

ALLOW NATURAL DEATH AND DO NOT RESUSCITATE DECISIONS

In child health care we start with the idea that we will do everything we know how for a patient. Sometimes families and staff come to the conclusion that the treatments are no longer helping the child, and in fact, may become burdensome to the child. When this happens, the physician, family, and team talk about what is best. If they decide that limiting some treatments is best and if the family agrees, the physician can write an order, called an Allow Natural Death (AND)/Do Not Resuscitate (DNR) Order to say we will not use certain treatments. It is always a hard decision, but for children, as with adults, sometimes it can be the right thing to do.

Sometimes it is hard for parents even to admit to themselves they are thinking about this. Yet for children with terminal diseases and a lot of suffering, parents usually see the harms as well as the benefits of treatment and wonder if the treatment is the right thing. If you think about this, you should talk to your physician or health care team. Deciding what is best and right for your child is every parent's job, even though it is a hard job.

The decision to Allow Natural Death (AND)

There are many different ideas about death, but most people have some notion that death is part of the life cycle of all people. Usually we think about this with the elderly, but death can affect people of all ages. With children, it often seems unfair since they haven't had the chance for a full life. That makes it more complicated to think about what treatments are the right thing for a child.

It can be hard to even think about placing limits on a child's treatment. Everyone, parents and health care providers, have a strong response to want to do everything for a child. Sometimes it becomes clear that doing everything is not the right thing, and some limits on treatment are the best thing for a patient. When a child's condition cannot be cured and treatment will only cause more suffering, many people feel limiting aggressive, life-sustaining treatment can be best, and switching to a comfort only treatment is a good idea.

Sometimes the treatments will only prolong a dying process, but cannot bring the person back to health or a life where they can experience joy. When the treatments cause more burden than benefit, it is reasonable to think about whether those treatments make sense and should be used. If the parents and the health care team agree the treatments do not benefit the patient, then they can discuss an AND/DNR Order. This makes clear to everyone that the parents and team agree that some limits to treatment should be made, and spells out the exact treatments that will be used and not used.

Do Not Resuscitate (DNR): Deciding not to do cardiopulmonary resuscitation (CPR)

DNR refers specifically to a decision not to do cardiopulmonary resuscitation (CPR). CPR is a set of treatments that can be used to try to start breathing or heart beat if they have stopped for some reason. Since each patient is different, the elements of CPR that would be used are different. They can be split into pulmonary, or lung related treatments, and cardiac, or heart related treatments. Some of these are easy and not invasive, like clearing the upper airway. Other parts of CPR, like putting a breathing tube down the throat (intubating) or cardiac electrical stimulation, are invasive and have significant side effects. The AND/DNR Order lists each of the elements of CPR and asks the physician and family to discuss and decide what is best for the particular child in this particular time. It is a good idea to ask your child's physician about the likely impact of these treatments on your child given the unique situation.

Some children are already on a ventilator, which is a machine continuously doing pulmonary resuscitation. In that situation, sometimes parents and the team decide that not doing cardiac resuscitation is the best course. Other times, children are on cardiac medications but not on a breathing machine, and parents and the team decide not to intubate. Your child's doctor will talk with you clearly about each element and what makes sense. In the end, the parent is the decision-maker with recommendations from the physician and team.

Withholding or withdrawing other treatments

In some cases there are many other treatments being used besides CPR. In fact, every medical treatment has a time when it makes sense and a time it does not make sense. Each treatment should be used only if it helps the person more than it harms them, and if it meets the goals of treatment for that person. For that reason we can decide to not start or to stop any medical treatment. These decisions about withholding or withdrawing treatment are always difficult. Like DNR they are different for each person, and it is the condition and possibilities for the person that determine what treatment is proper.

This applies to even minor procedures such as taking temperature or monitoring, and to big procedures like surgery or transfer to the ICU. As with DNR, your child's physician and health care team will discuss the specific situation with you. The point is always the effect on the child, not what the treatment is. It is also important to think about how all the treatments come together, and if together they are bringing a benefit for the child.

Supportive care continues

Even when a family and health care team decide to place some limits on treatment, both the parents and the team still provide a lot of care for the child. Being sure the child is as comfortable as possible, and continuing to think about the child's needs is important. Most important is sharing your love, reassurance and support through this time. The scariest thing at times of illness and death is being alone. The child, family, and team being with each other becomes the major goal of care even when limits are placed on the treatment being provided.

There are many services to assist children and families at these times- chaplains, child life, ethics, hospice, palliative care service, psychology, and social workers all work with the family, physicians, nurses, and other members of the health care team to provide supportive care to the end. Bereavement support for families is also available after a child's death.

Some specific considerations in AND/DNR orders

While the most important questions are those of finding what is best and right for the child, there are many important details. A few of them are listed here. There are specific forms and policies you can see that talk about the details.

- AND/DNR orders are written by the physician but must be authorized by the parents and are completely under your control — you can change them or have them removed at any time. You should always feel free to let your child's physician, nurse, or other health team members know if you want a change in the order.
- Even with an AND/DNR order a child continues to get many kinds of care to help with comfort and to relieve suffering; most important, there will be discussions of how to let the parents' caring and love be there for the child.
- AND/DNR orders can be in place in the hospital or at home; you should talk with us clearly about where you believe your child will be most comfortable.
- AND/DNR orders are renewed every five days in the hospital when things are changing rapidly, and every 90 days at home. Your child's doctor will check with you to be sure you still want the order in place. Check with your health care team about the rules that apply in your community.
- Home care, palliative care, and hospice staff, as well as your regular health care team, can help you to understand and work with this situation.
- Adult patients (18 and older) have the right to make these decisions for themselves if they are capable of doing so.
- AND/DNR orders generally do not stay in effect during surgery, but can be started again after surgery.
- You can request to talk to your child's doctor, nurse, or other health care team member at any time about the AND/DNR order, as well as contact the office of ethics if you want someone else to talk to about how these orders work for your child's specific situation.
- If an AND/DNR order is written for home care, bring it with you when you come to the hospital. It is valid for the first 24 hours of a hospital stay, but then it must be rewritten.

AND/DNR decisions are difficult and sad for everyone involved. At times they can be the best decision for a child who we cannot help to get better. Think carefully, use your resources outside and inside the hospital, and talk with your child's physician and other health care team members about decisions like this. Your hospital's ethics committee is available to help you. The Office of Ethics is also available to discuss these issues with you.