

# Talking About Serious Illness

## Potential Barriers and Suggested Ideas for Change

**Key Activity:** Prepare to conduct discussions for patients identified with serious illness.

**Rationale:** The American Academy of Pediatrics (AAP) advocates for palliative care that is centered on the child and provides care across the age spectrum and life span. Communication and shared decision making are critical elements of pediatric palliative care, but many pediatricians\* feel ill prepared to have discussions addressing goals of care for children with serious illness.

Before addressing the content and structure of the discussion, it is important to recognize that these discussions are improved by focused preparation. This EQIPP course includes a hands-on tool to assist pediatricians in assembling the basic background information required for a serious illness discussion.

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
<b>Gap: Pediatrician believes they do not understand the patient’s illness trajectory or anticipated needs.</b>		
Lack of information about the patient’s illness trajectory and anticipated needs	<ul style="list-style-type: none"> <li>Conduct research to increase knowledge of the patient’s likely illness trajectory, including the duration of survival (and what the shortest and longest scenarios might be), symptoms that may develop or change over time, the potential increasing impairments, and questions about medical technology support that may arise.</li> <li>Reach out to other pediatricians, including pediatric subspecialists involved in the patient’s care, who may have more experience with the problems the child and family are facing.</li> <li>Involve the patient’s subspecialists in the decision-making process before the serious illness discussion.</li> <li>Have a discussion with the patient’s case manager to gather more information.</li> <li>Look at previous notes on the patient or request access to the patient’s full medical record.</li> <li>Accept that this discussion typically involves issues that have some</li> </ul>	<ul style="list-style-type: none"> <li>Reach out to the Palliative Care team at your hospital or clinic for guidance.</li> <li>Talk with the patient’s primary subspecialist to learn more about the patient and the patient’s condition.</li> <li>Review the appropriate <a href="#">Courageous Parents Network (CPN) video(s)</a>.</li> </ul>

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
	<p>degree of uncertainty, and this uncertainty is an important topic for discussion.</p> <ul style="list-style-type: none"> <li>Complete the <a href="#">Preparation Worksheet – For Pediatricians</a> and review the <a href="#">Discussion Guide – For Pediatricians</a> to understand what aspects of the illness are likely to be addressed in the discussion.</li> </ul>	
<b>Gap: Pediatrician is unsure whether he or she is the right person to have the serious illness discussion.</b>		
Lack of ownership or authorization to have the discussion	<ul style="list-style-type: none"> <li>Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to prepare adequately for the discussion.</li> <li>Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to review important details that are essential for your serious illness discussion.</li> <li>Notify the patient's primary subspecialist that you'll be having the discussion to gain support and increase awareness.</li> <li>Review curriculum topics that cover the importance of continuity of care and nonabandonment for seriously ill children.</li> <li>Review the parent video that answers pediatrician concerns about their involvement.</li> <li>Reflect on your unique role, responsibilities and perspective for the child and family.</li> </ul>	<ul style="list-style-type: none"> <li>Work with colleagues to become comfortable having the discussion.</li> <li>Learn more about serious illness discussions by taking <a href="#">VitalTalk</a> courses.</li> <li>Review the appropriate <a href="#">Courageous Parents Network (CPN) video(s)</a>.</li> </ul>
<b>Gap: Pediatrician is unsure whether it's the right time for the serious illness discussion.</b>		
Uncertainty about appropriate timing of the discussion	<ul style="list-style-type: none"> <li>Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to prepare adequately for the discussion.</li> <li>Review the curriculum topics that cover appropriate timing of the discussion.</li> <li>Review the parent video that answers pediatrician concerns about their involvement.</li> <li>Review the appropriate <a href="#">Courageous Parents Network (CPN) video(s)</a>.</li> </ul>	<ul style="list-style-type: none"> <li>Work with colleagues to become comfortable having the discussion.</li> <li>Consider having the patient's psychosocial team members join the discussion.</li> <li>Learn more about serious illness discussions by taking</li> </ul>

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
	<ul style="list-style-type: none"><li>• Reach out to the patient's family to explain the value of a straightforward discussion about their child's illness and overall situation and clarify whether they want such a discussion.</li><li>• Be self-reflective to understand the emotional elements of such discussions.</li></ul>	<a href="#">VitalTalk</a> courses.

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## Appendix

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## Potential Barriers and Suggested Ideas for Change

**Key Activity:** Conduct discussions with patients and their families identified with serious illness.

**Rationale:** The Institute of Medicine (IOM) advocates improvement in pediatrician-led\* discussions about goals, values, and care preferences for patients with serious illnesses. The aim of this activity is to provide guidance on conducting a structured discussion about goals, values, and care preferences with a family of a child with serious illness. This approach will lead to greater prognostic awareness and more nuanced patient advocacy and decision making, and may also strengthen the patient-pediatrician relationship through greater shared understanding of family preferences and goals of care.

