

Appendix E: Materials – Description of video vignettes

As part of the pediatric palliative care campaign materials, a series of short video vignettes will serve as a resource to help health care providers (HCPs) start and manage a pediatric palliative care conversation with patients, their parents/caregivers and families. Each vignette will focus on an aspect of pediatric palliative care and have a specific communications aim. The vignettes will serve as a resource for HCPs by reinforcing the importance of pediatric palliative care and by providing concrete references to enhance HCP communications skills by illustrating how to initiate, manage, and guide a conversation about palliative care.

Vignette 1: Setting the Stage

The first vignette will introduce and provide an overview of palliative care and why it is important. It will address palliative care terminology and help to correct the misconceptions that many HCPs and their patients and families believe about palliative care and when it is appropriate. The vignette will also provide rationale for why HCPs should initiate conversations about palliative care early in treatment and continue these conversations as their patients' needs change over the course of illness while listening to the child and family to understand their unique needs.

Vignette 2: How to Start and Manage the PC Conversation

The second vignette will provide an example of an HCP starting a pediatric palliative conversation with a parent(s) of a child living with a serious illness or life-limiting condition. The video will include tips for starting this difficult conversation, reinforce HCP self-efficacy to discuss/recommend pediatric palliative, and show HCPs how to manage the discussion.

Vignette 3: Family Perspectives

The third and final vignette will feature 1 story from 'real' parent or family who has navigated a serious illness or life-threatening condition with their child. It will reinforce the necessity for ongoing discussions around palliative care and provide anecdotal evidence for how these conversations improved, or would have been the first step to improve, their child's quality of life.

Appendix E: Materials – Script for video module 1 (will be read when showing the storyboards)

**National Institute of Nursing Research (NINR)
Video on pediatric palliative care
Module #1**

Video	Audio
NINR Logo NIH and HHS logos in lower right/left third	Dr. Grady, V.O.: This video is a presentation of the National Institute of Nursing Research.
Campaign Logo Pediatric Palliative Care	Dr. Grady, V.O.: Pediatric Palliative Care
Open with Office Dr. Grady speaking to camera	:10- 47 Dr. Grady, on camera: Hello. I am Dr. Grady, Director of the National Institute of Nursing Research. One of NINR’s main missions is to enhance the care of persons with chronic and life threatening conditions. This can be especially important for children. Palliative care is an important part of the treatment for pediatric patients living with a range of serious illnesses or life-limiting conditions – no matter the age of the child, prognosis, or the stage of the illness. It can reduce a child’s pain or distressing symptoms and also provide important emotional support to the child and his or her family.
Cut to Hospital room: Nurse administering medicines and talking to patient and his/her father Lower third reinforces key message points as Dr. Grady mentions them: <ul style="list-style-type: none"> • You have the expertise to explain the benefits of palliative care 	:47-:1:14 Dr. Grady, V.O.: As health care providers, we are uniquely positioned to initiate conversations about pediatric palliative care. You do not need to specialize in palliative care to help others understand its benefits. To clarify any misconceptions about palliative care, make sure that you clearly explain that a patient can receive palliative care with potentially curative or life-prolonging

<ul style="list-style-type: none"> • Explain that palliative care can be delivered with life-prolonging treatment 	<p>treatment.</p> <p>Also reiterate that palliative care may be appropriate early in the course of an illness and can continue throughout treatment. Patients can benefit from palliative care services whether they are in a hospital-based, outpatient, or home setting.</p>
<p>Cut to:</p> <p>Close up of Dr. Grady</p>	<p>1:14-1:24</p> <p>Dr. Grady, on camera:</p> <p>Recommending palliative care to patients and families <i>early</i> can increase overall satisfaction with care and improve patient outcomes. So don't hesitate.</p>
<p>[GRAPHIC]</p> <p>Bullets fly in as Dr. Grady mentions them:</p> <p><u>Pediatric palliative care</u></p> <ul style="list-style-type: none"> • Initiate conversation about pediatric palliative care early and frequently • Palliative care does not mean that curative treatment will stop • Pediatric palliative care can extend to the entire family 	<p>1:24-2:00</p> <p>Dr. Grady, V.O.:</p> <p>Remember:</p> <p>Initiate a conversation about palliative care as soon as possible and continue the dialogue throughout the course of the illness.</p> <p>Make sure that your patients and their families understand that palliative care does not mean that curative treatment will stop or that it is only appropriate at the end of life.</p> <p>Help the patient and caregivers understand that palliative care can extend to parents, siblings, and other family members.</p>
<p>[GRAPHIC CHANGES TO]</p> <p>Campaign logo</p> <p>For more information about pediatric palliative care, please visit [CAMPAIGN URL]</p>	<p>2:05</p> <p>Dr. Grady, V.O.:</p> <p>For more information about pediatric palliative care, please visit [CAMPAIGN URL]</p>
<p>Credits:</p> <p>NINR Logo</p> <p>NIH and HHS logos</p>	

