

Good Morning!

Today's message addresses "multiple goals of care" based upon the materials from the EPEC (Education in Palliative and End-of-life Care) Project.

Why should the relief of suffering not be pursued at the same time as cure and life prolongation?

Do not wait to focus on the relief of suffering until all attempts at cure have been exhausted or the patient and family plead for such efforts to stop. With earlier access to symptom management and supportive care, patients and families may feel better, continue more of their normal lifestyle and maintain more capacity to fight their illness and sustain treatment.

So, multiple goals often apply simultaneously and may very well be contradictory. For example, a patient may want prolongation of life as the overriding goal but also insist that nothing should be done to increase the discomfort. It is the physician's role to help the patient and family understand the balance between the benefits and burdens of a particular treatment.

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OSF Supportive Care®

P.S. Be sure to visit <http://www.osfhomecare.org/medical-professionals/> to see all the Supportive Care "Connections!"

Good Day!

Our Corporate Ethicist, Joseph Piccione, SThD, JD, requested that I devote one of my weekly messages to informing you about the two OSF HealthCare Ethics Seminars scheduled for October 25<sup>th</sup> in Rockford and November 3<sup>rd</sup> in Peoria. The reason being is that I will be addressing the topic, “Supportive Care: Current State and Opportunities to Change the Culture.”

*At the end of this session, the learner will be able to:*

- 1. Describe how the development of OSF Supportive Care began a change in culture as a result of an Ethics consultation.*
- 2. Identify the current culture of Supportive Care in OSF, and the vision for the future state.*
- 3. Exemplify appropriate Supportive Care management of patients and populations with serious illness.*
- 4. Demonstrate the value of interdisciplinary teams in the care of patients with chronic progressive or life limiting illness, and know how to access advanced teams for more complex needs.*

If you would like to register for this program simply contact Kathy Crittenden in Corporate Mission Integration, 309-655-4837, or [Kathy.L.Crittenden@osfhealthcare.org](mailto:Kathy.L.Crittenden@osfhealthcare.org).

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Good Morning, last week I interrupted the EPEC series on “Goals of Care” to alert you about the OSF HealthCare Ethics Seminars and next week I’ll return to that series but today I wanted to address typical grief responses. Everyone responds to grief in a unique way, and yet it may be helpful to realize that the following are normal and natural responses to the grief process.

<b>Physical Sensations</b> <ul style="list-style-type: none"><li>• Tightness in the throat</li><li>• Heaviness in the chest</li><li>• Empty feeling in the stomach</li><li>• Lack of appetite</li><li>• Difficulty in sleeping</li><li>• Dry mouth</li><li>• Lack of energy, fatigue</li><li>• Pounding heart</li></ul>	<b>Thought Patterns</b> <ul style="list-style-type: none"><li>• Difficulty believing the loss is real</li><li>• Inability to concentrate</li><li>• Preoccupation with the deceased</li><li>• Difficulty with decision-making</li><li>• Loss of time perception</li><li>• Confusion</li></ul>
<b>Feelings</b> <ul style="list-style-type: none"><li>• Sense of numbness</li><li>• Sadness and crying</li><li>• Anger, irritability</li><li>• Guilt</li><li>• Loneliness</li><li>• Depression</li><li>• Relief</li><li>• Mood swings</li></ul>	<b>Behaviors</b> <ul style="list-style-type: none"><li>• Wandering aimlessly, looking for the loved one</li><li>• Withdrawing from others</li><li>• Increased independence</li><li>• Assuming mannerisms or traits of the loved one</li></ul>

It is important to remember that grief lasts as long as it lasts and is directly related to the relationship the bereaved person had with the deceased, the nature of the death and the personality of the person who is grieving.

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P.S. Still time to sign up for the Ethics Seminars on October 25<sup>th</sup> in Rockford or November 3<sup>rd</sup> in Peoria – contact Kathy Crittenden in Corporate Mission Integration, 309-655-4837, or [Kathy.L.Crittenden@osfhealthcare.org](mailto:Kathy.L.Crittenden@osfhealthcare.org) to register.

Good Morning, last week I addressed typical grief responses and as you can imagine and might know first-hand children do respond somewhat differently. Thanks to Laura Sollenberger, MA, LCPC, NCC, CT Counseling Supervisor, Pediatric Supportive Care at Children's Hospital of Illinois for these guidelines in helping children cope with death:

For children **ages 5-6**, their world view is very literal. So explain death in basic and concrete terms. You may explain that "dying" or "dead" means that the body stopped working. Avoid euphemisms, such as telling kids that the loved one "went away", "is sleeping" or "lost."

