What Do We Mean When We Say "Good Parent"?

A message from Courageous Parents Network

For more than a decade, pediatric palliative care professionals have been curious about how parents of a child with serious illness think about their role and consider whether they are achieving their "good parent" ideal. Courageous Parents Network has avidly consumed what these researchers informally refer to as "the good parent research" and has helped identify families to participate in the research.

It is important to note that the term "good parent" is not a judgment from clinicians. The term originated from parents of children in treatment for illness. In all the studies about being a good parent to any ill child, parents frame being a "good parent" as positive and what they strive to be. They do not speak to the idea of being a "bad" parent.

So, what have we learned? The content on these pages comes out of the clinicians' research, plus insights and experience of families and clinicians who generously share themselves with Courageous Parents Network. It is not possible to normalize this difficult parenting journey. However, where the CPN community can offer comfort, provide encouragement, and model parental courage, that's what this Guide is meant to do.

What Do We Mean When We Say “Good Parent”?

Most anyone would agree that a parent should do their best to provide shelter, food, clothing, and education; to make appropriate decisions on their child’s behalf; to ensure that their child feels supported and loved; to help their child develop and grow to reach their fullest potential.

These traditional measures of good parenting basically apply to all parenting, but parenting a child with medical complexity adds layers of nuance to these ideals. The stakes may feel higher. For example, families say:

- Advocating for their medically complex child (for example, with pediatric clinicians, insurance, school systems) is a primary task. It is constant and time-consuming.
- They spend more time doing research (on the diagnosis, prognosis, team, available support, and other resources).
- The sense of responsibility for a medically complex child weighs more heavily than it does for their typical children, if they have them.
- A child who is ill or medically complicated needs more attention and hands-on care, which typically takes more time and may conflict with parents’ concern for the welfare of their other children.
- There is a different sense of the future with their child and what it means to prepare them for autonomy.

These differences come with other challenges too. The hospital and medical “system” are new and bewildering to many parents. Clinicians may have diverse perspectives on what and how to treat symptoms; few clinicians seem to have a view of the whole child and their family and their life at home. Family members may feel isolated or even alienated from others who don’t fully understand their situation. Navigating medical complexity is exhausting, and there is little or no time for a caregiver to consider their own needs. And perhaps most of all: there are so many difficult decisions to be made, and a parent may feel paralyzed by fear of making the “wrong” decision or regretting a decision made.

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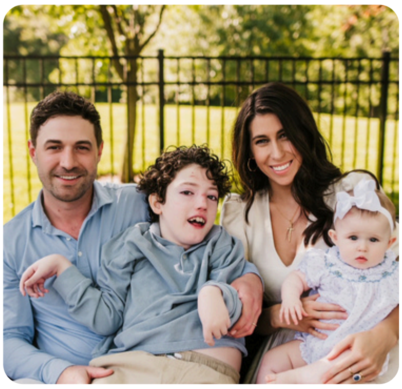
Being the Best Parent That You Can Be

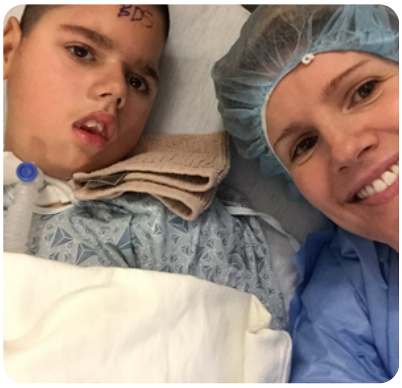
The journey is not always predictable, and things may not unfold exactly as you would expect or hope. But it is possible to feel that you are, and have been, the best parent possible all along the journey. Families and clinicians offer this advice.

Time is your great ally as you grow into the role as caregiver. Be patient with yourself and trust that your expertise will come. With time and hands-on experience, you can expect to feel increasingly confident.



"Although it [tracheostomy] was one of the most difficult decisions I've ever had to make, I eventually found peace in knowing that I was no longer acting out of desperation. Instead, I moved forward with the confidence that this was what Bubba truly needed—comfort, dignity, and the unwavering presence of a mother attuned to both her child's needs and her own inner guidance. The anxiety that had weighed on me for years didn't vanish entirely, but it was eased by the clarity and love that came with the decision. In that space, I was able to simply be with Bubba—holding his hand, loving him deeply, and continuing our journey together."
—Blair, parent of Bubba

You are the expert on your child, including what the child is able or not able to do, and how they communicate. Own your expertise and advocacy. You know your child best and your loving insights are good. Your insights will be extremely valuable to the medical team. You can request support if you feel that you are not being heard.



