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Palliative Care

2023 Annual Dialysis Conference:

What Matters Most:
Goals of Care Discussions

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Disclosures

- No financial disclosures

- I am an adult palliative care doctor

Beep, beep, beep…..paging Dr. Smith

- “New consult - Danielle Jones (PICU2) 11F s/p renal txplt a/f septic shock in s/o ongoing chronic rejection, intubated on pressors, needs CRRT”

- In addition to helping with the dialysis plan, you are wondering about the “big picture,” and you are concerned about a poor prognosis.

Roadmap

- Why care about GOC discussions?
- When to consider GOC discussions?
- A Framework and approach for GOC conversations
- Language you can use & Pro Tips
- Approaching GOC as a consultant

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Why Care About Goals of Care?

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There are Many Barriers to Talking About GOC

- Pediatricians worry about:
  - Unrealistic expectations
  - Differences between clinician and patient/parent understanding
  - Lack of readiness to have the discussion
  - Taking away hope
  - Uncertainty about prognosis
  - Not knowing the right time to address the issues

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Pediatrics 2012:129(4):e975-982

BUT…We Know We Should Talk About GOC

- Most pediatricians believe that:
  - These conversations **happen too late**
  - Discussions about overall goals should **occur upon diagnosis** or **during a period of stability**

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Pediatrics 2012:129(4):e975-982

Children with Renal Disease Need GOC Discussions

Many children with CKD have a **life-limiting** or **life-threatening disease**

30x

Worse survival w/ ESKD

12x

Relative risk for death after renal transplant

Kidney360 2021;2(June):1063-1061.; Pediatr Neprhol 2012;27:507:363-373; Pediatr Nephrol 2009;24:475-484.; Pediatr Nephro 2016;31:1579-1591; Qual Life Res 2018;27:1445-1454.

Children with Renal Disease Need GOC Discussions

- Children living with CKD report lower quality of life compared to peers.

Kidney360 2021;2(June):1063-1061.; Pediatr Neprhol 2012;27:507:363-373; Pediatr Nephrol 2009;24:475-484.; Pediatr Nephro 2016;31:1579-1591; Qual Life Res 2018;27:1445-1454.

Children and Parents Want More Information

- Most parents of children with special needs **want to receive all medical and prognostic information**, regardless of how serious or potentially upsetting the information is.

of bereaved parents regretted talking to children about death

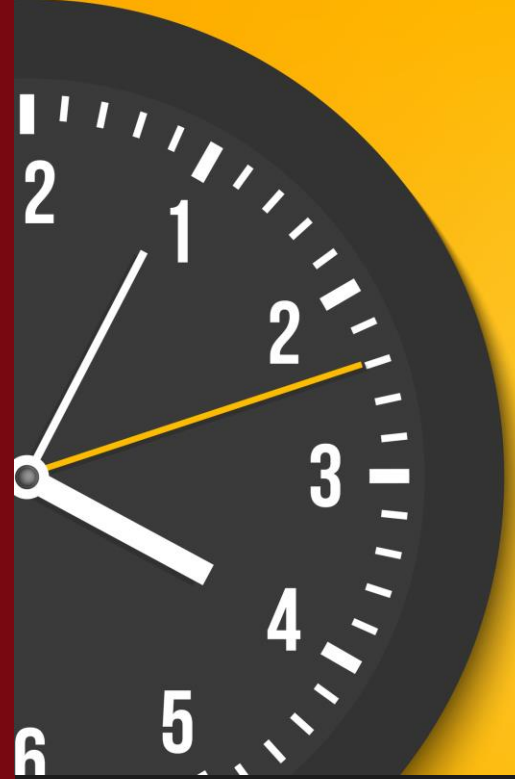
of bereaved parents regretted **NOT** talking to children about their death

Am J Kidney Dis 2018:72(4):547-559; Pediatrics 1996:97(5):682-687; NEJM 2004:351:1175-1186

Children and Parents Want More Information

- Children living with CKD and their parents **want more information** and education to inform decision making.
- Parents have a **strong desire for shared-decision making** and to share their expertise in their lived experience.

Am J Kidney Dis 2018:72(4):547-559; Pediatrics 1996:97(5):682-687; NEJM 2004:351:1175-1186



When to Consider Goals of Care Discussions?

