From Goals of Care to Resuscitation:

Helping Families with Difficult Decisions

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Objectives

- Review the medical evidence supporting the potential benefits of GOC and ACP discussions in pediatrics

- Explore real and perceived challenges of having these discussions with our patients/families

- Provide practical suggestions to overcome these challenges and facilitate these crucial discussions

Think of 3 personal goals or dreams…

GOALS

Short-term
- wake up at 6am
- run a 5K
- read 1 book each month
- eat 1 veggie each meal
- do a handstand
- complete 30 day yoga challenge
- do 20 push-ups daily
- ten

Long-
- Run a n
- fit into
- lose
- fin
- h

What we know…

- Priorities change when end-of-life is near
  - On avg, parents appreciate the terminal nature of their child's cancer 3 months after the MD[1]

- Most of our patients do not die in the way that we would want our own deaths to look like
  - The majority die in the hospital, in the PICU[2]

- Many parents have regrets about their child's end-of-life care[3,4]

1. Wolfe J et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA*. 2000 Nov 15;284(19):2469-75.
2. Meert K et al. End-of-Life Practices Among Tertiary Care PICUs in the United States: A Multicenter Study. *Pediatr Crit Care Med*. 2015 Sep;16(7):e231-8.
3. Hechler T et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klin Padiatr*. 2008 May-Jun;220(3):166-74.
4. Butler et al. Experience and PICU Death: A Meta-Synthesis. *Pediatrics*. 2015 Oct;136(4):e961-73.

Why does this matter?

- Wolfe et al. *JAMA*. 2000
  - On average, parents understanding of terminal nature of cancer lagged behind MD's by 3 months
  - When parent and MD recognition came earlier…
    - ➢ Palliative care was more likely to be introduced
    - ➢ Parents were more satisfied with home care at EOL
    - ➢ Child less likely to receive cancer-directed therapy in last month of life
    - ➢ Goals of care more likely to be directed at minimizing suffering

Why is it hard to talk about these things?

- We worry about...
  - Upsetting the family
  - Raising an issue that had never been considered
  - Destroying hope
  - Fracturing our relationship
  - Looking like we're giving up
  - Disrespecting cultural/religious/spiritual beliefs
  - Failing - what if they still want CPR?!!

Another reason we struggle…?

Are expectations realistic?

- 2/3 of patients receiving CPR on television survive to hospital discharge

- What’s the reality?

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What percentage of children who receive CPR survive to be discharged from hospital?

ⓘ Start presenting to display the poll results on this slide.

Are expectations realistic?

- 2/3 of patients receiving CPR on television survive to hospital discharge

- What's the reality?
  - 25% of pediatric patients survive to discharge[1]
  - If arrest in the PICU – 45% survive to d/c;
    89% with "favourable neurologic outcomes"[2]
  - If arrest in the community – 11.3% survive to d/c;
    9.1% neurologically favourable outcome[3]

1. Topjian AA et al. Cardiopulmonary resuscitation in children. *Curr Opin Crit Care*. Jun 2009;15(3):203-208.
2. Berg RA et al. Incidence and Outcomes of Cardiopulmonary Resuscitation in PICUs. *Crit Care Med*. 2016 Apr;44(4):798-808.
3. Naim MY et al. Association of Bystander Cardiopulmonary Resuscitation With Overall and Neurologically Favorable Survival After Pediatric Out-of-Hospital Cardiac Arrest in the United States: A Report From the Cardiac Arrest Registry to Enhance Survival Surveillance Registry. JAMA Pediatr. 2017 Feb 1;171(2):133-141.

Overcoming our fears

1) “It’s not you...it’s me”
    - The anxiety is ours; therefore, it is something we <u>can</u> control

2) All parents of children with serious illness have thought about death

Overcoming our fears

3) Pediatric patients[1], parents[2] and even siblings[3] value the opportunity to openly discuss fears and wishes about death

1. Beale EA, Baile WF, Aaron J. Silence is not golden: communicating with children dying from cancer. *J. Clin. Oncol. May 20 2005;23(15):3629-3631.*
2. Wharton, R.H., et al., Advance care planning for children with special health care needs: a survey of parental attitudes. *Pediatrics*, 1996. 97(5): p. 682-7.
3. Stallard P, Mastroyannopoulou K, Lewis M, Lenton S. The Siblings of Children with Life-threatening Conditions. *Child and Adolescent Mental Health. 1997;2(1):26-33.*

Overcoming our fears

4) Rather than lose hope, some families may gain hope from these discussions

Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J. Clin. Oncol. Dec 10 2007;25(35):5636-5642..*

Overcoming our fears

5) They’re not upset with you; they’re upset with the situation...and that’s ok

Parental preferences for prognostic information….

