

Referral Script

As you work with families whose child faces a serious illness, you often try to elicit the issues that most occupy them. Use the concern or the difficulty identified by the family as your entrée for a possible referral to CPN. Those concerns might include worry about the siblings, the parent partnership, the upcoming medical decisions, or they might be reflections on the state of anticipatory grief or of not wanting to look too far into the future.

Listen for "I'm worried about, I wonder about, What if..."

1> Identify, name and confirm the issue

Look/Listen for the "place" where you can meet them, and start there. Meet them where they are.

"As I listen, I can hear that you are worried about (your other children, your parent partnership, making the right choices, etc...). Is that right?"

OR

"It sounds like you are feeling a great sense of loss with this new diagnosis and what it means for your child and your family. Is that right?"

2> Assess Readiness/Explore whether hearing about other families' experiences would be helpful

"I have heard very similar struggles from other families whose child has a serious medical problem. Parents have taught us that it can be helpful to hear how other families have thought about this."

3> Introduce CPN generally.

You might say:

"One of the ways I have learned about other family experiences is from listening to family stories on a website that was created by a parent for other parents whose child has a serious medical condition. It's called Courageous Parents Network. There is a blog attached to it, but at its core it is a library of video interviews, mostly with parents but also with a few providers as well. I can't really know what it's like for you. But these parents may. They've been there.

It's by parents like you, for parents. And there's a little professional guidance thrown in."

"Many of the medical specifics don't apply to you or your child, maybe none of the families are in the same exact situation as you, but parents tell us that they still find it helpful to hear how others have thought about things."

"You are in control: You can poke around at your own pace, in your own time, in your own safe, private place. You don't have to listen to anybody you don't like--just click it off. And you don't have to talk to anybody."

4< Introduce CPN specifically (based on a theme you have identified)

"There is a short handout on helping siblings cope—let me show you where that is and print that out for you."

"A number of CPN families talk about how differently each parent copes with the situation. It's challenging to give each other the space and understanding to do and feel things differently. Let me show you several clips where parents talk about this."

"There is a good interview with a grief counselor who talks about anticipatory grief, and the many losses that families face from the time of diagnosis onward—let me show you where to find that. Let's watch together."

It can be helpful to also show/provide parents:

- Written guides from the website for example:
 - <u>Understanding Anticipatory Grief</u>

https://courageousparentsnetwork.org/guides/coping-with-anticipatory-grief/

- <u>Navigating the Hospital</u> -<u>https://courageousparentsnetwork.org/guides/navigating-the-hospital/</u>
- <u>Helping Siblings Cope</u> https://courageousparentsnetwork.org/guides/helping-siblings-cope/
- The **family referral card** for reference (hard copy only)
- Video: <u>A mother's testimonial of how CPN helped</u>

https://courageousparentsnetwork.org/videos/a-mothers-testimonial-howcourageous-parents-network-helped-a-family-do-the-unimaginable/

• <u>Provider videos</u> such as grief counselor talking about Anticipatory Grief, chaplain and parent talking about navigating the hospital, nurse and mom talking about palliative care, doctor and parents talking about feeding tubes

https://courageousparentsnetwork.org/video-library/provider/

www.courageousparentsnetwork.org