"Be empowered… as a parent you have an innate sense of what's best for your child and what's going on with your child… Don't say, 'Oh, he's the doctor, he knows.' No. They don't know everything. We should all be humble enough to know that we don't know everything, and therefore we need to seek guidance from others… It's your child, leave no stone unturned… For your own piece of mind you can say, 'I feel like something is still missing. I feel like we haven't covered everything. I don't know what to ask you, but … is there something else that we should be doing?'"
—Jenessa, parent of Chloe, Zachary and Alex

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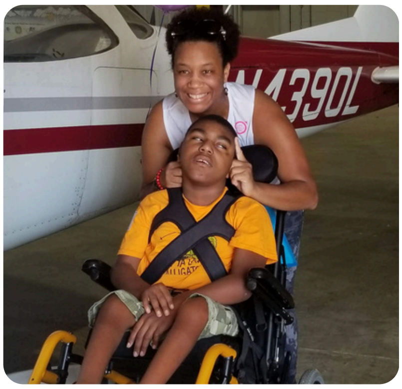
Let your care goals guide you as you make decisions for your child and family. If you have access to a palliative care clinician, they can help you think about what matters most to you and what your priorities are for your child.

"I don't think that there is any one right choice or wrong choice, because every family and every child is different. But if we, as parents, are trying to center our child's experience every day with every choice, I don't see how we can go wrong. Is his present moment comfortable? Does he feel safe? That's his whole world. And so, we were really careful: if we take him out of his comfort zone, we wanted to make sure that we had a really good reason."
—Ashley, parent of Viggo

Help the medical team make things easier, not harder, for you. Encourage the clinicians to be open, honest, direct and compassionate. Explain your boundaries: what and how much you need and want to know at any time (and that your boundaries may change). Let the team know how their behavior affects you—anything that makes you feel uncomfortable, confused or disrespected. And, that you appreciate their kind words and support.



"I have to use a lot of energy caring for and engaging on my child's behalf. In many of my son's appointments I've asked providers to use words that I can easily understand, or to explain [a word or concept] to me as if I were a five-year-old. I don't have the energy to consult my mental dictionary and decode what's being explained to me. Conversing in simple, non-medical jargon is a must."
— Naomi, parent of Noah

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If spirituality is important to you, it can (and should) be an important part of your caregiving journey. You may feel that it is important to help your child's spiritual self be connected to family, nature, activities, forms of self-expression, questions about a higher power. For some parents this is a way of honoring their child's uniqueness. Clinicians aren't always comfortable talking about beliefs and practices that for some people are very private, so they don't always tend to them. You can guide your child or ask for help from a spiritual advisor or clinician to guide you and your child.

"After his transplant, when David was in isolation, he started having changes in his personality. He was a very sweet boy and suddenly he was confrontational with us and the staff. The staff said they'd seen this before, but no one would do anything about it. I kept insisting that someone go in and speak with him, someone to really connect with him. The doctor was uncomfortable, but he did it. And after, David was smiling and he said, 'Let's play a game.' It was like this burden had been lifted from his shoulders."
—Robin, parent of David

Don't automatically accept terms like "should" or "have to" or "need to." Ask the clinician what they mean when they use these terms, especially if they are making recommendations about an intervention. In most cases you can take time to think about how the treatment will affect your child, and whether going forward is in your family's best interest.

"We had a shared philosophy which I think made a lot of decisions much easier, in that we always looked at any kind of intervention with Ben with one basic question: is this going to benefit his quality of life or our family's quality of life? And we framed every decision around that. So it wasn't, should he have this surgery, should he have this intervention, should he have this test. We were always asking doctors, well, what are the tests going to tell you? Here is one answer, here is the other answer, and what are you going to do about it? And if there is nothing that was going to be done, regardless of what the answer would be, we'd say, 'Well, then, we don't need the test.'"
—Stuart, parent of Ben

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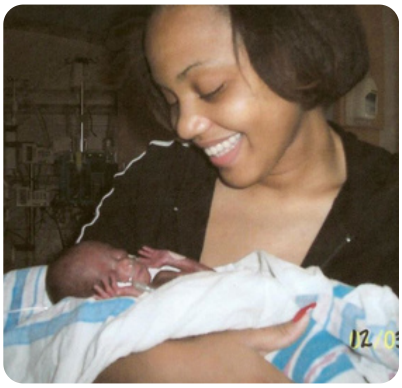
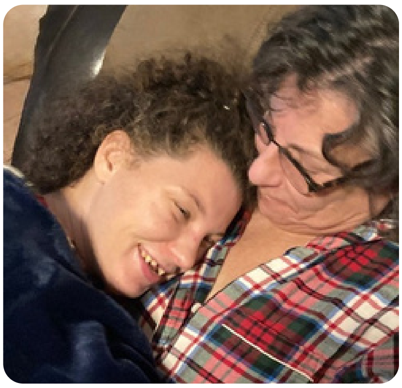
Allow that your goals may shift over time with changes in your child's abilities. Studies show that parents who recognize and respond to changes in their child's health and functioning are more likely to set new goals for their child and family, and to consider ways to attain them. Some things may become more important, and some less important. This doesn't mean that you have made bad or wrong choices before, only that you have different information to work with now and are adjusting.