- Survey of 194 parents at DFCI during treatment
  - 87% desired as much prognostic info as possible
  - 36% found prognosis “extremely” or “very upsetting”
    - ➢ Just as likely to say prognostic info was important and helped with decision-making
    - ➢ Most wanted more information (only 1 wanted less)
    - ➢ More likely to be upset if poor prognosis was not previously discussed

Mack JW et al. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol*. 2006;24(33):5265-70.

Before we go any further, let’s get a few things straight…

‘Goals of Care’ & ‘Advance Care Planning’

Goals of care

- Helping the child/family examine what’s most important to them in the context of the current situation
- Should occur over the continuum, from diagnosis through death

Advance Care Planning

- Extension of usual discussions about treatment plan
- Focuses on short-term and long-term goals
- May include advanced directives - what should or should not be provided under specific circumstances

CPS Bioethics Committee. Advance care planning for paediatric patients. *Paediatrics & Child Health. 2008;13(9):791-796.*

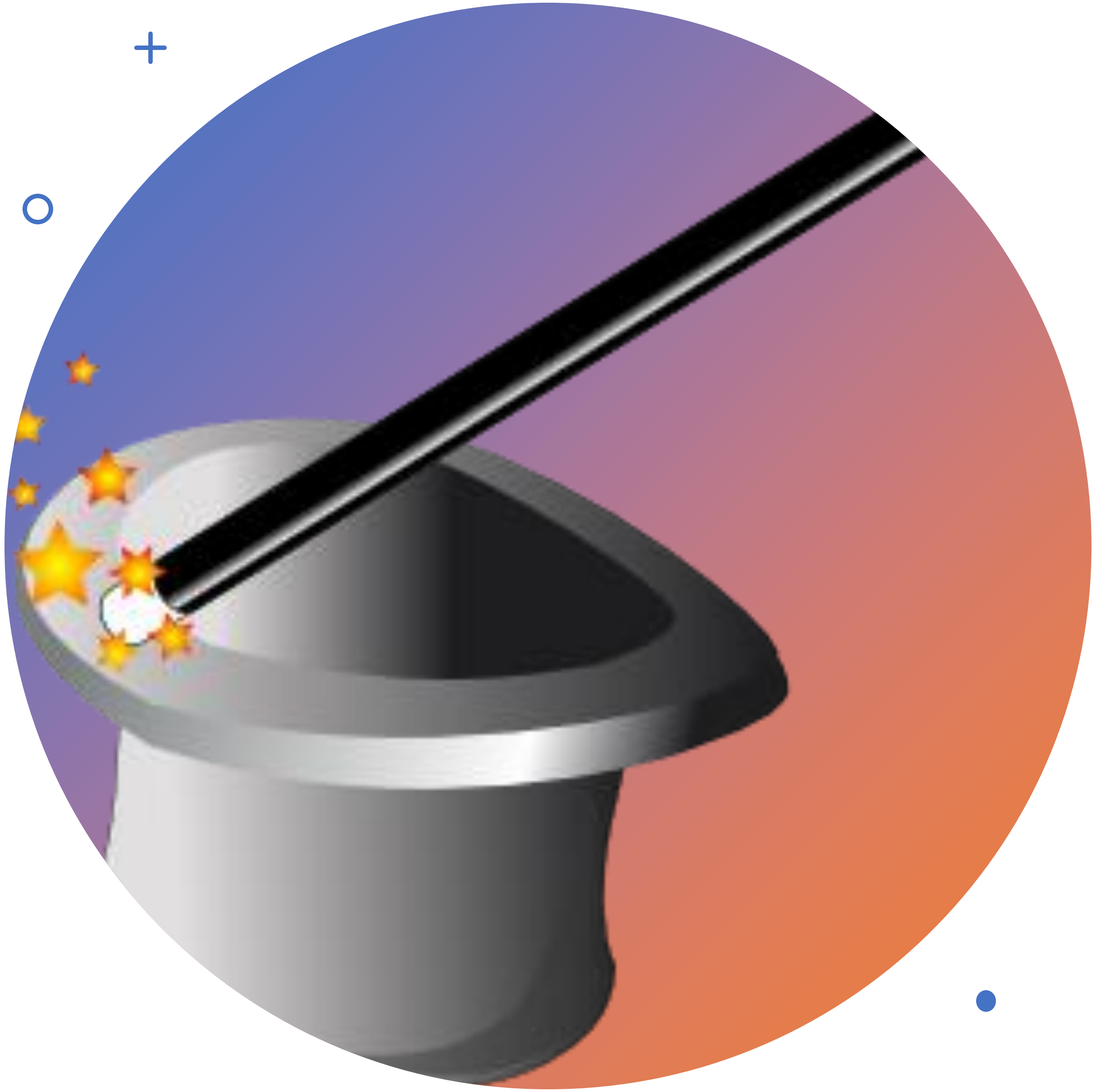
GOC vs ACP

Goals of Care

- Guide treatment in the present
- Based on current situation
- Essential; clarity needed to guide current care