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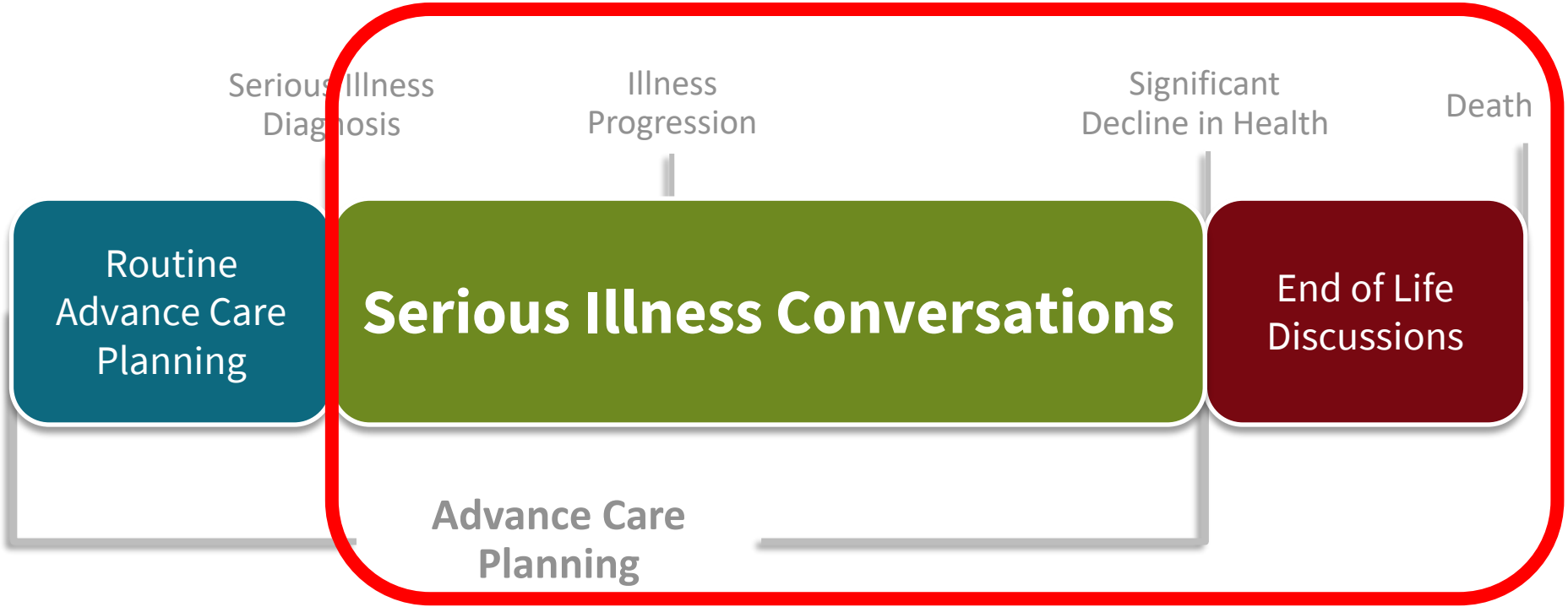
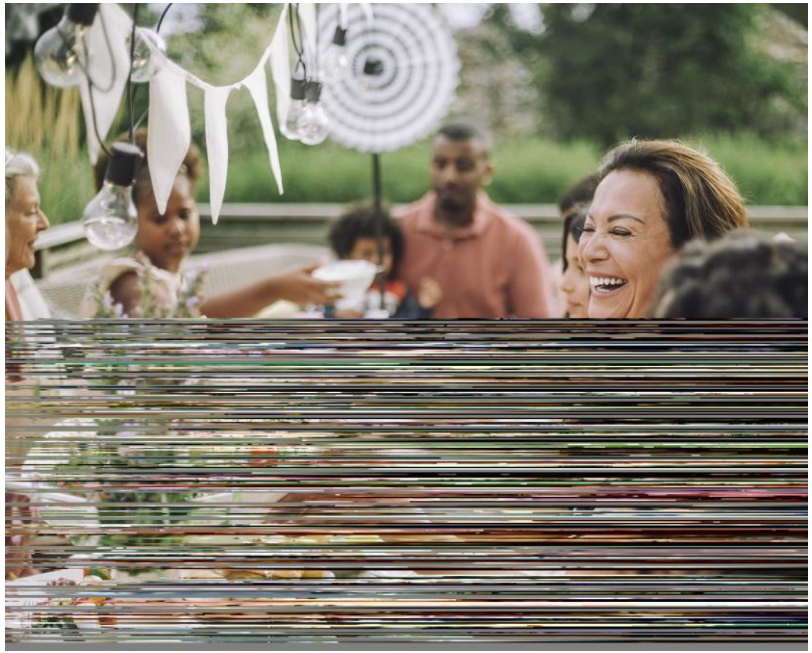
Advance Care Planning & Serious Illness Communication



