

# Caring for Patients and Families in Challenging Circumstances: Preparing for and Engaging in Difficult Conversations

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## ABSTRACT

As clinicians we have the privilege of caring for patients and families who are living with an often unexpected illness or injury. While we have chosen our profession, those we care for are here due to their circumstances. We have undoubtedly experienced the successes and challenges inherent in this work and know that difficult conversations are an inevitable part of it.

In our effort to provide high-quality care, it is essential that we spend time in self-reflection and develop a practice of good self-care. Knowing who we are as caregivers, while also nourishing our mind, body, and spirit, will enable us to bring the best version of ourselves to work.

## JOINING TOGETHER WITH PATIENTS AND FAMILIES

Having been in the field of healthcare for many years—initially as a nurse and then as a clinical social worker in a pediatric cancer and blood disorders program—I am acutely aware of the difficul-

ties associated with providing care to patients and families as they face unexpected health crises. I know the courage, strength, and perseverance required. I also understand the privilege it is to walk with patients and families through experiences they rarely could have anticipated or imagined. As healthcare practitioners we have selected this challenge; we have studied and prepared for our vocation. We choose to come to work each day ready to deal with the numerous demands for our expertise, skill, and time. When meeting patients and families I often comment, “You are embarking on a journey that may be frightening and unfamiliar. It is likely something you didn’t plan on and you may feel ill equipped for the obstacles you will encounter along the way. In a sense, it is similar to being in a foreign country—the language is unfamiliar and the terrain seems confusing and strange. You are an unwilling guest and will be required to learn things at a time when you are not the best student. We are fluent in the language and can traverse this land with relative ease. As a healthcare team, it is our role to help you become well versed, to assist you in navigating the geography. We want to help you become as comfortable as possible in this setting.”

As professionals immersed in the field of healthcare, we must acknowledge that each day can have a life of its own. We may start it with a plan of what

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the hours will hold, only to find it take a different direction based on the needs of the patients who present themselves. We learn to be flexible, to adapt to our circumstances. At times we will do this well; at other times it can pose a significant challenge.

In order to provide exceptional care in our various roles, it is imperative for us to spend time in reflection and to develop the practice of good self-care. Contemplating on who we are as individuals—

### **CARING FOR OURSELVES AS WE CARE FOR OTHERS**

It is important we take time to care for ourselves as we simultaneously care for our patients and their families. As the saying goes, we need to put on our own oxygen mask before helping others with theirs, lest we become unable to breathe and therefore useless. We must understand what refreshes and nour-

## ***Patients and families have a right to honest and accurate information regarding their health.***

understanding the values and principles that inform our practice—will serve us well as we strive to meet patients and families where they are. Implementing self-care as part of our daily routine will enable us to refresh and rejuvenate our mind, body, and spirit. This, in turn, will allow us to bring the best version of ourselves to work, each and every day.

### **KNOWING OURSELVES AS WE CARE FOR OTHERS**

We do our best to provide exceptional care. We accept that it will require commitment and sacrifice. Do we take the time to reflect on this? Have we pondered the following?

1. Do we recognize our genuine intent to do well by our patients, while also understanding that myriad issues will surface that make this difficult?
2. Have we spent time contemplating what is meaningful to us in this work?
3. Do we understand the value we place on life? Do we pursue it with little or no thought for the burden or cost it may exact?
4. Are we able to acknowledge death as a reality and to accept that there are limits to what we can do to save or cure a patient?

It is essential to contemplate these and other related questions if we are to provide compassionate clinical care. Families have entrusted their loved one's life to us, believing our care will be comprehensive and stellar. We need to be confident that we have given to the best of our expertise and ability, regardless of the outcome.

ishes our being and build it into our daily routine, to the extent possible. If we become depleted, we will have little, if anything, to share. We must be intentional in our efforts to replenish and rejuvenate. It is time well spent, a gift to ourselves and to the patients and families we serve.

### **ESTABLISHING RELATIONSHIPS IN DIFFICULT SITUATIONS**

We all know the desire to protect those we care for from harm and to promote an optimal experience for ongoing growth and development. At the same time we must recognize our human limitations. While we may not be able to prevent an illness or injury, there are important things we can do once it has occurred. We can provide honest information and offer medical recommendations based on our knowledge and expertise. We can offer care and compassion in a comprehensive, professional manner.