Advance Care Plans

- Guide treatment in the future
- Based on hypothetical state
- Not essential; some prefer to "*cross that bridge when we get there*"



ACP
Tricks of the Trade

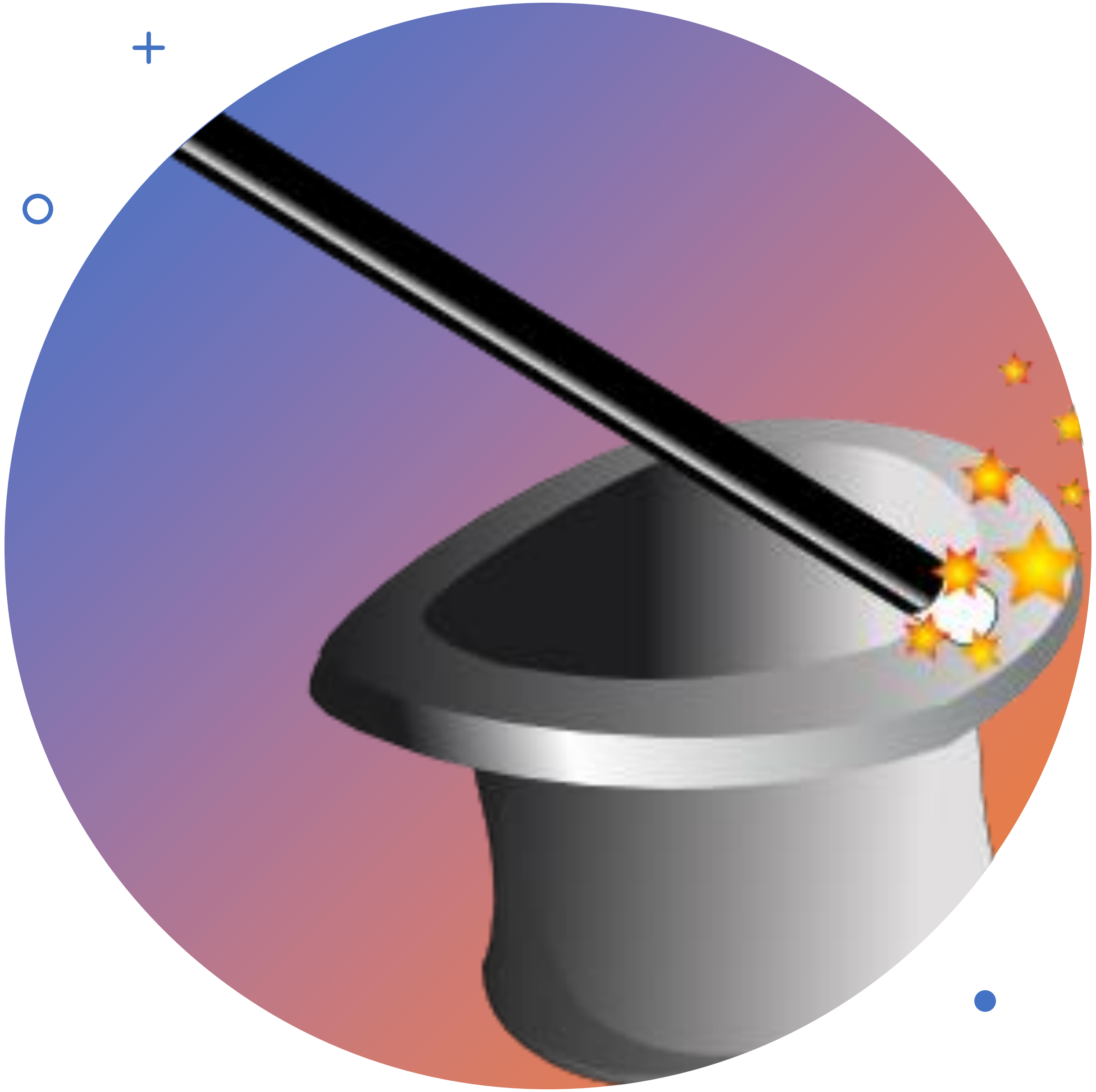
Use uncertainty to your advantage

It's <u>because</u> we are uncertain that we need to consider these things

ACP
Tricks of the Trade

ACP is typically a process, not a single discussion

Most useful when families consider wishes outside of a crisis, when they have time to think



Pace & timing of ACP

- ACP is about helping patients/families think about their preferences as things change

