

Outline for a New Patient/Family Visit

Pre-visit preparation

- Obtain medical information from clinical team
 - Diagnosis, and patient/family understanding of it
 - Prognosis, and patient/family understanding of it
 - Current treatment and response
 - Identified goals of care/advanced care plan, if any
 - Pressing concerns or questions
- Persons to consider speaking with prior to intake
 - Referring clinician
 - Primary care pediatrician (if not the referring clinician)
 - Community partners, to the degree permitted by HIPAA
- Background information on family unit (if available)
- Reason for referral

Setting up a visit

- Initial call, within 48 hours of receiving the referral
 - Identify yourself by name and professional role from the Pediatric Palliative Care Team at ___ (VNA/HHA)
 - Ask for the person identified as caregiver for the patient
 - “I received a referral from Dr. ___”
 - “You may have also received a letter in the mail about being eligible for the Pediatric Palliative Care Program.”
 - “I’d like to set up a time to meet you and your family/support people to see how we can help.”
 - Inquire about questions or any pressing concerns to be addressed in the initial phone call
- If you sense resistance
 - “I understand your child has been going through a lot.”
 - “I can’t imagine what this might be like for you.”
 - You might name some of these issues, if you are aware of them from conversations with clinical team
 - Emphasize that the goals of palliative care include optimizing quality of life and addressing physical, emotional, spiritual, and practical needs
 - Connect expressed needs to program services that could address them
 - Assure that services are available as they need them, at no cost to the family
- Discuss who should be present during the initial interview, and whether it is more important to meet sooner without everyone present, or wait until everyone can attend

- Primary
 - Primary caregiver(s)/guardian(s)
 - Patient (for all, part, or potentially none of the initial intake)
- Other
 - Other caregiver(s)/support people, as desired by the primary caregivers
 - Siblings, if the primary caregivers would like them present
 - Any other relevant members of the pediatric palliative care team from the agency

Visit

- Standard preparation (e.g., pager/cell phone off, tissues available, etc.)
- Use *suggested* outline for an initial intake, which each person will modify based on their own personality/style
- Be clear about time
 - “I have about 45 minutes...”

Conclusion of Visit

- Inquire about final questions/concerns
 - “I am aware of the time...”
 - “Has this visit brought up anything for you that wasn’t there before?”
 - “What I am hearing (summarize)...”
- Clearly identify next steps
 - Schedule next visit
 - Ensure they know how to reach you
- Assure them that you will communicate with their clinical team, based on permissions given by primary caregiver(s)

Follow-Up

- Follow-up with primary caregiver(s) in the following 1-2 days
- Close loop of communication with referring clinician and primary care pediatrician

Pearls

- ✓ Ask open-ended questions
- ✓ Allow for silence
- ✓ Name emotions
- ✓ Patient/family should always speak > than providers

Theme	Examples		
Open-ended beginning	“Tell me about your child. What is s/he like as a person?”		
	“Tell me about what you’ve been going through.”		
	“What worries you the most right now? For your child, your family, or yourself?”		
	“What’s your understanding of why Dr. _____ referred you to the Pediatric Palliative Care Program?”		
Patient’s medical diagnosis	“What is your understanding of your child’s diagnosis/illness?”		
	“What’s your sense of where your child’s illness is heading?”		
	“Have your doctors told you if this will get better? Or worse?”		
	“What has your child been told about their illness?”		
Physical aspects of care	“What treatment is your child getting now? How is it working?”		
	“What are you expecting from the treatment/medical interventions that your child is receiving?”		
	“Has your child been experiencing any distressing symptoms?” Further exploration of the symptom(s) the parents note, followed by review of systems	“Has your child been experiencing pain or discomfort?”	If yes, consider use of tools: NRS, FACES, INRS If yes, consider use of tools: ESAS, EFAT, PPS
		“Has your child been having any difficulty pooping, like diarrhea or constipation?”	
		“How is your child’s appetite? Has s/he experienced any nausea or vomiting?”	
		“How does your child sleep at night? Any naps during the day?”	
		“Does your child have the energy to do the things s/he enjoys?”	
		“How is your child’s breathing? Any problems like cough, getting short of breath?”	
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Psychosocial aspects of care	“How has your child’s illness impacted their daily life? Your own life?”		
	“Does your child seem anxious? Sad? Angry?”		
	“What are some of the other things, besides your child's illness that your family is dealing with right now?”		
	“Besides your child's health, what do you find yourself thinking about day to day?”		
Spiritual and cultural aspects of care	“Do you have particular beliefs that guide you?”		
	“What is most important for your child and your family right now?”		
	“Who do you turn to for help?”		
	“Tell me what helps you get through these days.”		
	“Do you have particular beliefs that guide you?”		
Care at the end of life, if applicable*	“What’s been your—or your child’s—experience with death?”		
	“Have you discussed as a family what happens if your child gets sicker?”		
	“If your child’s illness does get worse, have you thought about what’s most important to you?”		
*Might choose to start with an open-ended question, and proceed incrementally as feels appropriate, pulling back at whatever point there is resistance			

Content adapted from Wolfe J, Hinds P, Sourkes B. *Textbook of interdisciplinary pediatric palliative care*. Philadelphia: Elsevier; 2011