Understanding Medical Orders for advanced care planning

One of the most difficult (and surreal!) decisions that you as a parent may have to make about your child's care—especially when you are no longer pursuing a cure and when comfort is THE goal of care—is whether or not there should be any attempts to revive (or resuscitate) your child if and when your child's heart or breathing stops. As part of this decision-making process, you may be asked by your child's medical team to consider one or more of the alphabet-soup of medical orders for your child.

What they are:

- A DNR or "Do Not Resuscitate" order applies to situations where your child has a
 respiratory arrest (stops breathing) or a cardiac arrest (heart stops beating). DNR means
 that no CPR (chest compressions, cardiac drugs, or placement of a breathing tube) will
 be performed.
- A DNI or "Do Not Intubate" order means that chest compressions and cardiac drugs may be used, but no breathing tube will be placed.
- An AND or "Allow Natural Death" order is a term used at some hospitals as an
 alternative to the more traditional DNR order. While a DNR simply states that no
 attempts should be made to restart breathing or restart the heart if it stops, an AND
 order is used to ensure that only comfort measures, designed to provide excellent
 control of pain or other symptoms, are taken. This includes withholding or discontinuing
 resuscitation, artificial feedings, fluids, and other treatments that prolong the dying
 process without adding to your child's quality of life. Allowing a natural death means not
 interfering with the natural dying process.
- A MOLST or Medical Orders for Life-Sustaining Treatment form is similar—it guides medical providers' treatment of your child and covers your wishes to use or withhold a range of interventions—including intubation, ventilation and artificial nutrition.

What you decide for any of these orders will be guided by your care goals for your child, which you will discuss over time with your medical team. Pediatric palliative care providers can be particularly helpful in guiding these conversations.

What you need to know:

- These orders do *not* mean "do nothing" in the event of an emergency. They do not prevent giving your child oxygen and medications to manage pain and other distressing symptoms. The goal is always to give your child the best care that will maximize their comfort and minimize unwanted outcomes.
- The goal of these orders is to tell clinicians what not to do should your child stop
 breathing or his/her heart stop beating. It limits cardiopulmonary interventions
 that you, as a parent, feel are unlikely to benefit your child who has a life-limiting illness.
 Emergency personnel such as paramedics, EMTs, and emergency physicians must
 follow these orders. Without them, paramedics and EMTs are required to provide every
 possible medical treatment to sustain life.
- If able, your child should participate in the discussion so you know that you are carrying out what your child wants.
- DNR/DNI/AND/MOLST decisions are reversible and can be withdrawn or modified at any time. Your child's medical team should be talking with you regularly about whether you still want the order(s) in place.