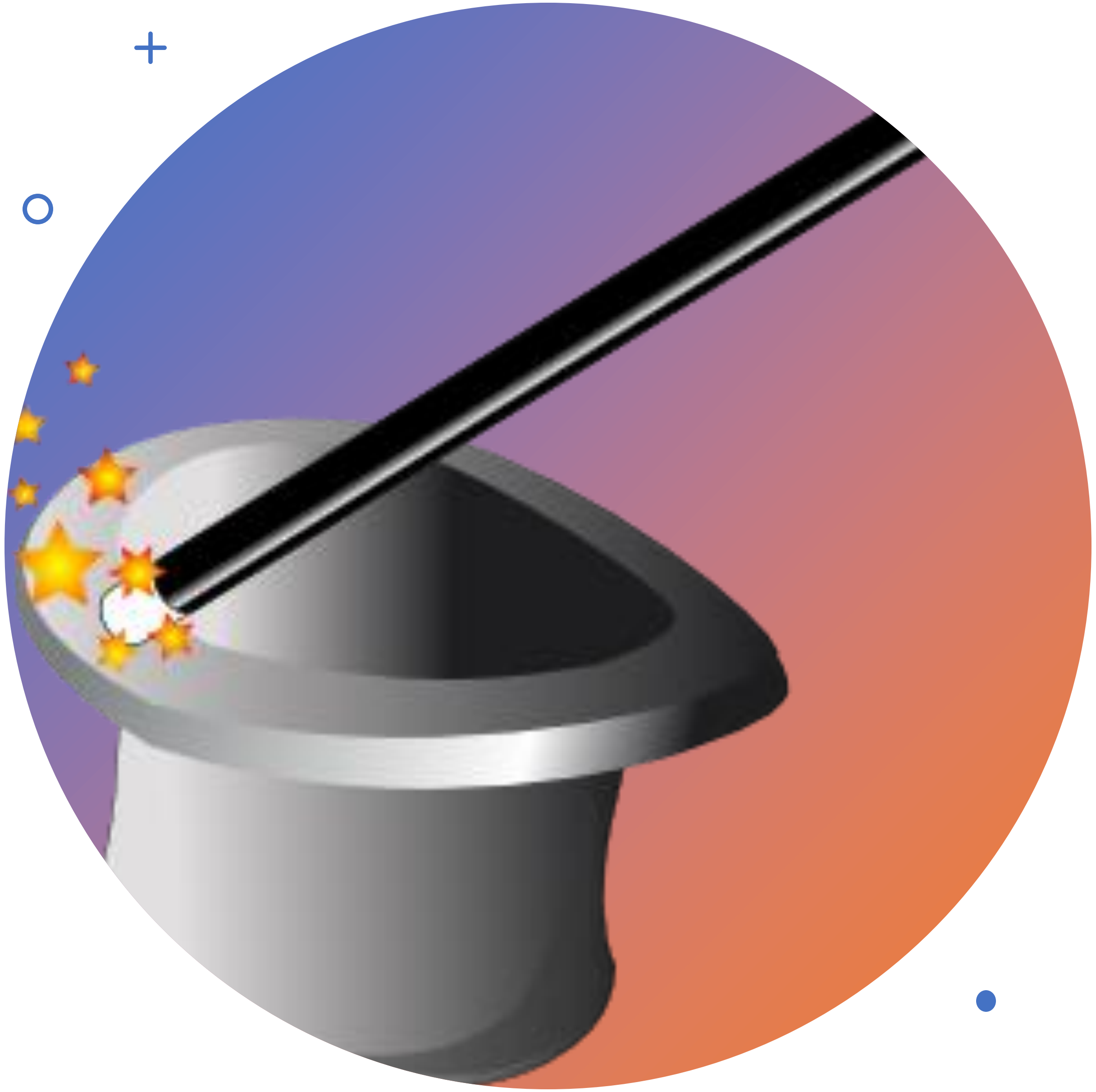
- Generally involves 2 steps
  1. HCP conveys the (possible) landscape up ahead so that families know what to consider
  2. Families reflect on what would be most important to them in the event of…

Pace & timing of ACP

- Ideally ACP should be done regularly, over time
  - Allows thinking about difficult situations from a safe distance
  - Lived experiences influence thinking more than anything
  - Normalizes ACP, thereby avoiding "the talk"

- Relationship between clinician and family is much more important than the pace of ACP

Orkin J et al. Toward an Understanding of Advance Care Planning in Children With Medical Complexity. *Pediatrics*. 2020 Mar;145(3):e20192241.



