PRINT-Pediatric oncologist promotes 'regret prevention' care approach

Justin Baker, MD, clutches a tiny koala bear as he talks about his approach to treating children facing a life-limiting or life-ending illness. The oncologist and palliative care specialist was a keynote speaker at a recent OSF Innovation showcase at the Jump Simulation & Education Center in Peoria, Illinois. Dr. Baker has also served as a consultant for palliative care at OSF HealthCare Children's Hospital of Illinois.

The koala reinforces his message: Quality of Life for All Kids or QoLA which means embedding palliative care early and into every aspect of caring for a very sick child. Dr. Baker is a nationally recognized leader in pediatric palliative care with more than 30 years of experience and helped develop one of the country's first integrated programs dedicated to this approach. He is now the chief of the Division of Quality of Life and Pediatric Palliative Care at Stanford Medicine. Additionally, he serves as the associate chief quality officer for Patient Experience and Holistic Care at Stanford.

Dr. Baker says palliative care works along with traditional treatment to reduce suffering, not only physically but emotionally and spiritually. It's not an either/or situation but a yes-and approach, combining disease treatment and quality of life care. It's what Dr. Baker describes as a holistic approach that involves every member of the care team, from social workers and psychologists to radiation and medical oncologists and nurses – everyone.

"When we think about quality of life, when we think about making every single day the very best day possible, there are some very practical techniques. One is making sure that we're listening and that we're listening with an open heart, because the second thing is to apply compassion. Compassion literally means to suffer with … to suffer with our patients and families, to help them carry this very heavy burden."

One aspect of holistic palliative care involves fostering communication. Dr. Baker says often families engage in something called "mutual pretense" where everyone pretends everything is OK. Instead, he recommends the care team promote honest communication to discuss goals for the child and family to drive treatment decisions.

"All of a sudden, people can take a breath, talk about the things that really matter, and all that energy that was being used to pretend that things are OK, it is now being channeled into doing things that make everything better. We can then focus on how we make today the best day possible."

Communicating bad news does not steal hope according to Dr. Baker. He says hope is a coping mechanism that gives a sense of purpose and adds to quality of life.

"When we think about promoting hope, what we try to do is hope for the best and plan for absolutely everything. And one of the most important things we do is we provide anticipatory guidance."

Preventing regret is a key strategy

Anticipatory guidance helps families make difficult decisions by thinking about the best and worst case scenarios. Specifically, Dr. Baker says he emphasizes the importance of helping families prevent regret.

"I think preventing regret is one of the most important things we can do and the best way to do it is to walk alongside that family, helping them make these very difficult decisions and that we carry some of that weight."

Research also reveals that regret can significantly impact grief and bereavement, leading to increased anxiety, depression and higher mortality. So, Dr. Baker preaches about the need for pausing and reflecting to consider whether medical interventions ensure that treatment aligns with the patient and family's wishes.

"Usually, we just do things, and we do things *to* the patient rather than thinking 'Are we doing this *for* the patient? Are we doing this *for* the family?' And so, too often we *do* because we *can* without fully contemplating whether we should. It's a way to be a little bit provocative to say, 'Did you really pause and think about this?'"

Lastly, Dr. Baker stresses the medical community often views pediatric palliative care as end-of-life care, but this is not the case for most patients and families who embrace the idea of reducing stress and having support from *everyone* who they come in contact with throughout their care journey.