

# Delivering the Diagnosis or Bad News



## Learning Objectives

**After reviewing this Guide you will be able to:**

- Recognize the extraordinary impact on families learning a diagnosis or other bad news
- Anticipate issues and challenges that families face upon receiving this news
- Support the family's process with respect for unique cultures, ways of understanding, spiritual well being, needs and wishes

## Hearing the News

Parents will tell you that they never forget the day they receive the diagnosis of their child's serious illness. It is as important as the day of their child's birth—and the day of death. They remember who was in the room and how the news was given. No matter the details of the disease or illness, it is a life-changing moment. Immediately they have questions about how this could have happened to their child, and they begin to worry about how they will tell others. How will they survive? What does it all mean for their child and family?

Families also begin to mourn the ways in which their child's future will be changed, even if they do not yet understand how it will be changed. It is important to respect whatever reaction there is, and offer a steadying presence for the family, as everything else they have relied on and believed in has been turned upside down. Observing this practice goes a long way in establishing trust and connection. It indicates, through actions not simply words, your willingness to be present and accompany a family with respect and compassion.

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## Establishing Connection and Trust

Whether your relationship with a patient and their family is a longstanding one or relatively new, as a clinician delivering bad news you may dread being confronted with reactions that feel overwhelming: shock, grief, anger, pain. As one CPN parent has said, for most families, “Any diagnosis is a loss.” We understand this to mean the loss of some degree of hope of a normal life for one’s child. While the family’s reaction is not something you can predict, you can start with an open, honest, nonjudgmental approach.

## Delivering the News

Delivering difficult news is one of the clinician’s most challenging tasks. It remains a significant stressor despite years of practice. The natural impulse may be to shield families from pain; however, most parents want and appreciate direct information, if it is given honestly and with sensitivity.

The first step might be to suggest a family meeting. Consider having at least one other team member attend the sharing of difficult news, and rely on their strength and experience as well as your own. Here are some phrases that may help in starting these conversations —at diagnosis or as time goes on, as the disease or condition progresses.

“I’d like to talk about how your child is doing and where things might be going. Would that be okay with you?”

“First I want to hear how you feel your child is doing. What is your understanding of this so far?”

“What questions do you have of us? What are your concerns?”

“What are your hopes at this time?”

“Would it be helpful if we talked more about what might lie ahead? May I share my hopes and worries?”

## Awareness of the Family Perspective

### Anticipatory Grief

While grief is commonly associated with death, diagnosis and every subsequent delivery of bad news will bring with it waves of grief, worry, guilt and questions. These thoughts and feelings can be normalized, and families report that it can make a helpful difference when they are offered a name for the emotional locus in which they find themselves: anticipatory grief. They appreciate knowing that grief is a natural response to loss—and that anticipatory grief is a response to losses that have not yet occurred.

## A New Culture

As the family members begin to experience and cope with anticipatory grief, they will find themselves plunged into an alien culture of medicine, dysregulated schedules, financial stresses, and the need to cover all the bases, many of them new and unfamiliar. The language, tempo, and culture of the medical and hospital “system” is very different, and families must quickly adapt to conditions they have never experienced before. Some quotes from family experiences as told to CPN staff:

“We received the diagnosis on a Friday afternoon. I was sent home with no plan to follow up. My entire world changed that day.”

“The doctor walked into the room, told us this devastating news. We had so many questions but there were no answers and no one to ask.”

“At diagnosis I felt weirdly relieved, I knew something was wrong for so long. Then reality sank in, we were trapped in the hospital facing surgery and a completely new life inside the hospital.”

“I found palliative care on my own and thought this is what we needed from the beginning.”

## Follow-up strategies

There are many ways to affirm your willingness to continue to accompany the family in this new world, or identify who will take on that role for them. Ensuring follow-up, so that the family does not feel so isolated and alone, is absolutely critical. Here are some ideas to use in your practice.

- Validate the overwhelming changes the family is facing
- Ask about what has helped the family in other difficult times
- Schedule timely follow-up appointments
- Introduce and describe the roles of the care team members, and establish best ways to contact the team members
- Recommend a palliative care consult



## Conclusion

Delivering and receiving bad news is a profound experience for the clinician and family. When the news is related with respect for what caregivers need and can internalize, trust becomes the foundation for a relationship in which everyone communicates openly, decision-making is shared, and families can navigate the illness journey with a greater sense of agency.

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## Resources for Clinicians



### Downloadable Guides

#### Understanding the Lived Family Experience

Central themes in caring for a seriously ill child.

<https://preprod.courageousparentsnetwork.org/guides/introduction-to-the-lived-family-experience>

#### Introducing Families to Pediatric Palliative Care

When and how to describe the value of PPC and recommend a consult.

<https://courageousparentsnetwork.org/guides/introducing-pediatric-palliative-care-to-families>

#### Introducing Families to Courageous Parents Network

A guide to assist clinicians in introducing CPN to families so that they might hear other family perspectives and feel less isolated.

<https://courageousparentsnetwork.org/guides/introducing-families-to-cpn>

#### Serious Illness Conversation Guide

Aligning family values with goals of care.

<https://api.courageousparentsnetwork.org/app/uploads/2021/05/Pedi-SeriousIllnessConvo-Guide.pdf>

## Resources for Families



### Handouts/Downloadable Guides

#### Anticipatory Grief

Explanation and validation for families experiencing the impact of their child's diagnosis and illness.

<https://api.courageousparentsnetwork.org/app/uploads/2017/10/2-Anticipatory-Grief.pdf>

#### Navigating the Hospital

Resource for understanding the medical “system,” a new and alien culture.

<https://api.courageousparentsnetwork.org/app/uploads/2016/03/CPN-Navigating-Hospitals.pdf>

#### Family Meeting: Being Prepared

Resources to help families prepare for clinical updates, considering decisions about interventions, check-ins on how they are coping, and/or addressing their and/or clinician questions.

<https://courageousparentsnetwork.org/guides/a-framework-for-the-difficult-decisions>

## Videos



### **“It’s really entering a whole new culture.**

Pediatric psychologist reflects on the impact of diagnosis, which catapults the family into a new world with language and systems to learn.

<https://courageousparentsnetwork.org/videos/its-really-entering-a-whole-new-culture/>



### **“Learning the Diagnosis: Shock, Denial, Grief”**

A selection of parents recount how they felt upon receiving a diagnosis.

<https://courageousparentsnetwork.org/videos/the-shock-of-learning-the-diagnosis/>



### **“I was drowning in grief but trying to avoid it.”**

Mother and father reflect on how their difficulties in absorbing and coping with their child’s diagnosis.

<https://courageousparentsnetwork.org/videos/i-was-drowning-in-grief-but-trying-to-avoid-it/>



### **“I’m like, I don’t need a bucket list right now.”**

Parents share their differences in focus—making memories, finding a cure—following diagnosis and prognosis.

<https://courageousparentsnetwork.org/videos/im-like-i-dont-need-a-bucket-list-right-now/>

## Blog

### **Connecting the Dots**

Palliative care pediatrician reflects on the power of asking, listening, and accompanying families as they “connect the dots” to see a more complete picture of what has occurred, and what they may face, along their child’s illness journey.

<https://courageousparentsnetwork.org/blog/connecting-the-dots>