

# The Pediatrician's Role in Serious Illness



## LEARNING OBJECTIVES

After reviewing this Guide you will be able to:

- Recognize the value that families place on the pediatrician's role in caring for very sick children
- Formulate a personal approach to your role in caring for the child, and acting as a resource for the family and extended care team



## INTRODUCTION

### This is Where Good Care Begins

The first relationship most parents have with child-related medicine is with a pediatric primary care provider, typically a pediatrician (or family practitioner). The pediatric provider usually follows the child through to adulthood, generally age 18. They are the provider delivering routine wellness care, and diagnosis and treatment of typical childhood illnesses and conditions.

Pediatricians come to know the family in a particular way. In addition to providing clinical care, they offer parents reassurance and comfort. Their understanding of personalities and other dynamics plays a vital role in helping the family members feel confident and secure in their ability to raise a child who thrives physically and emotionally. If there are other children—siblings—the pediatrician also cares for those children, and thus has perspective and some care responsibility for the larger family.

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## WHEN A CHILD IS SERIOUSLY ILL

A serious illness brings complexity to this very important relationship. Subspecialists become critical members of the child's care team and are, at times, the clinicians best prepared to address complicated medical issues. The pediatrician can complement treatment, providing support for the family in considering and identifying their goals of care. These goals become the foundation for making decisions about treatments and interventions.

## THE FAMILY PERSPECTIVE

The pediatrician's engagement has a significant impact on the family's lived experience. Parents in the CPN network report that if the pediatrician is disengaged, the family perceives abandonment or abdication of responsibility. They report that involvement, or lack of involvement, leaves a lasting impression that affects the provider-family relationship. In fact, that impression may extend to how the family regards the pediatrician's care for other children in the family.

You can make clear that you are a resource as you:

- **Find ways to stay in touch with the family.** If they are overwhelmed with hospital and specialist appointments, suggest telephone or virtual check-ins or a home visit.
- **Connect with the family's palliative care team.** Make certain that they have your contact information and be available to answer any questions that they may have. If you can make yourself available and the parents and care team are agreeable, attend a family in person or virtually.
- **Engage with other siblings you care for.** Ask about their experience and offer your support.

## RESOURCES FOR THE PEDIATRIC PRACTITIONER

### *From Courageous Parents Network*

#### **Video**

##### **It Seems to be a Terrible Waste if the Primary Care Doctors are Not Part of the Process**

<https://courageousparentsnetwork.org/videos/it-seems-to-be-a-terrible-waste-if-the-primary-care-doctors-are-not-part-of-the-process/>

##### **The Pediatrician and Shared Decision-Making: It was a True Collaboration**

<https://courageousparentsnetwork.org/videos/it-was-a-true-collaboration>

##### **Our Primary Care Pediatrician was Our Most Important Doctor**

<https://courageousparentsnetwork.org/videos/our-primary-care-pediatrician-was-our-biggest-support>

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## **Our Pediatrician was the Key that Held Everything Together for Us**

<https://courageousparentsnetwork.org/videos/our-pediatrician-was-the-key-that-held-everything-together-for-us>

### **“We Should Talk”**

Presentation at MassGeneral Hospital for Children’s 2018 Primary Care Pediatrics conference by Dr. Pat O’Malley, MassGeneral Hospital for Children and Courageous Parents Network Executive Director Blyth Taylor Lord, on advance care planning and serious illness conversations in primary care pediatrics

<https://courageousparentsnetwork.org/videos/we-should-talk-advance-care-planning-in-primary-care-pediatrics>

## ● **Blog**

### **Is Your Pediatrician On Board?**

<https://courageousparentsnetwork.org/blog/is-your-pediatrician-on-board>

## *From the American Academy of Pediatrics*

### **“Cameron’s Arc: Creating a Full Life”**

Five short video clips exploring effective parent-professional communication across four critical points in the care of a seriously ill child. Includes a teaching and resource guide

<https://publications.aap.org/pediatriccare/book/343/Cameron-s-Arc-Creating-a-Full-Life>

### **“Talking about Serious Illness”**

Education in Quality Improvement for Pediatric Practice (EQIPP) course available to AAP members. Designed to foster or buttress pediatricians’ skills in initiating and having discussions that facilitate open, honest and compassionate care in the practice setting:

[https://eqipp.aap.org/File%20Library/Courses/Palliative%20Care/BarriersIdeasGrids\\_All.pdf](https://eqipp.aap.org/File%20Library/Courses/Palliative%20Care/BarriersIdeasGrids_All.pdf)

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## SUPPORTING THE TRANSITION FROM PEDIATRIC TO ADULT MEDICINE

New challenges emerge as a child with a serious illness or condition matures. Services available to the family may change based on chronological age, without regard for the adult-child's continued physical and psychosocial needs. The family-centered model of care will shift to one that is patient-centered; the parent's role shifts from decision-maker to guardian—if the parent chooses that role.

Pediatricians may have concerns about their ability to continue to care for the child, and the family may have their own questions and concerns. While the child's complex care team and social workers are likely to be the instigators of the transition process, frank and open conversation between the parents and pediatrician about this event, which has both practical and emotional aspects, should ideally begin when the child turns 14.

Courageous Parents Network [offers resources](#) to support the family and clinicians in planning for transition for the fully-dependent child.

## CONCLUSION



The primary care pediatrician can, and should, remain an involved member of the child's care team throughout a serious illness. The nature of their involvement will depend on the situation, but being available to the family and colleagues can make a considerable difference in how the journey proceeds—and is experienced.