Children **ages 6-10** start to grasp the finality of death. They deal best with death when given accurate, simple, clear, and honest explanations about what happened. Always allow the child to determine what they want to hear. Ask them if they have specific questions they want answered. Let them know you will answer their questions as long as they have them.

Next week I'll share Laura's guidelines for teens.

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Good Morning!

Helping children cope with death varies by the ages of the children. This week I'd like to share the guidelines from Laura Sollenberger, MA, LCPC, NCC, CT Counseling Supervisor, Pediatric Supportive Care at Children's Hospital of Illinois for children ages 11 thru teens:

As kids mature, they start to understand that every human being eventually dies. As teen's understanding about death evolves, questions may naturally come up about mortality and vulnerability. Teens also tend to search more for meaning in death of someone close to them. Whatever a teen is experiencing, the best thing you can do is to encourage the expression and sharing of grief.

Next week I'll resume with our EPEC series on "Goals of Care."

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PS – Did you know November is National Home Care and Hospice Month? It's a great time to recognize and learn more about the many great services OSF Home Care Services provides such as: home health, hospice, home medical equipment, home infusion pharmacy, personal response systems, diabetes supplies and more. To learn more, visit [www.osfhomecare.org](http://www.osfhomecare.org).

Go Cardinals!

Good Morning, because the feedback from 90 of you who completed our readership survey was so positive, I'll continue with these weekly messages and incorporate your suggested topics from time to time. Thank you very much for your feedback.

Now, back to the EPEC (Education in Palliative and End-of-life Care) Project series on "Goals of Care." As patients approach the end of their lives, goals of care and treatment priorities frequently change. Some goals will take precedence over others. As a patient's prognosis and health status worsen, the goals of prevention, cure or avoidance of death may become less important as they become less possible. At the same time, the goals of maintaining function, relieving suffering, and optimizing quality of life may become the focus of care.

The shift in goals (from curative/life-prolonging to relieving suffering, i.e. palliative care) is an expected part of the continuum of medical care.

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Good Morning,

Continuing with the EPEC (Education in Palliative and End-of-life Care) Project series on "Goals of Care," there is a 7-step protocol to negotiate goals of care with your patients:

- 1) Create the right setting – sit down, ensure privacy and time
- 2) Determine what the patient and family know
- 3) Explore what they are expecting or hoping for
- 4) Suggest realistic goals, e.g., comfort, peace, closure, loving care, withdrawal of interventions
- 5) Respond empathetically
- 6) Make a plan and follow through
- 7) Review and revise periodically, as appropriate.

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Good Morning,

The next module of the EPEC (Education in Palliative and End-of-life Care) Project series on "Goals of Care," addresses "Communicating Prognosis."

As part of the decision-making process to determine goals for their care, patients and families rely on physicians for answers to two fundamental questions:

- 1) What is wrong with me? Or, in the case the patient is a child, the parent will want to know, "What is wrong with my child?"
- 2) What will happen to me? Or, as a parent of the patient, "What will happen to my child?"

Prognostication is never easy. Studies suggest that evidence-based prognostication doesn't explain customary medical practice. Even when physicians refer patients for hospice care, they seem to markedly overestimate prognosis in that patients live for only days or weeks once referred to home hospice care, rather than the months of life that the physician thought remained. Next time I'll cover some tips on ways of effectively communicating prognosis.

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Hello readers and friends. As some of you already know, I have an annual tradition of writing a story of this season, which I share as my small gift for the days ahead. Feel free to read it, share it or send friends the link. It will remain available here until the new year.

Of course I'd be pleased if you'd consider making a holiday gift of one of my books, *Last Rights* or *Authentic Patriotism*. And as always, I'd be delighted to hear your reactions to the story.

Thanks for supporting my work. Serving you is a great privilege.  
Happy winter.

-- Stephen

## ONE MORE SNOWFLAKE

Thomas stepped out of his truck into an inch of fresh snow, and it gleamed from the light post he'd installed by the mailbox twenty years before. A backbreaking job it had been, digging a trench for the wires from the house, and seeming to strike every underground rock along the way. Oh to be that strong again, that tireless. Now his pants sagged in the seat. With a grimace he tightened his belt another notch, his thumb feeling two holes up to the leather's usual groove.