ACP Tricks of the Trade

Decision-making during ACP is facilitated by establishing **“goals of care”** using a shared-decision making model

Stella's Signature Desserts

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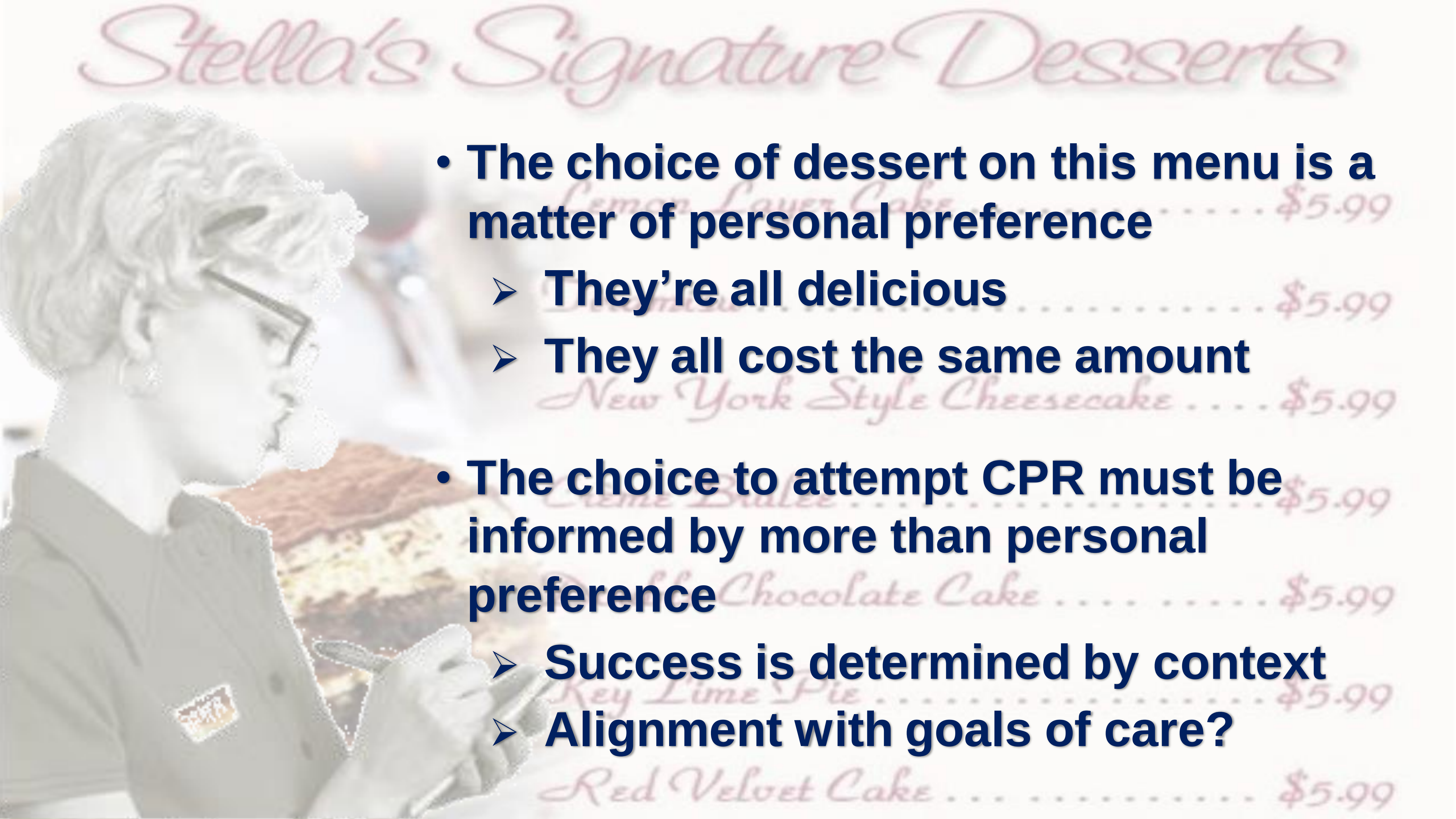


- **The choice of dessert on this menu is a matter of personal preference**
  - **They're all delicious**
  - **They all cost the same amount**

- **The choice to attempt CPR must be informed by more than personal preference**
  - **Success is determined by context**
  - **Alignment with goals of care?**