"I was one of those parents who would do everything that I could for him, which was physical therapy, speech therapy, occupational therapy, going back and forth to the hospitals and all those things, two or three times a week. He had pool therapy as part of his PT… he absolutely loved it. But we had to give it up because you had to do land therapy if you wanted to do pool therapy. You had to do both for his insurance. I realized that I had to stop all of it because [land therapy] was hurting him more than it was helping him. But the mom in me, the one who was wanting to see him get better and be around for all these years, that mom was like, let's keep those legs loose, keep muscles from getting too tight, we are going to do all this. But that was not what was best for him. And I had to really look at myself and see why I was doing it and understanding that grieving aspect of being a mom… his body just was not capable, and I had to accept that."
—Aubrey, parent of De'Aubrey

Resist the need (or desire) to be perfect. The do-to list gets long, and it may not be humanly possible to do everything on it. You may worry about what others (including clinicians) expect of you, that they are judging you. You may expect a lot of yourself, too. Consider the effort required for a task and think about the outcome you want to achieve. Prioritize as much as you can. You don't have to do everything, or even everything that you really want to do, all at once —or ever.



"When Katie was little the occupational therapist would work with her and say, 'I want you to do just these two things, this and this, and tell me how it goes next week.' And I'd go, 'Oh, okay.' And the teacher would come and say, 'Make sure you're trying to do this during feeding.' 'Oh, okay.' And then Speech would add another little homework assignment. And each one was very reasonable, but by the end of the week, I had 12 things I needed to try in addition to giving her 14 medications four times a day and remembering the timing of which one goes where. I felt like I had to do every one of those things to be a good parent and eventually you realize you just actually can't. I mean, maybe some people can but I couldn't. So I had to figure out what my priorities were for Katie and what my partner's priorities were for Katie. And I put the most attention to those, even if that had meant that some days I had to say, 'We didn't try that this week' or "No, I didn't get to that.'"
—June, parent of Katie

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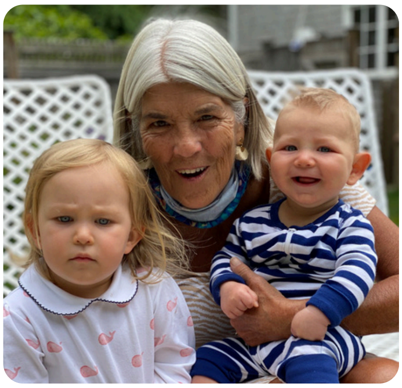
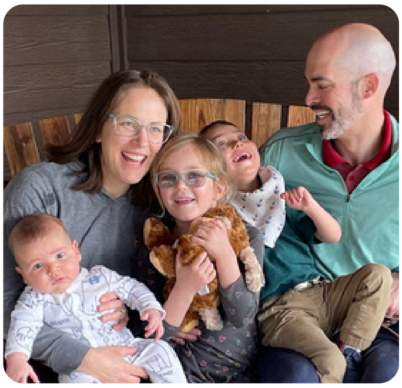
Establish boundaries and roles. You will no doubt find that some opinions are welcome and other opinions are not. Let your friends and family know what advice you welcome. Consider everything else a distraction and let it go. Be specific about your needs and your family's needs, as much as you are able. You naturally want to be sensitive to others, but don't spend a lot of time taking care of their feelings.



"We didn't have the bandwidth to take care [of the grandparents]. As a caregiver I wanted to be able to support them back, but I couldn't. I heard a lot of things that particularly my mom said, as she was grieving, that were really hard for me to hear as the mother. It was her grieving process, but It didn't help me."
—Laura, parent of Alden

Acknowledge and celebrate your own growth. Accompanying your child is one of the most stressful things you will ever do. Consider how your ability to learn and to be flexible are serving your family now and will help you thrive in the future.



"There are so many challenges; there's always something new, whether it's emotional stress or pressures that are created at home or at work or with a medical situation. It's easy to focus just on that, it's easy to let yourself be upset or disappointed. But if you reflect on where you were immediately after the diagnosis and the progress you've made and the incredible things you've accomplished—I take some pride in that, and how far how far we've come. It's a ton of work. I feel like you need one of those reminders that an app will send—a 'this was last year' type of recap. You need to see that you've gotten through it and got to the next stage and are continuing to progress and be stronger."
—Dave, parent of Alden

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Thank You

CPN wishes to thank the sources for this material, including the parents and

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