

Palliative Care: Developing Your Goals of Care

"Happy birthday."

Angela Valerio's birthday - and her son's birthday - are less than two weeks apart.

"Happy birthday to you."

They're celebrating with Angela's niece, Elisa, and her mom, Camelia.

"My mom lives with us. If it wasn't for my mom, I don't know, like where I'll be. She's truly an angel."

Celebrating their special days together is something Angela has always treasured. And six years ago, it became extra special. That was when Angela learned she had what's known as a Desmoid Tumor. Though it's not cancerous, she needed to go on Chemotherapy to keep the painful tumor from spreading. Since then, she has been on six different types of chemo, which have caused a number of side effects.

"Nausea, vomiting, bone aching - horrible; fatigue, loss of appetite, um mood swings."

But over the last few years, it's been a little easier for Angela to cope. She's been getting extra help, from a separate medical team, to ease the physical - and emotional - toll of her condition and treatment.

"They're really good. They care about your needs, they want to know what's going on, they wanna help you - with anything."

"When would you say your pain is worse?"

The additional treatment Angela gets is called "Palliative Care." It focuses on providing relief from the symptoms and stress of living with a serious condition - regardless of age, the stage of the illness, or prognosis.

"What Palliative Care Teams do is that they will often give people choices, and have 'Goals of Care' discussions, where they find out what has been important to you, for most of your life. And what is important to you now."

"And then here and here. Does that feel the same?"

"One of the hallmarks of Palliative Care as a specialty is that the care is - patient-centered. The patient is front-and-center at every stage of the treatment; at every decision."

As your health status changes, your goals and needs may change, as well. Speak up about these changes so your care team can adjust your treatment plan. This may include services such as: Physical help - like Occupational or Respiratory therapy or Nutritional support; Emotional support- talking about the impact your illness is having on you and your family; and spiritual support.

"Now, by spirituality, what do we mean? We mean a sense of meaning and purpose - what gives you meaning. If you feel that you would like to talk to somebody about these things in more depth, you can speak to the social worker on the team, you can ask to see a Chaplain and you might find it very comforting to talk to that person, even if you don't consider yourself to be religious."

"Shortness of breath, constipation."

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Palliative care is family-centered. So, it's important that the loved ones you want involved in your care talk openly with the Palliative Care Team, as well. This can happen during individual conversations and "Family Meetings." The first meeting is typically intended to answer any questions you or your family may have, and to discuss goals, values, and beliefs. Later issues covered in family meetings may include: updates on your health status; test results; changes in your goals of care; and financial concerns. Sometimes family meetings involve conflict, most commonly over the patient's medical treatment.

"Conflict can emerge when serious illness takes place; but research tells us that when consensus is reached, and families come to support the patient's wishes, that there's better outcomes, in terms of peace, quality of life, for the family."

To Angela, having 'quality of life' means spending as much time as possible with her mom and children something she says she could not do without Palliative Care.

"Working with the team has definitely improved my quality of life, because I'm able to spend more time with my mom and my kids. If it wasn't for them, I wouldn't be able to get up from the bed, honestly."