**Note:** When appropriate, this activity should include talking to the child directly, respecting family culture and the child's development. Because one implication of these discussions is potential end-of-life decisions, care must be taken to engage those actually making these decisions within the individual family structure. These discussions may affirm the benefits of care planning for families while strengthening the patient-pediatrician relationship.

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
<b>Gap: Pediatrician is unsure of how to begin the serious illness discussion.</b>		
Feeling lost about how to have the discussion	<ul style="list-style-type: none"> <li>• Watch the demonstration videos to learn more about how the discussion might play out.</li> <li>• Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to prepare adequately for the discussion.</li> <li>• Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to understand the child's overall condition and care.</li> <li>• Watch the demonstration videos to see the importance of these discussions to families.</li> <li>• Review the curriculum topics that cover how to approach the discussion with patients and families.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider having the patient's psychosocial team members join the discussion.</li> <li>• Reach out to the Palliative Care team at your hospital or clinic for guidance.</li> <li>• Learn more about serious illness discussions by taking <a href="#">VitalTalk</a> courses and using the related application.</li> </ul>

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
<b>Gap: Pediatrician is unsure of what to do during the serious illness discussion.</b>		
Discomfort with some of the topics	<ul style="list-style-type: none"> <li>• Watch the demonstration videos to learn more about how the discussion might play out.</li> <li>• Use the <a href="#">Discussion Guide – For Pediatricians</a> to help provide structure for the discussion.</li> <li>• Use the <a href="#">Discussion Guide – For Pediatricians</a> script and read it aloud as practice; consider using the script during the actual discussion, if needed.</li> <li>• Role-play the discussion with colleagues or in front of a mirror.</li> <li>• Discuss the situation with colleagues and solicit their ideas before having the discussion.</li> <li>• Reflect on what you believe is most important in your relationship with families and their seriously ill children.</li> <li>• Review the curriculum topics that cover how to handle difficult discussions.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider having the patient's psychosocial team members join the discussion.</li> <li>• Reach out to the Palliative Care team at your hospital or clinic for guidance.</li> <li>• Learn more about serious illness discussions by taking <a href="#">VitalTalk</a> courses and using the related application.</li> </ul>
<b>Gap: Pediatrician is unsure of how to respond during the serious illness discussion.</b>		
Feeling unprepared or uncomfortable with strong emotional responses from the parent	<ul style="list-style-type: none"> <li>• Permit emotion without responding immediately.</li> <li>• Remember that tolerance of emotions is an important skill and is important to the success of these discussions.</li> <li>• Remember the acronym NURSE (from VitalTalk) to guide your reaction: <b>N</b>aming, <b>U</b>nderstanding, <b>R</b>eflecting, <b>S</b>upporting and <b>E</b>xploring.</li> <li>• Consider having the patient's psychosocial team members join the discussion.</li> <li>• Bring tissues to the discussion.</li> </ul>	<ul style="list-style-type: none"> <li>• Reach out to the Palliative Care team at your hospital or clinic, either to talk through how to have the discussion, or to see if they can join you.</li> <li>• Learn more about serious illness discussions by taking <a href="#">VitalTalk</a> courses and using the related application.</li> </ul>
Feeling that it may take too much time	<ul style="list-style-type: none"> <li>• Make sure you've scheduled adequate time, generally around 45 minutes, for the discussion.</li> <li>• Consider having someone in your office sit in to take notes to capture all</li> </ul>	<ul style="list-style-type: none"> <li>• Talk with a colleague who has more experiences with these discussions, and see if you can</li> </ul>

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
	<p>of the discussion highlights.</p> <ul style="list-style-type: none"> <li>Use the <a href="#">Preparation Worksheet – For Pediatricians</a> and <a href="#">Discussion Guide – For Pediatricians</a> to help you prepare for and facilitate the discussion.</li> <li>Remember that you can identify and acknowledge the importance of an issue and suggest that it be addressed at a later time.</li> </ul>	<p>pick up specific tips.</p> <ul style="list-style-type: none"> <li>Talk with clinic, office, or hospital-based leadership or staff to determine how you could carve out more time.</li> <li>Practice having the discussion with a colleague to get a better sense for the time it takes and your pacing.</li> </ul>
Not knowing how to manage disagreement or conflict	<ul style="list-style-type: none"> <li>Recognize that the intent of these discussions is not agreement but careful consideration. Know when to move on during the discussion—you don't need to agree on everything or settle all the issues.</li> <li>Recognize the expertise that the parents have regarding their child and respect their cumulative experience; they may have perspectives that you have not considered, or you may not have previously recognized the importance of a concern to the parents.</li> <li>Learn more about conflict management by taking <a href="#">VitalTalk</a> courses and using the related application.</li> </ul>	<ul style="list-style-type: none"> <li>Take a mediation course to learn more about these difficult discussions.</li> <li>Perform further self-learning on conflict management strategies.</li> <li>Consider having the patient's psychosocial team members join the discussion.</li> <li>Reach out to the Palliative Care team at your hospital or clinic for guidance.</li> </ul>
The parents' concerns seeming to be removed from the pediatrician's concerns	<ul style="list-style-type: none"> <li>Recognize that avoidance may be an emotional response to feeling overwhelmed.</li> <li>Ask yourself whether your concerns stem from their interpersonal style and whether they are actually very aware and engaged. Some parents have a detached style or naturally have more flat responses.</li> <li>Learn about the ask-tell-ask technique of approaching difficult topics.</li> <li>Refocus on the patient's or parent's concerns and ask them to tell you more; remain curious and open to their thinking.</li> </ul>	<ul style="list-style-type: none"> <li>Take a motivational interviewing course to learn more about these difficult discussions.</li> <li>Reach out to the Palliative Care team at your hospital or clinic for guidance.</li> </ul>

