



## NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Nine

### The Decision to Sign a Do Not Resuscitate Order

BY BONNIE DAVIS, ADAM'S MOM

As parents of terminally ill children, we have some of the most unthinkable decisions to make. The majority of these decisions, while difficult, are made out of an abundance of love for our children and in an effort to give them the best life possible.

At some point you may need to decide whether to create a DNR (Do Not Resuscitate) order. A DNR instructs medical personnel not to do CPR (Cardiopulmonary Resuscitation) if a person's breathing stops or their heart stops beating.

Deciding to have a DNR in place does not mean you are "giving up" on your child. It also doesn't mean that healthcare providers will do nothing. Comfort measures such as medications or oxygen may still be used. What you are doing is planning for a time when you feel that CPR will do more harm than good for your child, which can prevent further suffering. Having the DNR in place eliminates having to make decisions in a crisis. You can take your time to thoughtfully make this decision when your child is stable and your thinking is clear.

There are many nuances and variations of this order. The following articles explain some of the issues around a DNR order. Practices and laws vary by state, so it is important to talk to your child's healthcare provider in your area.

#### [Understanding Medical Orders DNRs and Advance Planning](#)

A DNR order is reversible and can be withdrawn at any time. If you are in a situation where you feel that CPR is appropriate, you can either not show the DNR order to the medical provider, or verbally override it at that time.

Again, this is a difficult decision to make as you care for your child. [This video](#) from Courageous Parents Network provides several families' thought processes around creating the DNR that you might find very insightful.

"The right decisions are always the hardest to make"

Trent Shelton

## Resources:

### Making and Honoring End of Life Decisions for the Seriously Ill

POLST: Portable Medical Orders, or POLST for short is both a process and a form. Portable means that the order is valid outside the clinic or doctor's office. Read more about making these important medical decisions, [here](#).



#### Contact Us:

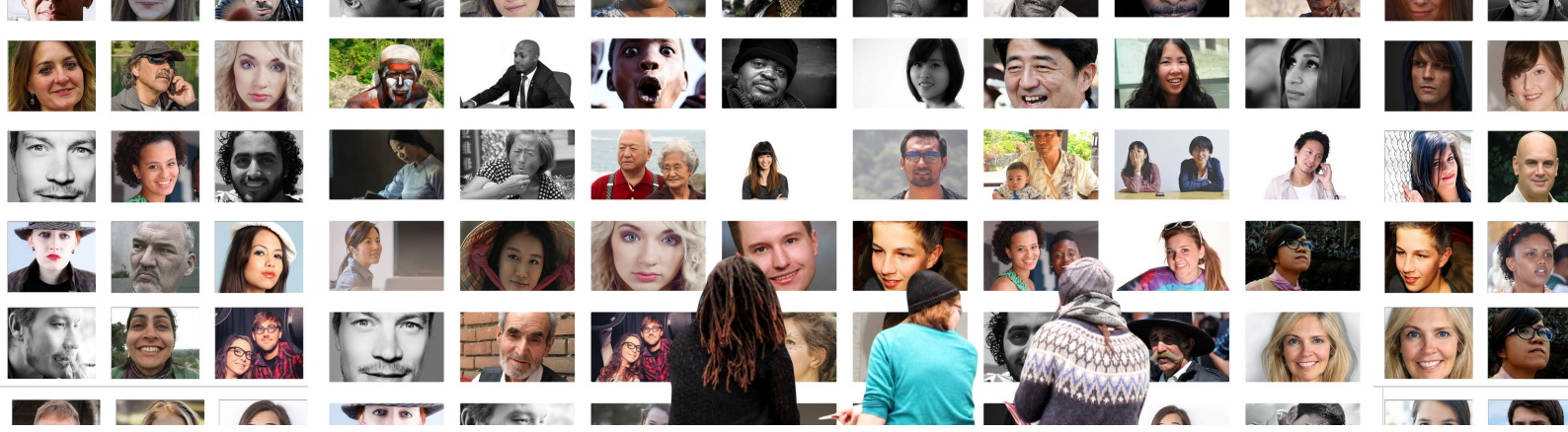


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## The Value of Connection and Community

BY BECKY BENSON, MISS ELLIOTT'S MOM

While no one wants to have to join the rare disease community, one thing we can all agree on is that while it saddens us whenever another member is brought into the fold, we're also so grateful to have each other. It's through these connections that we are sustained by those who have walked in our shoes. We often refer to our rare disease community as *the family you never wanted to be a part of, but one you couldn't live without*. The NTSAD community offers a sheltered place of knowing. This group also offers a place of comfort and understanding. While many parents often struggle to connect with those in their lives in the same ways as they have before, they find solace in this new connection.

Some of the ways families connect with others are via our [NTSAD Family Support Group](#) on Facebook and in attending our [Annual Family Conference](#).

As one newly diagnosed and first time conference attendee mom wrote, "I get by with a little help from my friends." Kim Rudness, mom to Greyson attended her first Annual Family Conference virtually in 2021 and posted about the experience on her blog, writing:



"This group of people know exactly what Adam and I are going through because they have been through it or are going through it too...These families are so incredibly warm, welcoming, and brave. They're honest and they are so willing to put themselves and their stories out there to help us."

Read Kim's full post on her first time conference experience as a newly diagnosed mother, [I Get By With A Little Help From My Friends](#), on her blog, [Greyson's Story](#).

"I define connection as the energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgment and when they derive sustenance and strength from the relationship."

- Brené Brown