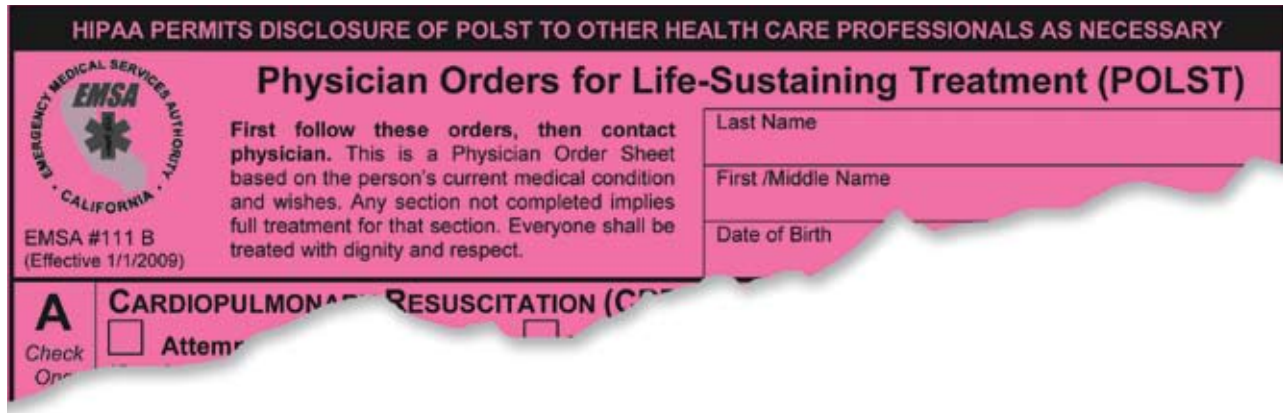


Parents Talk POLST



How can a form printed on bright pink cardstock help a family and a medical team through one of life’s hardest conversations? The Physician Orders for Life-Sustaining Treatment or, as it is more commonly known, “POLST,” is more than a form; it is a conversation catalyst. The POLST promotes clear, concise and honest dialogue between the medical provider and family as they discuss end-of-life healthcare planning. Once completed, the POLST is honored across care settings—in the community, at respite, and in the hospital, freeing families from repetitive, difficult conversations.

Children’s Hospice and Palliative Care Coalition asked their Family Advisory Council (FAC) to consider the use of the POLST when the patient is a child and to offer guidance to healthcare professionals working to implement the new form. Their hard-won advice:

Explain that comfort measures are medical treatment. “When a doctor you have worked with over the last two years on your child’s treatment 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.”

Provide honest information in plain language. “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.”

Offer a compassionate approach. “I look back and I can’t remember the exact words of the medical conversation—mostly I remember how people spoke to us.”

Acknowledge the child and relay information appropriately. “My child wanted to know everything that was going on but only wanted to hear the information from her mom. The medical team honored this request. It made me feel like they respected her as a person.”

Validate the 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.’”

Respect family ethics, values, and faith. “Medical facts aren’t the only part of the decision-making process. We decided to forego experimental treatment for our son. The probability of success was low and we are a family of strong faith. We knew, and he knew, that even if he died, he would be okay.”

To use the POLST effectively, FAC members agreed, the medical team must carefully **define each treatment option**, discuss how each option will **affect quality of life**, and explain **who will provide the treatment and where**. Using the POLST as a guide, informed choices can be made. ●

SO WHAT'S ACTUALLY ON THE POLST?

Talking with physicians about palliative care for your child is tough, but it's also important. The POLST gives you concrete choices while making it easier to talk about your child's care.

The POLST forms may vary from state to state, but they all cover common ground. One section allows you and your family to decide if and how resuscitation will be attempted. Another part outlines three levels of medical intervention to choose from – comfort measures only, limited additional intervention, and full treatment. It also gives you options for artificial nutrition. With the POLST, you can personalize your child's care and change your mind at any time.

Once the POLST is signed by you and your child's physician, it goes wherever your child goes. You won't have to repeat yourself, and that's the point.

The Physician Orders for Life-Sustaining Treatment was signed into California law on January 1, 2009. For more information about POLST, visit <http://finalchoices.org>

up to speed

NHPCO Shines Light on Unmet Need

The National Hospice and Palliative Care Organization (NHPCO), in conjunction with the Children's Project on Palliative/Hospice Services (ChiPPS), developed the first national pediatric principles—"Standards of Practice for Pediatric Hospice and Palliative Care Programs," based on data collected through their pediatric services survey (2007). The survey revealed that while the majority of hospice agencies and palliative care programs serve pediatric patients, only a small minority had formal pediatric programs with specially trained staff. Providers demonstrated a real need for the education, resources, tools, and methods required to create high quality, sustainable programming.

National Hospice and Palliative Care Organization



The Standards, along with a recent report "Facts and Figures on Pediatric Palliative Care and Hospice," by Sarah Friebert, MD, offer clear insights into best practices and the current culture of pediatric palliative care. Both resources are available online at www.NHPCO.org/pediatrics.

Also on tap, ChiPPS quarterly E-Newsletter provides up-to-date information on the latest news in pediatric hospice and palliative care. Email CHIPPS2@NHPCO.org to receive this free newsletter. ●

In Focus

California HealthCare Foundation

Since 2005, the California HealthCare Foundation (CHCF) has partnered with the Children's Hospice and Palliative Care Coalition (CHPCC) to increase access to palliative care for children with life-threatening conditions. At the debut of this partnership, only 422 children used the Medi-Cal Hospice Benefit – a small fraction of the children and parents who could benefit from it each year. Too many children receive ineffective and expensive care while their pain and other serious discomforts go poorly addressed.



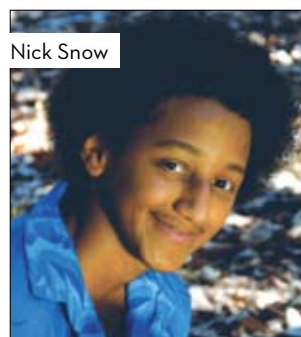
CALIFORNIA HEALTHCARE FOUNDATION

California is now poised to dramatically

expand access to palliative care for children and their families, following enactment of the 2006 Nick Snow Hospice and Palliative Care Act, and subsequent federal approval of the state's

Pediatric Palliative Care Benefit in 2008. These achievements wouldn't have been possible without the strong leadership, tireless passion, creative thinking, and collaborative spirit of CHPCC.

CHCF is extremely proud of CHPCC's accomplishments – yet much remains to be done. For this reason, the foundation continues its partnership with CHPCC to promote awareness of the palliative care services available through Medi-Cal, to build and strengthen pediatric palliative care skills that integrate the experiences of parents and families, and to build operational capacity among counties selected for the Medi-Cal pilot for appropriate referrals. ●



Nick Snow