Shared-decision making

Expertise & Knowledge

Goals & Values

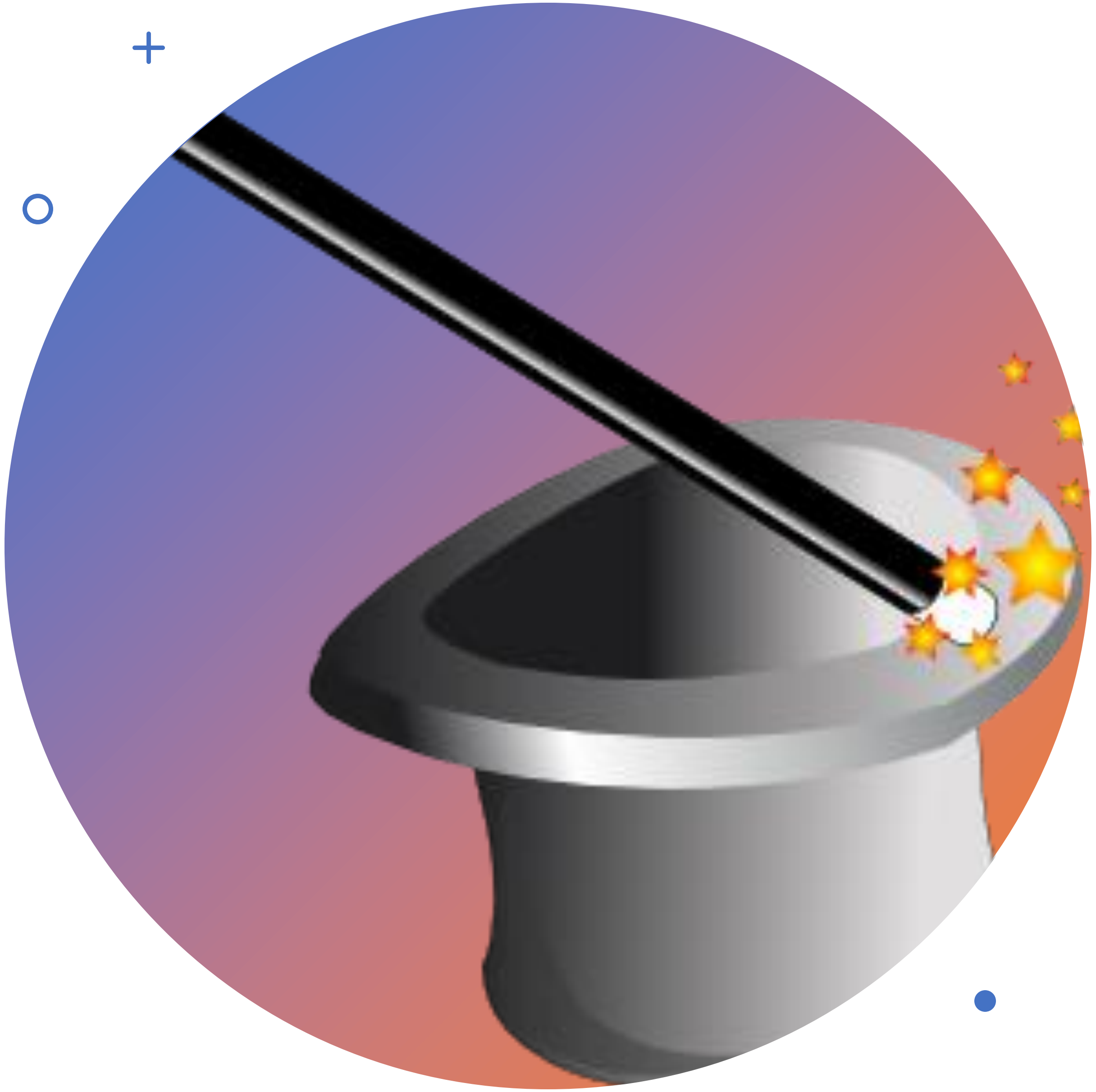
"Medical" Best Interests

Bear the Burden

It's My Body

ACP
Tricks of the Trade

Always start by inquiring about the perceived health status and QOL of the child



“Tell me, where are things are at right now?”

- We are very worried
- It feels like we’ve tried everything, but nothing seems to be helping
- If this last treatment doesn’t work…well there doesn’t seem to be any other options
- He’s always suffering

- Things are good
- This is a minor setback; the team always finds something new to offer
- All we have to do is fix problem “X”; thankfully “X” isn’t related to the underlying disease
- He’s usually happy and active

Understanding of prognosis

- When there is an accurate appreciation of the situation, decisions are more likely to be…
  - Realistic
  - Achievable (likelihood of achieving at least understood)

- Gaps in understanding should be filled by an expert, or at least someone who is trusted
  - Often, this is <u>not</u> a palliative care clinician
  - When I discover a ‘gap’, I let the primary team know

Where to begin?

- Useful phrases to start GOC or ACP discussions
  - “Given the situation, what matters most to you?”
  - “What are you hoping for?”
  - “Looking ahead, what worries you?”

