

POLST Pediatric Case Study

Baby Emma is 8 months old. She has a diagnosis of SMA Tyle 1, a severe neuromuscular disorder characterized by muscle weakness and respiratory failure. SMA Tyle 1 is known to significantly shorten life expectancy. Emma has been under specialized care since her diagnosis, receiving supportive treatments including respiratory support and nutritional management through a feeding tube. Emma is now admitted to the children's hospital with respiratory failure. She is being supported with non-invasive mechanical ventilation.

Emma's parents are familiar with the hospital staff, as she has had several hospitalizations. Given the progressive nature of her disease and poor prognosis, Emma's parents have been in discussion with the healthcare team about her quality of life and future care options. This has included difficult conversations about the balance between prolonging life and the potential suffering due to the progressive illness and invasive treatments. The primary concern for Emma's parents is her quality of life. They observe that Emma experiences significant discomfort, such as crying and grimacing, during invasive procedures and hospitalizations.

During her current hospitalization, the treatment team is worried Emma may need intubation and discuss this with her parents. Given her diagnosis, Emma's parents have been discussing care options with the medical team throughout her hospitalizations. The medical team has hoped this will help Emma's parents understand the risks, benefits, and outcomes of invasive treatments, to allow them to make informed decisions when the time comes. Because of these conversations, their experiences with Emma's care, and their spiritual beliefs, Emma's parents are able to make decisions they feel are in Emma's best interest, even when difficult. They share with the treatment team that they do not want Emma intubated and placed on a ventilator, knowing it will result in long-term ventilation. Although this is a difficult decision, Emma's parents feel supported by the treatment team, who come around them and acknowledge their decision is made with love for their child.

Fortunately, after several days of treatment, Emma is improving enough that her medical team is preparing her for discharge from the hospital. Due to Emma's serious illness, and her parent's decision regarding no intubation, a follow up discussion occurs regarding their wishes for Emma's future care. With an understanding of Emma's condition and options, Emma's parents express that they would like for Emma to return to the hospital with any decline, for treatment similar to that she received during this hospitalization. However, when she progresses to the point where more aggressive treatment would be required to prolong her life, they do not want her to receive intubation or CPR. Emma's medical team recommend a POLST form to Emma's parents, explaining that this documentation would help to document this conversation in order to support their wish for her care.

After thorough conversation and emotional support, the POLST form was completed and signed by Emma's parents and her treating provider. The documentation expressed NO CPR (section A) and Selective Treatment (section B). Sections C and D were intentionally left blank, given sections B, C and D are optional, not required sections. The POLST form was shared with her healthcare team, including the primary care provider and specialty providers who see her in the community. Her parents brought it home and placed it on the refrigerator. They are instructed to present it to EMS should they need to call for a medical emergency, to ensure first responders understand their wishes for Emma's care. Emma's parents are reassured that Emma will receive care in event of an emergency, such as difficulty breathing, in line with their wishes.

POLST Best Practice Highlights

- The POLST form is for those with a serious medical illness, regardless of age.
- POLST conversations with pediatric patients require a tailored approach of support and empathy.
- The POLST model extends beyond the documentation itself and starts with a conversation.
- It is essential that caregivers of those with a POLST form understand how to use it at home should a medical emergency arise.
- Sections B, C, and D are optional and may be left blank to allow for the standard of care. When section B is left blank, full treatment will be followed.