



Inner Circle Resources

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When you are caring for children with medically complex needs, the ripple effects touch every heart in the family. Parents often carry the weight of constant care decisions, juggling love and logistics while grieving the loss of “normal” routines and life expectations. Grandparents may struggle between wanting to help and feeling unsure how, their hearts are compassionate but their hands sometimes tied by fear, distance or uncertainty. Siblings, too, live this story— learning compassion beyond their years, and needing reassurance that their own needs and feelings matter just as much. Every member of the family is deeply affected, not only by the challenges, but also by the profound love, resilience and connection that grows in the process. Understanding each person’s experience within this circle helps the family move together— stronger, seen and supported.

For Parents

50 Great Websites for Parents of kids with special needs

Care Mapping is a process that guides and supports the ability of families and care professionals to work together to achieve the best possible health outcomes.

Courageous Parent Network

Courageous Parents Network (CPN) Video – Mom discusses realities of nursing shortage affecting self-care. **Watch here**

Courageous Parent Network (CPN) Video – Mom shares how others can approach the reality of not taking her burdens away. **Watch here**

GIVE IN KIND is a versatile, flexible, virtual support tool anyone near or far can use. Organize providing meals, rides, childcare, gift cards, donations and more. All for free.

Government services for Children with disabilities and their families

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For Grandparents

Family Voices helps close the gap between special care needs and coordinated healthcare.

AARP Blog for Grandparents of kids with special needs.

Critically Loved Grandparents corner for chronically and critically ill children.

For Siblings

PPCC Sibling Toolkit Resources that give special attention to siblings who live and share their lives with a brother or sister with medical complexities.

Ryan's Case for Smiles Sibling Coping Space Helping siblings adjust to family care and routines due to medical needs.

Family Voices helps close the gap between special care needs and coordinated healthcare.

Siblings with a Mission is dedicated to creating opportunities for brothers and sisters of medically complex children to receive the information and resources they need to support their families and themselves.

Wish Resources

A Kid Again

Children's Wish Foundation

Dream Factory grants dreams to critically and chronically ill children from the ages of 3-18 nationwide.

The Granted Wish Foundation grants sports and celebrity athlete wishes to children and young adults from ages 5-25 nationwide.

Hunt of a Lifetime provides wishes for individuals 21 and under interested in hunting and fishing.

Jamie's Dream Team organization that grants dreams to children 18 and under.

Kid's Wish Network grants wishes to children ages 3-18 nationwide.

Make-A-Wish America grants wishes to children 18 and under nationwide.

The Quinn Madeleine Foundation grants wishes to children under the age of 3.

Starlight grants wishes to hospitalized children nationwide.

Sunshine Foundation organization that grants wishes to children ages 3-18 with serious or chronic illnesses, or have suffered abuse.

Team IMPACT matches children with a college athletic team.

Emersyn Isla Shining Star Foundation our-services PA-based organization that sponsors day trips for children and their families.

PPCC Resources

PPCC Toolkits:

- [PPCC Care Plan Book](#)
- [PPCC Self-Advocacy Toolkit: A Guide for Parents, Caregivers, Children and Adolescents](#)
- [PPCC Creative Expressions Toolkit](#)
- [PPCC Caring Conversations Toolkit: For Parents and Caregivers - How to Talk With Your Child's Providers](#)

PPCC Resource:

- [PPCC What is Pediatric Palliative Care? - FAQs](#)

PPCC Briefs - One page bulletins for Families:

- [Finding Your Community: Parenting a Child with a Rare Disease](#)
- [Staying Organized in the World of Medical Complexities](#)
- [Managing Complex Care in the Home Setting](#)
- [Making Wishes Come True](#)
- [Organizational Tools for Back to School](#)
- [A Parent's Perspective on Advocating for Your Child](#)
- [Advocating for Your Child: Steps Parents Can Take to Advocate for Their Child](#)
- [How to Work with your Local Legislator on Advocating for Your Child](#)
- [The Challenge of Being a Caregiver: The Unique Perspective of a Parent and a Provider](#)
- [The Value and Use of Photo-Narratives for Children with Medical Complexity](#)