When Should GOC Discussions Happen?

- Goals of care discussions should not occur in a vacuum.
- Ideally, begin at the kitchen table, continue in clinic, and evolve with time.
- **Should not be limited to goals of end-of-life care (i.e. focusing on death and dying) but should be as much about how the patient wants to live**.



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When Should GOC Discussions Happen? (Adults)

1. Too sick to tolerate dialysis or requiring CRRT.
2. ESRD with ongoing functional decline, complications despite RRT
3. Would you be surprised if this patient died in the next year?
4. Concerns that burdens > benefits of treatment

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J Palliat Med. 2010;13(7):837.; Am J Kidney Dis. 2017; 70(1):93-101.

When Should GOC Discussions Happen? (Peds)

- Renal Physicians Association (RPA) Clinical Practice Guidelines endorses "development of a palliative care plan" for all children with:
  - **ESKD, from time of diagnosis**
  - **Children with AKI who forgo dialysis**
  - **ESKD who "suffer from burdens of their disease"**

- Kidney Disease Improving Global Outcomes (KDIGO) Controversies Conference, called for "kidney supportive care" for:
  - **All patients with advanced CKD**

Renal Physicians Association 2010; Kideny Disease Improving Global Outcomes 2013

When Should GOC Discussions Happen? (Peds)

1. Premature babies and newborns unlikely to survive to transplant
2. Ineligible for transplant due to immunodeficiency
3. Concerns that burdens > benefits of treatment
4. Initiation of renal replacement therapy

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Acta Pediatrica. 2017:107:403-407; Kidney 360. 2021:2:1063-1071

A Framework and Approach for GOC Discussions

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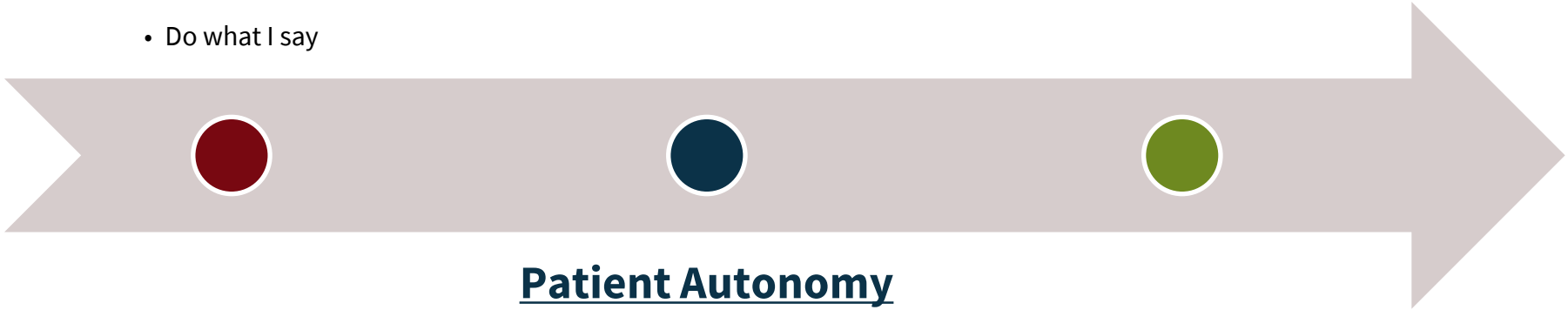
The Philosophy of Decision Making has Changed