- Then listen and wait...
  - “We’re hoping for a miracle – that this will just disappear”
  - “She hates being in the hospital, so that’s something that we really want to avoid”
  - “We want to be sure he’s not suffering; that pain isn’t a problem”

It’s our job to make recommendations

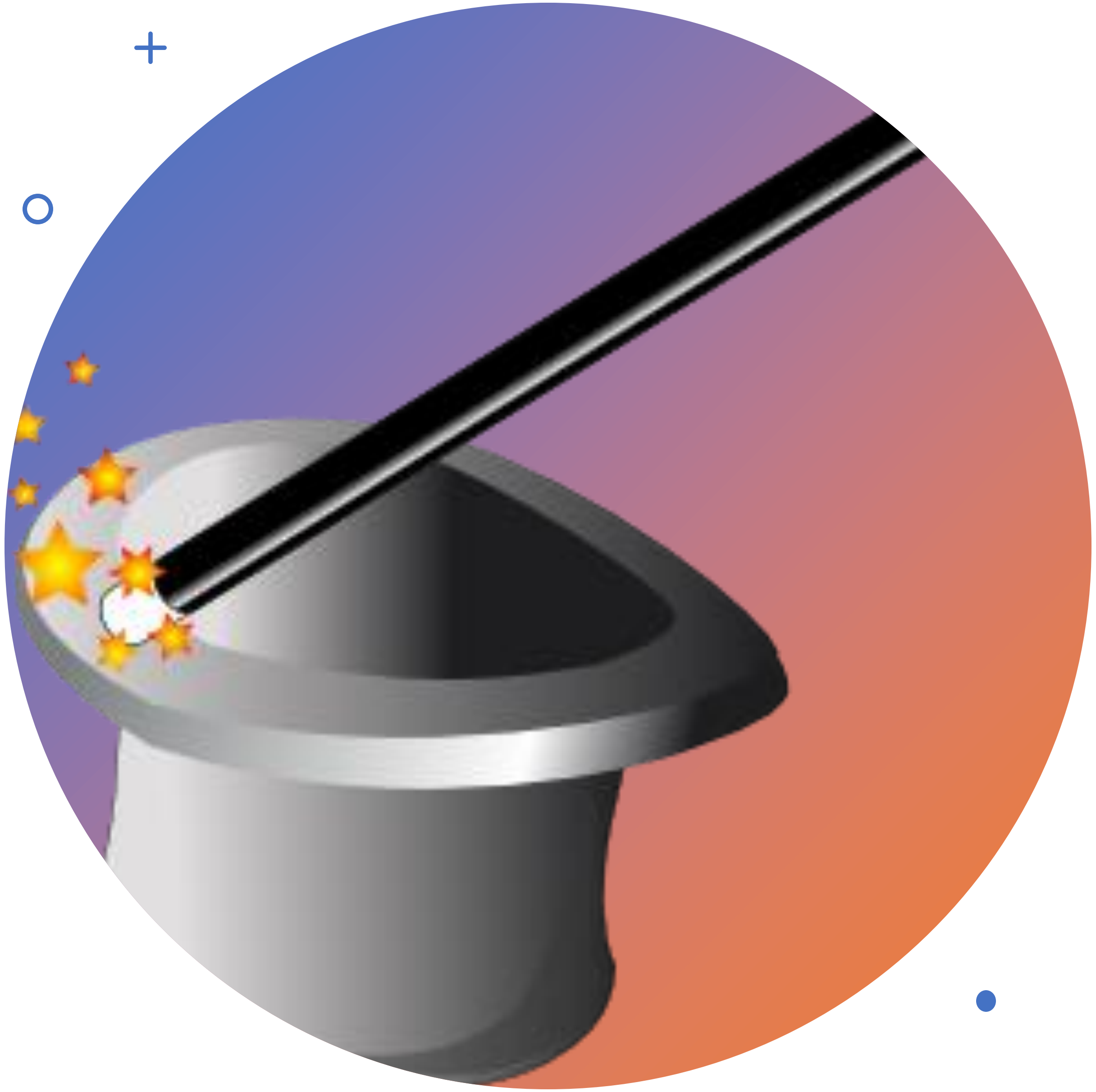
- Even those who accept death and are focused on comfort may struggle with a DNR order

- No parent should have to decide to ‘*pull the plug*’
    - To some, it feels like an active role in their child’s death by forgoing a life-sustaining treatment

Recommendations should align with goals

- Statements that may be aligned with “No CPR”
  - “I just want my child to be comfortable”
  - “No more suffering”
  - “I want to be at home; no more hospitalizations”
  - “We’re focused on quality of life”
    (need to explore what defines a good QOL)

- Statements that suggest “Full Code” is appropriate
  - “I need to know I’ve tried everything”