Thomas took a deep breath, drawing the chill far into himself, then releasing it with a cloud toward the heavens. The silence was impeccable, not the faintest hush of wind through the row of spruces he'd planted eighteen years ago. The lights of the house beckoned; he reached back into the truck for a canvas grocery bag. His face leered from the side mirror, flecks of white paint in his grey beard. It took three slams for the door to catch and stay closed. Then he strode toward the lights and warmth.

Before he'd gone ten steps, Thomas smelled the wood smoke and it stopped him as always. Something animal in him was stirred and comforted by that scent. But it was a false stirring, and a false comfort. All it really meant was that Barbara had thrown a birch log on the flames along with the usual hardwoods. And he knew better than to think she had done it for his benefit. Thomas came onto the porch and rang the bell. The house remained silent. After waiting long enough to begin shivering, he rang the bell again.

A moment later the entry light went on and he could see her hurrying in her apron, then the outside overhead shone. He opened the door himself. "How are you Barbara?"

"Anna's flight was delayed," she said, already heading back into the house.

“I wondered,” he called after her while he slid out of his boots. “I noticed mine were the only tire tracks.”

“She insisted on taking a cab,” Barbara boomed from the kitchen. “So I wouldn’t have to wait at the airport.”

He walked through the house in his socks, past the statue of lovers he’d bought seventeen years ago, the incense burner for her birthday fourteen years ago, and on a side table stood the evidence of his ever-expanding ex-husband expertise, a village of miniature buildings he had given her one piece per Christmas these past twelve years. If ever a gift could not be construed as offensive, vindictive or manipulative, it was a Victorian-era tack shop or butcher or hat maker three inches high with a little light inside.

Barbara was still talking at top volume. “There’s no telling what time she’ll actually get in. Half the world is flying today, and LaGuardia was completely backed up.”

“Apparently the storm swung south of us,” Thomas said in a soft voice that made her turn. “It went out to sea.”

“Since when have you been Mister Weather?”

He shrugged. “Never. I just was hoping for a blizzard. To make the holiday complete, I guess. I could use a good dumping of snow.”

“Even if it makes your daughter late?” She returned to stirring something on the stove. The tree stood bare in the next room, boxes beside it with lights and decorations awaiting Anna’s return. It smelled, Thomas thought, heavenly. Barbara had lit candles, as she did every December night, and the platter of them behind the stove gave her a halo of light.

“You look lovely tonight.”

She spoke to the stove. “You’re not in one of your moods, I hope.”

He gave a dry laugh. “Perpetually, I suppose.”

“You’ll just have to ration it out, then. Anna won’t be here for at least an hour.”

Thomas went to the cabinet, peered inside, and stepped back. “You moved the wine glasses.”

“I’m not tall enough to reach there. Never have been, though it took me twelve years to realize it.” She pointed with her spoon. “Over by the silverware drawer.”

He nodded and crossed the room, finding two flutes and setting them on the counter. Barbara glanced over. “Champagne?”

“Why not?” He pulled a bottle from the canvas sack, unwrapped the foil and began uncoiling the wire hood. “It’s not every week your daughter gets into law school.”

“You are OK with her being a lawyer?” She paused in her stirring.

“I’m amazed.”

“I am OK with Anna, period,” he said. The cork gave a satisfying pop and Thomas watched closely as vapor rose from the bottle. He poured one glass till bubbles reached the top, waited for them to subside, then filled it again generously. He handed it to Barbara before pouring his own.

She took a sip. “Wow. What kind is this?”

He turned the label toward her. “I splurged.”

She set her glass on the counter. “You’re not spending money from pieces you haven’t sold yet, are you?”

“Not at all.” He took a big gulp, closing his eyes as he felt the effervescence in his nose. Then he contemplated the glass from the side, bubbles rising and a few clinging partway. “It’s just that my financial goals have changed recently.”

She snorted. “You have financial goals?”

“OK, let’s say my financial needs.”

“What, have you met someone? And is she loaded?”

“You are the only loaded woman I’ve ever loved.”

“Fat lot of good that did you.”

“Well, there is Anna.”

“There is.” She noticed him looking for a place to sit, but both kitchen stools were stacked with papers. Barbara grabbed a pile of magazines and catalogs from a corner of the counter. “Try there.” She carried the pile out to the entry closet, where he knew a blue recycling bin sat on a shelf he’d built. “Does this have anything to do with the retrospective at the Institute this spring?” she called over her shoulder.

“No.” Thomas rubbed his nose. “Though I suppose I have you to thank for that good fortune?”