Paternalism

- Do what I say



Patient Autonomy

Traditional ACP

- Complete ADs
- Decide *everything* ahead of time
- Many hypotheticals

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Maternalism

Modern ACP

- Goals/Values
- Preparing for future decisions

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“The Tree of Life”

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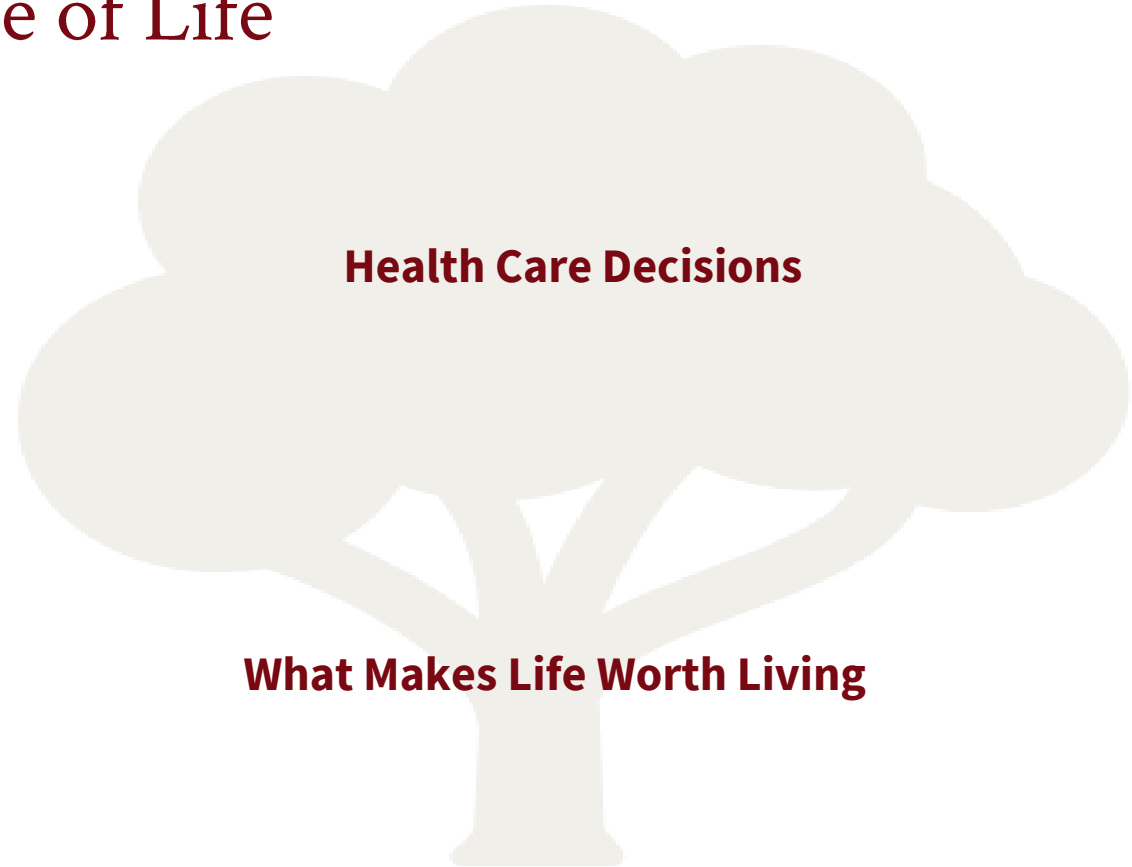
“The Tree of Life”



Health Care Decisions

What Makes Life Worth Living

Health Status

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Language You Can Use & Pro Tips

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Structuring the GOC Conversation

- **Serious Illness Conversation Guide**
  - Developed at Harvard/Dana Farber/Brigham & Women's Hospital
  - Collaboration between Atul Gawande, Susan Block, & Rachelle Bernacki

ARIADNE LABS

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https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/

Structuring the GOC Conversation

- Integrate a Pediatric Perspective
- Mack & Wolfe (2006) *Current Opinion in Pediatrics* 18:10-14.
- Provides **pediatric-specific language** to start goals of care discussions