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Struggling with making recommendations	<ul style="list-style-type: none"> <li>• Ask parents directly whether they expect you, as their pediatrician, to make a recommendation. Let their response be your guide as you offer recommendations.</li> <li>• Before having the discussion, review the situation with colleagues and solicit their ideas on providing recommendations.</li> <li>• Watch the demonstration videos to learn more about how a recommendation can be framed.</li> <li>• Double check your own expectations about what your recommendations should be; consider meeting again in a few months, if compatible with the child's situation.</li> <li>• Engage with parents after offering your recommendations to get feedback about the recommendations you made and the style of your recommendations.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider having the patient's psychosocial team members join the discussion.</li> <li>• Consider reaching out to your hospital or clinic's palliative care team for help.</li> <li>• Learn more about serious illness discussions by taking <a href="#">VitalTalk</a> courses and using the related application.</li> </ul>



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## Appendix

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## Potential Barriers and Suggested Ideas for Change

**Key Activity:** Document and disseminate results of the serious illness discussion to all pertinent stakeholders.

**Rationale:** Pediatric palliative care seeks to improve quality of life and reduce distress for patients and families facing serious illness. There are many pediatricians\* with unique and important contributions to make to the palliative care needs of their patients—and their contributions can make care more seamless between settings and provide insights gained during times of lower acuity. Disease-directed care and transitions in care would be improved if offered with an understanding of the larger hopes and goals for each individual child and family. In order for each pediatrician in a child's healthcare team to contribute, their viewpoint must be shared.

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
<b>Gap: Pediatrician lacks experience in documenting a serious illness discussion.</b>		
Unfamiliar with the documentation process	<ul style="list-style-type: none"><li>• Use the <a href="#">Discussion Summary Sheet – For Pediatricians</a> to help you document the discussion.</li><li>• Consider having someone in your office sit in to take notes to capture all of the serious illness discussion highlights.</li></ul>	<ul style="list-style-type: none"><li>• Discuss the documentation process with colleagues who have already completed the <a href="#">Discussion Summary Sheet – For Pediatricians</a>.</li><li>• Reach out to the Palliative Care team at your hospital or clinic for guidance.</li></ul>
<b>Gap: Pediatrician is unsure how to share information gathered from the serious illness discussion.</b>		
Unfamiliar with how to share information with the family	<ul style="list-style-type: none"><li>• Review the curriculum topics that cover how to share discussion information and next steps with the family.</li><li>• Mail the <a href="#">Family Summary Sheet – For Parents and/or Caregivers</a> to the parents after the discussion.</li></ul>	<ul style="list-style-type: none"><li>• Consider delegating any of the patient/family documentation tasks by assigning to a resource in your office.</li></ul>

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Potential Barriers	Suggested Ideas for Change	Still Not Seeing Results?
Unfamiliar with how to share information with other healthcare team members	<ul style="list-style-type: none"> <li>Review the curriculum topics that cover how to share discussion information with the broader healthcare team.</li> <li>Use the <a href="#">Discussion Summary Sheet – For Other Healthcare Professionals</a> to guide documentation of the discussion in the child’s medical record.</li> <li>Securely send the <a href="#">Discussion Summary Sheet – For Other Healthcare Professionals</a> to identified key clinicians.</li> <li>Speak directly with central clinicians about the discussion.</li> <li>Consider delegating some of the documentation tasks to an administrative colleague in your office.</li> </ul>	<ul style="list-style-type: none"> <li>Consider delegating any of the documentation tasks by assigning to an administrative colleague in your office.</li> </ul>
<b>Gap: Pediatrician is unsure how to bill after completing the serious illness discussion.</b>		
Unfamiliar with the billing process	<ul style="list-style-type: none"> <li>Review the curriculum topics that cover billing procedures.</li> <li>Talk to someone in your hospital or clinic’s billing department.</li> <li>E-mail the AAP billing hotline at <a href="mailto:aapcodinghotline@aap.org">aapcodinghotline@aap.org</a> for assistance. Alternatively, fax the coding hotline at 847/434-4996.</li> </ul>	<ul style="list-style-type: none"> <li>Consider delegating billing tasks described here by assigning it to a resource in your office.</li> </ul>

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## Appendix