

Using POLST with the Pediatric Population

The Family Advisory Council (FAC) of the Children's Hospice and Palliative Care Coalition, along with key pediatric palliative care providers, have developed the following recommendations about discussing Physician Orders for Life-Sustaining Treatment (POLST) with families of seriously ill children.

Comfort measures are medical treatment. One mom states, "When a doctor who has told you over the last 2 years what is next in your child's treatment plan tells you, 'there is nothing more that we can do,' you believe him. When the doctor told us that, we didn't know that there were comfort measures that could be taken. We literally thought, there was nothing more that he could do for our daughter." Another mom says, "Doctors need to talk about comfort measures early. Families should always have that on the menu."

Relationship must guide the timing and content of the discussion.

Maureen Horgan, program coordinator for Stepping Stones Pediatric Palliative Care and Hospice Program in Seattle, Washington where they have used the POLST since 2005 states, "It is essential to ensure that some level of trust and rapport has been established with the family before conversation begins about POLST, while also assessing cultural considerations and the context of familial hope. Our experience has been that pushing this discussion because of community agency protocol is not effective or helpful in assuring best patient care. Instead we've seen that families may decline care if this discussion is forced."

Honest information in plain language is important: “It was hard for me to process what the doctor was saying. I didn’t understand all the terms but was too stunned to ask.”

Combined with compassion: “I look back and I can’t remember the exact words in the medical conversations but mostly how we were talked to and treated as human beings.” Another parent said, “To hear the words is hard enough. But when he talked about it like he was talking about the weather, it was really too much to take. This is my baby we were talking about! I wanted to say, ‘Do you have children?’”

The families interviewed from the FAC agree that in order to be effective, a POLST discussion should transmit three key types of information:

- 1) **Definition** of treatment option
- 2) **Consideration of Quality of Life** (secondary effects of treatment option,)
- 3) **Who** will provide the treatment option and **where** will the treatment option be given.

Families can only truly give “informed consent” when they know information from these three domains. Said one parent, “Professionals need to take responsibility and guide parents through the options and the consequences of those options. They need to explain the players on the medical team. The titles don’t make sense to us. We don’t know what they do. Tell me why they are specifically important to my family.”

- 1) **Definition:** Use plain honest language when describing treatment option. For example, "Intubation is used when a child can no longer breathe well on his own. A tube goes down a child's throat and into his windpipe. The tube is connected to a machine that forces air in and out of the child's lungs."
- 2) **Consideration of Quality of Life:** Help the family to understand the possible secondary effects of each treatment option. For example, "When a child is intubated, he will be sedated, as though he is asleep, and he will be unable to speak."
- 3) **Who and Where:** Help the family understand who would deliver that option of care and where the care will be delivered. For example, "Intubation requires that a child be in the Intensive Care Unit."

Use your humanity: "It is important to be human as a doctor. Your humanity will help because the family is feeling very vulnerable. Don't withdraw behind the white coat. I want to know what you have to say both as a doctor and as a dad." Another mother said, "Our doctor told us not to look on the internet. He didn't know me. I am an information gatherer. That is how I cope."

Include the child in health discussions, if appropriate. This recognizes his/her personhood and can lend some sense of control over frightening circumstances. Stated a mom, "My child wanted to know everything that was going on but only wanted to hear the information from me. The medical team honored this request. It made me feel like they respected her as a person."

A family's values, ethics and faith, not just medical facts, may play a major role in decision-making. When explaining why they decided to forego experimental treatment with very low probability of success, one parent stated, "We are a family of strong faith. We knew that even if he died, he would be okay." Her 8 year old son had told her, "Mom, I am sorry you are sad. It sucks that a kid my age has to die. But I will be ok. I will be in heaven."

Provide validation for parents: "It is important to hear from the doctor, "You have done everything you could. You are a good mom. Whatever you choose to do, trust that you are making the right decision."

Validate the child's unique place in the world: A parent states, "Each child is special, in body and in spirit. It's important that the doctor recognizes that he's not just a patient in a bed."

Appreciation and gratitude: And finally, every family appreciated and valued their child's medical team. "There were a few isolated incidents, but 90% of the time people were very caring, sympathetic and helpful. We knew they cared about us as people." "I have respect and gratitude for the medical community. They were able to diagnose my daughter and give her state of the art treatment." "I feel for the doctors. They have such a hard job and have to see so much sadness every day."

The innovation of the POLST form and the compassionate and honest discussion that accompanies the form, provide an opportunity for partnership between the family and medical team at the one of the most profound moments in human life.

In this way, a beloved child may attain the best quality of life for as long as he lives, and die as gentle a death as possible. . "When he died," a dad said, "we felt sadness, relief, peace, and gratefulness that we could hold him at his last breath."