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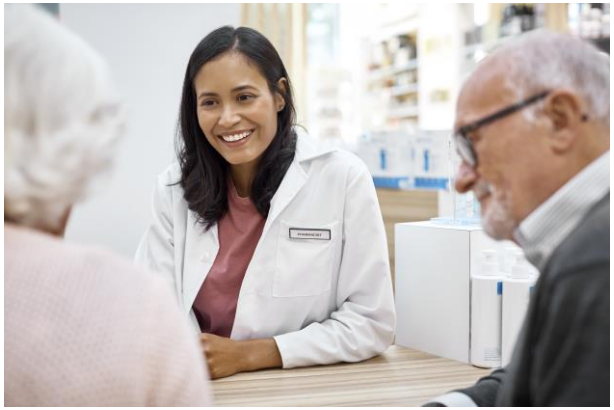
Curr opin Pediatr. 2006:18:10-14

Set Up The Conversation



- Introduce all team members and family members present
- Introduce the purpose
- Prepare for future decisions
- Ask permission

- *“I’d like to talk about what is ahead with your (child’s) illness and do some thinking about what is important to you so that I can make sure we provide you with the care you want – is that OK?”*

Assess Understanding & Information Preferences

- *"What is your understanding of what is ahead for your child?"*
- *"What have you heard from us (or the doctors) about where things are with your child's illness?"*

Assess Understanding & Information Preferences

- *"What is your understanding of what is ahead for your child?"*
- *"What have you heard from us (or the doctors) about where things are with your child's illness?"*

- *"How much information about what is likely to be ahead with your child's illness would you like from me?"*
- *"As you think about what is ahead for your child, what would you like to talk about with me? What information can I give you that would be helpful to you?"*
  - *"Some people tell me they want all the details, others want just the big picture, and some people prefer we speak to their family about this and not directly to them."*

https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/

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Share Prognosis

- *"I want to share with you my understanding of where things are with your illness…"*
  - ***Uncertain**: "It can be difficult to predict what will happen with your (child's) illness. I hope you (your child) will continue to live well for a long time but I'm worried that you (your child) could get sick quickly, and I think it is important to prepare for that possibility."*
  - ***Time**: "I wish we were not in this situation, but I am worried that time may be as short as weeks to months"*
  - ***Function**: "I hope that this is not the case, but I'm worried that this may be as strong as you (your child) will feel, and things are likely to get more difficult."*

https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/

Share Prognosis

- *"I am hoping that we will be able to control the disease, but I am worried that this time we may not be successful."*

- *"Although we do not know for certain what will happen for your child, I do not expect that your child will live a long and healthy life, most children with this disease eventually die because of this disease."*

- *"I have been noticing that your child seems to be sick more and more often. I have been hoping that we would be able to make him or her better, but I am worried that his or her illness has become more difficult to control and that soon we will not be able to help him or her to get over these illnesses. If that is the case, he or she could die of his or her disease."*

Curr opin Pediatr. 2006:18:10-14

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Expect and Respond to Emotion

- Silence is OK.
- *"That may have been hard information to hear, how are you feeling about all of this?"*
- *"Was that information new or surprising to you?"*

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Explore Goals/Values/Priorities

- Goals
- Fears and Worries
- Critical Abilities
- Tradeoffs

Explore Goals/Values/Priorities

- *"Given this information, what are your (child's) most important goals? What are you **hoping** for?"*
- *"As you think about your child's illness, what are your **hopes**?*

Explore Goals/Values/Priorities

- *"Given this information, what are your (child's) most important goals? What are you **hoping** for?"*
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- ***"What else….?"***
- *"You mentioned that what is most important to you is that your child be cured of his or her disease. I am hoping for that too. But I would also like to know more about your hopes and goals for your child's care if the time comes when a cure is not possible."*

Explore Goals/Values/Priorities

- *"What are your biggest **fears** and **worries** about the future with your (child's) health?"*
- *"As you think about your child's illness, what are your **worries**?"*
- *"What gives you **strength** as you think about the future with your (child's) health?*
- *What **abilities** are so critical to your (child's) life that you can't imaging living without them?*
- *"If you (your child) become(s) sicker, how much are you **willing to go through** for the possibility of more time?*

Close the Conversation

- Summarize
- Make a recommendation
- Check-in with patient
- Affirm commitment

- *“I’ve heard you say that being home with your family and being comfortable is important to you. Keeping that in mind, I recommend we talk more about how hospice might be able to help meet that goal.”*
- *“How does this plan seem to you?”*
- *“I will do everything I can to help you through this”*

