“They Just Don’t Get It!”
Talking with patients and families about a changing plan of care

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In this overview

• Recognize common challenges
• Outline a new talking map
• Highlight skills that make a difference
The usual story

- He [the family or pt] is not ‘getting it’
- Their expectations are ‘off the wall’
- ‘Don’t they see what is happening?’
The challenge

• History - active/aggressive treatment to extend lifespan
• Hope been based on ‘next treatment’
• End of disease-directed treatment seen as failure
What comes next?
The typical story

- Comfort Care = ‘nothing more to do’
- Focus on technical aspects/evidence
- Discussion centers on treatments rather than goals
- We make patient/family make “choices”
Talking Map: “REMAP”

1. **Reframe** why status quo isn’t working.
2. **Expect** emotion, respond with empathy.
3. **Map out** what’s important.
4. **Align** with patient values.
5. **Plan** to match values.
1. **Reframe**: current plan isn’t working

- “Given this news, it seems like a good time to talk about what to do now.”
- “We’re in a different place than before.”
- “We’re at a point where doing what we’ve been doing is unlikely to help and may make her worse”
2. Expect emotion: respond empathically

- Bad news $\rightarrow$ emotions
- Emotion brain shut down cognition
‘NURSE’ Statements of Empathy

- **Naming** – “You seem frustrated.”
- **Understanding** – “This helps me understand what you’re thinking.”
- **Respecting** – “I can see how much you love your mom.”
- **Supporting** – “We’ll work on this together.”
- **Exploring** – “Tell me more about that.”
3. Map out the future

- “Given this situation, what’s most important?”

- “As you think about the future, what concerns you?”

- Consider referencing Advanced Directives
Map out the future examples:

• “I wish but I worry.”
• Ask – Tell – Ask
  “What were you hoping this could do?”
4. Align with values

• “As I listen, it sounds like what’s important is...”
• “I think we can help you do xx...”
• “By planning ahead, we can avoid things like...”
5. **Plan treatments that match values**

- “Here are things we can do now...”
- “For this situation, here are some things that would help”
- “What do you think?”
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Brief Demonstration of REMAP
Harry and Dottie Jones
Harry and Dottie Jones

- Harry - 76 year old retired farmer with CHF

- On CHF home monitoring program through visiting nurses for two months, after 3 hospitalizations in 6 months

- Getting weaker – has had some falls

- Dottie is insisting that he up get up and walk around the house several times a day so he can stay strong.
Talking Map: “REMAP”

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2. Expect emotion, respond with empathy.
3. Map out what’s important.
4. Align with patient values.
5. Plan to match values.
Surrogate discussion

• “What would your dad think if he was sitting hear and could hear what we are saying?”

• Attend to the emotion of this question
Time limited trials

• Be clear about the time: “We will do this for another week”

• Be clear about what ‘working’ means: “We will know if it is working if she is able to wake up more and eat.”

• “The dying process is sometimes a rollercoaster”
REMAP Pointers

• Show your work – how you got there
• Focus on what *can* be achieved
• Make clear recommendations about what cannot be achieved and thus you do not suggest
• Focus on their ability to meet new goals
Pearls

• Invite the conversation
• Respond to the emotion
• Move the conversation forward:
  ■ “I wish but I worry…”
  ■ Ask – Tell – Ask
• Reaffirm your commitment to the patient
QUESTIONS?
What will you take away?