“Not at all,” she said, returning. “I don’t even sit on that committee anymore. They have me doing development now, if you can believe that. Me, asking people for money.” She shook her head.

“I imagine that thrills you down to your toes.”

“Yass, Thomas dearest, would you happen to have any spare change?”

He sat on the counter. “If I did sweetheart, I’d give it all to you.”

She looked at him, almost for the first time that night, then turned away. “I’m sorry to be cooking on you, and not have appetizers or anything. But I decided on risotto, and if I stop stirring it will burn.”

“Not to worry. It’s worth waiting just to taste your risotto.”

Barbara considered him with one eye. “What are you up to?”

“Whatever are you talking about?”

“I’m talking about sweetheart this, risotto that. Because if you came here intending to ask for another loan –“

“Please.” He held up one hand. “Please. I don’t want anything from you, Barbara. I mean yes, I would love to do three or four years over again with you. Two years at least. But in terms of right now however stupid this sounds, I am glad just to be sitting here while you cook something flavorful, and our inexplicably suddenly grown-up daughter flies home for the holidays, and we sip something as ordinary and extraordinary as champagne.”

“Come now. Honestly?”

“What I want right now, Barbara, is all of the richness that life has to offer. The beauty in every single moment. I want a blizzard, sweetheart. And if I can’t have that ... well, then I want a snowflake. Just one more snowflake.”

She wisted a stray hair back from her forehead. “You *have* met someone.” She poured broth into the pan and continued stirring.

Thomas drained his glass, refilled it, put a fresh inch atop hers. He took a plate from a cabinet, rummaged in his canvas bag, and produced an array of food that he brought back to the counter.

Barbara was holding her glass, sipping while stirring, till he set the plate down. “Smoked trout?”

“Still your favorite, right?”

“What are you doing, Thomas? Of course it is.”

“Why do I have to be doing something? Can’t I just be a man who knows what life is worth? Why can’t I bring foods you like and booze you like and wait with you for our beautiful daughter to come home?”

“Because it is not like you, dammit.” She put her spoon hand on her hip. “I know you, Thomas, we have done this Christmas Eve thing for twelve years now, and we both know precisely how it goes. You arrive insultingly late. And starving. And distracted. And all you can talk about is the current painting or the next show. And you argue about everything. Last year it was cloth napkins versus paper napkins, in case you forgot. And you make snarky comments that to ordinary people would sound fine but that you just know will prick me good. And usually you haven’t washed. And most of the time you –“

“Enough,” Thomas said. “Enough.”

“Well it’s true.” She took a piece of trout and gobbled it.

He contemplated his hands. Paint clung to the cuticles. One stain on his thumb was shaped like Idaho. After a moment he raised his eyes, then pointed. “Your spoon is dripping.”

She startled, put it in the risotto, then grabbed a sponge and wiped the floor. But while she was down there, she slowed. When Barbara straightened she studied the sponge like it was a foreign object, and the silence grew.

“Which was I in favor of?” Thomas eventually asked.

“Which what?”

“Cloth or paper?”

Her shoulders dropped. “I can’t remember, Thomas. It didn’t matter then, and it doesn’t matter now.” She tossed the sponge in the sink and went back to stirring in her haloed place.

“You know sweetheart, I am so glad you never cut your hair.” She went still, the spoon barely circling, listening as he continued. “When I see so many women now of a certain age who chop their hair so short, to make it easy to care for I suppose, I think they don’t realize how masculine it might make them, how less likely to be admired in a certain kind of light, and well, I am just glad that you have never been afraid to be beautiful, in all the ways a woman can be beautiful for her age, whatever age, glad not for myself but

for what it says about how you see yourself, glad that you can love and accept yourself in that way. Am I making any sense?"

Barbara turned the heat off under the pan. She stood near him and took his hand. "What is it, Thomas?" she said. "Tell me."

He shrugged. "It's not enough to savor life?"

She shook her head. "You have always savored life. Like no one I have ever known. Now tell me what's going on."

Thomas straightened his back and let out a sigh, but it caught on the way out.

"You're scaring me," she said.

He inclined his head, a boyish tilt. "It's back."

"It? Which it?"

"Sweetheart." He put down his glass. "It's in my bones."

Understanding dawned on her face. "Oh, Thomas. That's why you've become so skinny."

His voice was soft now. "And my liver."

"Oh God."

"And my brain. My brain, honey."

She could not help herself. She placed her free hand on his face.

“Not in my lungs this time, though.” He took a deep breath. “There is that.”

“What are you going to do?”