Bring It All Together

Step	Phrasing
Set up	“I’d like to talk about what is ahead with your illness so that I can make sure we provide you with the care you want. Is that OK?”
Assess Understanding	“What have you heard from us about where things are with your illness?”
Information Preferences	“How much information about what is likely to be ahead with your illness would you like from me?”
Share Prognosis	“I wish we were not in this situation, but I am worried that time may be as short as weeks to months”
Assess Goals/Values	“Given this information, what are your most important goals?”
Summary and Recommendations	“I’ve heard you say ….. Keeping that in mind, I recommend …..to help meet that goal. How does that sound to you?”

Pro Tips for Effective Family Meetings

- What are you hoping for from the meeting?
- Is now the right time for a meeting?

Pro Tips for Effective Family Meetings

- How does the family make decisions?
- Who is the surrogate decision maker?
- Do we need an interpreter?
- Are the “right” members of the primary and consultant teams available?

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Pro Tips for Effective Family Meetings

- Don’t confuse “what the care should be” with “where or how the care should be delivered”
- Remember that code status reflects a decision about a very-limited range of treatments
- There is never “nothing more we can do” or ‘they could do nothing for the patient any longer”

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Pro Tips for Self-Care

- Your goals/values may not align with the patient's goals/values
- Some people need to go through difficult things to make difficult decisions
- Our perspective is only 1 part of how patients and families make decisions

Approaching GOC as a Consultant

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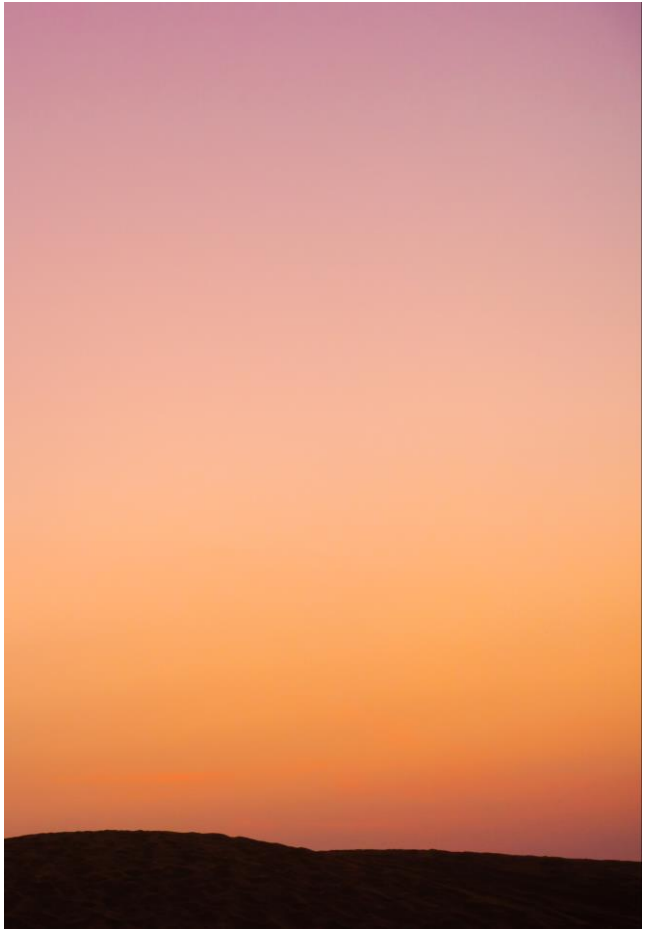
Nudging to Address "Big Picture"

- If ***you*** are worried, ***they*** are probably worried, even if they don't know how to express it.

- Ask questions:
  - *"How do you think it's going with this patient?"*
  - *"What do you think is this child's prognosis?"*

- Express your worry:
  - *"I am worried that things aren't looking good for this child"*



Invite in Team Members

- *"I wonder if having palliative care involved could be helpful, even if for a longitudinal connection."*
- *"Have social work, spiritual care, or child life been involved?"*

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“The goal is to add ***life*** to the child’s years, not simply years to the child’s life”

-American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care

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Thank you

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