Patients and families have a right to honest and accurate information regarding their health. As healthcare providers we develop relationships based on trust and mutual respect. We engage in an agreement to provide safe and high-quality care and expect people to participate in ongoing decision making regarding it. We recognize our responsibility as medical experts to inform, guide, and direct, while also understanding the virtue of patient/family self-determination and autonomy. When we provide information, we know we must do so in a way that is clear and comprehensible to our audience. We need to be cognizant of any bias. This can be particularly difficult when a decision is made that differs from what we believe is in the other person's best inter-

est. We need to accept that while we think we may know what we would do if faced with similar circumstances, we can never really be sure. If we are truly offering an option for care, we need to be prepared to accept and support a decision that has been carefully made, regardless of potential disagreement.

### **UNDERSTANDING AND WORKING WITH CHALLENGING DYNAMICS**

At times in our interactions with patients and families we may encounter behaviors and psychosocial dynamics that are a challenge to manage. Patients and families are often in intense, emotionally laden situations, and their responses may reflect such strain. Although it is difficult, it is imperative that we separate the circumstances from the person, recognizing that we are meeting people at their most vulnerable. They are working through private matters in a public setting that allows them limited control. They look to us for our professionalism and compassion, not judgment or blame.

When I interact with families who are in the midst of struggle and uncertainty, I find myself wondering:

1. If I were in a similar situation, what labels would be assigned to me in my floundering attempts to advocate for myself or others? Would staff see me as a strong champion or would they perceive me as adversarial?
2. How would I feel in a situation where I experienced little if any control? Would others allow me opportunities to make choices, irrelevant as they might seem, in order that I regain a sense of focus?
3. Would my dignity as a person be respected? Would people be willing to meet me where I was, or would they attempt to impose their own way on me?
4. Would others understand the difference made by consideration of these concerns? Would they recognize the positive impact of such thoughtful care?

### **ENGAGING IN DIFFICULT DISCUSSIONS**

When we engage in difficult conversations with patients and families, our intent is to present necessary information respectfully in a manner that doesn't overwhelm, intimidate, or patronize. There are strategies we can employ to promote a meaningful discussion. In preparing for a meeting with a patient and family, we can:

1. Identify the professionals who are integral to the

case and ensure there is agreement about the issues to be addressed.

2. Clarify whether information is being presented primarily to facilitate an informed decision that takes into account risks, benefits, and alternative options, or if a specific medical recommendation is being made.
3. Consider whether the patient and family will have time to pause, reflect, and get back to us in a specified time frame, or whether the circumstances necessitate a more immediate response.
4. Allow time for staff to process their emotions so they can engage in a respectful, nonjudgmental manner.
5. Ensure that healthcare providers are prepared to accept a decision that the patient and/or family determine to be in their best interest—regardless of our potential disagreement—if it is proposed as a viable option.

During a meeting we can:

1. Have a staff person identified to facilitate the discussion and take notes so the patient and family can focus, without worry about the need to retain information.
2. Begin with introductions and a shared agenda.
3. State your expectations and define a time frame for making decisions.
4. Have someone from the psycho-social team present to provide emotional support, and to articulate questions or concerns raised in previous conversations if the family is in agreement.
5. Ensure that the patient and family are acknowledged and heard. Let them know there will be ongoing conversation during the delivery of care.
6. Be mindful of your verbal and nonverbal communication, understanding that more may be conveyed through tone and inflection, gestures and mannerisms, than the actual words spoken.

Difficult conversations are inevitable, and it is essential that we be prepared to engage in them with competence, integrity, and compassion. As previously stated, we have each chosen to deliver care in the context of the healthcare setting. In doing so, we have invariably experienced the successes and challenges inherent in this work. It is my sincere hope that you take time for reflection and self-care. By doing this you become self-aware, which, in turn, will convey a sense of confidence to those who turn to you for your expertise. It will also ensure you are strong in body, mind, and spirit, and therefore in a position to be the best version of yourself, as you provide exceptional care.