

Perinatal Palliative Care Communication Tools Cheat Sheet

Conversation Frameworks:

Delivering Bad News	SPIKES	Use when family could NOT know/infer the bad news (i.e. new diagnosis)	Setting	Quiet space, no interruptions, sit down with family, ideally needed subspecialist present	
			Perception	Can you tell me what you know about your pregnancy (or baby's medical issues)? Has anyone mentioned any concerns about your pregnancy/baby?	
			Invitation	I have some difficult news that I need to share with you. I did receive back your/baby's test results, I am concerned about the findings. I have some concerns about your/baby's health. LONG SILENCE, wait for family to acknowledge.	
			Knowledge	Give information. Would focus on big picture and then give details as family asks questions. Do frequent check ins with family, "what questions do you have about what I have said so far?"	
			Emotion	This is hard. I wish I did not have to share this information. These are not words a mommy or daddy should ever have to hear.	
			Summary	Big picture review, next steps	
	Ask-Tell-Ask	Use when family already knows some information	Ask	Can you tell me what you know about your/baby's CURRENT medical concerns. *If your leave out "current" you may get a 6 month rehashing of events, maybe helpful, maybe distracting. What are you most concerned about for your baby? What else (ask until family reaches your concern OR you feel sure family does not know the concern)	
			Tell	Understands→Validate	Yes, your baby's illness is very serious and it sounds like you have a very good understanding. *If the family says die you DO NOT need to keep saying it. They clearly get it.
				Lacks Understanding→Reframe	I wish your baby's illness was something we could easily treat. I worry that your baby will be very sick when s/he is born. Babies with this diagnosis often die shortly after birth (hours, days, weeks, months etc). OR Babies with this illness need lots of extra help as they grow...explain. *You must say die if this is a concern and family does not say it.
			Ask	What is most important to you after you baby is born? Are there things you want to make sure happen after your baby is born? How are you celebrating your pregnancy (baby shower, pregnancy photos)? How can we celebrate her/his life? Your baby is so special, and even though s/he may not live very long, s/he will impact you and others for a lifetime. It is important to celebrate her/him.	
Changing Goals	REMAP	Use when baby has a decline and need to discuss new goals/plans	Reframe	Last time we talked, we were really hopeful that baby was going to respond to X/improve. It seems like baby is struggling more. It seems like baby is in a different place now. SILENCE	
			Emotion	This has been a very difficult pregnancy/hospital stay. What are you most concerned about? What else? *if family is missing the critical concern, "Is it ok, if I tell you what the medical team is really worried about?" Be brief and to the point. "We are worried that he is slowly dying/declining/suffering."	
			Map	I worry that our time with baby is limited. Tell me what is most important to your family now.	
			Align	What I hear you saying is X is really important. (having family come to bedside, going home, meeting siblings etc)	
			Propose a Plan	Given everything you told me, I propose we do X.	

Perinatal Palliative Care Communication Tools Cheat Sheet

Delivery Room Facilitation

Transitioning to Comfort Care/Legacy	We had talked about doing X, does this sound like a good time to do that? We talked about doing X after BABY was born, what is most important to you right now?
Normalizing Interaction with Baby	Does s/he have a name? Look how tiny her hands are. Look how perfect her nose is. He has such big feet. He has LOTS of hair! Who does he look like?
Validating Emotions	This is hard. No mommy or daddy should ever have to say goodbye to their baby. It is ok to cry. It is ok to be mad. (avoid "I am sorry") (Never talk about siblings as a replacement for baby who passed)
Providing Reassurance	He never felt any pain. All she ever felt was your love and the warmth of your embrace. She is just perfect. I do not know why this happened. BUT, I do know that his life is very important. Some of us need 100 years to accomplish our tasks, some only need moments. She will have a huge impact on your family and everyone here.
Baby as a part of the family	Even though baby is no longer physically here, he will always be a part of your family. Talk about him. If it is helpful, find ways to remember him at holidays and family events. We know from studies that examined how families cope after the loss of a baby, those families who talk about their baby are mentally healthier. Your baby lived. He is important. (Encourage family in the room, to help the mom and dad remember the baby).

Other Phrases I Like

References

1. Bumb M, Keefe J, Miller L, Overcash J. Breaking Bad News: An Evidence-Based Review of Communication Models for Oncology Nurses. Clin J Oncol Nurs. 2017 Oct 1;21(5):573-580. doi: 10.1188/17.CJON.573-580. PMID: 28945712.
2. Childers JW, Back AL, Tulskey JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. J Oncol Pract. 2017 Oct;13(10):e844-e850. doi: 10.1200/JOP.2016.018796. Epub 2017 Apr 26. PMID: 28445100.
3. Ebelhar JS, Brock KE. Communicating difficult news in pediatric radiology. Pediatr Radiol. 2024 May;54(5):663-670. doi: 10.1007/s00247-024-05861-4. Epub 2024 Feb 7. PMID: 38326566.
4. Hashim MJ. Patient-Centered Communication: Basic Skills. Am Fam Physician. 2017 Jan 1;95(1):29-34. PMID: 28075109.
5. Mahendiran M, Yeung H, Rossi S, Khosravani H, Perri GA. Evaluating the Effectiveness of the SPIKES Model to Break Bad News - A Systematic Review. Am J Hosp Palliat Care. 2023 Nov;40(11):1231-1260. doi: 10.1177/10499091221146296. Epub 2023 Feb 13. PMID: 36779374.
6. Schell JO, Arnold RM. NephroTalk: communication tools to enhance patient-centered care. Semin Dial. 2012 Nov-Dec;25(6):611-6. doi: 10.1111/sdi.12017. Epub 2012 Oct 19. PMID: 23078102.
7. Tatterton MJ, Fisher MJ. 'You have a little human being kicking inside you and an unbearable pain of knowing there will be a void at the end': A meta-ethnography exploring the experience of parents whose baby is diagnosed antenatally with a life limiting or life-threatening condition. Palliat Med. 2023 Oct;37(9):1289-1302. doi: 10.1177/02692163231172244. Epub 2023 May 2. PMID: 37129319; PMCID: PMC10548777.