Appendix E: Materials - Script for video module 2 (will be read when showing the storyboards)

National Institute of Nursing Research (NINR)
Video on Pediatric Palliative Care
 Module #2

Video	Audio
NINR Logo NIH and HHS logos in lower right/left third	Dr. Grady, V.O.: This video is a presentation of the National Institute of Nursing Research.
Campaign Logo Starting a conversation about pediatric palliative care	Dr. Grady, V.O.: Starting a conversation about pediatric palliative care
Open with Office Dr. Grady speaking to camera	:10-:33 Dr. Grady, on camera: Starting a conversation about palliative care with parents and family members of a seriously ill child can be difficult, yet palliative care is central to a patient’s treatment and can help build trust with a child’s parents or caregivers. At NINR we believe that communication is at the heart of palliative care.
Fade to : Nurse in hospital room listening to pediatric patient and family, talking and interacting. Lower third under scene of nurse in hospital showing graphic/bullets <ul style="list-style-type: none"> • Provide clear, easy to understand information. • Palliative care can be provided along with primary medical treatment Fade/cut to scene of Conference room: Physician talking to the parent(s). Lower third under Conference	:33-1:03 Dr. Grady, V.O.: It’s important to initiate a conversation about palliative care needs as soon as possible to help patients and parents understand available options and their benefits. When talking with pediatric patients and families, it is important to be clear and direct, yet compassionate. Start by clarifying what palliative care means and help the patient and family understand that palliative care is different than hospice care. Palliative care is comprehensive care that can enhance a child’s quality of life. Explain the services that are included in palliative care,

<p>room scene showing graphic/bullets:</p> <ul style="list-style-type: none"> • Palliative care services include: <ul style="list-style-type: none"> - Pain and symptom management - Emotional support and counseling - Advanced care and planning 	<p>Palliative care services include:</p> <ul style="list-style-type: none"> - Pain and symptom management - Emotional support and counseling - Advanced care and planning <p>...and that palliative care is provided by a broad team of health professionals from doctors to nurses to counselors, chaplains and social workers.</p> <p>Remind parents and families that receiving palliative care does not mean that curative treatment will stop.</p>
<p>Cut to Dr. Grady- close up.</p>	<p>1:03-1:30 Dr. Grady, on camera:</p> <p>During these conversations, we need to ask questions about the patient and family’s cultural, social, and spiritual preferences. Also ask about their goals for care and quality of life. Encourage caregivers to share their broader concerns about a child’s overall quality of life and well-being and listen to their concerns. Try not to focus only on the child’s illness.</p>
<p>GRAPHIC</p> <ul style="list-style-type: none"> • Talk about palliative care as soon as possible • Explain what pediatric palliative care is • Be clear, direct and compassionate • Ask questions and listen 	<p>1:30-1:48 Dr. Grady, V.O.:</p> <p>Remember:</p> <ul style="list-style-type: none"> • Initiate a conversation about palliative care as soon as possible • Explain what benefits pediatric palliative care can provide • Be clear and direct but compassionate • Ask questions and listen to learn about any specific or changing needs
<p>[GRAPHIC CHANGES TO]</p> <p style="text-align: center;">Campaign logo</p> <p>For more information about pediatric palliative care, please visit [CAMPAIGN URL]</p>	<p>:05 Spokesperson, V.O.:</p> <p>For more information about pediatric palliative care, please visit [CAMPAIGN URL]</p>
<p>Credits: NINR Logo NIH and HHS logos</p>	