ACP
Tricks of the Trade

If you don’t go in with the goal to “get the DNR”, you won’t fail

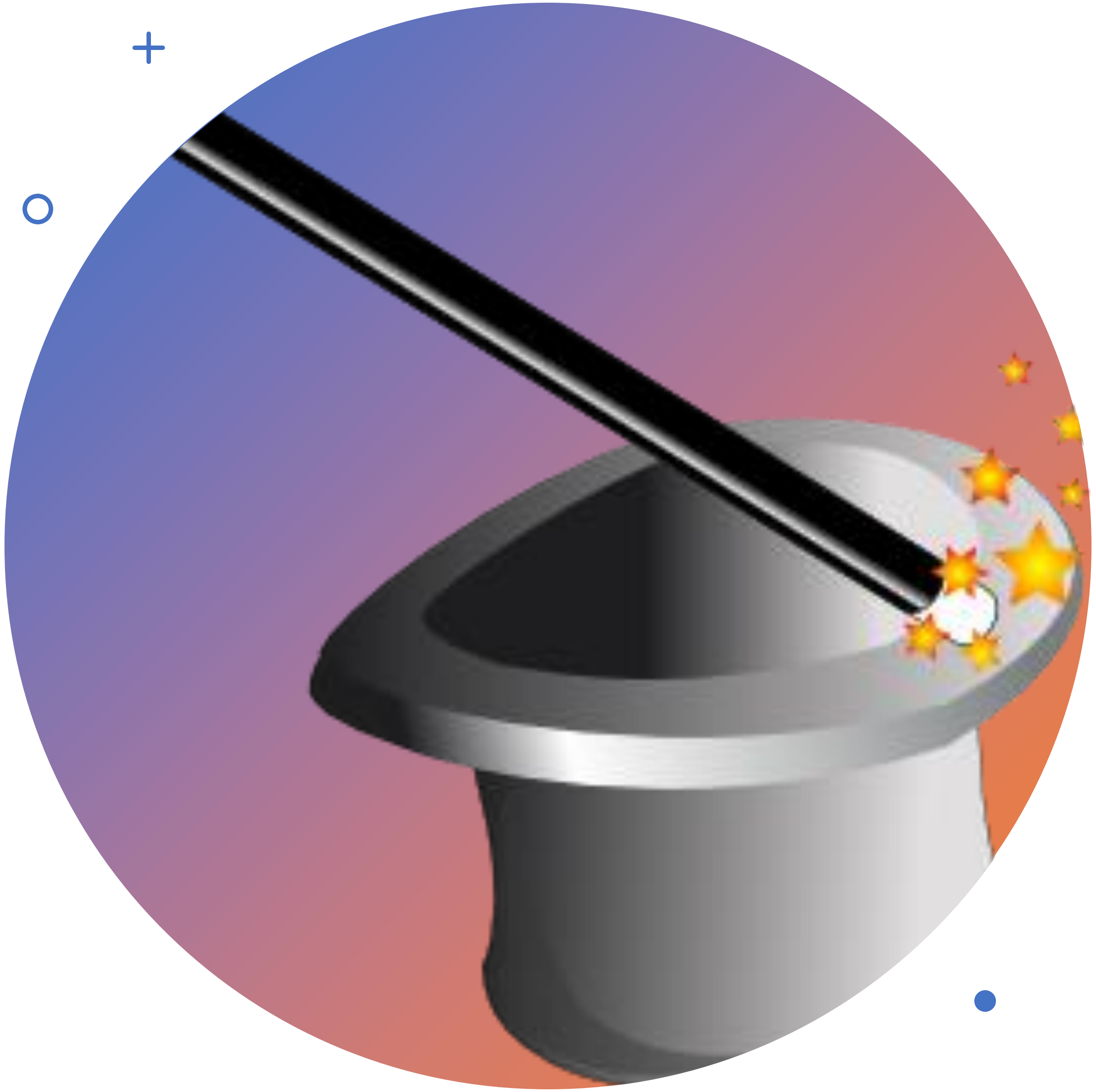
What about the family that insists on CPR?

- Remember, the goal is not to “get the DNR”

- When CPR does not appear to align with the goals of care, point it out to the family…
  - “Can you help me to understand your decision…?”

- Alternatively, ask what they are hoping CPR will accomplish

ACP
Tricks of the Trade



When counselling about the option of ‘no CPR’, focus on what WILL be actively provided, rather than what will not.

DNR = Do Nothing, Right?

- WRONG!!!

- Many parents think that when a patient has a “No CPR” we just stand around
  - Routine care will continue
  - We will be as aggressive as necessary to ensure your child’s comfort
  - We will not abandon you – there is always more that we can do

Things to remember

- Advance care planning is a process that should occur over time
- Always frame the discussion in relation to the goals of care
- Clarify misconceptions and focus on what WILL be provided
- Participate in the decision – you have something to add!

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What is your key takeaway from today's session?

ⓘ Start presenting to display the poll results on this slide.