



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Eleven

Palliative Care, Help In The Time Of Transition

BY ASHLEY ISON, MSN, CNP, AND SALLY FENIK, CNP
CLEVELAND CLINIC CHILDREN'S

Life has a way of being unpredictable and quite honestly, unfair. Unfortunately, one of those instances is when a parent learns their child has a degenerative neurological disorder. Often these diagnoses result in much uncertainty and families are required to discuss topics they never imagined to be a part of their parenting journey. One of the most avoided conversations and arguably one of the most important, but also the scariest, is deciding how to proceed when a cure is no longer an option. These discussions influence how a patient lives as their disease progresses, how they die, and how the family continues on. These difficult conversations are often initiated by your primary medical team with the help of the Pediatric Palliative Care team (PPC). As Nurse Practitioners on the PPC team we meet patients and families during the most vulnerable time of their life. Our focus is to help families navigate this overwhelmingly scary time and hopefully make it a little easier. Sadly, when we can no longer offer a cure, the team begins to talk about end of life care.

Most of us would agree that losing a child is the worst thing that can happen to a parent. For many, the process of dying can be frightening and chaotic, so people often avoid discussing or planning for fear that they are giving up hope. We promise, no one on your team is giving up or losing hope but we've learned that it's best to plan for the worst, while still hoping for the best. That plan is likely to change along the way, probably more than once, but you know your child best and you should trust your gut because there is no right or wrong path. Allow us to guide you, but always remember this is your journey.

As you begin to explore the next steps you will learn there are many options to consider. Many parents start to think about what "quality of life" means to them, especially when they learn that time with their child is limited. Some families want to limit their time in the hospital and others fear being at home without the support of their medical team close by. Rely on your palliative care team to help you identify community resources including outpatient palliative care and/or hospice supports. These support teams will help to keep your child comfortable and focus on symptom management, which can promote a better quality of life. This can happen in the home, hospital, or sometimes in a hospice care facility. The team will walk alongside you and your child while exploring treatment options and ensure that the family's wishes are always understood. *Continued on page 2*

"You are stronger and braver than you think, and more loved than you will ever know." - Unknown

Resources:

End of Life Care

The Courageous Parent's Network offers a pathway to help parents on their journey as they plan for their child's end of life care. You can access the pathway and view additional articles, [here](#).



COURAGEOUS PARENTS NETWORK

Contact Us:



Diana Pagonis
Director of Family Services
diana@ntsad.org
(617) 458-9013



Becky Benson
Family Services and Conference Coordinator
becky@ntsad.org

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Even though we don't always have the outcome we desire, our patients truly touch our lives deeply and we are honored to be part of their journey along with their family. One thing we've learned through the years was best said by Bonnie Jo Freeman, a Palliative Care Advocate. "Death does not have to be dark and frightening if we talk about it openly and work to make every moment special. Love and laughter can coexist with loss and heartache".

Navigating Anticipatory Grief

From The Courageous Parents Network

Learning that your child has a rare and/or life-limiting condition may be unexpected and a complete shock to you. It literally changes everything. It's an overwhelming and isolating new world. And it's impossible to avoid the sense that this is just the beginning. The Courageous Parents Network offers a guided pathway on anticipatory grief. As they note:

"That sense brings with it a rush of feelings. A serious illness means a series of losses to anticipate and dread. Many families find it helpful to name these feelings. They also find it comforting to learn that the feelings are normal, and part of a process with its own name: anticipatory grief. We usually associate grief with thoughts and feelings to be experienced in the future, but anticipatory grief means grappling with and grieving the loss before it completely unfolds. It can take many forms: sadness, tearfulness, anger, irritability, loneliness, guilt, anxiety, a desire to talk or to withdraw. It may show up in physical problems, such as sleep or memory difficulty, headache or other physical pain. It may include a mental rehearsal of death and the hours/days following the death. It may include a need to engage in immediate decision-making around preparation for the death. It could also be complete avoidance of these issues. This all can be confusing and scary, and make you doubt your ability to cope. Understanding and naming it can go a long way toward helping you to accept your feelings and to stay functional."

Learn more about CPN's anticipatory grief offerings and their guided pathway for families, [here](#).



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"If there ever comes a day when we can't be together,
keep me in your heart. I'll stay there forever."

- Winnie The Pooh