence, group development guidelines and a quarterly newsletter.

The Compassionate Friends provides highly personal comfort, hope, and support to every family experiencing the death of a child.

www.compassionatefriends.org

Parents of Murdered Children

1-888-818-7662

The National Organization of Parents of Murdered Children, Inc. (POMC) is the only national self-help organization dedicated solely to the aftermath and prevention of murder. POMC makes the differences through on-going emotional support, education, prevention, advocacy, and awareness.

www.pomc.org

American Association of Suicidology

1-202-237-2280

Serves as a clearinghouse for referrals to support survivors of suicide. Publishes quarterly newsletter.

www.suicidology.org

Mothers against Drunk Driving (MADD)

1-800-GET-MADD (1-800-438-6233)

National office will refer victims of drunk drinking crashes to their nearest local chapter of MADD. If a nearby chapter is not available, telephone counselors will offer guidance and support.

http://www.madd.org/victim-services/

Post Office Box 980664
Richmond, Virginia 23298-0664
804-828-0928

Artwork courtesy of Unicia Buster, Art Specialist
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