“Nothing *to* do, sweetheart. I could chemo it again, but look where that got us. It’s in far too many places to radiate. And I won’t let them surgery me to ribbons, if they even proposed it, which they haven’t.”

“What did the doctors say?”

“One said I should get my affairs together. Affairs, there’s a word for you. Another gave me a brochure about hospice, which actually was fascinating. The last one said ‘Go with God’.”

“He said what?”

Thomas nodded. “That’s right.”

Barbara stepped away, pushed back her hair, then used one forefinger to count off the fingers of her other hand. “All right. First thing, we’ll call my contact at Dana Farber, get you in to their best people. Of course John knows people at Sloan Kettering too, from his residency.”

“I really don’t think your brother –“

“And then there’s Mayo. I’ll get online later tonight and see if I know anyone on the board.”

“Barbara.” He took her hands in both of his. “You are kind, but you do not understand.”

“What’s not to understand? There are plenty of people and resources to help you fight this. Now Thomas, don’t allow your pride to stop you from letting me help.”

“There isn’t going to be any fight,” he said. “It’s too advanced.”

“Dammit Thomas,” she said. “If you don’t fight it, then what *are* you going to do?”

He smiled. “I am going to appreciate.”

“To what?”

“Appreciate, sweetheart. Champagne. Anna in law school. Painting yes, color and light every chance I get for as long as I can. Blizzards, trout, *everything*. Even you. Especially you.”

Eyes brimming, Barbara turned to face the stove. “How am I supposed to cook risotto, with you like this?”

“Please cook it exquisitely, sweetheart. I cannot wait to experience the flavor.”

“I don’t know what to say to you.”

“Whatever you have to say, even in scorn, I cannot wait to hear.”

She put the spoon aside. “That sounds like an exhausting way to live.”

“I hope to become very tired by my appreciating. I am tired already.”

“Maybe this year ...” Barbara took both of his hands this time.

“Maybe you’d better stay, and help decorate the tree.”

He whispered. “I would love that.”

She leaned forward, an inch at a time, till her forehead pressed against his upper arm, and they held there, still, silent.

Just then a horn honked; it startled them both. Barbara backpedaled. Thomas dropped from the counter and peered out the front window. “It’s a taxi,” he said.

They went to the porch together and stood outside in the cold, watching Anna hoist her bag from the trunk. Her back was to them while she paid the cabbie. As he returned to the driver’s side he thanked her and wished her a Merry Christmas. Thomas noticed how tailored Anna’s coat was, how it complemented her long, slender back.

He found himself distracted for a moment then, by a snowflake tumbling down into the spill of light. Just one, it hovered so briefly as he watched. Then it caught an invisible wind and spun off somewhere unknown, into the infinite dark.

**From:** Sawicki, Robert  
**Sent:** Friday, January 06, 2012 8:11 AM  
**To:** SupportiveCareConnection  
**Subject:** Supportive Care Connections

Good Morning and Happy New Year!

I would like to continue with the EPEC (Education in Palliative and End-of-life Care) Project series on "Goals of Care," and today address "Communicating Prognosis."

Consider offering a range that encompasses average life expectancy, e.g., hours to days, days to weeks, weeks to months, or months to years.

Alternatively, consider offering averages: "People with your illness circumstances can live for a long or a short time. About half live for about 3 months. There is a lot of variation for the other half. Some find it is best to plan for little time, and hope for more time."

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**From:** Sawicki, Robert  
**Sent:** Friday, January 13, 2012 8:27 AM  
**To:** SupportiveCareConnection  
**Subject:** Supportive Care Connections

Good Morning,

Continuing with the EPEC (Education in Palliative and End-of-life Care) Project series on "Goals of Care," today I'd like to address one of the chief obstacle to negotiating goals of care in the face of life-threatening illness and poor prognosis which is hope. Apparently Hippocrates stated that physicians should express hope to the patient and family that the patient will enjoy a full recovery from the current illness, even if it is not true. This principle has been mistakenly taken so far as to administer treatments that are known to be ineffective, all in the service of maintaining hope.

When surveyed, most Americans said they would rather *know the truth* about their illness. Unfortunately, a false sense of hope may deflect the patient and family from finding final meaning and value, and closing their lives together. Physicians agree that a positive attitude and a sense of hopefulness should be maintained throughout the course of an illness. To achieve this end, some find it useful to frame discussions using words like: "we can hope for the best, but we also need to plan for the worst."

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<< OLE Object: Picture (Device Independent Bitmap) >>

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